1987 - February 8

Annual Meeting Texas Polio Survivors' Association. Speaker: Polio Experience - Past, Present, and Future.

Houston, Texas

TPSA

A VERY SPECIAL GENERAL MEETING
SUNDAY, FEBRUARY 8, 1987
2:00 P.M.
A VERY SPECIAL SPEAKER!
GINI LAURIE

Our T.P.S.A. meeting on February 8th is also our annual meeting at which we elect a Board of Directors to serve for 1987. A slate of nominees will be presented, but you are welcome to nominate board members from the floor at this meeting. We need board members who have the time to serve, who are willing to serve, and who are dedicated to doing the very best they can to help Texas Polio Survivors' Association in any way they can. Being a board member does require attending regular board meetings once a month, and other meetings when necessary. If you know of someone you'd like to nominate, please call Jacoba at the office so she can pass the name along to the nominating committee.

You should be receiving your membership renewal form in the mail soon, if you have not already received it. Please complete all the information requested, and send it back to the office as soon as possible, so that our new list of members can be compiled for our next Newsletter. When you receive it, why not just fill in the information, enclose a check, and put it with your outgoing mail--before you even put it down?!! Putting something down is usually my worst mistake, as far as getting it done goes!

GINI LAURIE, our special guest speaker for the February 8th meeting, has been involved with disabillity since the year before she was born (!), when, in 1912, polio struck four of her siblings and caused the death of three. She is founder and chairman of Gazette International Networking Institute (G.I.N.I.), a publishing and information center run from her home in the central West End of St. Louis. She began volunteering at a respiratory polio center in 1949, encouraging independent and productive living through her international journal, Rehabilitation Gazette, which she founded in 1958. It now reaches 40,000 readers in 87 countries. Laurie was among the first to recognize the new health problems of polio survivors. She organized the first post-polio conference in Chicago in 1981. The 1985 conference attracted over 500 polio survivors and health professionals from around the world, and featured such renowned speakers at Dr. William Masters and Dr. Albert Sabin, developer of the oral polio vaccine. Another conference is planned for 1987 in St. Louis. (Watch your next Newsletter for details!)

Her speech will be titled "The Polio Experience: Past, Present, and Future." Her executive director, JUDY RAYMOND, will also be with us at this meeting at the HOBBY HILTON HOTEL, 8181 Airport Blvd. (free parking in back of hotel off Hinman) LET'S ALL MAKE A REALLY EXTRA SPECIAL EFFORT TO BE AT THIS VERY SPECIAL MEETING!!

HOUSTON - POLIO SUPPORT GROUP - Feb 8, 1987

Jacoba Schneider   Nita Weil

Polio Experience - Past, Present, and Future

Great to see so many old GAZETTE FRIENDS and NEW NETWORKERS... Thank hospitality

Polio experience is my life.......Intertwined Involved LONG TIME...since before born....

4 siblings.......

RESP CENTER....1949.... Hot packs Epidemics....Wonderful human experience. Never so many on respirators....Physicans/patients learned together. Family & patients members of team.

Late 50's
...vaccines eliminated. At home. Two vital needs: PEOPLE & INFORMATION....wanted to keep up & share experiences.... needed network to exchange information.

One way or another, husband Joe-late & I started to meet needs: in 1958.
Built pool...first polio support group...Big annual Readers the writers

RG...exchange info... support group...and an IL by mail.

Now RG ... 40,000.....87.....Japanese....library. .. All disabiliite
Non-profit..supported by donations (majority readers)...memberships & subscritpions. & Dedication of volupnteers.
Joe and I and our family and our friends and readers around world - all volunteered.

3 years ago made CHANGES SO COULD KEEP GOING after Joe & me.

Chgd name: GINI..big Gini...little. Reorganized board.

JUDY RAYMOND, who had volunteered for ~~20~~ 17 yrs, became exec dir.

Reorganization timely...coincied with great increase in our polio network as result of late effects.

Although expanded...had never stopped maintinaing LIVING NETWORK. since I first started in 1949.

CONSEQUENTLY....<u>first</u> to notice late effects & to publish facts...

<u>first</u> to organize a plan to confront the problem & to take the national & interational lea

* * * * * * * * * *

1979...letter....MD's not knowing...think psychological...

Had flood of mail from others with same problem.

+ others with respiratory problems

FIRST PRIORITY...share info of older polio-experienced physicians with younger physicians. oldest MDs BEST WAY; bring older and younger together with polio survivors at conferenc

So, our organziation started conferences....every other year.

UNIQUE...pay own way. Brown bags.

<u>1981</u> ... 125 attended...good nucleus of interested physicians..

Getting togeher started survivors thiniing about getting togher & supportingeach other.

3 Houston. support grp.... Feb 8, 1987

Quickly

Began to BROADEN AIMS OF CONFERENCES...

1. Encourage reserach
2. Need for psychological support through self-help groups
3. Importance of sharing polio experience of 30 yrs on ventilators with SCI, Musc Dys, ALS, etc.
4. Relate to all aging, all zging disabled.
5. Educate public & poliosurvivors in nonthreatening way.... Avoid "victims" suffereres"...patronizing & exploiting... pitiful bra~~c~~ve cripples of the 1950s. Insist on dignity.... On self-help groups being self-help.

1983 Conference... more than 400....40 on vent...7 lungs. Support groups starting. Attracted more & more MDs. Dr. Halstead asked to speak on sex & SCI. Fascinated by polio late effects. Joined with Dr. Dave Weichers to organize two scientific conf in in 1984, 1986

1984...Judith and I & Dr. Maynard & Dr. Fischer: Handbook. Dr. M & Dr. F had both started helping at 1st conf... typical of concerned, caring physicians. Real- RDs...

They & other physicians attuned to LISTENING and appreciating ~~the~~ your expertise ~~of the survivors~~. Such as your Dr. Spencer & Dr. Valbona. Same type as at old resp ctrs....Polio seems t0 be magnet for best.

1985 CONFERENCE.... more than 500. Dr. Albert Sabin. Dr. Masters of M & Johnson.

NETWORKING increases every time there is PUBLICITY with our address or phone number. If it isnt given, they sleuth.

Lines hum day & night. Most need to talk. Judith & I are good listeners.
If cant answer from library, we know someone who can.

Most need basic info that is in handbook, IPN newsletter or the Gazette.
Some need a simple bit of info_ shoe exchange
Some blame every physical problem on polio....arthritis... heart trouble...diabetes.... Even - story of breast/menstruati

Some more serious..special networking. Willa Schuster. double-barrelled.

Over years, Gazette involved in some large networking.

- 1960 - national attendant care
- Mid-1960's - Talking books - Mrs. Cyrus Eaton C&O
- 1984 - Ventilators/HCFA
- 1986 - Russian polio survivor Simon, Tamara, Mark Levin

CHOLOGICAL

BUT MOST OF THE SURVIVORS PROBLEMS ARE PSYCHOLOGICAL... THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLE.

The majority of you survivors ~~are~~ were left relatively mildly disabled. You passed for normal. You adjusted. You overadjusted. You compensated. You overcompensated.

You lived for 30 years with a limp or a cane...
Untouched by world of disability,
by problems of discrimination & prejudice,
by the barriers of steps & inaccessible bathrooms.

NATURALLY, when y9u began to experience late effects & began to use wheelchairs or other trappings of disability, you faced overwhelming psychological adjustments.

YOU NEEDED HELP & UNDERSTANDING...
YOU NEEDED A NETWORK OF PEOPLE with whom you could share long-denied feelings and emotions.
YOU NEEDED A CENTRAL SOURCE OF POLIO INFORMATION.

FORTUNATELY, Our G.I.N.I. organization was still there with the information & networking you needed to interlock the support groups that you began to form after ~~the~~ our 1983 polio conference.

At the 1985 conference, GINI was asked to coordinate the support groups & tie them in with longtime polio networking.

So, formalized IPN (International Polio Network).....

July Started quarterly newsletter, Polio Network News

Sponsored a workshop of the leaders of the support groups - 86

Isn't It ~~is~~ AMAZING what we have all accomplished TOGETHER - the support groups....the physicians....and GINI's International Polio Network....all in such a short time.

And, it is a short time.

We only started in 1979

Now the problems of the late effects are being recognized

by medical community & gen public

And, through your support groups reaching more & more survivors.

National TV coverage - Chas Kuralt Sunday Morning, Nightline, Today Show, Cable Network News, "Hour" Magazine last Tues.... and, of course, local fealtures.

Articles in NEW YORK TIMES....prestigious medical journals, the latest in Archives of PM&R.

RESEARCH...funded by National Inst on Dis & Rehab Research, March of Dimes, Easter S.

Now...looking forward to our next conf on Polio & Indep Living. June 4-7, this year...in St. Louis at the Sheraton.

Judy will tell you more about it.and about the International Polio Network.....

But, I especially wa-nt to invite Texans to attend.... some of the other states' support groups areplanning to come together in caravans....with this great group, you should have a super caravan.

We look forward to seeing you in St. Louis

Thank you.

Most support groups are small, informal, financially insecure, and fluid. Members come and go as the group meets their needs. The usual pattern of their national organization is a loose network of autonomous groups. The most common is an association, supported by dues from the affiliated local branches or chapters that are authorized to use its name.

Support groups differ from professionally-run groups, which are more likely to resemble group therapy rather than self-help, and they can provide benefits that professional groups cannot. Self-help groups are not meant to replace professional services but they supplement and may even prevent the need for them.

Professional human service agencies and mutual help groups may have a tense and competitive relationship. Historically, professionals have often tried to co-opt mutual help organizations, and they are frequently regarded as intruders.

The networking and self-help support group movements are growing rapidly, filling the gaps left by the disappearance of family and community support. Presently, self-help groups involve about 15 million persons in more than one-half million groups.

The recent development of the polio support groups for survivors with the late effects of polio is uniquely and strongly influenced by the survivors' early experiences - especially those during and following the to the March of Dimes that covered the expenses of staff, research, patient care, equipment and maintentance, and home care with attendants. Most of ther centers were in contagious wards and directed by pediatricians who had had little experience with adults or respirators. Consequently, they evolved creatively to meet the unknown problems of the epidemic years.

The centers functioned as a team that included staff, patients and families, engineers, and the community. The resulting rehabilitation was extraordinarily positive. By the mid-1950's the majority of the respirator-dependent individuals were at home, trained to take responsibility for their equipment, attendants, and their lives.[3] They went back to school or work, attained training or higher education, married, raised children, and lived full and productive lives - after a long, hard struggle.

The struggle began in 1959 when the March of Dimes had to close the centers and cease funding attendants, medical care, equipment, and reserach because the success of the vaccines had stopped donations from the public.[2] The polio survivors faced extraordinary adjustments. They were suddenly left on their own after being pampered, praised, and protected from all financial worries. Fortunately, they had had the protection and assistance when they needed it - during early rehabilitation - and they reacted with a fighting spirit of adaptation. The less severely disabled learned to "pass" as nondisabled. Others muddled on with their old braces or other equipment and worked out their own solutions. Many avoided medical care because of economy or early experiences. Those were lean years - before Medicaid, Medicare, SSI, Social Security disability benefits, independent living centers, and expended vocational rehabilitation services. The survivors had to rely on their own resources, their families, or welfare. But they also needed mutual support of those who had shared their polio experience.

The survivors with respiratory involvement and others who were severely disabled had the most need for sharing. They had spent months and years together learning to live with iron lungs or portable respirators. They had evolved strong feelings of togetherness, of mutual support, of warm friendships, and a need to keep in touch to share information and experiences.

To fulfill these universal needs for people and information, the "alumni" of some of the respiratory centers fostered social meetings and published mimeographed newsletters of their at-home doings for a few years after the centers closed. Among these were groups in Los Angeles, San Francisco, Buffalo, Omaha, Houston, Ann Arbor, and Cleveland. For a few years, too, nonrespiratory survivors shared newsletters from Sister Kenny Institute and Warm Springs and a group met as the Chicago Polio Swim Club.

Eventually, they all faded away except two. The Los Angeles group was revived as the Polio Survivors Association, primarily for advocacy for ventilator users. The

Cleveland respiratory center group was continued by the author, a volunteer at its Toomey Pavilion. She started a publication, Rehabilitation Gazette, to share do-it-yourself equipment and experiences and provide information. The publication has evolved into the Gazette International Networking Institute and the International Polio Network.

The history of the evolvement of the Rehabilitation Gazette into an international journal and polio network is the history of the current awareness of the late effects of polio and of the evolvement of the support groups and clinics.[4]

Starting in 1958, the Cleveland "alumni" had large annual picnics at the home of the author and her husband, Joe, and daily summer "support group" gatherings of survivors and volunteers in and around their swimming pool. Together the group wrote the Gazette and answered requests for information and networking with other survivors.[5]

Written by the alumni of the Cleveland and other respiratory polio centers, the Gazette became the only national advocacy organization of polio survivors, their only permanent network.

The Gazette expanded in the 1960s and the 1970s into an international journal devoted to independent living for people with all disabilities in 87 countries. Yet it never ceased to maintain a living network of polio survivors. Consequently, in 1979, it was the first to notice and to publish the problems its readers were having with the late effects of polio and with their physicians whose education had not included polio.

In 1980,[6] the author discussed these late effects and the need to educate physicians with Dr. David Dickinson of Ann Arbor, Dr. Robert Eiben of Cleveland, and Dr. Allen Goldberg of Chicago. Dr. Dickinson referred the author to Dr. Frederick Maynard, a physiatrist, who had seen a few polio survivors with the problem. Together, they planned an international polio conference.

The Gazette's first international polio conference in Chicago in 1981 drew 125 survivors and physicians. All of them paid their own expenses. There began the unique partnership of lay and professional persons working together to solve an undocumented problem. There began the special spirit of mutual respect and sharing that characterizes all the Gazette's international polio conferences, the publications, and the support groups.

Six years later, Dr. Maynard reported in an interview in the ST. LOUIS POST-DISPATCH,[7] "Gini Laurie was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?

"I remember thinking at that first conference, 'Who am I to talk?' I told them I didn't know if what I was seeing in the handful of people in my clinic was typical or just odd cases. The audience said yes, they had the same symptoms, knew others with them. After that meeting, I was convinced."

Soon after the 1981 conference, another physiatrist, Dr. Stanley Yarnell, and polio survivor Renah Shnaider organized a regional polio conference in Oakland, California, a polio clinic was opened at the University of Wisconsin, Madison, and a support group was begun in Buffalo, New York.

From the very beginning, clinics and support groups worked as a team , reinforcing each other. The clinics refer people to support groups and the support groups refer their members to clinics. Many clinics participate in the support group programs and some support groups arrange for a polio survivor to be available during all clinic hours.

The Gazette's 1983 international polio conference in St. Louis drew 400 registrants from Australia, Canada, England, Germany, India, Japan, Mexico, South Africa, and Sweden. About 40 of the registrants used ventilators; most brought their own portables, seven rented iron lungs for night use. The ventilator users and respiratory specialists began to share their variations on face masks and other night aids. The mobility impaired, physiatrists, and therapists shared information on the symptoms and treatments of the fatigue, pain, and muscle weakness caused by the late effects.

The goals stated at those early conferences are still viable:

- To work as a team of polio survivors and health professionals and organizations and coalitions of people with disabilities for networking, information, research, mutual support, education, treatment, and worldwide immunization;
- To relate the positive experiences of polio survivors to other persons with disabiities, including the aging and other ventilator users;
- To promote independent living;
- To influence legislation for in-home support services.

The conferences were the catalysts for the support groups. They brought survivors of all degrees of disability together and revived their former joy of being together and sharing problems and information. The first two conferences awakened the registrants to their vital psychological need for mutual support and they returned home to start support groups.[8]

The conferences brought together medical clinicians and researchers and triggered Dr. Lauro Halstead and Dr. David Wiechers to organize the 1984 and 1986 international scientific conferences to stimulate more research into the cause and treatment of the late effects. The National Institutes of Health became involved in research as did the National Easter Seal Society and the March of Dimes Birth Defects Foundation.

In 1984, the Gazette reorganized and expanded to become the Gazette International Networking Institute to coordinate information and networking on the late effects.

Its publishing of a summary of the knowledge in a clear, concise handbook was timely and significant. The <u>Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors</u> was written by Gini Laurie, Judith Raymond, Frederick Maynard, M.D., and D. Armin Fischer, M.D. It is now in its third printing and has been translated into Swedish and is being translated into German, Italian, Spanish, and Finnish, and excerpted in Chinese.

The networking and flow of information on the late effects of polio from lay persons to health professionals has been unique - a reversal of the usual order. Publications, support groups, and local and national publicity have gradually informed the general public and alerted health professionals. ARticles have appeared in THE NEW YORK TIMES, the WASHINGTON POST, the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, the NEW ENGLAND JOURNAL OF MEDICINE, and TV shows, such as Kuralt's <u>Sunday Morning Show</u>, <u>Hour Magazine</u>, <u>Nightline</u>, etc., have covered the topic.

In 1985,[9] more than 500 registrants came to G.I.N.I.'s Third International Polio and Independent Living Conference in St. Louis. Registrants from more countries were added to those of the previous years: The Netherlands, Denmark, and Taiwan. Highlights were the session chaired by William Masters, M.D., and the conference banquet honoring Albert Sabin, M.D.

An important session brought together the leaders and members of the support groups to share plans and problems. The groups asked G.I.N.I. to coordinate and act as the official clearinghouse for the support groups in the United States and to maintain a directory of support groups, physicians, resource persons, and clinics. As a result, the Gazette's longtime international polio network was formalized into the International Polio Network (I.P.N.) and the quarterly newsletter, Polio Network News, and directory were initiated for members.

In the last two years, more than 200 support groups and 50 clinics have been started and many regional and local conferences held. The conferences have been organized by support groups, often in cooperation with local independent living centers, universities, hospitals, rehabilitation centers, Easter Seal, or March of Dimes. The conferences educate health professionals and the general public and foster an esprit de corps in the support groups.

In June 1986, International Polio Network organized a workshop for about 70 of the leaders of the support groups in St. Louis. The workshop highlighted the creativity, individuality, and organizational ability of the leaders. Since then, some support groups have accomplished outstanding statewide organizations and systems of educating health professionals and survivors.

Meanwhile, two polio survivors and I.P.N. eased the way for approval of social security disability claims submitted by polio survivors unable to work due to the

Summary

Support groups are a specialized type of networking composed of equals who help each other by sharing information and common experiences and who have a sense of ownership of their voluntary, nonprofit organizations.

Support groups are intended to supplement, not replace, professional human service agencies. The relationship may be competitive because, historically, some professionals have sought to co-opt mutual help organizations.

The history of the polio support groups is interwoven with the history of the International Polio Network which was founded in 1958 as a local newsletter for polio survivors, which called attention to the late effects in 1979, and which now coordinates more than 200 support groups in the United States, publishes a handbook, quarterly newsletter, and directory, and organizes biennial international conferences and leaders' workshops.

The need for psychological support for polio survivors experiencing its late effects is often as critical as the need for physiological treatment and is influenced by their initial medical experiences and the attitudes of the public and the press during the epidemic years.

The current interest in the late effects evolved upwards from the grassroots, from lay persons to an extraordinarily caring group of professionals. There are presently more than 50 polio clinics in the United States. They work with local support groups as a team, reinforcing each other.

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10. Raymond J. ed. Social security issues post-polio guidelines. Polio Netwk News 1987:3:3:7-8.

11. Raymond J ed. Russian polio survivor granted exit visa thanks to polio network. Polio Netwk News 1986:2:4:1.

1987 - February 10

St. Louis Occupational Therapy
Physical Disabilities Special
Interest Group (PDSIG). Joint
OT/PT Meeting. Washington U
School of Medicine. Speaker:
"Post Polio Update: Practical Suggestions
for Polio Survivors and Health
Professionals Who Work With Them."

St. Louis MO

#1 OT/PT FEB 10, 1987 BARNES

HISTORY OF G.I.N.I.

IS MY HISTORY

LIVED POLIO HISTORY SINCE BEFORE BORN. 4 SIBLINGS.

49 EPIDEMICS...VOLUNTEERED RESP CENTER FOR 10 YEARS...HOT PACKS, ETC

58 VACCINES...KEEP IN TOUCH & SHARE INFO (UNIVERSAL NEED FOR PEOPLE & INFO) STARTED RG

RG Now: 40,000 87 COUNTRIES JAPANESE ALL DISABILITIES/AGES

LIBRARY INFORMATION CENTER FOR WORLD (IN YOUR BACKYARD)

HOPE YOUHAVE SET OF BACK ISSUES OF RG IN YOUR LIBRARY. VALUABLE INFO ON COPING, EMPLOYMENT, EDUC. CREATIVE EQUIP ADAPTATIONS.
EVERY FACET OF LIVING INDEP WITH DISABILITY

OUR ORGANIZATION NEVER STOPPED ITS LIVING POLIO NETWORK

THEREFORE, FIRST TO NOTICE LATE EFFECTS & TO TAKE LEAD IN DOING SOMETHING ABOUT THEM.

1ST STEP 1. TO EDUCATE SURVIVORS & PHYSICIANS....CONFERENCES EVERY OTHER YEAR. FIRST IN 1981.....MORE & MORE PHYSICIANS & SURVIVORS EVERY YEAR. 1983 - 1985 - Proceedings - available.
1987 CONFERENCE: EXPECT NEARLY 1000 ... 75% DISABLED...
LEADING PHYSICIANS & PROFESIONAL PERSONS FROM AROUND WORLD.
HAVE HAD AS MANY AS 40 ON VENTILATORS. JUNE 4-7..SHERATON.
WE HAVE REGISTRATION FORMS & INFO.

FURTHER Education 2. HANDBOOK......IPN ~~TRANSLATED INTO SEV. LANGUAGES~~

3. PROMOTE RESEARCH. NATL INST ON DIS & REHAB RESEARCH..ES..M OF D
2 SCIENTIFIC CONFERENCES

4. PSYCHOLOGICAL PROBLEMS...SUPPORT GROUPS...(JUDY WILL COVER)

5. RELATE POLIO EXPERIENCE TO
   - A) OTHERS WITH VENTILATORS LEARN FROM 30 YRS AT HOME... ALS...MD...SCI...
   - B) ALL AGING DISABLED - YOU pts PROBABLY SEEING SCI WHO HAVE USED MANUAL W/C FOR 20 OR 30 YRS NOW HAVING SHOULDER OR CARPAL TUNNEL PROBLEMS
   - C) ALL AGING

WHAT DID ORIGINAL POLIO AFFECT?

AS YOU KNOW, AFFECTED MUSCULAR SYSTEM ONLY. (UNLIKE SCI, POLIO SURVIVORS ARE NOT IMPOTENT....NOT ANAESTHETIC..NOT INCONTINENT.)

IF AFFECTED INTERCOSTALS, BREATHING PROBLEMS AS AGE.
BACK IN L950'S, FIRST THOUGHT WEANING A VIRTUE. LEARNED TOO MANY UNDERVENTILATED. BROUGHT BACK, REEVALUATED, SENT HOME WITH NIGHTTIME VENTILATORS. LIVED 30 YEARS.
SAME TRUE TODAY. AS AGE, MAY NEED NIGHT AID.
POLIO SURVIVORS USED NONINVASIVE RESPIRATORY AIDS - NEGATIVE SUCH AS IRON LUNG OR CUIRASS, POSITIVE PRESSURE ORAL~~EY~~ OR Face Mask ~~NASALY~~.

