

# INTERNATIONAL POLIO NETWORK POLIO NETWORK NEWS

SUMMER 1994 ♦ VOL. 10, NO. 3

## G.I.N.I. CONFERENCE POSTSCRIPTS

The Sixth International Post-Polio and Independent Living Conference organized by Gazette International Networking Institute (G.I.N.I.) attracted 400 individuals from around the world June 16-19, 1994. Participants, many of whom were attending their sixth G.I.N.I. conference, included polio survivors, ventilator users, disability rights leaders, health professionals with disabilities, and health professionals interested in home mechanical ventilation and post-polio issues. Half of the individuals attending were accompanied by a family member, friend, or attendant.

The expertise of the panelists, along with the sophistication and diversity of the attendees, provided excellent opportunities for open discussion — a hallmark of G.I.N.I. conferences. The conference welcomed first-time presenters volunteering their time and sharing their professional opinions while “rubbing elbows with their patients.”

The issues facing polio survivors are multi-faceted and complex and the program provided something for everyone — the theoretical, philosophical, psychological, and practical. Individuals were able to choose sessions discussing alternative or complimentary therapies. Many of the presenters in these well-attended sessions were challenged by individuals in the audience — consumers and health professionals alike.

The recurrence of the virus issue was revisited. The question will continue to be asked until further research is completed. At the moment, researchers appear to favor the theory that polio damaged nerve cells are wearing out as evidenced by new weakness. The issue was discussed in more detail at the New York Academy of Sciences Meeting (April, 1994, see page 10) where studies which imply a reinfection, or a new infection, were questioned.

Users of ventilators and health care professionals discussed issues relating to home mechanical ventilation. Polio survivors, the pioneers of living at home on a ventilator, exchanged their time-tested experiences with other users and health professionals. Additionally, personal issues were addressed such as recurring infection, changing equipment, and the search for a better face mask.

Despite the unseasonable heat, many participants took advantage of the central location of the St. Louis Marriott and St. Louis' new accessible light rail system to visit the Arch grounds, view the site of the “500

year flood,” dine with old and new-found friends, and watch baseball.

### REFLECTIONS

“Thank you for inviting me to speak. Most of all thank you for helping me get back my ‘voice.’ Your gentle questions and taking the time to listen to my feelings gave me the inspiration to start thinking about what I have learned all these years.”

Joyce Tepley, TX

“The most gratifying thing, however, was the spirit of fellowship and friendliness exhibited by virtually everyone I saw.” Douglas M. Smith, MD

“This one was tops in attention to detail, organization, and content.” Jean Graber, KS

“It was particularly outstanding in the balance between comprehensiveness in scope and thorough in substance, not to mention the fact that it was a lot of fun.” Margaret Campbell, PhD, Downey, CA

“...glad to see some of the alternative treatments highlighted so we can have a chance to be informed and make choices that we feel good about.” Jim Powell, IL

“The educational and networking opportunities were just great. I also enjoyed the tourist opportunities in your fair city.” Sharon Goodenow, NY

“It was so filled with information, and I loved the socializing. I spent some time with the Remmers and Hanna Laine after the conference and taught them about American things. When we are in Stockholm in July he will make me a new nasal mask.”

Gail Genereau, WI

“Last week while vacationing in Chicago one of our members who is a crutch user fell and broke her arm. Her husband called and my reputation was instantly embellished because I could send them to Dr. Irwin Siegel, an orthopedic physician who was a panelist during the session I moderated during the conference. Really, it was all thanks to you.”

Nickie Lancaster, RN, TN

*Many of the sessions were audio and video taped (See pages 9-10 of last issue of Polio Network News (Vol. 10, No. 2) for an order form). All sessions will be transcribed, edited, and published in future G.I.N.I. publications, including Rehabilitation Gazette, I.V.U.N. News, and Polio Network News (see page 4). ■*



## G.I.N.I. CONFERENCE PHOTOS

International friends attended from Australia, Canada, Denmark, France, Germany, Israel, New Zealand, Norway, Panama, Sweden, Switzerland, and Taiwan.