FEW TRACHEOSTOMIES. SUCTIONING ONLY. CLOSED WHEN UNNEEDED.

I~~VUN TO MEET THESE NEEDS.~~

WHAT ARE THE LATE EFFECTS?

NOMENCLATURE. PREFER LATE EFFECTS. NOT TRUE SYNDROME.
MISTAKENLY LABEL ALL AS PPMA (PROGRESSIVE POST-P MUSC ATROPHY)
DR. DALAKAS OF NIH FOUND VERY RARE.

#3 OT/PT FEB 10, 1987 BARNES

NUMBERS DR. CODD AT MAYO ESTIMATES 300,000 IN U.S. AND 25% OF THESE MAY HAVE SOME PROBLEM WITH LATE EFFECTS.

SYMPTOMS PAIN......UNACCUSTOMED FATIGUE.....MUSCLE WEAKNESS.
MAY HAVE BREATHING & SLEEP PROBLEMS
USUALLY ABOUT 30 YEARS AFTER INITIAL ATTACK.
OFTEN FOLLOWS STRESS: OPERATION OR PSYCHOLOGICAL (DEATH, LOSS OF JOB)

FUNCTIONAL PROBLEMS: CLIMBING STAIRS...WALKING DISTANCES.... DOING CHORES....FREQUENT FALLS

DIAGNOSIS - ONE OF EXCLUSION....FIRST RULE OUT:

1. ARTHRITIS
2. ANY OTHER AGE-RELATED DISABILITY BECAUSE THE NERVE CELLS DAMAGED BY ORIGINAL INFECTION MAY BE ESPECIALLY VULNERABLE TO THE AGING PROCESS.
3. DISUSE ATROPHY FOLLOWING ILLNESS OR INJURY OR RELATED TO PAIN FROM CHRONIC, STRAIN-INDUCED INFLAMMATORY DISORDERS OF MUSCLES, TENDONS, AND LIGAMENTS.
4. CHRONIC OVERUSE OF WEAKENED MUSCLES MAY STRESS METABOLISM OF REMAINING MOTOR NEURONS...AND THIS IS A SELF-DESTRUCTIVE CYCLE AS THE DAMAGED MOTOR NEURONS DROP OUT.
5. PINCHED NERVE ROOTS AND RADICULOPATHIES
6. PERIPHERAL NEUROPATHIES, INCLUDING COMPRESSION NEUROPATHIES.
8. MAY NEVER HAD HAD POLIO (INNOCENTLY OR DELIBERATELY MISDIAGNOSED)

   MAY HAVE HAD ORIGINALLY: GUILLAIN-BARRÉ,...ECHO OR COXSACKIE VIRUS...OR ONE OF MANY POLYMYOPATHIES OR A FORM OF POLYNEURITIS.

9. TOO MANY TRANSPLANTS AND FUSIONS. ORTHOPODS HAD MANY OF THE CHILDREN IN AND OUT OF CASTS FOR YEARS WITH ONE OPERATION AFTER ANOTHER. SOME HAD 30 OR MORE.
SEEMS THAT THOSE WITH THE MOST TROUBLE NOW ARE THOSE WHO HAD THE MOST OPERATIONS.

YOU ARE ALL PROBABLY WORKING OUT YOUR OWN HYPOSTHESES TO EXPLAIN THE LATE EFFECTS...LIKE TO READ EXCERPT FROM AN ARTICLE BY DR. ROBERTA TREISCHMANN, AUTHOR OF NEW BOOK, AGING WITH A DISABILITY, WHICH PRESENTS A CLEAR SUMMARY:

CERTAIN MUSCLE FIBERS WERE ORPHANED WHEN THE POLIO VIRUS KILLED THE NERVE WHICH 'DROVE' THE MUSCLE. ADJACENT NERVES, WHICH WERE UNIMPAIRED, SENT OVER NEW FIBERS TO THE ORPHANED MUSCLES, WHICH LED TO RECOVERY OF MUSCLE FUNCTION. HOWEVER, AS A RESULT, A NERVE NUCLEUS WHICH WAS DESIGNED TO DRIVE PERHAPS 500 MUSCLE FIBERS MAY HAVE BEEN CARRYING THE LOAD OF 1500 MUSCLE FIBERS. OVER TIME, SOME OF THE RECOVERED MUSCLES MAY BE LOSING FUNCTION AS THE NERVE NUCLEUS BECOMES TIRED. THUS, IT IS HYPOTHESIZED THAT SOME OF THE EXTRA NERVE FIBERS MAY BE DETERIORATING AND THE MUSCLES ARE BECOMING ORPHANED AGAIN ~~OVER TIME~~."

TREATMENT; EXPERIENCED PHYSICIANS AND THERAPISTS SAY TREATABLE AND REVERSIBLE - IF TREATED IN TIME - AND IF STOP THE OVERUSE, STOP THE OVEREXERCISE. STOP AND THINK OF CONSERVATION, USE COMMONSENSE...DIET, (SO MANY ARE OVERWEIGHT) REST, CHANGE LIFESTYLE.

DO NOT EXERCISE TO PAIN

MAY NEED BRACE - SIMPLE PLASTIC OR ONE OF OLD LONG LEG BRACES

MAY JUST NEED SHOE LIFT (CLOG STORY)

MAY NEED TO CHANGE FROM CRUTCHES TO MANUAL W/C...OR MANUAL W/C
TO MOTORIZED,(THREE-WHEELERS MOST USED)

SWIMMING MOST RECOMMENDED

ALSO RECOMMENDED: GENERAL CONDITIONING AND AEROBIC EXERCISES
TO MAINTAIN CARDIOVASCULAR ENDURANCE

FOCUS ON BUILDING ENDURANCE, NOT STRENGTH

FOR FATIGUE, ENCOURAGE PACING (MID-MORNING & AFTERNOON RESTS)

SURVIVORS KNOW THEIR BODIES...LISTED THEM...THEY ARE THE EXPERTS. THE OLDTIME PT'S SAY THEY LISTEN AND THEY LEARN FROM THE POLIO SURVIVORS.

SOME ALTERNATIVE ~~CREATIVE~~ TREATMENTS BEING TRIED........ACUPUNCTURE FELDENKRAIS....TRIGGER POINT MYOTHERAPY...
THESE AND MANY OTHER TREATMENT MODALITIES WILL BE COVERED AT THE CONFERENCE.

~~BECAUSE MANY OF THE PHYSICIANS ATTENDING ARE PULMONOLOGISTS, AND~~ MANY OF ~~THE SURVIVORS ARE VENTILATOR-USERS, WILL HAVE SEVERAL SESSIONS~~ NEED TO ALERT MEDICAL PROFESSION TO WATCH FOR UNDERVENTILATION AND SLEEP PROBLEMS check vital capacity ...FOR HIGH CO_2 LEVELS. which cause irritability - Headaches - unable to sleep at night, fall asleep in day —
IF ANY OF YOU ENCOUNTER THEM, TELL THE POLIO SURVIVOR ABOUT OUR IVUN...AND SEND THEM TO DR. OSCAR SCHWARTZ AT ST. MARY'S. HE IS A PULMONOLOGIST WHO HAS HAD CONSIDERABLE EXPERIENCE WITH POLIO SURVIVORS.

FINALLY, READ A SUMMARY OF THE LATE EFFECTS BY DR. JACQUELIN PERRY, DIRECTOR OF PATHOKINESIOLOGY AT RANCHO LOS AMIGOS IN DOWNEY, CA. THIS WAS PART OF A LETTER WHICH SHE GIVES TO PATIENTS SO THEY WILL UNDERSTAND THEIR PROBLEMS.....

"THE BASIC PROBLEM IS THAT POLIOMYELITIS DESTROYED SOME OF THE MUSCLE FIBERS AND THUS THE REMAINING MUSCULATURE HAS HAD TO FUNCTION AT A HIGHER DEMAND THAN NORMAL.

AS A RESULT, THE MUSCLES ARE WEARING OUT EARLIER.

QUALITATIVE MEASUREMENTS OF DIFFERENT GRADES OF PARALYSIS DEMONSTRATED THAT OUR MANUAL MUSCLE TESTS HAVE OVER-ESTIMATED THE AMOUNT OF RECOVERY.

FOR EXAMPLE, THE POST-POLIO 'NORMAL' STRENGTH IS AT LEAST 25% LESS THAN TRUE NORMAL AND MAY EVEN LACK 40%.

SIMILARLY, THE GROUP GRADED 'GOOD' IS ONLY 40% OF NORMAL.

THESE STRENGTHS ARE STILL ADEQUATE FOR A PERSON TO CARRY ON CUSTOMARY ACTIVITIES IN A NORMAL FASHION BUT AT A DEMAND THAT IS 2-2½ TIMES USUAL INTENSITY.

HENCE, THE MUSCLES HAVE BEEN EXPERIENCING STRAIN OVER ALL THESE YEARS WITH GRADUAL ACCUMULATION OF THE STRESS.

THE ABRUPT LOSS IN THE ABILITY TO FUNCTION RELATES TO TWO PHENOMENA. ONE, IS THAT ALL OUR PHYSIO ~~PSYCH~~OLOGICAL SYSTEMS HAVE A 'BUFFER ZONE' WHICH MAKES THEM ABLE TO ACCEPT STRAIN FOR A CONSIDERABLE LENGTH OF TIME WITHOUT SHOWING A FRANK LOSS.

ONCE ONE EXCEEDS THE BUFFER LIMIT, THE LOSS IS VERY PROMINENT.

SECONDLY, ACTIVITY SUCH AS WALKING OR LIFTING OBJECTS PRESENT FIXED MECHANICAL DEMANDS. AS LONG AS ONE'S MUSCLE STRENGTH

EXCEEDS THAT DEMAND EVEN
BY 2 OR 3% A PERSON CAN CONTINUE TO PERFORM IN A USUAL MANNER BUT IF THE STRENGTH GOES BELOW THE ESSENTIAL LIMIT, SUDDENLY THAT FUNCTION IS LOST."

THANK YOU.....

NOW, I'D LIKE TO INTRODUCE MY PARTNER, JUDITH RAYMOND ~~JUDITH WILL CONTINUE WITH INFORMATION ON PSYCHOLOGICAL PROBLEMS~~.

~~AND THE MUTUAL BENEFITS FROM THE SUPPORT GROUPS,~~

Gini spoke about the physiology of a polio survivor -- I'd like to talk about the psychology of a polio survivor.

There are really two categories of polio survivors: ~~those that~~ which Gini and I call "old" polios and "new" polios. ~~They~~ The "old" polios are the polio survivors who came through the acute phase very severely disabled, who have been using a wheelchair and/or a ventilator for the last 30 or more years.

The "new" polios are polio survivors who came through the acute phase only mildly disabled. They may have managed all these years with just a limp, a funny gait, a cane, or a brace, or a shoe lift. They have passed as "~~average~~ NORMAL". ~~all these years.~~

FOR THE MOST PART, it is this group of "new" polio survivors who are having the most problems with the late effects.

[redacted]

~~For the most part~~, polio survivors are generally resourceful, intelligent, adaptable. They are pushers and overachievers -- some theorists have even gone so far as to label them all Type A behaviors, but I think that is stretching it. Above all, they are not quitters.

After the ~~inital~~ acute phase, polio survivors pushed hard to walk again, to get rid of the brace, the cane, or the crutches, they ~~worked~~ struggled to get out of the iron lung. Many regained function through great physical and emotional effort. They correlated achievement and activity with individual worth.

If any of you P.T.s worked during the 50s epidemics, you pushed your polio survivors to do more. You encouraged them to believe that hard work cured polio. The message they heard was "If you just keep trying and try hard enough, you can do it." That message came not only from you therapists, but it came from physicians, from nurses, from parents, from teachers. and from the general public.

Polio survivors ~~were~~ mainstreamed themselves into our society ~~better than most disability groups~~. ~~And, essentially, they did it themselves.~~ Theirs was a socially acceptable disease. For a time, they received assistance and acknowledgement from the March of Dimes, until they were abandoned as March of Dimes moved on to a different cause, a different poster child. They were left to fend for themeselves, and they have done so for the last 25-30 years.

What happens Now to these overachievers, these pushers ~~now~~, these "new" polios as they are suddenly hit with unaccustomed and overwhelming fatigue, when they feel so weak they can't work a full 8 hour day or continue a daily household routine or even traverse the length of the local shopping mall?

They become depressed, frustrated, angry, stressful --- many feel as though they are facing the old polio all over again. They have worked hard to achieve both functional and economic independence, and now that is threatened. They are reluctant to return to the use of aids or adaptive equipment that would label them disabled. They see rest periods as a sign of giving up or giving in.

Since They have not been a part of the world of disability and are not as aware of the resources available.

Gerontological research has shown that when a person's level of functional independence is changed, some degree of depression is normal. Returning to the use of a wheelchair or a brace after struggling to overcome the need for one may activate some long-denied emotions that must be faced and dealt with.

The timing of these late effects is another factor - being faced with something you thought you had licked as a child or a teenager is much different now that ~~there is~~ you may have a spouse, children, job or career - daily life is much more complex. You may also be experiencing the climacteric.

This is where the value of support groups lies. In Support groups, ~~offer~~ polio survivors have a neutral forum where they can share their experiences, where they can share their anger, their frustrations. Once they move beyond that, they can start problem-solving -- they can trade techniques for having more energy, for maintaining mobility and independence, for managing pain or fatigue. They can compile a list of good bracemakers, a list of good therapists, of physicians who are willing to listen, of swimming programs in the area.

We have a wonderful support group that meets monthly in Crestwood, and it is truly a supportive group. We have been meeting since Sept. 1984 and are more like a large extended family. ~~And~~ There are over 155 support groups across the country that we coordinate and network with. Through the International Polio Network or IPN.

~~Let me tell you about~~ our even larger polio family - ~~the International Polio Network or IPN as we call it.~~

Via our network, We receive phone calls and letter from all across the U.S.: People want to know where a post-polio doctor or clinic is near them or support group. Most of them just want confirmation that there is indeed something physically wrong; that they are not neurotic, that it is not "just in their heads."

Unfortunately, there are still far too many physicians who have never seen a polio survivor, or a respiratory polio survivor, who have never learned about polio as a disease in medical school, who have never heard about post-polio syndrome, or if they have, won't admit it. Their excuses are no longer valid, because more and more articles are appearing in the medical literature; in JAMA, in NJEM, in Archives of PM & R. (biblio.)

In Canada, we network with polio survivors and health professionals in British Columbia, Alberta, Manitoba, Quebec, Newfoundland, and Ontario. West Park Hospital in Toronto just opened and already they have a mailing list.

In Europe, we network with the British Polio Fellowship, the Scottish Polio Fellowship, the German version of the March of Dimes -- Pfennigparade, which means Parade of Pennies. The Swedes, the Norwegians, the French, and the Italians have polio survivor associations, and our polio handbook is being translated into French, Itlian, German, and Swedish.

We receive reports from polio survivors organizations in Mauritius, in Zaire, in Singapore, in Austalia and New Zealand, and in Taiwan and Japan and Korea.

You can see that the network and the networking are extensive. We put people in touch with people for help -- whether it is a physician, a therapist, an equipment dealer, or another polio survivor who has found a solution. As Gini stated earlier the two most important things are information and people, and through the Network we do just that.

The membership of the IPN is closely involved with the upcoming polio & independent living conference in June. Many of those international polio survivors will be attending as well as the top physicians in post-polio.

On Thursday and Friday of the conference, we wil concentrate on the medical and physiological aspects of the late effects of polio, starting with the symptoms: muscle weakness, fatigue, pain, sleep, breathing, and swallowing problems. The panels on treatment will discuss exercise, weight control and nutrition, bracing and other orthotic devices, and the effects of environmental toxins by Dr. William Rea, also a polio survivor.

Dr. Lauro Halstead will moderate the post-polio research session, and I think we will be hearing some interesting new information. Two of the panelists will be discussing epidemiological studies they are working on: Dr. Jonathan Ramlow of Pittburgh and Dr. Anthony Windebank of Mayo Clinic. Since Mary Codd's estimate of 20-25% incidence of the late effects that Gini quoted, no one has confirmed that figure. Drs. Ramlow and Windebank may have data that increase the ~~statistics~~ percentage.

On Saturday, we move from the physiological to the psychological -- to adjustment, to adaptation, to coping,to the effects of the late effects on the family - husbands, wives, children.

Our conference banquet is always a conference highlight. This year we celebrate the 10th anniversary of the implementation of Section 504 of the Rehabilitation Act of 1973 which has come to be known as the Bill of Rights for persons with disabilities. To help celebrate, Ted Kennedy, Jr., who lost a leg to cancer, and James Roosevelt, son of FDr, who now is mildly idsabled due to Parkinson's disease will be honored guests. The new commissioner of the RSA, Justin Dart, Jr., will be with us - Justin is a polio survivor, and longtime advocate of independent living.

The final day of the conference will be an international forum - all of our friends from around the world who have come will discuss the cultural attitudes toward disability in their own courntries. Represented will be not only the polio survivors I described earlier, but Zhang Li from Beijing, China, disabled by cerebral palsy; Geurt Heykmaps, Spinal cord inj, FoKUS; Netherlands; Kate Jagoe, a quad/amputee, disabled advocate from S. Africa.

Our faculty list is impressive: what we call our "old" polio docs - Dr. Maynard, Own, Dalakas, Alba, Perry, Fischer, Spencer, Hugh Newton - John, Australia and some "new" polio doctors -- Dr. Neil Cashman, formerly of the University of Chicago Medical Center and now at the Montreal Neurological Institute, has been studying fatigue and the use of mestinon, and he will bre presenting new data. Dr. Jim Agre of University Hospital in Madison, WI is also working on fatigue, and he will be presenting. Many of these physicians are polio survivors themselves. There will also be many physical therapists speaking.

We hope you are sufficiently excited about the conference to attend, and to spread the word among your medical colleagues in St. Louis. We have not been successful in getting representation from the St. Louis medical community at the conference. Perhaps because St. Louis is not a rehabilitation town - it's a cutting town. Gini and I would appreciate any suggestions or advice.

Thank you for your attention. I'd like to introduce Nancy Caverly, an occupational therapist and polio survivor, who has some personal observations about the late effects of polio.

1987 - April 10

Post-Polio Syndrome: Meeting the Challenge. Polio Echo and Arizona Easter Seal Society. Speaker: "Polio Experience, Past, Present and Future."

Phoenix, Arizona

20 min PHOENIX
ARIZONA

~~HOUSTON~~ - POLIO SUPPORT GROUP - Feb 8, 1987

~~Jacoba Schneider~~ ~~Nita Weil~~

Polio Experience - Past, Present, and Future

THANK YOU, Ellen — and thank you for to good to ~~see~~ feel ~~the~~ your working ~~[illegible]~~ partnership ~~[illegible]~~

Great to see so many old GAZETTE FRIENDS and NEW NETWORKERS...Ellen – You're ~~[illegible]~~ a litany of friendships — ~~Thank~~

also Bobbie, Bob——
Jan
Marilyn—
mainly

Intertwined LONG TIME...since
Polio experience is my life.......Involved before born....

4 siblings.......

RESP CENTER....1949.... Epidemics....Wonderful human experience.
old or so / or so many kept alive – magic wand penicillin
Never so many on respirators....Physicans/patients learned together. Family & patients members of team.

Late 50's ...vaccines eliminated. At home. Two vital needs:
PEOPLE & INFORMATION....wanted to keep up & share experiences.... needed network to exchange information.

Joe-late
One way or another, husband & I started to meet needs: in 1958.

Built pool...first polio support group...Big annual.

RG...exchange info... support group...and an IL by mail.

Now RG ... 40,000.....87.....Japanese....library. .. All disabiliite
Non-profit..supported by donations (majority readers)...memberships & subscritpions. & Dedication of volupnteers.
Joe and I and our family and our friends and readers around world - all volunteered.

3 years ago made CHANGES SO COULD KEEP GOING after Joe & me.

Chgd name: GINI..big Gini...little. Reorganized board.

JUDY RAYMOND, who had volunteered ~~for 20 17 yrs~~ since 1967, became exec dir. a PARTNER

Reorganization timely...coincied with great increase in our polio network as result of late effects.

Although expanded...had never stopped maintinaing LIVING NETWORK. since I first started in 1949.

CONSEQUENTLY....<u>first</u> to notice late effects & to publish
facts...
<u>first</u> to organize a plan to confront the problem & to take the national & interational lead

All started in Tucson - * * * * * * * * * *

1979...letter....MD's not knowing...think psychological...
Had flood of mail from others with same problem.

FIRST PRIORITY...share info of older polio-experienced physicians with younger physicians. BEST WAY; bring older and younger together with polio survivors at conferenc

So, our organziation started international conferences....every other year.
UNIQUE...pay own way. Brown bags.

<u>1981</u> ... 125 attended...good nucleus of interested physicians..
Getting togeher started survivors thiniing about getting togher & supportingeach other.

3 Houston. support grp.... Feb 8, 1987

Immediately saw —
CONFERENCES NOT ENOUGH

Began to BROADEN AIMS OF CONFERENCES...

1. Encourage reserach
2. Need for psychological support through self-help groups
3. Importance of sharing polio experience of 30 yrs on ventilators with SCI, Musc Dys, ALS, etc.
4. Relate to all aging, all zging disabled.
5. Educate public & poliosurvivors in nonthreatening way.... Avoid "victims" suffereres"...patronizing & exploiting... pitiful brave cripples of the 1950s. Insist on dignity.... On self-help groups being self-help — running their own show.

50's Like a 'good [illegible] Aids —

1983 Conference... more than 400....40 on vent...7 lungs.

Support groups starting.

Attracted more & more MDs. Dr. Halstead asked to speak on sex & SCI. Fascinated by polio late effects. Joined with Dr. Dave Weichers to organize two scientific conf in in 1984, 1986

1984...Judith and I & Dr. Maynard & Dr. Fischer: Handbook.

medical model

Dr. M & Dr. F had both started helping at 1st conf... typical of concerned, caring physicians. Real - RDs...

They & other physicians attuned to LISTENING and appreciating the expertise of the survivors. Such as ~~your Dr. Spencer~~ Dr. YARNELL & Dr. PERRY ~~Dr. Valbona~~. Same type as at old resp ctrs....Polio seems t0 be magnet for best.

1985 CONFERENCE.... more than 500. Dr. Albert Sabin.
Dr. Masters of M & Johnson.

NETWORKING increases every time there is PUBLICITY with our address or phone number. If it isnt given, they sleuth.

Lines hum day & night. Most need to talk. Judith & I are good listeners.

If cant answer from library, we know someone who can.

Most need basic info that is in handbook, IPN newsletter or the Gazette.

Some need a simple bit of info_ shoe exchange

Some blame every physical problem on polio....arthritis... heart trouble...diabetes.... Even - story of breast/menstruati
impotency...obesity

Some more serious..special networking. Willa Schuster. vol 26
double-barrelled. , Network for people with aging parents _

Over years, Gazette involved in some large networking.

1960 - national attendant care
Mid-1960's - Talking books - Mrs. Cyrus Eaton C&O
1984 - Ventilators/HCFA
1986 - Russian polio survivor Simon, Tamara, Mark Levin

PSYCHOLOGICAL

BUT as you know MOST OF THE SURVIVORS' PROBLEMS ARE PSYCHOLOGICAL...
THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLE.

The majority of you survivors are relatively mildly disabled. You passed for normal. You adjusted. You overadjusted. You ~~were conditioned to~~ compensate~~d~~. You overcompensated.

You lived for 30 years with a limp or a cane... You had been conditioned against w/c & Looking disabled
Untouched by world of disability,

by problems of discrimination & prejudice,

by the barriers of steps & inaccessible bathrooms.

& fights for ~~504~~ rights through 504 –

NATURALLY, when you began to experience late effects & began to use wheelchairs or other trappings of disability, you faced overwhelming psychological adjustments.

YOU NEEDED HELP & UNDERSTANDING...
YOU NEEDED A NETWORK OF PEOPLE with whom you could share those long-denied feelings and emotions.
YOU NEEDED A CENTRAL SOURCE OF POLIO INFORMATION.

FORTUNATELY, Our G.I.N.I. organization was there with the information & networking you needed to interlock the support groups that you began to form after ~~the~~ our 1983 polio conference.

At the 1985 conference, GINI was asked to coordinate the

support groups & tie them in with its existing longtime polio networking.

So, we formalized IPN (International Polio Network).....

Started quarterly newsletter, Polio Network News

Sponsored a workshop of the leaders of the support groups - '86 (wonderful gathering of talent & creativity. Can you imagine 50 Ellen Pitchers in one room?)

It is AMAZING what we have all accomplished TOGETHER - the support groups....the physicians....and ~~our~~ GINI's International Polio Network....all in such a short time.

And, it is a short time.

We only started in 1979 with that Tucson letter -

Now the problems of the late effects are being recognized by medical community & gen public

And, through your support groups you reaching more & more survivors.

National TV coverage - Chas Kuralt Sunday Momming, Nightline, Today Show, Cable Network News, "Hour" Magazine last Tues.... and, of course, local fealtures.

Articles in NEW YORK TIMES....prestigious medical journals, the latest in Archives of PM&R.

RESEARCH...funded by National Inst on Dis & Rehab Research, March of Dimes, Easter S.

Now...looking forward to our next conf on Polio & Indep Living. June 4-7, this year...in St. Louis at the Sheraton.

~~Judy will tell you more about it.and about the International Polio Network.....~~

But, I especially wa-nt to invite ~~Texans~~ ARIZONANS to attend.... some of the other states' support groups areplanning to come together in caravans....with this great group, you should have a super caravan.

We look forward to seeing you in St. Louis

Thank you.

1987 - April 11

Southern Arizona Conference on the Alte Effects of POlio. Sponsored by PolioEpic, Northwest Hospital, etc. Speaker: Overview.

Tucson, Arizona

10 minutes

TUCSON POLIO SUPPORT GROUP

April 11, 1987

Good morning

"OVERVIEW"

Dr Larsen · thank you, Ernie, & Northwest Hospital & everyone else who has been involved in creating this very successful conference

THANK YOU....~~great to see old Tucson Gazette friends~~

and ~~so many new networkers~~....

and thank you for your cordial & jovial hospitality & all your graciousness!

Overview...... Been overviewing polio all my life....

two sisters and brother died of polio.

1949...epidemics...started volunteering...hotpacks...

By late 50's...vaccines...polio stopped...At home...

Two vital needs: PEOPLE & INFORMATION...wanted to keep up with others & share experiences...needed network to share information.

One way or another...Joe ( ) & I started to meet needs. In 1958 built <u>pool</u>....first polio support group...Big annual.

RG...exchange info...support group & IL by mail.

NOW RG....40,000.....87....Japanese....library... All dis. Non-profit...supported by donations (Majority disabled)..and memberships & subscriptions....and by dedication of volunteers.

Although expanded....never stopped LIVING POLIO NETWORK started in '49...

CONSEQUENTLY....<u>first</u> to notice late effects...

first to publish facts

first to organize a plan to confront the problem

first to take national & international lead.

. . . .

A letter from Larry Schneider of Tucson was the catalyst.

Published in 1979 G.....flood of letters with sameproblems: aging & no M.D. understaod.

<u>First priority</u>...share info of older polio-experienced physicians with younger physicians.

Asked M.D.s what <u>best way</u>. Bring together with polio survivors at conference.

So...our organization started conferences in 1981...every other year since. Conferences unique. Pay own way..."Brown bags"

In 1984.....Judith & I, Dr Maynard & Dr. Fischer: <u>Handbook</u> "the Bible"...... Dr. M & Dr. F. started helping at 1st conference. Dr. Perry & Dr. Yarnell little later. Never stopped. Typical of concerned, caring physicians. Medical degree: RD.

[redacted]

Their medical help is invaluable –

PSYCHOLOGICAL

BUT MOST OF THE SURVIVORS PROBLEMS ARE PSYCHOLOGICAL... THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLE.

The majority of you survivors ~~are~~ were left relatively mildly disabled. You passed for normal. You adjusted. You overadjusted. You compensated. You overcompensated.

You lived for 30 years with a limp or a cane... ~~You avoided disability~~ Untouched by world of disability,

by problems of discrimination & prejudice,

by the barriers of steps & inaccessible bathrooms.

NATURALLY, when y9u began to experience late effects & began to use wheelchairs or other trappings of disability, you faced overwhelming psychological adjustments.

YOU NEEDED HELP & UNDERSTANDING...

YOU NEEDED A NETWORK OF PEOPLE with whom you could share long-denied feelings and emotions.

YOU NEEDED A CENTRAL SOURCE OF POLIO INFORMATION.

FORTUNATELY, Our G.I.N.I. organization was still there with the information & networking you needed to interlock the support groups that you began to form after ~~the~~ our 1983 polio conference.

It is amazing what we have all accomplished TOGETHER --
the support groups - the physicians - and GINI's International
Polio Network......all in such a short time.

And, it is a short time...
From that letter from Tucson in the 1979 issue of the Rehab Gazette –

Now the problems of late effects recognized by medical
community & general public

And, through your support groups reaching more & more survivors.

There's national TV coverage...
Articles in prestigious medical journals.
Research being funded by National Institute on Disability
& Rehabilitation Research, NIH March of Dimes, & Easter Seal.

Now...looking forward to next conf on Polio & Indep Living.
June 4-7 of this year...in St. Louis at the Sherastoa Hotel.

Judy Jr will tell you moee about it and about the International
Polio Network....

We look forward to seeing many of you in St. Louis. especially Ernie and
~~your president~~ some professional persons from this hospital

Thank you......

Judy Raymond

TUCSON, APRIL 11, 1987

Gini has described part of our organization's services. ~~and~~ Certainly a large part of our work in the last few years has been ~~the~~ our International Polio Network. The latest post-polio directory ~~should have reached you by now, and you will have noted that there are~~ includes over 155 support groups across the country, not including those in Canada and the rest of the world, ~~and~~ 42 post-polio clinics, and additionals physicians & health professionals who know about post-polio, but who don't have a clinic.

Most of our work in the Network involves answering questions from polio survivors: first, do I have it? where do I find a doctor or a therapist who knows about the late effects of polio? where is there a support group in my area? And if there isn't one, how can I start one? What do I do when I'm turned down for disability benefits by Social Security or Insurance? Most of what we do is just listen - I think Gini and I have earned honorary social work degrees. Health professionals also get in touch with us for information on polio research projects or for suggestions or biblio of medical journal articles or statistics about the best speakers for post-polio meetings such as this.

Our networking is not confined to the U.S. The international post-polio directory that we are updating lists people from Australia to Zaire. Our polio handbook has been translated into Swedish and Chinese, and translations are in progress in French, German, and Italian. And we ~~There~~ are in touch w/ organizations of polio survivors in Norway, in England, in Denmark, in France, in Mauritius, (the island off the east coast of Madagascar in the Indian Ocean), in Taiwan, and in Lesotho.

The most vital role of our Network is putting people in touch with people - whether it is a physician, a therapist, a ventilator equipment dealer, an orthotist, or another polio survivor who has found a solution to a similar problem. As Gini stated earlier, the two most important things are people and information, and that is precisely what we connect.

Our upcoming conference in June is a perfect example of our networking and our internationality. Our faculty list is extensive and impressive: most of the directors of the best post-polio clinics in this country will be in attendance, including your speakers today - of course. We will have some "new" polio doctors: Dr. Neil Cashman, who used to be with the University of Chicago Medical Center and is now with the Montreal Neurological Institute will present his findings ~~nutrition +~~ Stet on fatigue, & ~~as will~~ Dr. Jim Agre from the Madison Wisconsin post-polio clinic. will speak also on fatigue Dr. William Rea, himself a polio survivor, will present his recent studies on environmental influences affecting polio survivors.

Dr. Gow from New Zealand / Dr. Spencer England
Dr. Newton - John " Australia

Two panelists on the polio research session will be discussing current epidemiological studies: Dr. Jonathan Ramlow of the University of Pittsburgh and Dr. Anthony Windebank of Mayo Clinic.

You may remember reading Mary Codd's article that we reprinted in the Polio Network News last year. Dr. Codd came up with the first figures on the percentage of polio survivors who may experience the late effects of polio. Since her study in 1984 which reported between 20-25% of 300,000 no one else has done a significant epidemiological study to confirm that percentage. It will be interesting to see if Drs. Ramlow and Windebank up that percentage.

We've also been promised 2 Chinese representatives to discuss post-polio in PRC

That's the working side of the conference. But even if we scrapped the program, it still would be a terrific conference, because it simply brings together a great many wonderful people from all over the world.

If you come, you will meet polio survivors from # # Sweden, New Zealand, Lesotho, ETC.

The last Polio Network News reported that the Social Security Administration had placed a moratorium on all issuances going out to the district offices and state agencies, which means that the proposed program circular on post-polio and the revisions for their POMS manual are delayed. I talked with our mole in SSA and she said that the moratorium is in effect until mid-May.

This does not mean that you cannot obtain a favorable reply if you must file for Soc. Sec. Dis. Ben. due to the late effects of polio. It just means that the district office personnel will not be as well informed as they could be when you first appear, because

The medical listing for polio is still in effect. The best ammunition that you can have if you have reached the point where you must apply for social security disability is as much medical evidence and documentation as possible. Try to obtain your hospital records from the acute stage, because it first must be established that you did indeed have polio. Present a diary or a record of when work became limiting. You can't just say, "I'm tired, I can't do it anymore." You must say, "I'm tired. I used to be able to six blocks, and now I can only do three." You must put some measurement on what you are able to do now as opposed to what you used to be able to do.

If you think there may come a time when you might have to file, get a good medical evaluation now, and use it as a baseline against which to measure your health 6 months or a year ahead.

If you have difficulty finding a sympathetic ear when you first apply at the district office do the same as you would if you were returning a product at a department store and the clerk is being uncooperative. ~~was giving you trouble~~: ask to see the supervisor and keep asking until you get to a higher level. The people at SSA HQ in Baltimore have told us that they cannot really help - that the decisions rest with the local office. But HQ will be a help once the moratorium is lifted and the post-polio instructions can be issued.

Thank you ...

1987 - April 25

Post-Polio Workshop. Abilities Expo '87. Los Angeles Convention Center. Keynote speaker.

Los Angeles, California

ABILITIES EXPO 87

Post-Polio Workshop....Saturday, April 25

9 am to 4 pm

Opening speaker: GL History...STate of art of support groups

25 minutes

THANK YOU.....DELIGHTED TO BE IN THE LAND OF RANCHO LOS AMIGOS - THE MECCA OF RESPIRATORY POLIO SURVIVORS - BECAUSE HAVE SO MANY OLD FRIENDS ON RESPIRATORS (V~~ENTILATORS~~ HERE ~~NOW)~~. WITH WHOM I HAVE CORRESPONDED FOR 30 YEARS ... and some of whom I have never met —

ASKED TO DO HISTORY OF POLIO & POLIO SUPPORT GROUPS.

POLIO PART OF LIFE - SINCE BEFORE I was born

EASY..BECAUSE LIVED THAT HISTORY...TWO SISTERS & BROTHER DIED. SO STARTED VOLUNTEERING DURING 1949 EPIDEMIC &NEVER STOPPED.

STARTED BY DOING HOTPACKS AT TOOMEY PAVILION ~~IN CLEVELAND, OHIO'S CITY HOSPITAL. I~~ WHICH T BECAME ONE OF 16 RESP CTRS IN US. SET UP BY M OF D.

THE LARGEST AND ~~ONE OF~~ THE LONGEST-LIVED HERE AT RANCHO.

RANCHO WAS PIONEER OF SYSTEM OF HOME CARE FOR RESPIRATOR-DEPENDENT PEOPLE. STARTED IN 1953 TO SAVE MONEY. ($10 DAY AT HOME VS $30 AT HOSP). THAT SYSTEM COPIED OTHER CTRS ALL OVER U.S. PEOPLE WENT HOME WITH M OF D FUNDING, AVERAGING $300 A MONTH FOR ATTENDANT.

BUT BY LATE '50S VACCINES STOPPED POLIO & PEOPLE STOPPED GIVING TO M OF D. SO, M OF D STOPPED FUNDING THE CENTERS AND HOME CARE. ATTENDANTS ~~IN [illegible]~~ —

THIS TRIGGERED ACTION BY MEDICAL DIRECTORS OF THE TWO CALIFORNIA CENTERS - DR. LEON LEWIS AT FAIRMONT HOSP IN S.F. AND DR. JOHN AFFELDT AT RANCHO.

WORKING WITH THEIR FORMER PATIENTS, THEY EFFECTED THE ATTENDANT CARE LEGISLATION WHICH IS STILL ENABLING DISABLED & ELDERLY PEOPLE TO LIVE AT HOME AND WHICH WAS THE CATALYST FOR THE BERKELEY INDEPENDENT LIVING MOVEMENT.

MEANWHILE, I WORKED AT THE CENTER IN OHIO UNTIL IT CLOSED AND KEPT UP WITH MY OLD POLIO PALS WHO HAD GONE HOME FROM THE CENTER.

IT BECAME APPARENT THEY HAD TWO VITAL NEEDS: PEOPLE & INFORMATION. WANTED TO KEEP WITH OTHERS...WANTED TO SHARE INFORMATION.

ONE WAY OR ANOTHER, MY LATE HUSBAND, JOE, AND I STARTED TO MEET THOSE NEEDS.

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#3

THAT TRIGGERED OUR TOOMEY TO ACTION TOO —

CONSEQUENTLY, WHEN M OF D STOPPED FUNDING ATTENDANTS, WE LED NATIONAL CAMPAIGN BY READERS TO WRITE TO THEIR CONGRESSMEN TO TRY TO EFFECT NATIONAL ATTENDANT CARE LEGISLATION.

DIDNT HAVE THE SUCCESS OF CALIFORNIA.
STILL DONT HAVE NATIONAL...ONLY FEW STATES

OUR ATTENDANT CARE ADVOCACY WAS UNSUCCESSFUL....BUT, SINCE THEN, HAVE USED NETWORK TO WORK TOGETHER WITH POLIO SURVIVORS & OTHER PEOPLE WITH DISABILITIES TO EFFECT LEGISLATION AND POLICY....

O TOGETHER, WE CHANGED THE TALKING BOOKS PROGRAM FROM ONE EXCLUSIVELY FOR BLIND TO ALL DISABILITIES.

O TOGETHER, WE STOPPED HCFA FROM FUNDING more than 1 vent ~~LIMITING INDIVIDUALS TO ONLY ONE VENTWLATOR~~.. EXPLAIN Medicaid/medicare

O MOST RECENTLY, TOGETHER WE INFLUENCED THE SOVIET UNION TO RELEASE A REFUSENIK POLIO SURVIVOR WHO HAD BEEN KEPT APART FROM HER HUSBAND FOR SEVEN YRS.

EVENTUALLY,
WE EXPANDED TO INCLUDE ALL DISABILITIES
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A NETWORK AND AN INFORMATION CENTER.......

WE CHANGED OUR PUBLICATION'S NAME TO <u>REHABILITATION GAZETTE</u>....
WE CHANGED OUR UMBRELLA ORGANIZATION TO GAZETTE INTERNATIONAL NETWORKING INSTITUTE....G.I.N.I. SO BIG . LITTLE GINI

#4

NOW....WE REACH 40,000......87.....JAPANESE...LIBRARY....
NONPROFIT, SUPPORTED BY DONATIONS (MAJORITY DISABLED)
& MEMBERSHIPS & SUBSCRIPTIONS
AND BY DEDICATION OF VOLUNTEERS.
VOLUNTEERS IN THE OFFICE
AND VOLUNTEER WRITERS - ALL ~~THE~~ OF YOU WRITERS ARE PEOPLE WITH DISABILITIES. ~~THEY~~ YOU SHARE THEIR LIFESTORIES & THEIR EQUIPMENT IDEAS.

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ALTHOUGH EXPANDED...NEVER STOPPED OUR LIVING POLIO NETWORK.

CONSEQUENTLY...FIRST TO NOTICE LATE EFFECTS
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IN 70's

HAD NOTICED INCREASING RESPIRATORY PROBLEMS & PEOPLE RETURNING TO NIGHT VENTILATORS...BUT LATE EFFECTS INVOLVING LESS SEVERELY DISABLED DIDNT HIT US UNTIL PUBLISHED LETTER FROM SURVIVOR IN TUCSON IN 1979 ISSUE OF <u>GAZETTE</u>.....FLOOD OF LETTERS..SAME PROBLEM: AGING & M.D. NOT UNDERSTANDING.

<u>FIRST PRIORITY</u> SHARE INFO OF OLDER PHYSICIANS WITH YOUNGER.
ASKED M.D.S BEST WAY. CONFERENCE.

SO, STARTED CONFERENCES IN 1981...UNIQUE. PAY OWN WAY...BROWN BAGS. EVERY OTHER YEAR SINCE....

#5

ORGANIZED A STAFF + BOARD

GREAT TREASURE

IN 1984......JUDITH RAYMOND (PARTNER & EXECU DIR) AND I AND DR. A. FISCHER OF RANCHO & DR. Fred MAYNARD of Ann Arbor..WROTE HANDBOOK... "BIBLE" OF BASIC FACTS ON LATE EFFECTS - GOOD FOR SURVIVORS & EDUCATING YOUR PHYSICIANS.

DR. FISCHER, DR. MAYNARD, DR. PERRY AND OTHERS ARE TYPICAL OF THE CONCERNED, CARING PHYSICIANS WHO HAVE BEEN HELPING WITH THE CONFERENCES AND PUBLICATIONS...
MEDICAL DEGREE: RD.

THEIR MEDICAL HELP INVALUABLE...BUT
MOST OF THE PROBLEMS OF YOU~~R~~ SURVIVORS ARE PSYCHOLOGICAL...
THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLE.

MOST OF#YOU LEFT RELATIVELY MILDLY DISABLED SO YOU COULD "PASS" FOR NORMAL.
BUT..YOU OVER-ADJUSTED AND YOU OVER-COMPENSATED AND YOU OVERUSED ALREADY WEAKENED MUSCLES.

NATURALLY...
~~UNCONSCIOUSLY OR CONSCIOUSLY~~ YOU SCORNED WHEELCHAIRS AND OTHER TRAPPINGS OF DISABILITY.
SO, WHEN YOU HAD TO USE THEM, YOU FACED OVERWHELMING ADJUSTMENTS.

YOU NEEDED HELP & UNDERSTANDING.
YOU NEEDED NETWORK OF PEOPLE - SHARE LONG-DNIED FEELINGS.
NEEDED CENTRAL SOURCE OF POLIO INFORMATION.

FORTUNATELY......
OUR G.I.N.I ORGANIZATION WAS STILL THERE WITH THE INFORMATION & NETWORKING YOU NEEDED TO INTERLOCK THE SUPPORT GROUPS THAT

AS YOU RANCHO PEOPLE KNOW, A FEW LONGTIME SUPPORT GROUPS KEPT GOING AFTER THE 50'S...THE LARGEST OF THESE IS YOUR POLIO SURVIVORS ASSOCIATION.

~~SO MANY NEW ONES HAVE SPRUNG UPAROUND THE COUNTRY THAT~~ THERE ARE NOW NEW 155 SUPPORT GROUPS AND 42 POST-POLIO CLINICS.

WE HAVE MELDED TOGETHER ALL THESE AUTONOMOUS GROUPS IN THE INTERNATIONAL POLIO NETWORK WHICH WE COORDINATE FROM OUR HEADQUARTERS IN ST.L.

AS YOU WILL SEE (HOLD UP IPN PAGE) ON THE TAN ORDER FORM IN YOUR KITS, WE HAVE A SMALL MEMBERSHIP FEE FOR THE NETWORK WHICH ENTITLES YOU TO A QUARTERLY NEWSLETTER & AN ANNUAL LIST OF SUPPORT GROUPS, CLINICS, AND RESOURCES.

ALSO LISTED ARE THE HANDBOOK, THE PROCEEDINGS OF THE CONFERENCES, AND BACK ISSUES OF THE GAZETTE WHICH ARE DEVOTED TO THE LATE EFFECTS, INCLUDING RESPIRATORY PROBLEMS & SOLUTIONS.

MOST OF OUR WORK IN NETWORK INVOLVES ANSERING QUESTIONS FROM POLIO SURVIVORS....

WHERE DO I FIND A PHYSICIAN OR THERAPIST WHO KNOWS ABOUT THE LATE EFFECTS?

WHERE IS A SUPPORT GROUP NEAR TO ME?

ONE OF THE MOST FREQUENTLY ASKED QUESTIONS IS "HOW DO I START A SUPPORT GROUP?"

#7

THE ANSWER IS: YOU JUST START...START WITH ONE OTHER PERSON. MEET IN A HOME....GET LOCAL RADIO & NEWSPAPER OR TV TO MENTION IT....

PUT SIGNS UP IN THE GROCERY STORES OR WHEREVER THERE ARE BULLETIN BOARDS.

AS YOU GROW, YOU MAY WANT TO MEET IN A CHURCH, OR REHAB CENTER, OR VOLUNTARY AGENCY, OR INDEP LIVING CENTER.

LET THE GROUP GROW NATURALLY...EVOLVE AS IT FITS THE WILL OF THE GROUP.

BUT NEVER LOSE SIGHT OF THE PURPOSE OF A SELF-HELP SUPPORRT GROUP. IT IS SELF-HELP.

WE'VE FOUND A GOOD DEFINITION OF A SELF-HELP GROUP – THE ONE USED BY THE SURGEON GEN'S PLANNIG COMMITTEE ON SELF-HELP GROUPS & PUBLIC HEALTH. I'M A MEMBER OF THAT COMMITTEE AND I'VE LEARNED GREAT DEAL BOUT EXCITING MOVEMENT.

I WAS OVERWHELMED TO DISCOVER NOW 15 MILLION PERSONS IN MORE THAN ½ MILLION SELF-HELP GROUPS IN U.S.

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"A SELF-HELP SUPPORT GROUP IS A COLLECTION OF INDIVIDUALS WHO SHARE A COMMON CONCERN, PROVIDE EMOTIONAL SUPPORT TO EACH OTHER, GOVERN THEMSELVES, AND CHARGE MEMBERS LITTLE OR NO FEES FOR THEIR INVOLVEMENT IN THE GROUP.

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#9

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OUR INTERNATIONAL POLIO NETWORK IS NOT CONFINED TO THE U.S. OUR HANDBOOK TRANSLATED INTO SWEDISH & CHINESE, AND TRANSLATIONS IN PROGRESS IN FRENCH, GERMAN, & ITALIAN.

SUPPORT GROUPS OF THE AMERICAN TYPE ARE UNIQUE..BUT THERE ARE ORGANZIATIONS OF POLIO SURVIVORS ALL OVER CANADA AND IN NORWAY, ENGLAND, DENMARK, FRANCE, MAURITIUS, AND TAIWAN.

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OUR UPCOMING CONFERENCE - JUNE 4-7, AT THE SHERATON HOTEL IN ST. LOUIS IS A PERFECT EXAMPLE OF OUR NETWORKING & INTERNATIONALITY.

#10

OUR FACULTY IS EXTENSIVE AND IMPRESSIVE: MOST OF THE DIRECTORS OF THE BEST POST-POLIO CLINICS WILL BE IN ATTENDANCE, INCLUDING DR. PERRY Jr - OF COURSE. + Dr. Fischer

WE WILL HAVE SOME "NEW" POLIO PHYSICIANS...AND SOME NEW APPROACHES TO THE PROBLEM, SUCH AS THE ENVIRONMENTAL INFLUENCES.

BOTH PHYSICIANS AND SURVIVORS ARE COMING FROM AROUND THE WORLD - FROM ASIA, AFRICA, AUSTRALIA, CENTRAL & SOUTH AMERICA, CANADA, EUROPE AND UNITED KINGDOM.

FOR INSTANCE, THERE ARE MORE THAN 25 COMING FROM JAPAN AND 16 FROM NEW ZEALAND. THE GOVERNMENT OF LESOTHO IS SENDING THE HEAD OF THE DISABLED ASSOCIATION THERE. AND DR. HUGH NEWTON-JOHN FROM AUSTRALIA - WHOSE SISTER IS OLIVIA - WILL BE A SPEAKER.

THAT'S THE WORKING SIDE OF THE CONFERENCE. BUT EVEN IF WE SCRAPPED THE PROGRAM, IT STILL WOULD BE A TERRIFIC CONFERENCE BECAUSE IT SIMPLY BRINGS TOGERHR A GREAT MANY WONDERFUL PEOPLE FOM ALL OVER THE WORLD .

I HOPE MANY OF YOU HERE TODAY WILL BE THERE. IT WILL BE AN UNFORGETTABLE EXPERIENCE.

THANK YOU AGAIN...I CANT WAIT TO TALK TO MANY OF OUR OLDTIME GAZETTE FRIENDS....~~SOME OFYOU I'VE KNOWN FOR 30 YEARS AND~~ ESPECIALLY those with whom WE'VE NEVER MET....BEFORE ——

1987 - May 9

Polio: Living with Its Late Effects. Sponsored by D.T. Watson Rehabilitation Hospital, Pittsburgh Post-Polio League and the West Penn Chapter of the March of Dimes. Speaker: "The Polio Experience: Past, Present and Future."

Coraopolis (Pittsburgh) Pennsylvania

PITTSBURGH.....POLIO: LIVING WITH ITS LATE EFFECTS

SHERATON INN-AIRPORT, CORAOPOLIS PA 15108 SAT, MAY 9, 1987

TOPIC: THE POLIO EXPERIENCE: PAST, PRESENT AND FUTURE

11:30 TO 12:15 PM

THANK YOU.....DELIGHTED TO BE HERE....I'M LOOKING FORWARD TO MEETING SOME OF OUR LONGTIME PITTSBURGH READERS WITH WHOM I HAVE CORRESPONDED FOR 30 YEARS - BUT HAVE NEVER MET.

YOU ASKED ME TO TALK ABOUT THE POLIO EXPERIENCE: PAST, PRESENT, AND FUTURE.

EASY..BECAUSE LIVED THAT HISTORY ALMOST MY autobiography...TWO SISTERS & BROTHER DIED. SO STARTED VOLUNTEERING DURING 1949 EPIDEMIC &NEVER STOPPED.

STARTED BY DOING HOTPACKS AT TOOMEY PAVILION IN CLEVELAND, OHIO'S CITY HOSPITAL. IT BECAME ONE OF 16 RESP CTRS IN US. SET UP BY M OF D. THE LARGEST AND ONE OF LONGEST-LIVED ~~HERE~~ AT RANCHO.

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#2

Polio – good kid Aids – Money had poured in to M of D – funded centers – all medical treatment – equipment, attendants etc –

BUT BY LATE '50S VACCINES STOPPED POLIO & PEOPLE STOPPED GIVING TO M OF D. SO, M OF D STOPPED FUNDING THE CENTERS AND HOME CARE.

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#6

~~AS YOU RANCHO PEOPLE KNOW, A FEW LONGTIME SUPPORT GROUPS KEPT GOING AFTER THE 50'S...THE LARGEST OF THESE IS YOUR POLIO SURVIVORS ASSOCIATION.~~

AFTER 1893 conf support groups started to spring up

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slips on resource tables Is that

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(Spanish – New – announced at L.A. & someone raised hand – Chile – Magic

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1987 - May 7-8

Meeting with staff and family on Ventilator Dependency at Harmarville Rehabilitation Center. Speaker.

Pittsburgh, Pennsylvania

Pittsburgh...Harmarville

Family/Staff on Ventilator-Dependent 2hrs.

Lifelong involvement with disability...siblings.

36 years experience with ventilator-dependency.

Toomey.....pediatiricans...no experts...never before so many or so many older. Therefore, mutual learning experience.

Team - all disciplines & patients/families. ~~Dediced~~ Decided with patients.

17 resp ctrs shared expereiances.

GL watched phases. 1. watched discover they were over-weaning.
Brought back for re-evaluation. Home with night aid.
Watched discover over-ventilation. Addictive.
At first stay in hospital. After Rancho in 1953 & MofD funding, home with attendant care. II.
Watched development of rocking bed, chestpiece. Oral pos.

Trachs...watched development of prophylactic trach. If acutely ill, did before needed. Used until could without suchioning. Then closed or few with plug. MDs now too trach-minded.

Spirit of helping, sharing, caring. Kept going...still going.
Reason for developing RG & swimming support group....

Never thought of RN...trained patient to train attendant... to take care of equipment....(Rancho started with training attendants. Soon learned.) Suzy Williams.

After MofD cut back attendants..RG full of ideas of inexpensiv attendants...Mexican other Spanish-speaking...mental hosp.. high school..elderly...teams...other disbled..widows... foster care...change...change...

Dors
Ill. Rehab

Attitudes.....use ~~Expo~~...

What is going on now.....Good book...THE HOME HEALTHCARE SOLUTION. by Janet Zhun Nassif Harper & Row, 10 E 53rd NYC 10022. $12.85.

Children....Julie Beckett of Iowa

Waiver...Reconciliation Act of 1981.... Medicaid...

SKIP...Sick Kids Need Involved People. Founder: Karen Shannon.
216 Newport Dr, Severna Park, MD 21146. 301-647-0164
Has written a parent training & skills manual.

IVUN....(TAKE SAMPLES)...

LIFECARE....repr all over country. 655 Aspen Ridge, Lafayette,
Colo. 80026. 1-800-525-0501

HCFA....1984....

Work with any of good local home care with respriatory services whom your respiratory therapists recommend.

Article in FOCUS ON CRITICAL CARE....Home Ventilation. An Alternative to Institutionalization. By Ruth M. Frace.

Many good suggestions. <u>But</u> skilled nursing care @ $12,960 per
Per month Total; $14,635 with rental of equip)
month (Hospital: ICU room, $24,000, ventilator, $3,600,
Suction equipment, $3,000. Total: 30,600)

Home cmmpared to Hosp.

1. Obviously, more relaxing for family & dis indiv.
2. Nutrition, better
3. Dont move the hosoutal to the home.....

   Accomlplish same ends, without the rigidity.
4. Not cross infection. Home-made germs.
5. Dont have 24-hour attendants....Train family..Let them take part in care... Need to be alone...Need to bond and relax....
6. If family takes complete care, be sure they have respite.

Double barreled problem ... Parents for 30 yrs...

Vol 27. No. 1. Wilma Schuster.

Sources of information...case histories...& equipment

Back issues of RG...Covers.

Proceedings of 83 & 85 & forthcoming 87.

Equipment...portable iron lungs...rocking beds...

self-aspirators...windshild wiper suction.

oral pos pressure.....volume ventialtors...

1978...summary of respirators...making chestshell.

SHOW SLIDES OF 1983 VENTILATOR-USERS AT CONF...INVITED TO 1987 C

HISTORY OF POLIO SUPPORT GROUPS

BY GINI LAURIE

AUGUST 21, 1987

HISTORY OF POLIO SUPPORT GROUPS

The polio support groups of the 1980s are a natural evolvement for polio survivors who learned from onset to share and help each other because their treatment was prolonged and in groups at contagious wards, children's hospitals, respiratory centers, or rehabilitation centers. Former patients thought of themselves as "alumni" of the centers and those many months of friendships and pranks, intertwined with treatment, are still recalled thirty or even sixty years later.

The first polio support group was created by President Franklin Delano Roosevelt in the hot swimming pool at Warm Springs, Georgia, shortly after he was disabled by polio in 1921. He gathered recuperating polio disabled children around him because he liked company and wanted to share the benefits of hydrotherapy. Warm Springs continued as a center for longterm care for nonrespiratory polio survivors until polio was eliminated by the vaccines in the late 1950s and those days live on in the childhood memories of its "alumni."

In the early 1950s, polio struck people of all ages-it no longer was "infantile" paralysis. With improved medical management, people with respiratory involvement were saved. To meet their needs, the National Foundation for Infantile Paralysis (March of Dimes) created and funded 17 respiratory polio centers and around the country from 1951 to 1959.

From these centers, in which people spent months and years together adjusting to life with iron lungs or portable respirators, evolved strong feelings of togetherness, or mutual support, of warm friendships, and a need to keep in touch to share information and experiences after they have returned to their homes.

For a few years after the respiratory centers closed, the "alumni" of some of them fostered support groups meetings of their fellow "alumni" and published mimeographed newsletters of their at-home doings. Among these were the groups in San Francisco, Buffalo, Omaha, Houston, Ann Arbor, and Cleveland. For a few years, too, nonrespiratory survivors shared newsletters from Sister Kenny Institute and Warm Springs and a group met as the Chicago Polio Swim Club.

Eventually, they all faded away except two. The Los Angeles group was revived as the Polio Survivors Association, primarily for advocacy for ventilator users. Gini Laurie, who had been volunteering since 1949 at the Cleveland respiratory center Toomey Pavilion, created a publication and an organization that still flourishes. The publication, <u>Rehabilitation Gazette</u>, evolved into the Gazette International Networking Institute (G.I.N.I.), a national and international information center, network, and journal that is coordinating the present day polio support groups and international polio conferences as the International Polio Network.

Starting in 1958, the Cleveland "alumni" had large annual picnics at Gini and Joe Laurie's and daily summer "support group" working gatherings of survivors and volunteers in and around their swimming pool. Together they wrote the <u>Gazette</u> and answered requests for information.

With a volunteer staff of alumni of the Cleveland and other respiratory polio centers, the Gazette became the only national organization of polio survivors.

Consequently, it was quick to respond to the fright of its readers when the March of Dimes ceased funding attendant care for polio survivors in 1959. The Gazette led an unsuccessful national letter-writing campaign to urge Congress to pass national attendant care legislation. However, in California, the 1960 campaign by the alumni of the two centers resulted in permanent state legislation for attendant care.

A few years later, at the instigation of a polio survivor, the Gazette led a successful national campaign to expand the the Talking Books program for the blind to include people with physical disabilities.

The Gazette continued to expand in the 1960s and the 1970s into an international journal devoted to independent living for people with all disabilities. Yet, it never ceased to maintain a living network of polio survivors aroung the world. Consequently, in 1979, it was the first to notice and to publish the problems its readers were having with the late effects of polio and with younger physicians whose education had not included polio.

In 1980 Gini discussed these late effects with Dr. David Dickinson of Ann Arbor, Dr. Robert Eiben of Cleveland, and Dr. Allen Goldberg of Chicago. Dr. Dickinson referred Gini to Dr. Frederick Maynard, a physiatrist, who had seen a few polio survivors with the problem. Together, they planned an international polio conference.

The Gazette's first international polio conference in Chicago in 1981 drew 125 survivors and physicians. There began the unique partnership of lay and professional persons working together to solve an undocumented problem, and the special spirit of polio togetherness that characterizes all the Gazette's international polio conferences.

Six years later, Dr. Maynard reported in an interview in the ST. LOUIS POST-DISPATCH, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?

"I remember thinking at that first conference, 'Who am I to talk?' I told them I didn't know if what I was seeing in the handful of people in my clinic was typical or just odd cases. The audience said yes, they had the same symptoms, knew others with them. After that meeting, I was convinced."

Soon after the 1981 conference, Dr. Stanley Yarnell and Renah Schnaider organized a polio conference in Oakland, California a polio clinic was opened at the University of Wisconsin, Madison, and a support group was begun in Buffalo, New York. The Gazette's mail increased tenfold as polio survivors wrote and called for information on the late effects.

4A--Polio support group history

The Gazette's 1983 international conference in St. Louis drew 400 registrants from Australia, Canada, England, Germany, India, Japan, Mexico, South Africa, and Sweden. About 40 of the registrants used ventilators: most brought their own portables, seven rented iron lungs for nights. The ventilator users and respiratory specialists shared their variations on face masks and other night aids. The mobility impaired and physiatrists and therapists shared symptoms and treatments of the fatigue, pain, and muscle weakness caused by the late effects of polio.

The goals stated at those early conferences are still viable: 1) to work as a team of polio survivors and health professionals, and of organizations and coalitions of the elderly and disabled for networking, information, research, mutual support, education, treatment, and worldwide immunization; 2) to relate the positive experiences of polio survivors to other disabled and elderly persons and to other ventilator users; and to promote independent living and to influence legislation for in-home support services and national attendant care.

The conferences brought survivors together and revived their former joy in being together and of sharing problems and information. The first two international conferences awakened the registrants to their psychological need for mutual support and they returned home to start support groups.

The conferences brought together medical clinicians and researchers and triggered Dr. Lauro Halstead and Dr. David Wiechers to organize the 1984 and 1986 international scientific conferences to stimulate more research into the cause and treatment of the late effects. The National Institutes of Health became involved in research as did the National Easter Seal Society and the March of Dimes Birth Defects Foundation.

By 1984, the Gazette staff became more and more swamped with requests for information. It reorganized and expanded and became the Gazette International Networking Institute (G.I.N.I.) Judith Raymond, who had been volunteering parttime for 17 years, became the executive director and took over the organization of information on the late effects.

Of primary importance was the publishing of a summary of the knowledge in a clear, concise handbook. The Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors was written by Gini and Judith and Dr. Frederick Maynard and Dr. D. Armin Fischer. It is now into its third printing and has been translated into Swedish and is being translated into German, Italian, and Spanish, and excerpted in Chinese.

The flow of information on the late effects from lay persons to health professionls has been unique - a reversal of the usual order. Publications, support groups, and local and national publicity have gradually informed the general public and alerted health professionals. Articles have appeared in THE NEW YORK TIMES, The WASHINGTON POST, the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, MEDICINE and TV shows, such as Kuralt's

In 1985, more than 500 registrants came to G.I.N.I.'s Third International Polio and Independent Living Conference in St. Louis. Registrants from a few more countries were added to those of the previous years: The Netherlands, Denmark and Taiwan. Highlights were the session chaired by William Masters, MD, and the conference banquet honoring Albert Sabin, MD.

An important session brought together the leaders and members of the support groups to share plans and problems. The groups asked G.I.N.I. to coordinate and act as the official clearinghouse for the support groups in the United States and to maintain a directory of support groups, physicians, resource persons, and clinics. As a result, the longtime informal Gazette international polio network was formalized into the International Polio Network (I.P.N.) and the quarterly newsletter, <u>Polio Network News</u>, was initiated.

In the following years, many more support groups and clinics were started and many regional and local conferences were held. The conferences were organized by support groups, often in cooperation with local independent living centers, March of Dimes, Easter Seal, universities, or clinics. The conference educated health professional and the general public and created esprit de corps in the support groups.

In June 1986, I.P.N. organized a workshop in St. Louis for about 70 of the leaders of support groups. The individuality, creativity, and organizational ability of leaders are the keys

Some support groups, have accomplished outstanding statewide organizations and systems of educating the health professionals.

Meanwhile, two polio survivors eased the way for approval of social security disability claims submitted by polio survivors unable to work due to the late effects of polio. Marge Torre of Philadelphia singlehandedly tackled the Social Security Administration (SSA). Where she found an ally in another polio survivor, Jane Dummer, who works in the office of Voc. & Med. Policy at SSA headquarters in Baltimore. Their efforts resulted in issuance and distribution of a Program Circular which documents the late effects of polio throughout SSA.

Another accomplishment by members of the support groups working together involved the U.S.S.R. Responding to a request in the summer 1986 issue of Polio Network News, hundreds of U.S. polio survivors wrote letters to Russian leader Mikhail Gorbachev, President Reagan, and Dr. Armand Hammer urging an exit visa for Russian polio survivor, Tamara Tretyakova and her son, Mark, on humanitarian grounds. Those letters were responsible in large part for the granting of a visa in October, 1986, and Tamara, Mark, and her husband, Simon Levin, came to the Gazette International Networking Institute's Fourth International Polio and Independent Living Conference to express their thanks.

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Of particular interest were the sessions on fatigue, pain, exercise, bracing, face mask for nosturnal oral positive pressure ventilation developed by both users and prescribers, and the international exchange on independent living and attitudes toward disability.

The conference banquet celebrated the 10th anniversary of the implementation of Section 504, the bill of rights for people with disabilities, and the speakers included Ted Kennedy, Jr., and the leaders of the disabled movement who fought for the implementation.

At the conference G.I.N.I. initiated the first week of June as National Polio Awareness Week through the converted efforts of Congressman Richard A. Gephardt of Missouri and the other congressmen whom the support groups contacted to support his enabling legislation.

I.P.N. now coordinates over 160 support groups in the United States, works with a growing number across Canada, and spreads the support group spirit around the world through the polio survivors who attend its international conferences.

That polio support group spirit is the intangible, indescribable spirit of the conferences. Dr. Webster Cash of Georgia writes, "It is a mixture of friendship, laughter, empathy, and - yes - love....It is a remarkable tribute to polio survivors.... We are indeed a different breed." Charlene Bozarth of Michigan says, "The inspiration of being with so many who have not let their disabilities prevent them from living active, loving, joyous lives is beyond description."

Mariso Paro of Brazil writes, "The conference was mainly a constant interchange among everyone. It was everyone giving their time, their efforts themselves....It was giving and sharing....a sharing that will never end....the experiences of four days will last a lifetime."

Groups - Facts + Figures -

8/28/ - Judy's Speech

CLEVELAND

As Gini said, we formalized the International Polio Network or IPN in 1985, and it has over 20,000 members. The update of the post-polio directory that you should have just received brings the total of support groups in the U.S. to   and the number of post-polio clinics to   .

Outside of the U.S., we network with polio survivors and health professionals all across Canada. The largest group seems to be in Ontario province, but British Columbia is fast catching up. Quebec has a fair number of polio survivors, and they are in the process of translating the polio handbook into French. The first Canadian conference on the late effects of polio is being planned for November 1988 in Toronto.

In Europe we network with the British, the Irish, and the Scottish Polio Fellowships, the German version of the March of Dimes - Pfennigparade or parade of dimes - and they are translating the handbook into German and planning a polio conference for April 1988 in Munich. The French have several polio survivors' organizations, and the Italians are working on the Italian translation of the handbook.

The Swedes call their group RTP which is short for Riksforbundet for Trafik och Polioskadade (they have published the handbook in Swedish), the Finns have a Society for Respiratory Polio Survivors, and the Norwegian polio survivors publish a very slick quarterly newsletter.

-- All of this is to show you that you are not alone and this post-polio business is not just an American phenomenon. --

As for the rest of the world, there is a polio group in Mauritius, an island off the coast of Africa east of Madagascar in the Indian Ocean, and Zohra Rajah, who leads that group, attended our St. Louis polio conference in June.

Lwambwa Tshany, is a polio survivor in Zaire who manages an arts and crafts workshop. He also attended the June conference with a travel schedule that will tire you out just listening to it: Lubumbashi to Kinshasha to Brussels to Boston to Detroit to St. Louis.

Father Bob Ronald, polio survivor and amputee, has surveyed 260 Chinese polio survivors in Taiwan, organized the first Chinese polio conference, and translated some of the polio handbook into Chinese.

We have had a hard time getting information out of Mainland China about the number of polio survivors there, and recently just came across a staggering statistic published in the International Rehabilitation Review - an estimated 2 million people disabled by the 1960s epidemics. Two doctors from the Peoples' Republic of China were sent to the St. Louis Conference to report, but discussed mostly the orthopedic procedures for leg lengthening. Thanks to Dr. Huang who helped translate.

We network with polio survivors in El Salvador and Mexico, and in Australia and New Zealand. A group of 16 polio survivor attended the conference from New Zealand.

This is just the tip of the iceberg. You have been called dodos, dinosaurs, placed on the list of endangered species, because polio has largely been eradicated in the U.S. But - when one stops to think that there are an estimated 250,000 to 500,000 cases of paralytic poliomyelitis in the Third World every year - mostly small children - one can foresee that the late effects of polio will still be an issue in the rest of the world for a long time to come. Unless, of course, a cause and cure are found. and unless the vaccination programs of the World Health Organization and Rotary succeed.

It should be obvious by now that the network and the networking are extensive. We put people in touch with people for help - whether it is a physician, a therapist, an equipment dealer, or another polio survivor who has found a solution. As Gini stated earlier, the two most important things are people and information. And it is what we do best.

Certainly a prime example of this is our every-other-year polio conference, the most recent last June. We brought together 747 people - physicians, therapists, nurses, equipment dealers, and polio survivors from 18 countries and all across the U.S. And - if I do say so myself - it was pretty phenomenal.

The first two days concentrated on the medical and physiological aspects of the late effects, starting with the symptoms: muscle weakness, fatigue, pain, sleep, breathing and swallowing problems. Unfortunately, there were no new revelations or miracle pills ~~cures~~ announced. The panels on treatment discussed exercise, weight control and nutrition, bracing and other orthotic devices, and the effects of environmental influences. Again, there was nothing new about exercise - what kind, how much, how little - it still must be an individually tailored program.

And of course for nutrition and weight control, it is still a matter of common sense.

Two doctors presented preliminary findings of their epidemiological studies: Dr. Anthony Windebank of Mayo Clinic and Dr. Jonathan Ramlow of Pittsburgh. Each has tracked and is studying a significant population of polio survivors. Both indicated that when their final results are released this fall, they will show a higher percentage of incidence of the late effects.

An excellent panel made up of Irv Zola, Charlene Bozarth, Carrie Kaufmann, and Phyllis Rubenfeld discussed the psychology of disability and coping and dealing with the late effects.

This year at the conference banquet, we celebrated the 10th anniversary of the implementation of Section 504 of the Rehabilitation Act of 1973 which has come to be known as the bill of rights for persons with disabilities. To help celebrate, Ted Kennedy, Jr., Justin Dart, Jr., polio survivor and new head of the Rehab. Services Administration and Judy Heumann and Eunice Fiorito presented some stirring rhetoric about civil rights. Also on hand was Russian polio survivor Tamara Tretyakova with her husband Simon and son Mark who thanked everyone in the International Polio Network who was involved in the letterwriting campaign that helped Tamara's release from the Soviet Union last fall.

After the banquet, we had a special activity - that was so successful that we are going to have it every year - it was a Disco. And Gini has invented a new term for it - DISCO THERAPY! It took a while for people to warm up, Fred Maynard was one of the first on the floor — but when the band wanted to quit at midnight, the dancers wouldn't let them. It was incredible. All kinds of wheelchairs on the floor and crutches and canes - indescribable!

We are planning the 1989 conference now - May 31 - June 4, so save the dates and bring your dancing clothes!

NCIL

Washington, DC
May 9-11

INTERNATIONAL REHABILITATION AND INDEPENDENT LIVING

MONDAY, MAY 11 10-11:30
1987

THANK YOU....I'M DELIGHTED TO BE PART OF ANOTHER NCIL MEETING AND TO BE WITH SO MANY FRIENDS....

FIRST, I'LL EXPLAIN TO THOSE OF YOU WHO DON'T KNOW ME WHY I, A NONDISABLED PERSON, AM SO INVOLVED WITH PEOPLE WITH DISABILITIES.

MY INVOLVEMENT STARTED BEFORE I WAS BORN WHEN POLIO STRUCK FOUR SIBLINGS. THREE DIED.

CONSEQUENTLY, WHEN THE POLIO EPIDEMICS BEGAN IN 1949, I STARTED TO VOLUNTEER AND I'VE NEVER STOPPED.

I WORKED FOR 10 YEARS IN A RESPIRATORY POLIO CENTER, THEN STARTED A LITTLE NEWSLETTER THAT BECAME: A NETWORK OF PEOPLE WITH DISABIITIES, AN INFORMATION CENTER, ~~AND~~ AN INTERNATIONAL PUBLICATION, REHABILITATION GAZETTE, ~~AND~~ THE INTERNATIONAL POLIO NETWORK...
AND CONFERENCES ON INDEP LIVING & POLIO EVERY OTHER YEAR...JUNE 4-7!

I'VE WATCHED AND NURTURED THE INDEPENDENT LIVING MOVEMENT SINCE LONG BEFORE IT WAS A MOVEMENT.

SAY A FEW WORDS ABOUT THE EARLY ORIGINS OF IL MOVEMENT....

IT BEGAN WHEN THE RESPIRATORY POLIO CENTER IN LOS ANGELES - RANCHO LOS AMIGOS - PIONEERED SENDING PEOPLE HOME WITH IRON LUNGS AND ATTENDANTS IN 1953...IN ORDER TO SAVE MONEY.

THE MARCH OF DIMES, WHICH WAS PAYING FOR HOSPITAL CARE, TOOK UP THE HOME ATTENDANT SYSTEM WITH GREA-T ENTHUSIASM AND SPREAD IT ALL THE 17 CENTERS IN THE U.S.

AVERAGED ABOUT 6 YEARS
GREAT WHILE IT LASTED/...BUT, WHEN THE VACCINES WERE DISCOVERED, PEOPLE STOPPED GIVING TO THE M OF D SO THE M OF D STOPPED PAYING FOR ATTENDANTS AND CLOSED THE CENTERS.

SO, IN 1960, THE TWO CALIFORNIA CENTERS EFFECTED ATTENDANT CARE LEGISLATION THAT IS STILL FUNCTIONING AND WAS THE REASON THE INDEPENDENT LIVING CENTERS COULD START IN CALIFORNIA. ATTENDANT CARE IS A LINCHPIN OF INDEP

THE REST OF THE COUNTRY DIDNT DO AS WELL...AT THE TIME, I FOUGHT FOR NATIONAL ATTENDANT CARE LEGISLATION BY ORGANIZING THE READERS OF OUR PUBLICATION INTO A NATIONAL LETTER-WRITING CAMPAIGN TO THEIR CONGRESSMEN.

#

THE INDEPENDENT LIVING MOVEMENT RECEIVED FURTHER IMPETUS IN 1965 WHEN MARY SWITZER, THE COMMISSIONER OF VOCATIONAL REHABILITATION EXPANDED THE 1965 AMENDMENTS TO THE VOCATIONAL REHAB ACT TO MEET THE NEEDS OF THE SEVERELYDISABLED. MOST IMPORTANTLY, THIS INCLUDED TUITION AND SERVICES TO ENABLE QUADRIPLEGIC AND OTHER SEVERELY DISABLED PERSONS TO EARN HIGHER DEGREES. THUS, THERE WAS DEVELOPED AN EDUCATED LEADERSHIP - AN ESSENTIAL TO THE MOVEMENT. SO THE EARLY LEADERS WERE EDUCATED.. FRED FAY, BILL BEAN, ED ROBERTS, JOHN HESSLER, LEX FRIEDEN, ETC.

TWO OF THOSE STUDENTS - ED ROBERTS AND JOHN HESSLER - AT BERKELEY CARRIED THE PROGRAM ANOTHER STEP. IN 1970 THEY STARTED THE PHYSICALLY DISABLED STUDENTS PROGRAM TO ENABLE QUADRIPLEGIC STUDENTS TO LIVE OFF CAMPUS WITH ATTENDANTS. AT FIRST, THEY THOUGHT OF A GROUP RESIDENCE. FORTUNATELY, THEY REJECTED IT AND SET A PATTERN OF INTEGRATED LIVING. IN 1972, AFTER THEY HAD GRADUATED,THEY CARRIED THE PROGRAM FROM STUDENTS TO PEOPLE WITH DISABILITIES IN THE AREA AND THUS STARTED THE FIRST CENTER FOR INDEPENDENT LIVING.

THE NEXT STEP WAS A COALITION OF PEOPLE WITH VARIOUS DISABILITIES AND OF THE DIS LEADERS OF THE WEST AND EAST COASTS AND SOUTH AND MIDWEST . .....FRED FAY ORGANIZED THE FIRST MEETING OF THE AMERICAN COALITION OF CITIZENS WITH DISABILITIES IN JUNE 1974. (IWAS ON THAT FIRST BOARD - THEY USED TO TEASE ME ABOUT BEING THE TOKEN NONDISABLED MEMBER)...

YOU KNOW THE REST SO
I WONT REPEAT THE SUBSEQUENT STEPS - GRADUALLY SPREADING CIL's IN CALIFORNIA, THEN THE REST OF THE COUNTRY, THEN GOVERNMENT SUPORT, AND NOW NCIL....

I'VE GONE INTO THE EARLY STEPS BECAUSE THEY ARE IMPORTANT TO REMEMBER AS WE LOOK AT INDEPENDENT LIVING EVOLVING AROUND THE WORLD, AS WE FEEL IT PARALLELING THE EFOLVEMENT OF THE RIGHTS OF WOMEN AND OTHER MINORITIES.

THESE ELEMENTS; ATTENDANT CARE, LIVING IN COMMUNITY, NOT SEGREGATED, BY DIS EDUCATED LEADERSHIP...COALITION OF DISABIITIES.......ARE ESSENTIAL TO IL EVOLVEMENT EVERYWHERE....

#

IN 1980 I WENT TO EUROPE TO STUDY INDEPENDENT LIVING ON A WORLD REHABILITATION FUND FELLOWSHIP. I VISITED FRIENDS WHO WERE DISABLED IN 8 COUNTRIES.

I WENT AGAIN IN 1982 TO SPEAK AT A CONFERENCE ON INDEP LIVING IN MUNICH AND AGAIN I TRAVELLED AROUND EUROPE.

IN JANUARY OF 1986 I WENT TO CHINA AND JAPAN FOR A REHABIITATION MEETING.....AND I'VE BEEN ALL OVER MEXICO & CANADA.

I SHALL SKIP AROUND THE WORLD...GIVING BRIEF NOTES ON INDEPENDENT LIVING AND REHABILITAION...THEN SHOW SOME SLIDES.

AS I TALK AND SHOW THE SLIDES I WANT YOU TO NOTICE HOW OFTEN THE "SOLUTION" TO PROBLEMS HAS BEEN DECIDED BY THE GOVERNMENT OR WELL MEANING ORGANIZATIONS WITHOUT CONSULTING PEOPLE WITH DISABILITIES....AND, MOST OFTEN, THAT SOLUTION IS SEGREGATED, SPECIAL HOUSING.

ON THE MAINLAND OF EUROPE, THEY ARE LIKELY TO BE ENORMOUS RELIGIOUS-RUN INSTITUPTIONS.......ON THE BRITISH ISLES THEY ARE MORE LIKELY TO BE THE CHESHIRE OR SPASTIC HOMES IN FORMER MANSIONS.

BUT ALSO WATCH AND REALIZE THAT EUROPE IS AWAKENING TO THE AWFUL EFFECTS OF THESE INSTITUIONS AND THEY ARE MAKING SOME CHANGES TO SERVICE SYSTEMS THAT ENABLE PEOPLE TO LIVE IN THE COMMUNITY WITH MORE INDEPENDENCE....I'LL BE CALLING THIS TO YOUR ATTENTION IN ENGLAND AND DENMARK,=ESPECIALLY.

YESTERDAY YOU HAD AN AFTERNOON SESSION TITLED "TRANSTIONAL LIVING: A NEW SERVICE IN THE CONTINUUM OF ILC'S"

ID CHAMGE THE TITLE FROM SERVICE TO "DISSERVICE".

THINK TRANSITIONAL...PROVIDE SERVICES FOR TRANSTIION... BUT DON'T HOUSE IT.

YOU ARE CREATING A MINI INSTITUION. INSTITUIONALIZATION IS MORE DISABLINGTHAN DISABILITY BECAUSE IT SMOTHERS THE SOUL.

WHY SHOULD PEOPLE BE DUMPED TOGETHER BECAUSE THEY HAVE THE SAME DISABILITIES?

PEOPLE HAVE THE RIGHT TO TAKE RISKS AND TO MAKE CHOICES AS TO WHERE & HOW & WITH WHOM THEY LIVE.

I'D URGE ANYONE PLANNING A TRANSITIONAL TO GO LIVE IN SOME OF THEM FOR A WEEK....GO TALK TO THE STARKLOFFS ABOUT PARAQUAD...READ MY BOOK ON HOUSING ABOUT THE ONES THAT FAILED AND WHY....

4-B NCIL

HOPE YOU MAKE THE CONNECTION BETWEEN THESE SEGREGATED EUROPEAN RESIDENCES AND <u>TRANSITIONAL LIVING</u>.....

AND LEARN FROM THEIR MISTAKES....DONT BUILD BUILDING...EDIFICE COMPLEX....

DONT GET CAUGHT IN TRAP & GO BACKWARDS....

NO DIFFERENCE..EXCEPT IN NUMBERS...SAME SEGREGATION...

SAME INSTITIONALITIS...SAME STIGMATIZING...SAME PTRONIZING....

...SAME DEPENDENCY IN DISGUISE...

YOU LEARN BY DOING, BY ORDERING GROCERIES, BY BUGETING.

YOU LEARN TO TRANSITION BY TRANSITIONING IN AN ORDINARY ENVIOR-NMENT.

WHEN YOU GO TO COLLEGE, YOU DONT GO TO A TRANSTIONAL HOME TO LEARN HOW TO GO TO COLLEGE. YOU DO IT.

EX: WORCESTER HOME....COURAGE CENTER (NOW MANY HEAD INJURIES)

WHY LEAVE WHEN EVERYTHING IS DONE

TO MANY POTENTIAL ABRASIONS FROM COMMUNITY LIVING.

NO PRIVACY, PHYSICALLY OR EMOTIONALLY.

REGINMENTATION.

WHO HIRES THE STAFF? WHO FIRST? WHO MANAGES THE MONEY?

WHAT ABOUT MEALS? MENUS?

WHAT ABOUT GUESTS? PARTIES?

WHO DECIDEDS TIME OF QUIET? TV PROGRAMS? TYPE OF MUSIC?
TIMES OF MEALS?

WHAT ABOUT BOOZING? SMOKING?

SOUNDS PETTY...BUT THESE CAUSE PROBLEMS.

ARE SHARING A DISABILITY???

MORE EXPENSIVE...MICH STUDY: 8 IN SPE VS 80 IN COMMUNITY.......

LET THE SERVICES DO THE TRANSITIONING...
DONT BUILD BUILDINGS BECAUSE YOU NEED ATTENDANTS.
YOU STILL NEED ATTENDANTS AND YOU HAVE MORE PROBLEMS
WITH INSURANCE, FIRE LAWS, LIABILITY, ETC. ETC.

MUCH SIMPLER TO RENT SEVERAL OR ONE APT (EASTER PVA...)
HIRE ATTENDANTS TO SHARE...THEN LET EACH PAY RENT,
FIGURE MEALS, ETC. AND RUN OWN LIFE.

IF PROJECT CHANGES CAN UNRENT THE APARTMENTS...
NOT STUCK WITH A BUILDING THAT HAS TO BE KEPT FILLED.

IF SOLVING THE HOUSING PROBLEMS OF 16 QUADS SOLVES THE
CITY'S HOUSING PROBLEM. THEN NOT MUCH OF A PROBLEM
MUCH BETTER TO WORK ON STATE LEGISLATION FO ATTENDANTS
AND FOR ACCESSIBLE APARTS FOR ALL.

IF HAVE 16 IN SPECIAL BPILDINGS, THEN ABLE-BODIED THINK
THEPROBLEM IS SOLVED AND THOSE VERY SPECIAL DEARS ARE
ALL SETTLED OUT OF THE WAY.

IF TOO SPECIAL...THEN CANT ADAPT TO ORDINARY HOUSING
LATER.

DID ANY OF THE PRESENT CIL LEADERS WORRY ABOUT HAVING A
TOTALLY ACCESSIBLE SPECIAL ENVIOONMENT OR LIVING IN A
TRANSTIION HOME? NO....ED ROBERTS & JOHN HESSLER AST THE
VERY BEGINNIN G OF -CIL DECIDED AGAINST SEGREGATED HOUSING.

TRANSTIONAL HOUSING IS SEGREGATED. YOUARE CONNED BY THE POOR
DEAR SYNDROME.

THE SPIRIT OF THE AMERICAN CIL'S IS WAFTING AROUND THE WORLD AND AROUSING INTEREST AMONG THE LEADERS OF THE DISABLED MOVEMENTS EVERYWHERE.

OUR INTERNATIOANAL CONFERENCES HAVE BEEN A STRONG INFLUENCE...AND AND DISABLED PEOPLES' INTERNATIONAL MEETINGS AND MANY OF YOU HAVE HAD VISITORS AT YOUR CENTERS FROM JAPAN AND EUROPE, TRYING TO FIGURE OUT HOW THEY CAN INCORPORATE ~~IT~~ IL INTO THEIR CULTURES.

IT IS DIFFICULT, BUT IT IS GRADUALLY HAPPENING IN VARIOUS DEGREES.

WE IN U.S. HAVE SO MUCH MORE CHOICE, MORE FREEDOM HERE ~~IN THE U.S.~~ THAN ANY PLACE IN THE WORLD.

YOU DONT APPRECIATE IT UNTIL YOU HAVE BEEN OUT OF THE CONTRY AND FEEL HOW MUCH MORE STRUCTURED LIFE IS ELSEWHERE...

OUTSIDE THE U.S., ORGANIZATIONS ARE MORE LIKELY TO BE FOR, RATHER THAN BY PEOPLE WITH DISABIITIES....

ATTENDANTS ARE MORE LIKELY TO BE PROFESSIONALLY TRAINED, RATHER THAN DISABLED DIRECTED.......

AN INDEPENDENT LIVING CENTRE IS MORE LIKELY TO BE AN EQUIPMENT AND AIDES CENTRE RATHER THAN A SERVICE CENTER.....

REHAB CTR...LIKE FACTORY..YOU'RE TOLD WHAT YOU CAN DO....

BUT...WE MUST NOT FOREGET, WE ARE THE ONLY MAJOR COUNTRY WITHOUT FREE HEALTH CARE AND FREE EQUIPMENT..

JUDY H/
GERMAN

CANADA........CANADIAN PARAPLEGIC ASSOC RUN BY SCI SINCE WWII.......
GOVT'S SERVICE SYSTEM FOR SERVICES & EQUIP & REHAB
ALL OFFICERS IN EVERY PROVINDE ALWAYS BEEN SCI....

SERVICES VARY BY PROVINCE...ALBERTA & BC...HAVE ATTENDANTS AND APARTMENTS PAID .....OTHERS HAVE LITTLE OR NO SERVICES.

BC HAS EXCELLENT HOSPITAL FOR LONTIME STAY IF DO NOT WANT TO OR CANT BE HOME. $7.50 A DAY FOR RESP.

ALBERTA HAS ANOTHER EXCELLENT HOSPT FOR RESP POLIO SURVIVORS. ..HAVE RUN BUSINESS FROM HOSP - HORSE & COMPUTER.

ONTARIO HAS GOOD EQUIP & AIDS CENTER & GOOD SCI HOSPITAL WITH APT IN HOSPITAL SO CAN PRACTICE.

OF COURSE, CAP OFFICERS ARE ROLE MODELS & COUNSELORS... & HAVE HAD EXCELLENT PUBL, CALIPER, FOR YEARS.

MEXICO....... AFEER WWII...EVOLVED A SYSTEM FOR SCI VETS...THEN OTHERS IN GUADALAJARA.

ABOUT ½ DOZEN RESIDENCES, RUN BY DISABLED, OF ALL TYPES. FIRST MOVED TO RESIDENCE...THEN CHANGED FROM ONE TO ANOTHER...THEN MOVED OUT ON OWN, WITH ATTENDANT. $30 MONTH 34-HR ATTENDANT, SLEEP ON FLOOR.

GREAT VARIETY OF RESIDENCES..BABES/BOOZE OR SIGHTEESING/ SYMPHONY...

BLEW UP WHEN PESO DEVALUED...MOVED BACK TO US. EXCEPT FEW.

SMALL GROUP OF LOCAL DISABLED STARTED ORGAN...PEER MODELS & COUNSELING...PUBLICATION...MUTUAL SUPPORT.

CENTRAL & SOUTH AMERICA...

HAVE NO DIRECT EXPERIENCE...BUT CORRESPOND & TRY TO KEEP UP WITH... USUALLY, STRONG FAMILY ORIENTATION. AND ORGANIZATIONS <u>FOR</u> DIFFERENT DISABILITIES.

EL SALVADOR....A FRIEND WITH POLIO HAS SET UP A SELF-HELP GROUP....SOME CRAWL TO MEETINGS.

CUERNAVACA MEETING..CARRIED BY FATHER..

ROLF HOTCHKISS...AN ENGINEER WHO IS PARAPLEGIC, HAS DESIGNED A SIMPLE W/C...HELPED NICARAGUAN DISABLED SET UP WORKSHOP TO BUILD IT.

GROUP OF CALIFORNIA DISABLED HAVE CREATED PROJECT PROJIMO - VILLE-RUN REHAB PROGRAM FOR DISABLED CHILDREN IN WESTERN MEXICO.

EXCELLENT PUBLICATIONS DESCRIBING BOTH PROJECTS...

AUSTRALIA & NEW ZEALAND .....

AWAKENING SPIRIT...HAVE IL CENTRES THAT ARE CENTRES OF AIDS & EQUIPMENT RUN BY NONDISABLED.

SOME CENTERS APPROACH ILCS...BUT NOT QUITE...MORE SELF-EHLP SUPPORT GROUPS OR RECREATION CLUBS... LOTS OF TRIPS & PICNICS.

WORKING ON NATIONAL ATTENDANT CARE IN BOTH COUNTRIES.

NZ RECENTLY PASSED A 3-YEAR TRIAL LAW FOR 360 PEOPLE WHO ARE NOW LIVING IN NURSINGHOMES...BUT DID NOT ALLOW DIRECT PAYMENT TO INDIVIDUAL. INSTEAD, ORGANIZATIONS WILL HIRE AND TRAIN.
GREAT DISAPPOINTMENT TO MEMBERS OF DPI WHO WORKED ON IT.

INDIA & PAKISTAN......

PAKISTAN HAS SOME STRONG LEADERS IN DPI...MOSTLY BLIND ORGANZIATIONS...SPARKED BY A BLIND PHYSICIAN, DR. FATIMA SHAH. NOTHING APPROACHING ILC'S

INDIA.....STILL STONGLY FAMILY ORIENTED...
SOME ENGLISH CHESHIRE HOMES. "PITIFUL CRIPPLES" APROACH.
SOME ORGANIZSTIONS FOR SPORTS BY DISABLED.
AGAIN, NOTHING APPROACHING ILS'S.

SINGAPORE......

STRONG ORGANIZATIONS OF PEOPLE WITH DIS...UNDERTAND
RIGHTS...EMPOWER EACH OTHER...GOOD PUBLICTION.
PROBABLY CLOSE TO ILS TYPE OF THINKING.

TAIWAN........

JESUIT...POLIO/AMPUTEE...OPERATION DE-HANDICAP...
GROWING...WORKSHOP...RECRETION...CLUB...SELF-HELP.
WILL GO AS FAR AS CAN TOWARD ILC WITHIN CHINESE CULTURE.

REPUBLIC OF CHINA......

DENG PUFANG...CONF ON REHAB.
HOME OR INST. DIF CULTURE...STATE DECIDES WHERE GO TO
COLLEGE, WHAT UNIVERSITY, WHAT YOU STUDY, WHERE YOU WORK...
FREE MEDICAL & DQUIP..BUT SIMPLE TYPE...
LANGUAGE OF THE 50'S...LONG WAYS TO GO, BUT AWAKENING OF
COUNTRY, WILL AFFECT ATTITUDE TOWQRD DIS TOO.

JAPAN....... B IG PROBLEM: NO DISABLED WITH HIGHER EDUC (UNLESS ACCIDENT
AFTER UNIVERSITY)....UNIVERSITIES SO INACCESSIBLE...
SUPERELABORATE REHAB CTR...WAY WAY OUT OF CITY.
M.D. WHO IS A QUAD...A SENATOR WHO WAS AN ACTOR NOW A PARA..
SENATOR DOING GOOD FOR LEGISLATION. THE FEW LEADERS KNOW
WHAT SHOULD BE DONE...BUT GREAT CULTURAL DISPARITY.

ONE SEGREGATED GHETTO-TYPE
ONE SLAP-HAPPY IN COMMUNITY..QUAD WHO HAS BEEN TO U.S.

WORKSHOP...SWEAT-SHOP..LIVED IN CORRIDOR CUBBYHOLES. PRINT SHOP
COMPUTER SHOP..KEPT, NOT SENT TO JOBS.

KYOTO- ILC IN OFFICE BLDG...GOOD MUTUAL SUPPORT SYSTEM.
MOST DISABLED.
GOOD REHAB CENTER
TRANSPROTATION - VOUCHERS FOR TAXIS...ELEVATED, ACCESSBILE
WITH HELP FROM CONDUC TOR.

SOUTH AFRICA......

ONE PERSON MAKING A BIG DIFFERENCE....KATE JAGOE, PROF
AT U OF WITWATERSRAND IN JOHANNESBURG, QUAD...STARTED
ORGANIZATION, DISABLED SOUTH AFRICA. INTEGRATED.
HAS BEEN TO OUR CONFERENCES & VISITED AROUND U.S....
KNOWS & UNDERSTANDS IL.....

SA HAS IL CENTRES, BUT THEY ARE THE TYPICAL AIDS & EQUP
CENTERES RUN BY NONDISABLED.

MAURITIUS....HAS WORKSHOP OF SEVEREAL HUNDRED....RUN BY POLIO W/C PARA.

MALAWI.......WORKSHOPS TO MAKE EQUIP FOR OTHER DISABLED.

ZAIRE........ WORKSHOPS TO MAKE CERAMICS...RUN BY POLIO PARA W/C

SHOW SLIDES

SHOW SLIDES

EUROPE
******

FRANCE...... MARILYN SAVIOLA...

ATTENDANTS...SIMILAR INBELGIUM & SWITZERLAND...PAY SMALL PER DIEM TO HIRE OWN. BUT DURING VACATIONS, IT IS STOPPED, SO CHRISTMAS & SUMMER GO TO HOSPITAL FOR $100 OR $200 A DAY.

TAXIS SUBSIDIEZED...BUT WAIT FOREVER UNLESS REGULAR TRIP TO SCHOOL.

G.H.I.P.

NATIONAL INFO CENTER ONAIDES & EQUIPMENT.

BELGIUM......

FREE EQUIPMENT...AUGUST MICHAEL...TRYING TO BE ONE-PERSON ILC.

SWITZERLAND...

CHAS FROELICHER

AUSTRIA...BIG CATHOLIC...GOTTFRIED WETZEL MAKING ROUNDS.

DENMARK....

BIG CHANGES SINCE 1980...THEN PAID SOME FAMILIES & NO MORE THAN 3 HRS PER DAY...OTHERWISE TO NURSING HOME $L25 PER DAY.

SOCIAL LAWS MAKE POSSIBLE TO STAY IN HOME - EVEN IF SEVERELY DISABLED. MUNICIPAL AUTHORITIES ESTIMATE DEGREE OF DIS, AGE, EDUCATION, PERSONAL ACTIVITIES, MOTIVATION FOR EACH INDIV. THEN DECIDE HOW MUCH ECONOMICAL AND ATTENDANT HELP NEEDED.

BENTA MADSEN..COMING TO CONF..SAW IN 1980 "CAN US.DIS ON VENTS LIVE AT HOME?" LAST YEAR WROTE OF NEW CHANGES... SHE CAN NOW EMPLLY 6 PERSONS TO BE WITH HER AT HOME & ON VACATIONS. EACH PERSON (ALL MALES) WORKS 5 FULL DAYS (24 HOURS) A MONTH..PAID BY MUNICIPAL AND STATE FUNDS (50-50_.. BESIDES, SHE RECEIVES A MONTHLY PENSION OF ABOUT 75% OF AVERAGE INCOME IN DENMARK.

CHANGES NEW..ONLY 150 TO 200 DIS INCLUDED IN ATTENDANT PROGRAM...BUT POLITICIANS & SOCIAL WORKERS TRYING TO EXPAND.

HANDS KNUDS PLADS - EXAMPLE OF SEGREGATION.....
ILLEGAL TO BUILD NEW NOT-FOR PROFIT NURSING HOME.

SWEDEN......
ADOLF RATZKA - STUDIED AT UCLA...KNOWN TO MANY...RESP POLIO SURVIVOR....PH D.....HAS EFFECTED A SWEDISH ADAPTATION OF U.S. CIL... WORKING ON ACEESSIBILITY....

HE MORE INDEPENDENT THAN MOST...SOME SPOILED BY TOO MUCH ATTENDANT CARE...EX: PARA IN HIS BUILDING HAS FULLTIME.

DONT FORGET THAT FOCUS SHOWS ATTENDANT CARE CAN BE AN INSTITUTION...

OF COURSE, FREE EQUIPMENT...EXCELLENT INFO CENTRE...INDOOR & OUTDOOR W/C...

EUROPE...GREAT EMPHASIS ON USING EQUIPMENT TO REPLACE & SUPPLEMENT ATTENDANT CARE....

ALSO..NOTE DIFFERENCE...OF WOMEN DIS HAVING MALE ATTENDANTS... AND MEN DIS HAVING FEMALE ATTENDANTS.

ENGLAND......

CROSSROADS SCHEME... ATTENDANTS PICKED & TRAINED BY ABLE-BODIED ORGANIZAION....

SPINAL INJURY ASSOCIATION. GOOD ORGANIZATON, SIMILAR TO CPA..RUN BY SCI. NOT AS MUCH AUTHORITY AS THE CANADIAN... GOOD SOURCE OF INFORMATION AND ADVOCATE.

SCOTLAND

IRELAND

England...Cheshire Homes started 30 years ago....stately homes and some purpose-built. all over England. Total of 70 all over UK and 90 around world. 1820 residents in UK.

30-40 to a home....2,3,4 to a bedroom... hours to suit staff: some up at 5:30 am... most to bed early.

Started with ages 18-40....now 40-69 so evolved into homes for older disabled.

Mostly MS, CP, arthritics.

Wait to End

Let me read excerapts from an article on small residential homes by a British writer, Louis Battye, a quad because of neuro-muscular disability, lived in Cheshire Homes for many many years.

"People of diverse ages, personalities, tastes, and mental levels find themselves living together at uncomfortably close quarters, often with little privacy or personal freedom; under a system that is authoritarian and paternalistic rather than genuinedly democratic, and with the awful knowledge that in most cases they will have to live that way until they die .

"It doesn't need a psychologist to predict that in such a claustrophic environment the individual will experience intense and harmful social pressures and that IN a few years the atmosphere will have markedly deteriorated.
There will be cliques, mutual antagonisms and jealousies, sharp conflicts of needs and interests, outbursts of rage, enormous feelings of frustration, bitterness, apathy, and finally institutionalization - virtually the opposite of the happy, active,harmonious cooperation hoped for.

Key words are ' dispersal" & 'integration"

"There are, I think, no blanket solutions. Disabled people are no less individuals than the able-bodied....Society must seek solutions that benefit as many as possible yet are as flexible as possible... Society must be made to see that its duty is to takes its severely disabled members into its midst, not expel them from it."

15-NCIL

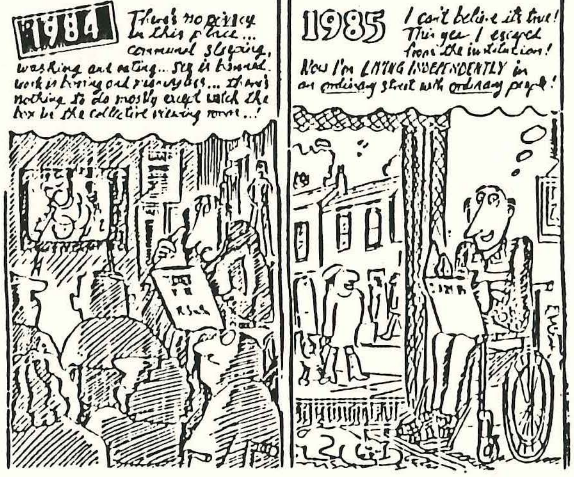
I've been reading publ Cheshire Smile since 1959...following the organizational work & kind thoughts of Grp Capt Leonard Cheshire and all those Lady Bountifuls who worked so hard to raise money for their local home...
by fetes, bazaars, festivals,
pony shows, whist drives, coffee mornings,
penny pillars, rummage sales,,,,,
all that work for the "poor dears."

Well, the "poor dears" started to rebel by about 1970 at the segregation and they formed an organization, UPIAS. But big change caused by John Evans — GL + Joe there in 1980 - Begged to come. Visited. John Came to US —
Cheshire Homes started to change to single rooms...
Now ~~changing to~~ moving residents to apts in normal housing ~~and~~ with attendants ~~on call~~. Services
~~and to~~ apts-with-serv~~ices~~
and latest: ~~to~~ Leonard Cheshire Care Service which brings services to those in neighborhood
and starting to use existing homes as center of attendants - almost CIL...

20 SIA NEWSLETTER
Feb 1985

An Ordinary Street with Ordinary People

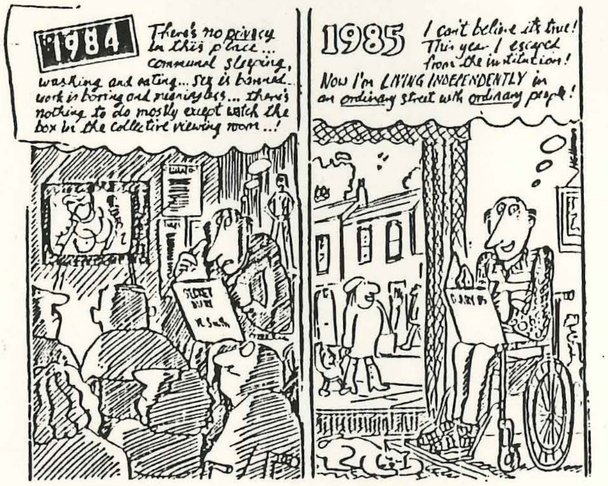
John Evans.....



1984: There is no privacy in this place... communal sleeping, working, and eating..... Sex is banned....Work is boring and meaningless... There's nothing to do mostly except watch the box in the collective viewing room..!

1985: I cant believe it's true! This year I escaped from the institution!
Now I'm living INDEPENDENTLY in an <u>ordinary</u> street with <u>ordinary</u> people.

An Ordinary Street with Ordinary People



SIA Management Committee member John Evans (C5), a member of the Hampshire Centre for Independent Living, describes how the right combination of housing and care support has made independent living a reality.

After many long and laborious soul-searching years, what was once a latent perception and hope finally became reality. Five long years of hard work and strife, excitement and adventure saw the struggle for independence, and a chosen lifestyle once again returned to me. It was a fact beyond words, a kind of liberation that emanated from the fact that I was the centre of the operation and it all rotated around me and my peers. I was in control. The door to the rest of my life had been opened. It was now up to me to make the most of it.

This is not a success story, but one person's struggle to live a normal life just like anybody else. Independent living is often seen by many professionals as being only suitable for a minority of disabled people who are articulate, educated and able to stick up for their own rights. This, of course, is absurd and I would argue strongly against it, and say it is for anybody who wants it, providing they are prepared to put their energy into getting it, and, more importantly, that they are able to receive the support they need from their authority to bring it about.

I would go as far as to say, however, that I was lucky - I happened to live in a place where my authorities where prepared to give me the support to help me live independently. The importance of all this is that there is a message about the quality of life that one leads, and what you put into it, which is fundamental to independent living. My only hope is that this message will be received positively by those working in the field of disability as a practical and viable alternative, and that they so can incorporate such schemes into their planning to extend their horizons.

Much has been expounded on independent living, but there still seems to be a lack of real understanding. On the academic side, the concepts seem to be interestingly appealing, opening new intellectual doors on the social and philosophical framework of disability living, to such an extent that various organisations are prepared even to stage conferences on it. They do this without consulting disabled people or involving them. To us, however, the concern is with the implementation of the practicalities of everyday living in a way that is reasonable, acceptable and workable. Independent living is the intelligent utilisation of the support available that can enhance the quality of life - it is not how much one can do physically.

WHERE DID IT ALL BEGIN?

For me it began the moment I wheeled into a residential home where I was going for an assessment period, which was presumably going to set me right for the rest of my life, providing I passed the test, trials and tribulations of my sentence. However, inwardly, I knew this was not right. It did not fit my character, lifestyle or approach to living. I was quite simply denied any choice in the matter, and at that time there were certainly no alternatives. My destiny had condemned me to an existence that went totally against the grain of my being. In some respects, however, I was lucky in that the home was known to be one of the most liberal in the country. Despite this, it was an institution, so alienating factors went along with it - like the lack of privacy, eating foods I would not have done at inconvenient times, living with people because they were disabled, without any other common interests, and a ruthless and contagious world of gossip. Criticism aside, I did prosper in this environment, for which I am thankful.

I decided to stay in this home in the hope that one day I could move on. I knew I would, but how was a mystery and a void. During the first year, I had regular discussions with a fellow resident who was thinking along similar lines, and from this some seeds of hope were sown. A glimmer of hope had emerged which filled us with great anticipation and wonder. We knew we were on to something - exactly what still eluded us - but it was a beginning.

Before long, a group of residents had found each other and *PROJECT 81* was formed, with the objective of exploring any feasible alternatives to residential care. We wanted the right to decide and choose our futures. We wanted to have our own homes, to control our own lives and to have a real part in making our life choices. We did not want to take the conventional route out through marriage, as this seemed grossly unfair and unnatural. We wanted to be ourselves whatever way we wanted. What we did know, and which was to give us much strength later, and still does, was that we had each other. The idea of independent living had been born among us and was slowly to grow as reality. For me it was also my personal search into what I was looking for.

FINDING THE RIGHT ACCOMMODATION

I knew that the location of the local shops, post office etc mattered to me as I felt I wanted them within wheelchair proximity, so I could come and go freely as I wished, without having to rely upon somebody always having to drive me there. I felt so strongly about this that I was not prepared to compromise. It seemed that the way ahead was to try and find accommodation through a housing association. This I tried and in my dealings with the Leonard Cheshire Housing Association looked at literally over 100 houses. I soon became disillusioned and realised that there were too many restrictions involved. There was no way I was going to secure appropriate accommodation for myself under the stringent guidelines of the Housing Corporation in the area where I was. I became frustrated and gave up this option.

Previously to all this, I had registered on the local council's waiting list. It did not seem that much was coming of this either, until one day, 'totally out of the blue, I had a telephone call from my OT saying that the council had offered me a flat which they were prepared to adapt. After all those rs of painstaking searches, I could hardly believe luck. I willingly accepted and signed the tenancy agreement so that I could immediately apply for the various grants to get the work started. During the next weeks I frequently met my OT, housing officer and technical adviser so that we could work out the details of the design features I wanted. These meetings I always found constructive and of invaluable help. I received good sound advice, but I ensured that what I wanted was always carried out to the best of my ability.

I worked closely together with my OT and she was able to help me apply for the different grants. The building work was mainly funded by the housing department, but supplemented through social services. I also received an improvement grant for some of the adaptation work. Considering that the cost of making the flat suitable for me was far from considerable, I believe that there is a great argument for converting what is available, and not always going for special build. There is no substitute for being in an ordinary street with ordinary people. I only wish other local authorities would take this approach. We had a good working relationship and it worked both ways. I would definitely advocate strongly that on projects like this, everybody (the disabled person, housing officer, OT, social worker or anybody else that may be involved in such a set-up) collaborates and works cooperatively together.

When it came to the design and its implementation, I worked with the housing officer, OT and technical adviser. I stated all the design features I wanted, d they carried them out. This consisted of ped access into the flat, widened doors, sliding doors installed, sockets and light switches at my level, bathroom and loo put together. It is a simple two-bedroom flat which I now feel very happy with. I had the kitchen adapted to wheelchair height to make everything possible to use, including a ceramic hob with easy controls, a sensitive tap unit, easy sliding doors and microwave oven. It is a solid, attractive design that can take a lot of knocking about. I was fortunate in receiving a lot of advice from my peers who had done something similar and which I was able to improve upon. As far as the design of my place is concerned, there is nothing too special about it, and, in fact, many of my able-bodied friends feel quite envious!

EMPLOYING CARE ATTENDANTS

While I was still looking for a home I had gone ahead in devising a care proposal, a kind of 'care package' for my authorities to look at, which defined and quantified my care needs and I presented it as an alternative approach to living. I had felt from the beginning that housing and care elements should go together, but be presented separately to avoid confusing the issues (and this is the way that the system is anyway). What felt so important about this application to help fund me to live independently in the community was the fact that it all seemed so commonsensical, and a method that could easily be used by other authorities. It could be a direct move to place the disabled person in complete control of their es: an entirely new approach to funding, but one t made sense.

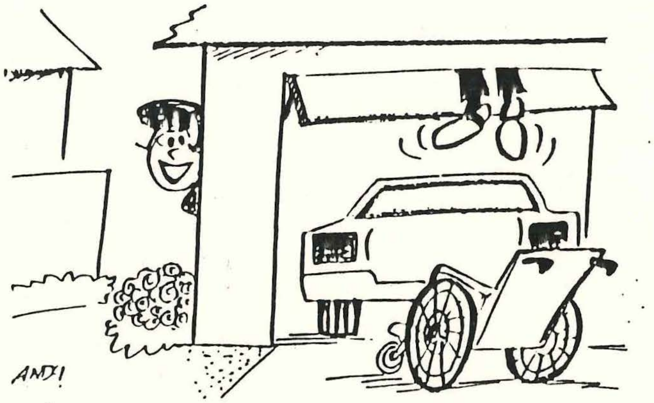
Now I am able to control, organise and deploy my care in the way that suits me best. I employ the people I choose. I have a full-time living-in care attendant who is backed up by a few part-time people who help get me up and put me to bed. It is important to have the part-time relief help as it takes away the kind of pressures that could be exerted on just one person. At the outset, though, [illegible] flexibility of this routines and duties that need to be done, one always needs to allow for changes to it. I also have a list of people whom I can call upon in the event of an emergency, like when one of my attendants might get sick, hurt themselves or have a holiday. This can be interesting in that you have to think up alternatives quickly. I am able to pay them through a combination of domestic care allowance, attendance allowance and funding from my local authority. I have found that the best market for care attendants are students and housewives, with a sprinkling of young unemployed nurses. As yet I have had no difficulty in finding and recruiting them, even at short notice. I have also found that as I establish my roots more, I build up contacts, which helps in expanding the emergency list.

The relationship between one's carer who lives in and oneself is a very intimate one. One shares the same space, but that space is your home, and changes should not be imposed upon from the carer. You have to live in it, but at the same time you know that you have someone attending to your needs for the rest of your life, so it is essential that you treat them with respect, as they should you. Obviously, it is important that you take the necessary precautions to cover yourself. Sensible guidelines should be established right at the beginning to avert awkward difficulties later.

Now that I have my own place and can do my own thing without having to worry about what others do, it is immeasurably satisfying, and I would not change it for the world. I can decide what I want to eat, how much and when, close my own front door, be by myself and enjoy it, have friends to stay when I want, and I have the freedom to come and go when I please. These might seem like small things to some people, but to me they mean a heck of a lot after having been denied them for so long. I have my own privacy now and life is a challenge. It can sometimes be pretty intense, demanding and even a hassle, but isn't that part of life? I also have the dignity of taking risks, as well as maintaining my security and not forgetting to pay the bills. My values now seem more real again after having been hidden in the institution's walls. It is all about quality of life.

No longer is it an impossible dream or delusion, but a reality, and the numbers are growing. All I hope is that the authorities will wake up and see the worth of integrated, independent living and see the advantages it has for both the disabled person and the community as a whole, and fully support its development.

(This article first appeared in 'Design for Special Needs' the journal of the Centre on Environment for the Handicapped, 126 Albert Street, London NW1).



"Dear, I put a new spring in the garage door!"

1987 - September 18-19

Facing the Future...A Polio Conference.

Services for Independent Living.

Keynote speaker.

Cleveland, Ohio

Margaret Meyer, Coord

CLEVELAND POLIO SUPPORT GROUP

Friday, September 18, 1987

Westlake Holiday Inn

Split 45 minutes with JR

GL: start with keynotes

Janet + Dave

Thank you....Margaret – Congratulations on a ~~[illegible]~~ ~~[illegible]~~ beautifully organized conf —

Wonderful to be here. Like coming home. Lived 20+ yrs in CF

Great to see so many dear old polio friends...~~from Toomey days....~~

and so many new networkers.

As many of you know, polio intertwined in my life.....since

before born. 1912 ...4 siblings... 3 died

smell Can still see + feel every inch from elevator to old open corridor

1949...hot packs...epidemics...Volunteered...never stopped.

10 years at Toomey resp ctr. Known Susan A since 10 and Mickie McG since 12.

Wonderful human experience.....Made many lifelong Treasured friends...~~Fun~~

Physicians/patients/famil learned together as team. ~~No omniscience.~~

~~Never before kept so many alive on iron lungs.~~ Ruth – Ida – Louise – Donna – covered from on on Van Dow, a Litany of Love – Remember (Miss Kessler, Miss Torok, Ada Barnes, Sister Theophane, Mike Goodiel in Can a, Bob Christopher – Therapist

Late 50's...vaccines eliminated. At home. Two vital

needs: PEOPLE & INFORMATION...wanted to keep up with others &

share experiences...needed network to share information.

1958...
One way or another, my late husband, Joe, & I started to meet needs

to keep up with others because we built pool - heated - lift. First

polio support group since FDRs in early 1920s...children in Warm Sprgs.

Came every day....Once year: big annual picnic.
Many here regulars...

1-A Cleveland Sept 1987

In 1958...too <u>Dr. Eiben</u> started us on way to a <u>network</u> to share <u>info</u>

....he suggested I do a newsletter for Cleveland "alumni".....

Still going.

Now RG....40,000....87.....Japanese....library....

Started polio...first US,...then world.....

Became all disabilities....and aging

Exchange information and experiences....support group by mail....

IL by mail.

Nonprofit...supported by donations, memberships, & subscriptions.

and dedication of volunteers.

From beginning written by people with disabilities....

helped by nondisabled volunteers....Started around pool.

Corresp in notebooks....LSD parties

3 years ago made CHANGES SO COULD KEEP GOING after Joe & me
Chgd name: GINI..big Gini....little. Reorganized board.
JUDY RAYMOND, who had volunteered for 17yrs, became exec dir.

Reorganization timely...coincied with great increase in our polio network as result of late effects.

Although expanded...had never stopped maintaining LIVING NETWORK. since I first started in 1949.

CONSEQUENTLY...first to notice late effects & to publish
facts...
first to organize a plan to confront the
problem & to take the national & internation lead

* * * * * * * * * *

1979...letter...MD/s not knowing...think psychological...
Had flood of mail from others with same problem.
~~Other with respiratory problems.~~
FIRST PRIORITY...share info of older polio-experienced physicians Eiben + Maynard + Dickson
physicians with younger physicians. Asked MD's BEST WAY: bring older and younger together with polio survivors at conference

So, our organization started conferences...every other year.
UNIQUE...pay own way. Brown bags.
1981.... 125 attended...good nucleus of interested physicians
~~Getting together stated survivors thiniig~~ about
~~getting together~~ & ~~supporting each other~~.

~~Began to BROADEN AIMS OF~~ 1st CONFERENCES..: Made us broaden our aims -

1. Encourage research
2. Need for psychological support through self-help groups
3. Importance of sharing polio experiences of 30 yrs on ventilators with SCI, Musc Dys, ALS, etx.
4. Relate to all aging, all aging disabled.
5. Educated public & polio survivors to nonthreatening way.....

1983 Conference.... more than 400...40 on vent...7 lungs.

Support groups starting.

Attracted more & more MDs. Dr. Halstead asked to speak on sex & SCI. Fascinated by polio late effects. Joined with Dr. Dave Weichers to organize two scientific conf in 1984, 1986

1984...Judith and I & Dr. Maynard & Dr. Fischer: Handbook.

Dr. M & Dr. F. had both started helping at 1st conf... typical of concerned, caring physicians. Real - RDs...

Those 2 RDs are here...and there is ~~also one of~~ the orginal RD here ~~respiratory center RDs~~ her - Dr. Bob Eiben.

Polio seems to be a magnet for the best.

1985 CONFERENCE..... more than 500. Dr. Albert Sabin Dr. Masters of M & Johnson.

NETWORKING increases every time there is PUBLICITY with our address of phone number. If it isn't given, they sleuth.

Lines hum day & night. Most need to talk. ~~Judith & I are good listeners.~~ We're good listeners! If can't answer from library, we know someone who can.

For most - answers are in the handbook

Some need a simple bit of info_ shoe exchange -
Some blame every physical problem on polio....arthritis...
heart trouble...diabetes.... Even - story of breast/menstruation

Over years, Gazette involved in some large networking.

1960 - national attendant care
Mid-1960's - Talking books - Mrs. Cyrus Eaton C&O
1984 - Ventilators/HCFA
1986 - Russian polio survivor Simon, Tamara, Mark Levin
1987 - batteries on airplanes...ventilators

PSYCHOLOGICAL

BUT MOST OF THE SURVIVORS PROBLEMS ARE PSYCHOLOGICAL... THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLES.

The majority of you survivors were left relatively mildy disabled. You passed for normal. You adjusted. You overadjusted. You compensated. You overcompensated.

You lived for 30 years with a limp or a cane... Untouched by world of disability,

NATURALLY, when you began to experience late effects & began to use wheelchairs or other trappong of disability, you faced overwhelming psychological adjustments.

YOU NEEDED HELP & UNDERSTANDING...
YOU NEEDED A NETWORK OF PEOPLE with whom you could share long-denied feelings and emotions.
YOU NEEDED A CENTRAL SOURCE OF POLIO INFORMATION.

FORTUNATELY, Our G.I.N.I. organization was still there the information & Networking you needed to interlock the support groups that you began to form after our 1983 polio conference.

At the 1985 conference, GINI was asked to coordinate the
support groups & tie them in with longtime polio networking.
So, formalized IPN (International Polio Network)......
Judy started quarterly newsletter, Polio Network News
Sponsored a workshop of the leaders of the support groups - 86

Isn't it AMAZING what we have all accomplished TOGETHER - the
support groups....the physicians....and GINI's
International Polio Network....all in such a short time.
And, it is a short time.
We only started in 1979
Now the problems of the late effects are being recognized
by medical community & general public

And, through your support groups reaching more & more survivors.

National TV ocverage - Charles Kuralt Sunday Morning, Nightline, Today Show, Cable Network News, "Hour" Magazine and, of course, local features.

Articles in NEW YORK TIMES....prestigious medical journals, the latest in Archives of PM&R.

RESEARCH...funded by National Inst. on Dis & Rehab Research, March of Dimes, Easter S.

Judy will tell you more about our 1987 conf and about the International Polio Network.....14th Judy ~~leaving~~ is moving for Calif... named Dr. Fischer will continue valuable editing & involvement... modem/computer..... Joan Headley.... Dir. IPN

Thank you.

Nov 88 - Canada

1987 - September 11

Post-Polio Syndrome. REspiratory and Sl-ep Disorders. Sponsored by The Departments of Internal Medicine and Neurology, Northwestern University Medical School and The Polio Network of Illinois. Luncheon speaker.

Chicago, Illinois

CHICAGO POLIO SUPPORT GROUP Sat. Sept 12, 1987

Oak Brook Marriott. 10-15 minutes at end of lunch.

Roberta Simon

Thank you.....Thank you for your gracious hospitality.. transportaton. I am delighted to be here with ~~Great to see~~ so many old Gazette friends...new networkers.

Especially glad to be at a conference put on by Polio Network of Illinois because one of best in country.

Roberta asked me to talk about my interest in polio — It is more than an interest —

Polio entwined ~~with~~ my whole life.. Yr .Before born...Hit 4 siblings, caused deaths of 2 sisters, brother.

Consequently, when contagious ward asked for volunteers.. hotpacks... 1949..volunteered...never stopped.

10 yrs at respiratory center. Became friends. Followed after went home. Late 50svaccines stopped polio, centers closed, & all at home.

Two vital needs: PEOPLE & INFORMATION. keep in touch & share information. That's what networking is all about.

One way or another, my late husband & I started to meet needs of our friends. In 1958, buil pool. Heated. Lift. 1st polio support group. Big annual picnic. Around pool started newsletter....became RG...40,000...87...Japanese. All disabilities.

3 years ago made CHANGES SO COULD KEEP GOING after Joe & me.

GINI for short –

Chgd name: GINI..~~big~~ ~~Gini...little.~~ Reorganized board.

JUDY RAYMOND, who had volunteered for ~~20~~ 17 yrs, became exec dir.

Reorganization timely...coincied with great increase in our polio network as result of late effects.

Although expanded...had never stopped maintinaing LIVING NETWORK. since I first started in 1949.

30 YEARS LATER,

CONSEQUENTLY....first to notice late effects & to publish facts...

and in 1981 - first to organize a ~~plan~~ conference to confront the problem & to take the national & international lea

* * * * * * * * * * *

1979...letter....MD's not knowing...think psychological...

Had flood of mail from others with same problem.

+ others with respiratory problems –

FIRST PRIORITY...share info of older polio-experienced physicians with younger physicians. BEST WAY; bring older and younger together with polio survivors at conferen

older MD's

So, our organziation started conferences....every other year.

UNIQUE...pay own way. Brown bags.

1981 ... 125 attended...good nucleus of interested physicians.

Getting togeher started survivors thining about getting togher & supportingeach other.

+ SURVIVORS

3 [illegible]

Rudy AFTER THE CONFERENCE SAW NEED TO

~~Began to~~ BROADEN AIMS OF CONFERENCES...

1. Encourage reserach
2. Need for psychological support through self-help groups
3. Importance of sharing polio experience of 30 yrs on ventilators with SCI, Musc Dys, ALS, etc.
4. Relate to all aging, all zging disabled.
5. Educate public & poliosurvivors in nonthreatening way.... ~~Avoid "victims" sufferered"...patronizing & exploiting... pitiful brace cripples of the 1950s. Insist on dignity.... On self-help groups being self-help.~~

1983. Conference... more than 400....40 on vent...7 lungs.

Support groups starting.

Attracted more & more MDs. Dr. Halstead asked to speak on sex & SCI. Fascinated by polio late effects. Joined with Dr. Dave Weichers to organize two scientific conf in in 1984, 1986

1984...Judith and I & Dr. Maynard & Dr. Fischer; Handbook.

Dr. M & Dr. F had both started helping at 1st conf... typical of concerned, caring physicians. Reall- RDs...

~~They & other physicians attuned to LISTENING and appreciating your ~~the~~ expertise ~~of the survivors~~. Such as your Dr. Spencer & Dr. Valbona. Same type as at old resp ctrs....Polio seems t0 be magnet for best.~~

1985 CONFERENCE.... more than 500. Dr. Albert Sabin.

Dr. Masters of M & Johnson.

NETWORKING increases every time there is PUBLICITY with our address or phone number. ~~If it isnt given, they sleuth.~~

Lines hum day & night. Most need to talk. Judith & I are good listeners.

If cant answer from our library, we know another polio survivor or a physician or someone who can.

Most need basic info that is in handbook, IPN newsletter or the Gazette.

Some need a simple bit of info_ shoe exchange

Some blame every physical problem on polio....arthritis... heart trouble...diabetes.... ~~Even - story of breast/menstruat~~

Some more serious..special networking. Willa Schuster. double-barrelled.

Over years, Gazette involved in some large networking.

1960 - national attendant care

Mid-1960's - Talking books - Mrs. Cyrus Eaton C&O

1984 - Ventilators/HCFA

1986 - Russian polio survivor Simon, Tamara, Mark Levin

1987 - ventilators - batteries in passenger section

As you all know,

PSYCHOLOGICAL

~~BUT~~ MOST OF THE SURVIVORS' PROBLEMS ARE PSYCHOLOGICAL... THE PROBLEMS OF ADJUSTING TO CHANGES IN LIFESTYLE.

The majority of you survivors ~~are~~ were left relatively mildly disabled. You passed for normal. You adjusted. You overadjusted. You compensated. You overcompensated.

~~You lived for 30 years with a limp or a cane...~~
~~Untouched by world of disability,~~
~~by problems of discrimination & prejudice,~~
~~by the barriers of steps & inaccessible bathrooms.~~

NATURALLY, when y9u began to experience late effects & began to use wheelchairs or other trappings of disability, you faced overwhelming psychological adjustments.

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[redacted]

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1st weekend in June 88

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And, it is a short time.

We only started in 1979

Now the problems of the late effects are being recognized by medical community & gen public – There are more than 160 support groups & 50 clinics – Handbooks Translated etc.

~~And, through your support groups reaching more & more survivors.~~

National TV coverage - ~~Chas Kuralt Sunday Momning, Nightline, Today Show, Cable Network News, "Hour" Magazine last Tues.... and, of course, local fealtures.~~

Articles in NEW YORK TIMES....prestigious medical journals, ~~the latest in Archives of PM&R.~~

RESEARCH...funded by National Inst on Dis & Rehab Research, March of Dimes, Easter S.

7-Chicago   Sept 1987

As many ofyou who were there know, our 1987 conference was great sucess...747... 18 around the world - Japan...New 5ealand,Australia, Zaire, Mauritius, South Africa...... China — El Salvador/Brazil — Europe

1987 is an eventful year....

Glad news....Judith Raymond/Armin

Sad news....for us to lose Judy...but will continue to edit -
proceedings, etc....and keep up with computer & modem....

Good news...have new director, IPN.....Joan Headley....LaGrange,Ind...

With super support groups like your Illinois network, we will all be doing great networking in the next years......

NEXT CONF - 89

May 31 — June 4

1987 - October 9

Women In Communications Headliners

Award.

Acceptance: "Watch Your Words"

Minneapolist-St.Paul, Minnesota

International Polio Network
4502 Maryland Ave. St. Louis, Missouri 63108 U.S.A.
(314) 361-0475

WICI 1987 HEADLINER AWARD LUNCHEON REMARKS
9 October 1987 by GINI LAURIE

Fellow WICI members, members of your Headliner Award Committee, and former recipients of the Award, I thank you for this prestigious award.

And, thanks to the hundreds and hundreds of other volunteers, both disabled and nondisabled, here in the U.S. and around the world.

Together, we have created a living network of people with disabilities who share life experiences and practical adaptations through our Institute's conference, information services, and publications.

Our living network is a positive power that has motivated countless thousands of persons with severe disabilities to work, play, travel, marry, raise families, and live independently and productively in their communities.

Most of them have been paralyzed by polio or spinal cord injury. Many of them have been using iron lungs or other ventilators for more than 30 years. Most of them have had successful careers and lived at home with the supporting services of their families.

ALL OF THEM HAVE BEEN FAR MORE VICTIMIZED BY SOCIETY'S NEGATIVE ATTITUDES AND SOCIETY'S ENVIRONMENTAL BARRIERS THAN BY THEIR DISABILITIES.

Some of the environmental barriers have been removed by legislation through section 504 of the Rehabilitation Act of 1973 - the Bill of Rights of people with disabilities.

But negative attitudes cannot be removed or changed by legislation.

Positive attitudes are the personal responsibility of each one of us. Each of us must use the words that promote positive attitudes.

The positive attitude words are the words of common consideration anf thoughtfulness - words that refer to people with disabilities, not disabled people.....words that emphasize our common humanity.

The negative words are the words that dehumanize - the pitiful, pedestal, ugly, saccharine, and helpless words.

The language of the media can reflect and shape the positive perception of people with disabilities as caring, feeling, responsive, sexual human beings who love, who need to be loved, who need to be needed - as do all people.

In giving me one of this year's Headliner Awards, WICI recognizes the humanity, the dignity, and the human rights of people with disabilities, and takes a commendable step toward removing soceityal barriers, achieving positive attitudes, and developing positive communications. As polio survivors Itzhak Perlman said,

> "With my violin I can make beautiful sounds, with your words, you can create a beautiful since of understanding among people. Both our contributions will make life more meaningful."

I thank you again for this honor....

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Not caps -

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1987 - October 30

Third Annual Post Polio Seminar. Gaylord Hospital. Speaker: "The Idea and History of Independent Living."

Wallingford, Connecticut

GAYLORD HOSPITAL'S THIRD ANNUAL POST POLIO SEMINAR
October 30, 1987. Meriden, Connecticut

INTRODUCTION TO OPTIONS AND ALTERNATIVES

THE IDEA AND HISTORY OF INDEPENDENT LIVING

by Gini Laurie

Thank you. It is a great pleasure to be back again experiencing Gaylord's warm and caring spirit.

And, I'm dleighted that I was asked to talk about the idea and history of independent living at a polio conference because polio survivors have been the leaders of the independent living movement and because polio and independent living and my life have been so closely intertwined.

My absorption with polio began because it caused the deaths of three siblings. I started volunteering at one of the 16 regional respiratory polio centers in 1949 - and I've never stopped.

Then and in the early 1950s, iron lungs were the only ventilators used and people did not go home, they stayed on at the hospital for years if they required respiratory aid.

But, in 1953 - at Rancho Los Amigos, the Los Angeles center, a home care program with attendant care was begun. that foreshadowed the I.L. Movement. The program was initiated to save money for the county, which was faced with the lifelong hospital care of 158 respiratory polio survivors at $37 a day.

When a feasibility study showed that, with an attendant care and ~~an~~ equipment program, they could live at home for $10 a day, 152 people went home with their ventilators.

At first, the hospital trained the attendants. But it was soon found it was more ~~less~~ satisfactory ~~than~~ to train~~ing~~ the ventilator-users and their families to train their own attendants.

The March of Dimes, which was paying for hospital care around the rest of the country, took up the home attendant system with great enthusiasm. The polio survivors at the other centers went home, too - with payments of about $300 a month for their attendants.

#

When the ventilator-using alumni of our center went home, I followed their lives closely and acted as a peripatetic newsletter.

In 1958, I started a small publication so they could keep in touch and share their adaptations and adjustments to life in their own communities.

It grew rapidly to include polio survivors at the other centers, then around the world, then all disabiities.

And it is still going and growing. It became the Rehabilitation Gazette and the International Polio Network and the Interantional Ventilator Users Network.

#

Also, in 1958, my husband and I built a small heated swimming pool, with an hydraulic lift, and it became the daily meeting place of ~~my~~ our polio friends and their friends and families - the first polio support group and the only one that has never stopped.

We all worked together creating the Gazette and answering letters. Naturally, with the magnet of the pool, there was never a shortage of volunteers.

At some of the other respiratory centers and at Sister Kenny and Warm Springs, the alumni at home kept in touch for a few years with a newsletter or an annual picnic. Eventually, they all faded away except the one in southern California, which was revived later as the Polio Survivors Association.

#

Meanwhile, by 1959, the vaccines had stopped polio and the public stopped giving to the March of Dimes and the March of Dimes stopped paying for attendants and closed the centers.

The sudden loss of attendant payments caused panic. There was no Social Security Disability, no Medicare, no Medicaid, no vocational rehabilitation for people with severe disabiities, There was only welfare or help from churches or family. Fortunately, they had had attendants for a few years and they had had time to work out some systems of community support, but they also needed the psychological support of other survivors.

The Gazette was the only national organization of polio survivors and its readers turned to it for support and action. The Gazette responded by leading a letter-writing campaign, alerting survivors in every state to write to their Congressmen urging national attendant care legislation.

The national campaign was unsuccessful but it called Washington's attention to the problems of people with severe disabilities and it demonstrated the power of working together.

The California campaign was successful and the alumni of the San Francisco and Los Angeles ~~two~~ centers effected the permanent state legislation for attendant care that later cleared the path for the independent living movement for attendant care is the linchpin of independence.

#1

The independent living movement received further impetus in 1965 when Mary Switzer, the Commissioner of Vocational Rehabiliation, expanded the 1965 Amendments to the Vocational Rehabilitation Act to include tuition and attendant CARE and other services to enable persons with severe disabilities to earn higher degrees. Thus, there was developed an educated leadership - an essential to the movement.

Two of those quadriplegic students at Berkeley - Ed Roberts, who was disabled by respiratory polio, and John Hessler, who had had a spinal cord injury at C5-6 - carried theprogram another step.

In 1970, they started the Physically Disabled Students program to enable 12 quadriplegic students to live off campus through the California attendant care program.

At first, ~~they~~ the students thought of a group residence.

because of the examples of [illegible] polio who

Fortunately, the ~~ventilator-users from the centers had pioneered living in the community, and~~ they rejected such segregated, dependent living. They set a pattern of living in the community and working in an office which offered counseling services to other people with disabilities.

In 1972, after they had graduated, they carried the program from students to people with disabiities in the area and thus started the first Center for Independent Living.

The next step was a coalition of people with various disabiities and of the disabled leaders of the West and East Coasts and the South and Midwest.

The first meeting of the American Coaltiion of Citizens with Disablities was organized in June 1974. (Phyllis will tell you a great deal more for she was president for many years.......I was on the first board. They used to tease me about being their "token" nondisabled member.)

home care services. But they did not sit idly at home. They went on to higher education and successful business or family careers. They married and have children and grandchildren. They travel and enjoy hobbies.

They continue to demonstrate the potential of people with severe disabilities to live independently. They are role models. Their accomplishments and their equipment adaptations and their fights for rights have been shared in the pages of the _Rehabilitation Gazette_ - so that IT has been serving as an independent living center by mail.

The _Gazette_ continues to evolve. Several years ago We reorganized and developed the umbrella organization, Gazette International Networking Institute (G.I.N.I. for short), a national and international information center for people with disabiities.

But we have never ceased to maintain a living network of polio survivors around the world. Therefore, we were the first to notice and to publish information on the recent appearance of the late effects of polio and, in 1981, to organize the first of its biennial international polio conferences to inform and TO network survivors, to educate health professionals, and to stimulate research.

In 1984, we published the <u>Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors</u> that is called the "bible" of polio information around the world. It has been translated into Swedish and Chinese and is being translated into French, Spanish, German, Italian, and Finnish.

The conferences and the handbook were among the catalysts for the two scientific conferences at Warm Springs in 1984 and 1986.

Following our 1985 conference, the Gazette's longtime polio network was formalized into the International Polio Network (IPN). IPN coordiantes the more than 250 support groups and 55 clinics that have been organized in the last few years. It publishes a quarterly newsletter, <u>Polio Network News</u>, and a directory of support groups and clinics for its members. It also acts as the information center for the world on polio's late effects.

When the leaders of the support groups gathered inSt. Louis in 1986 for IPN's leaders' workshop, the creativity and organizational skills of the groups were apparent and it was obvious why they had made such rapid progress.

As here in Connecticut, many of you have not only provided psychological support for members, but you have accomplished statewide organizations and systems of educating health professionals.

Many of the gorups have organized excellent regional and local conferences, such as this one, to educate health professionals and the general public, as well as individual members.

The support gorups and our International Polio Network have worked together onseveral exciting national advocacy projects. Together, we accomplished National Polio Awareness Week. We at IPN started it with our Representative Gephardt and the support goups followed up by contacting their representatives. Together, we generated letters that effected the freeing of a refusenik who is disabled by polio. She and her family came to the 1987 conference ~~with her family~~ to express their thanks. IPN and several support group members in Baltimore worked together to provide information to the Social Security Administration that has resulted in a Program Circular documenting the late effects. We'll be learning more about that from , the Social Security reprsentative.

We're planning ahead and I want to invite all of you to IPN's 1989 conference in St. Louis on May 31-June 4 and to invited you leaders to the 1988 Leaders' Workshop on June3-5.

The polio support group spirit is the intangible, indescribable spirit of the biennial polio conferences, which Charlene Bozarth described as "The inspiration of being with so many who have not let their disabilities prevent them from living active, loving, joyous lives."

Thank you!

1987 - November 7

Second Annual Post P-lio Syndrome Seminar. The Post Polio Support Group of Maine. Keynote speaker.

Augusta, Maine

Rich's Meade chauffering

MAINE......November 6, 1987

Maine lots
Indian padd
& a stack of
Maine fri

Thank you. and Thanks for gracious hospitality –

I'm delighted to be here at your superb seminar.

It is such a joy to travel arund the country and meet with polio survivors. I always have the feeling of being with old friends. – almost a family feeling –

And, I never get over the wonder of all that ~~has happened~~ we have accompl together – in such a short time.

I never get over the fact that all these support groups, and clinics, and reserach ...... all started because we OF A ~~published a~~ letter from a polio survivor in our 1979 issue of the Rehabiitaion Gazette. ~~describing his problems and the problem of being unable to find a doctor who knew about polio.~~ Some of you know the story...or parts of it...but I'll try to put it all together.

As ~~the~~ YOUR program said, I'm involved with polio because it caused the deaths of three of my siblings.

So, when the polio epidemics started in 1949 and our local contagious ward asked for volunteers, I started to do hot packs and I've never stopped.

Remember
the sme
of

The contagious ward became one of the ~~I volunteered at one of the~~ 16 reppiratory polio centers which the March of Dimes - then the Natl Fdn for Infantile Paralysis ~~had~~ set up around the country. And which they funded from 1951 - 19

2-Polio support group history - Maine

From these centers, in which people spent months and years together adjusting to life with iron lungs or portable respirators, evolved strong feelings of togetherness, of mutual support, of warm friendships, and a need to keep in touch in order to share information and experiences after they ~~have~~ returned to their homes.

For a few years after the respiratory centers closed, the "alumni" of some of them fostered support groups meetings of their fellow "alumni" and published mimeographed newsletters of their at-home doings. Among these were the groups in San Francisco, Los Angeles, Buffalo, Omaha, Houston, Ann Arbor, and Cleveland. For a few years, too, nonrespiratory survivors shared newsletters from Sister Kenny Institute and Warm Springs and a group met as the Chicago Polio Swim Club.

Eventually, they all faded away except two. The Los Angeles

support group was revived as the Polio Survivors Association, primarily to advocate for local ventilator~~y~~ users.

2nd

3

But the Cleveland respiratory center group was kept alive and is still going as the Interantional POlio Network. It was

Later: (people/information

kept alive because of two happenings in 1958...I started a emps

little newsletter so people could keep up with how people were doing at home.....that became the Rehabilitaton Gazette, our international journal.

And my late husband, Joe, and I built a little heated swimming pool with a hudraulic lift. It became the magnet for our polio friends and a polio support group that has never stopped.

.....We all worked on the Gazette around the pool - LSD parties

Once a year - annual picnic

Polio support group history Maine

Written by ~~[illegible]~~ by the

With ~~a volunteer staff of~~ "alumni" of the Cleveland and other respiratory polio centers, the Gazette became the only national organization of polio survivors. Their only permanent network.

Consequently, it was quick to respond to the fright of its readers when the success of the vaccines caused the March of Dimes to cease~~d~~ funding attendant care for polio survivors in 1959. The Gazette led an unsuccessful national letter-writing campaign to urge Congress to pass national attendant care legislation. ~~However,~~ In California, however, the 1960 campaign by the alumni of ~~the~~ its two centers resulted in permanent state legislation for attendant care. But, we learned the power of working together.

A few years later, at the instigation of a polio survivor, the Gazette led a successful national campaign to expand the the Talking Books program for the blind to include people with physical disabilities.

The Gazette continued to expand in the 1960s and the 1970s into an international journal devoted to independent living for people with all disabilities. Yet, it never ceased to maintain a living network of polio survivors around the world. Consequently, in 1979, it was the first to notice and to publish the problems its readers were having with the late effects of polio and with ~~younger~~ their physicians whose education had not included polio.

In 1980 ~~Gini~~ I discussed these late effects and the need to educate young physicians with Dr. David Dickinson of Ann Arbor, Dr. Robert Eiben of Cleveland, and ~~Dr. Allen Goldberg of Chicago~~. Dr. Dickinson referred ~~Gini~~ me to Dr. Frederick Maynard, a physiatrist, who had seen a few polio survivors with the problem. Together, ~~they~~ we planned an international polio conference.

The Gazette's first international polio conference in Chicago in 1981 drew 125 survivors and physicians. There began the unique partnership of lay and professional persons working together to solve an undocumented problem, and the special spirit of concern and sharing ~~polio togetherness~~ that characterizes all the Gazette's international polio conferences.

RD

Six ~~years later~~, Dr. Maynard reported in an interview in ~~the ST. LOUIS POST-DISPATCH~~, "Gini was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?

"I remember thinking at that first conference, 'Who am I to talk?' I told them I didn't know if what I was seeing in the handful of people in my clinic was typical or just odd cases. The audience said yes, they had the same symptoms, knew others with them. After that meeting, I was convinced."

Soon after the 1981 conference, another physiatrist, Dr. Stanley Yarnell, and polio Survivor Renah Schnaider organized a polio conference in Oakland, California; a polio clinic was opened at the University of Wisconsin, Madison, and a support group was begun in Buffalo, New York. ~~The Gazette~~'s exploded ~~mail increased tenfold~~ as polio survivors wrote and called for information on the late effects. From the very beginning, clinics and support groups worked as a team, reinforcing each other. The inics referred people to support groups and the support groups referred eir members to clinics.

4A--Polio support group history

polio

The Gazette's 1983 international conference in St. Louis drew 400 registrants from Australia, Canada, England, Germany, India, Japan, Mexico, South Africa, and Sweden. About 40 of the registrants used ventilators: most brought their own portables, seven rented iron lungs for nights. The ventilator users and respiratory specialists began to ~~shared~~ share their variations on face masks and other night aids. The mobility impaired, and physiatrists, and therapists shared symptoms and treatments of the fatigue, pain, and muscle weakness ~~caused by the late effects of polio.~~

El Salvador

The goals stated at those early conferences are still The goals of all of us viable: 1) to work as a team of polio survivors and health professionals, and of organizations ~~and coalitions of the elderly and disabled for networking~~, people with disabilities information, research, mutual support, education, treatment, and worldwide immunization; 2) ~~to relate the~~ positive experiences of polio survivors to other ~~disabled and elderly~~ persons with disabilities and to other ventilator users; ~~and~~ 3) to promote independent living and 4) to influence legislation for in-home support services and national attendant care.

PRESERVING

The conferences brought survivors together and revived their former joy in being together and of sharing problems and information. The first two international conferences awakened the registrants to their psychological need for mutual support ~~and they returned home to start support groups.~~

Psych most important — Need to share denial — help with acceptance

Clinics, both

Need to share early at them — put them in their place

The conferences brought together medical clinicians and researchers and triggered Dr. Lauro Halstead and Dr. David Wiechers to organize the 1984 and 1986 international scientific conferences to stimulate more research into the cause and treatment of ~~the late~~ effects. The National Institutes of Health became involved in research as did the National Easter Seal Society and the March of Dimes Birth Defects Foundation.

By 1984, the Gazette ~~staff became more and more swamped with requests for information. It~~ reorganized and expanded and became the Gazette International Networking Institute (G.I.N.I.) ~~Judith Raymond, who had been volunteering parttime for 17 years, became the executive director and took over the organization of~~ TO COORDINA information on the late effects.

~~to coordinate~~

Of primary importance was the publishing of a summary of the knowledge in a clear, concise handbook. The <u>Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors</u> was written by ~~Gini and Judith and~~ our staff Laurie Raymond Dr. Frederick Maynard, and Dr. D. Armin Fischer. It is now into its third printing and has been translated into Swedish and is being translated into German, Italian, and Spanish, and FINNISH, and excerpted in Chinese.

△

I see a triangle of survivors-physicians-researchers

The NETWORKING and flow of information on the late effects from lay persons to health professionls has been unique - a reversal of the usual order. # Publications, support groups, and local and national publicity have gradually informed the general public and alerted health professionals. Articles have appeared in THE NEW YORK TIMES, The WASHINGTON POST, the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, the NEW ENGLAND JOURNAL OF MEDICINE, and TV shows, such as Kuralt's <u>Sunday Morning Show</u>, <u>Hour Magazine</u>, <u>Nightline</u>, etc. have covered the topic.

6-Polio support group history

In 1985, more than 500 registrants came to G.I.N.I.'s Third International Polio and Independent Living Conference in St. Louis. Registrants from a few more countries were added to those of the previous years: The Netherlands, Denmark and Taiwan. Highlights were the session chaired by William Masters, MD, and the conference banquet honoring Albert Sabin, MD.

An important session brought together the leaders and members of the support groups to share plans and problems. ~~The groups asked G.I.N.I. to coordinate and act as the official clearinghouse for the support groups in the United States and to maintain a directory of support groups, physicians, resource persons, and clinics.~~ As a result, the Gazette's longtime informal ~~Gazette~~ international polio network was formalized into the International Polio Network (I.P.N.) and the quarterly newsletter, Polio Network News, and a directory [illegible] of support grps, clinics, was initiated. for members.

Last two years

In the following years, many more than 100 200 support groups and more than 150 clinics have been ~~were~~ started and many regional and local conferences ~~were~~ held. any of The conferences were organized by support groups, often in cooperation with local independent living centers, universities, hospitals, Rehabilitation CENTERS, March of Dimes, OR Easter Seal, ~~universities, or clinics~~. The conferences educated health professionals and the general public and foster an ~~created~~ esprit de corps in the support groups.

In June 1986, I.P.N. international polio network organized a workshop in St. Louis for about 70 of the leaders of support groups. astounding gathering The individuality, creativity, and organizational ability of The leaders have been ~~are~~ the keys to the development of the groups.

7-Polio support group history

Some support groups, such as yours in Maine, have accomplished outstanding statewide organizations and systems of educating the health professionals. we have all worked together on

Meanwhile, two polio survivors eased the way for approval of social security disability claims submitted by polio survivors unable to work due to the late effects of polio. Marge Torre of Philadelphia singlehandedly tackled the Social Security Administration (SSA). T Where she found an ally in another polio survivor, Jane Dummer, who works in the office of Vocational & Medical Policy at SSA headquarters in Baltimore. They were joined by representatives of the International Polio Network ~~Their~~ OUR combined efforts, resulted in issuance and distribution of a Program Circular which documents the late effects of polio throughout SSA.

Another NETWORKING accomplishment by members of the support groups working together involved the U.S.S.R. Responding to a request in the summer 1986 issue of Polio Network News, hundreds of U.S. polio survivors wrote letters to Russian leader Mikhail Gorbachev, President Reagan, and Dr. Armand Hammer urging an exit visa for Russian polio survivor, Tamara Tretyakova and her son, Mark, on humanitarian grounds. Those letters were responsible in large part for the granting of a visa in October, 1986, and Tamara, Mark, and her husband, Simon Levin, came to the Gazette International Networking Institute's Fourth International Polio and Independent Living Conference IN 1987 to express their thanks.

That conference brought together 747 medical experts, health professionals, and polio survivors from all across the United States and 18 countries, including several more from the Third World.

11

Of particular interest were the sessions on fatigue, pain, exercise, bracing, face masks for nocturnal oral positive pressure ventilation developed by both users and prescribers, and the international exchange on independent living and attitudes toward disability.

The conference banquet celebrated the 10th anniversary of the implementation of Section 504, the bill of rights for people with disabilities, and the speakers included Ted Kennedy, Jr., and the leaders of the disabled movement who had fought for the implementation.

At the conference, ~~G.I.N.I.~~ I.P.N initiated the first week of June as National Polio Awareness Week through the concerted efforts of Congressman Richard A. Gephardt of Missouri and the other congressmen whom the support groups contacted to support his enabling legislation.

[illegible] I.P.N. ~~now~~ not only coordinates over the more than ~~160~~ 2000 support groups in the United States, but works with a growing number across Canada, and spreads the support group spirit around the world through the polio survivors who attend its international conferences.

That polio support group spirit is the intangible, that spirit typifies the role of networks and support groups indescribable spirit of the biannial conferences. Dr. Webster Cash of Georgia writes, "It is a mixture of friendship, laughter, empathy, and - yes - love....It is a remarkable tribute to polio survivors.... We are indeed a different breed." Charlene Bozarth of Michigan says, "The inspiration of being with so many who have not let their disabilities prevent them from living active, loving, joyous lives is beyond description."

Invite you all to the 1989 conference in STL May 31 – June 4

~~and~~ thank you again for the privilege

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Boston,Massachusetts

THE ROLE OF NETWORKING AND SUPPORT GROUPS

by Gini Laurie

Chairman, International Polio Network

Contribution to

POST-POLIO SYNDROME

Edited by

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Tufts University School of Medicine

December 1987

THE ROLE OF NETWORKING AND SUPPORT GROUPS

by Gini Laurie

Networking is a new word for the ancient system of support services supplied by the family and the village. Networking links people who share common needs or common goals and provides a method and a structure by which they can meet their needs or accomplish their goals.

Support groups are a specialized type of networking which have four characteristics:

- Members help each other by sharing common problems or predicaments through mutual aid and self-help;
- They are composed of peers or equals, people who share a common experience or situation;
- They are primarily run by and for their members who have a sense of ownership, and
- They are voluntary, non-profit, charging little or no fee for the involvement of their members.

In most groups, there are three basic types of activity: emotional support, information exchange, and coping strategies. The degree of activity in each of these areas will vary according to the needs of the members.

Most support groups are small, informal, financially insecure, and fluid. Members come and go as the group meets their needs. The usual pattern of their national organization is a loose network of autonomous groups. The most common is an association, supported by dues from the affiliated local branches or chapters that are authorized to use its name.

Silverman, Gartner

Support groups differ from professionally-run groups, which are more likely to resemble group therapy rather than self-help, and they can provide benefits that professional groups cannot. Self-help groups are not meant to replace professional services but they supplement and may even prevent the need for them.[1]

Professional human service agencies and mutual help groups may have a tense and competitive relationship. Historicaally, professionals have often tried to co-opt mutual help organizations, and they are frequently regarded as intruders.

The networking and self-help support group movements are growing rapidly, filling the gaps left by the disappearance of family and community support. Presently, self-help groups involve about 15 million persons in more than one-half million groups.

The recent development of the polio support groups for survivors with the late effects of polio is uniquely and strongly influenced by the survivors' early experiences - especially those during and following the epidemics of the 1950's.

Until the 1950's, polio was "infantile" paralysis and the children learned to share and help each other because they were together for years at children's hospitals or centers. The most famous of the centers was started by President Franklin Delano Roosevelt shortly after he was disabled by polio in 1921. He gathered around him children recuperating from polio because he liked company in the pool at Warm Springs, Georgia, and he wanted to share the benefits of hydrotherapy.

There and at the other children's centers was the essence of the support group spirit which left happy memories of friendship and pranks. On the other hand, some spent years in and out of casts following repeated corrective surgery and felt lonely and abandoned by their families. Such mixed feelings, which were glossed over for thirty or even sixty years, are only now being faced and shared in the support groups.

In the 1950 epidemics, polio struck people of all ages. With improved medical management, adults with severe respiratory involvement were saved. To meet their needs, the National Foundation for Infantile Paralysis (March of Dimes) created and funded 16 respiratory polio centers around the country. 2

The respiratory centers were in operation from 1951 to 1959. They were magnanimously funded by contributions to the March of Dimes that covered the expenses of staff, research, patient care, equipment and maintentance, and home care with attendants. Most of ther centers were in contagious wards and directed by pediatricians who had had little experience with adults or respirators. Consequently, they evolved creatively to meet the unknown problems of the epidemic years.

The centers functioned as a team that included staff, patients and families, engineers, and the community. The resulting rehabilitation was extraordinarily positive. By the mid-1950's the majority of the respirator-dependent individuals were at home, trained to take responsibility for their equipment, attendants, and their lives.[3] They went back to school or work, attained training or higher education, married, raised children, and lived full and productive lives - after a long, hard struggle.

The struggle began in 1959 when the March of Dimes had to close the centers and cease funding attendants, medical care, equipment, and reserach because the success of the vaccines had stopped donations from the public.[2] The polio survivors faced extraordinary adjustments. They were suddenly left on their own after being pampered, praised, and protected from all financial worries. Fortunately, they had had the protection and assistance when they needed it - during early rehabilitation - and they reacted with a fighting spirit of adaptation. The less severely disabled learned to "pass" as nondisabled. Others muddled on with their old braces or other equipment and worked out their own solutions. Many avoided medical care because of economy or early experiences. Those were lean years - before Medicaid, Medicare, SSI, Social Security disabiity benefits, independent living centers, and expended vocational rehabiitation services. The survivors had to rely on their own resources, their families, or welfare. But they also needed mutual support of those who had shared their polio experience.

The survivors with respiratory involvement and others who were severely disabled had the most need for sharing. They had spent months and years together learning to live with iron lungs or portable respirators. They had evolved strong feelings of togetherness, of mutual support, of warm friendships, and a need to keep in touch to share information and experiences.

To fulfill these universal needs for people and information, the "alumni" of some of the respiratory centers fostered social meetings and published mimeographed newsletters of their at-home doings for a few years after the centers closed. Among these were groups in Los Angeles, San Francisco, Buffalo, Omaha, Houston, Ann Arbor, and Cleveland. For a few years, too, nonrespiratory survivors shared newsletters from Sister Kenny Institute and Warm Springs and a group met as the Chicago Polio Swim Club.

Eventually, they all faded away except two. The Los Angeles group was revived as the Polio Survivors Association, primarily for advocacy for ventilator users. The

Cleveland respiratory center group was continued by the author, a volunteer at its Toomey Pavilion. She started a publication, Rehabilitation Gazette, to share do-it-yourself equipment and experiences and provide information. The publication has evolved into the Gazette International Networking Institute and the International Polio Network.

The history of the evolvement of the Rehabilitation Gazette into an international journal and polio network is the history of the current awareness of the late effects of polio and of the evolvement of the support groups and clinics.[4]

Starting in 1958, the Cleveland "alumni" had large annual picnics at the home of the author and her husband, Joe, and daily summer "support group" gatherings of survivors and volunteers in and around their swimming pool. Together the group wrote the Gazette and answered requests for information and networking with other survivors.[5]

Written by the alumni of the Cleveland and other respiratory polio centers, the Gazette became the only national advocacy organization of polio survivors, their only permanent network.

The Gazette expanded in the 1960s and the 1970s into an international journal devoted to independent living for people with all disabilities in 87 countries. Yet it never ceased to maintain a living network of polio survivors. Consequently, in 1979, it was the first to notice and to publish the problems its readers were having with the late effects of polio and with their physicians whose education had not included polio.

In 1980,[6] the author discussed these late effects and the need to educate physicians with Dr. David Dickinson of Ann Arbor, Dr. Robert Eiben of Cleveland, and Dr. Allen Goldberg of Chicago. Dr. Dickinson referred the author to Dr. Frederick Maynard, a physiatrist, who had seen a few polio survivors with theproblem. Together, they planned an international polio conference.

The Gazette's first international polio conference inChicago in 1981 drew 125 survivors and physicians. All of them paid their own expenses. There began the unique partnership of lay and professional persons working together to solve an undocumented problem. There began the special spirit of mutual respect and sharing that characterizes all the Gazette's international polio conferences, the publications, and the support groups.

Six years later, Dr. Maynard reported in an interview in the ST. LOUIS POST-DISPATCH,[7] "Gini Laurie was the catalyst. If she had not held that first meeting, it is possible we might still not know about these effects. Eventually, we might have noticed that many post-polio people had problems, I guess. But when?

"I remember thinking at that first conference, 'Who am I to talk?' I told them I didn't know if what I was seeing in the handful of people in my clinic was typical or just odd cases. The audience said yes, they

- To work as a team of polio survivors and health professionals and organizations and coalitions of people with disabilities for networking, information, research, mutual support, education, treatment, and worldwide immunization;
- To relate the positive experiences of polio survivors to other persons with disabiities, including the aging and other ventilator users;
- To promote independent living;
- To influence legislation for in-home support services.

The conferences were the catalysts for the support groups. They brought survivors of all degrees of disability together and revived their former joy of being together and sharing problems and information. The first two conferences awakened the registrants to their vital psychological need for mutual support and they returned home to start support groups.[8]

The conferences brought together medical clinicians and researchers and triggered Dr. Lauro Halstead and Dr. David Wiechers to organize the 1984 and 1986 international scientific conferences to stimulate more research into the cause and treatment of the late effects. The National Institutes of Health became involved in research as did the National Easter Seal Society and the March of Dimes Birth Defects Foundation.

In 1984, the Gazette reorganized and expanded to become the Gazette International Networking Institute to coordinate information and networking on the late effects.

Its publishing of a summary of the knowledge in a clear, concise handbook was timely and significant. The <u>Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors</u> was written by Gini Laurie, Judith Raymond, Frederick Maynard, M.D., and D. Armin Fischer, M.D. It is now in its third printing and has been translated into Swedish and is being translated into German, Italian, Spanish, and Finnish, and excerpted in Chinese.

The networking and flow of information on the late effects of polio from lay persons to health professionals has been unique - a reversal of the usual order. Publications, support groups, and local and national publicity have gradually informed the general public and alerted health professionals. ARticles have appeared in THE NEW YORK TIMES, the WASHINGTON POST, the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, the NEW ENGLAND JOURNAL OF MEDICINE, and TV shows, such as Kuralt's <u>Sunday Morning Show</u>, <u>Hour Magazine</u>, <u>Nightline</u>, etc., have covered the topic.

In 1985, 9 more than 500 registrants came to G.I.N.I.'s Third International Polio and Independent Living Conference in St. Louis. Registrants from more countries were added to those of the previous years: The Netherlands, Denmark, and Taiwan. Highlights were the session chaired by William Masters, M.D. and the conference banquet honoring Albert Sabin, M.D.

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act as the official clearinghouse for the support groups in the United States and to maintain a directory of support groups, physicians, resource persons, and clinics. As a result, the Gazette's longtime international polio network was formalized into the International Polio Network (I.P.N.) and the quarterly newsletter, Polio Network News, and directory were initiated for members.

In the last two years, more than 200 support groups and 50 clinics have been started and many regional and local conferences held. The conferences have been organized by support groups, often in cooperation with local independent living centers, universities, hospitals, rehabilitation centers, Easter Seal, or March of Dimes. The conferences educate health professionals and the general public and foster an esprit de corps in the support groups.

In June 1986, International Polio Network organized a workshop for about 70 of the leaders of the support groups in St. Louis. The workshop highlighted the creativity, individuality, and organizational ability of the leaders. Since then, some support groups have accomplished outstanding statewide organizations and systems of educating health professionals and survivors.

Meanwhile, two polio survivors and I.P.N. eased the way for approval of social security disability claims submitted by polio survivors unable to work due to the late effects of polio. Marge Torre of Philadelphia singlehandedly tackled the Social Security Administration (SSA). There she found an unexpected ally in another polio survivor, Jane Dummer, who works in the Office of Vocational and Medical Policy at SSA headquarters in Baltimore. They were joined by representatives of the International Polio Network. Their combined efforts resulted in issuance and distribution of a Program Circular which documents the late effects of polio through SSA.[10]

Another networking accomplishment by members of the support groups involved the U.S.S.R. Responding to a request in the summer 1985 issue of <u>Polio Network News</u>, hundreds of U.S. polio survivors wrote letters to Russian leader Mikhail Gorbachev, President Reagan, and Dr. Armand Hammer urging an exit visa for Russian polio survivor Tamara Tretyakova and her son, Mark, on humanitarian grounds. Those letters were responsible in large part for the granting of a visa in October, 1986,[11] and Tamara, Mark, and her husband, Simon Levin, came to G.I.N.I.'s Fourth International Polio and Independent Living Conference in 1987 in St. Louis to express their thanks.

That conference brought together 747 medical experts, health professionals, and polio survivors from all across the United States and 18 countries, including several from the Third World.

Of particular interest were the sessions on fatigue, pain, exercise, bracing, face masks for nocturnal oral positive pressure developed by both users and prescribers, and the interantional exchange on independent living and attitudes toward disability.

At the conference, International Polio Network initiated National Polio Awareness Week through the concerted efforts of Congressman Richard A. Gephardt of Missouri and the other congressmen whom the support groups contacted to support his enabling legislation.

A conference session for the medical directors of the polio clinics resulted in plans for further exchange through a newsletter written by the directors and published by International Polio Network.

International Polio Network not only coordinates the more than 200 support groups in the United States, but works with a growing number across Canada and spreads the support group spirit around the world through its international conferences.

That polio support group spirit is the intangible, indescribable spirit of the biennial conferences which Webster Cash, Ph.D., of a Georgia support group describes as "a mixture of friendship, laughter, empathy, and - yes - love....The conferences are a remarkable tribute to polio survivors....We are indeed a different breed." Another polio survivor, Charlene Bozarth of Michigan, says "The inspiration of being with so many at the conferences who have not let their disabilities prevent them from living active, loving, joyous lives is beyond description."

Summary

Support groups are a specialized type of networking composed of equals who help each other by sharing information and common experiences and who have a sense of ownership of their voluntary, nonprofit organizations.

Support groups are intended to supplement, not replace, professional human service agencies. The relationship may be competitive because, historically, some professionals have sought to co-opt mutual help organizations.

The history of the polio support groups is interwoven with the history of the International Polio Network which was founded in 1958 as a local newsletter for polio survivors, which called attention to the late effects in 1979, and which now coordinates more than 200 support groups in the United States, and publishes a handbook, quarterly newsletter, and directory, and organizes biennial international conferences and leaders' workshops.

The need for psychological support for polio survivors experiencing its late effects is often as critical as the need for physiological treatment and is influenced by their initial medical experiences and the attitudes of the public and the press during the epidemic years.

The current interest in the late effects evolved upwards from the grassroots, from lay persons to an extraordinarily caring group of professionals. There are presently more than 50 polio clinics in the United States. They work with local support groups as a team, reinforcing each other.

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Rehabilitation Gazette

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Gini Laurie '34

The occasion of the first presentation of the Alumnae Achievement Awards to Judge Howorth, Dr. Parsons and me ~~mysel~~f was permeated with the warmth and graciousness of the faculty, alumnae, board members, and students. Once more, I would like to experss my gratitude for this touching and significant honor, which revived a surge of fond memories and a deep pride in our Alma Mater.

I am delighted that through honoring me the spotlight is directed at people who are disabled. Such spotlighting is vital because people with disabilities are more handicapped by attitudinal barriers than by their disabilities. Only through awareness and understanding will they be known as people, not as impersonal symbols of fear or pity.

The evolvement of the human rights of people who are disabled has followed a pattern similar to that of women and minority groups. Because this evolvement is reflected in our language we must all watch our words. Many words in the current vocabulary are left over from pitying, paternalistic, demeaning, prejudicial concepts. Their use continues to perpetuate negative attitudes and dehumanizing responses and expectations.

People who are disabled now choose to be termed "disabled" rather than "crippled" or "handicapped." They avoid such negative images as a "a victim" or "afflicted by" or "wheelchair-bound" or "confined to a wheelchair." Instead, they say "wheelchaired by polio" or "uses a wheelchair." Many people who are blind or deaf prefer to be termed "visually impaired" or "hearing impaired."

Especially demeaning are the qualifying phrases, "despite her disability" or "although she is disabled." Too well we all know such similar comparisons as "despite the fact that she is a woman she is vice president" or "although she is a (race or nationality) she has a law degree."

People with disabilities are doubly dehumanized by attitudes that depict them as asexual and endow them with super-human virtue and courage. They do not belong on pedestals. They have the same impulses, feelings, drives and desires. They make mistakes, lose their tempers, laugh, hate and love because people who happen to be disabled are the same as everyone else - human.

This human quality gives my annual journal, <u>Rehabilitation Gazette</u>, its very special quality because it embodies and reflects the imaginative, practical, down-to-earth experiences of its severely disabled writers and readers. If any alumnae are interested, I shall be happy to send a sample copy and to answer questions. My address is Rehabilitation Gazette, 4502 Maryland Avenue, St. Louis, Missouri 63108.

Gini Laurie '34