Alexander Shapira, MD,  
Director of  
Post-Polio  
Clinic, Tzrifin,  
Israel

Panelists included friends and advocates for home mechanical ventilation.



Patrick Leger, MD,  
Hopital de la  
Croix-Rousse,  
Lyon, France

Long-time friends of G.I.N.I. and the polio community participated once again.

Judith E. Heumann,  
Office of Special  
Education and  
Rehabilitative  
Services,  
Washington, DC



Many presenters were individuals with disabilities contributing their professional expertise filtered through personal experience.



Marny Eulberg, MD,  
Mercy Medical Center,  
Denver, CO

New G.I.N.I. friends were invited to share their perspective.



Steven P.  
Dinsmore, D.O.,  
Center for Aging,  
Stratford, NJ

## Networking, Networking ...



*In addition to 13 countries, attendees represented 42 states and seven provinces.*



Dedicated G.I.N.I. friends, old and new, served as moderators.



*Joan Headley, St. Louis, MO and Linda Bieniek, Chicago, IL.*

Behind the scenes were many, many loyal friends of G.I.N.I.



*Members of the Greater St. Louis Post-Polio Support Group*

*Michael Mudrovic and Joe Leone*

*Organizing and implementing a networking conference requires the dedication and contribution of many. The list of individuals who volunteered their time and talent is impressive.*

*I must specifically thank Mickie Cammerer, Judith Fischer, Joe Leone, Michael Mudrovic, and Shaaron Peters.*

*Finding a hotel capable of providing accommodations for a group projected to be composed of 50 plus individuals in scooters or wheelchairs; 15 or so using a ventilator part or full time is a little difficult. Finding a hotel managed by a team with the sensitivity and desire to provide the accommodations and the appropriate atmosphere is more difficult.*

*The St. Louis Marriott Pavilion's entire staff should be complimented for their excellence.*

*I personally thank Sherry McCool, General Manager; Helen Comer, Senior Sales Manager; and Mike Chamberlin, Director of Convention Services for their professional leadership.*

*Joan L. Headley*



## SIXTH INTERNATIONAL POST-POLIO AND INDEPENDENT LIVING CONFERENCE

# STATUS OF POLIO IN THE WORLD TODAY

Robert A. Keegan, public health advisor, Centers for Disease Control and Prevention told the story of the global eradication of polio. His report focused on the cases of polio caused by the wild polio virus and not those rare cases which are caused by the polio vaccine.

### A GOOD STORY WITHOUT AN ENDING

◆ The story began in 1988 when the World Health Assembly resolved to eliminate polio in the world by the year 2000. But Franklin D. Roosevelt, the National Foundation for Infantile Paralysis, the polio epidemics symbolized by iron lungs, Jonas Salk and the inactivated polio vaccine, and Albert Sabin and the oral polio vaccine all played key roles.

◆ In 1961 the year the oral polio vaccine was first used in the United States, polio was endemic in virtually every country in the world.

◆ In 1981 the situation had improved somewhat but polio cases were still being reported from nearly all countries.

◆ An outbreak of polio in The Netherlands in 1992 provided a reminder that no single country can be safe from polio until all countries are free.

◆ About 70% of all polio cases in the world are reported from India and Pakistan. In some African countries the routine coverage with the recommended three doses of the oral vaccine is as low as 9%.

### THE GOOD NEWS

◆ Using strategies such as National Immunization Days, active surveillance of polio cases, and mopping up\* immunizations, the last cases of polio in the Western Hemisphere were reported in Peru and Colombia in 1991.

◆ Polio-free zones are beginning to emerge in northern and southern Africa. There are only about 60 polio-endemic countries remaining in the world out of 209 countries and geo-political units.

◆ China, Viet Nam, Laos, and the Philippines conducted national immunization days this last winter. Cambodia has plans for national immunization days next winter. In this region, reported polio cases have decreased by 50% in the last two years and eradication remains quite possible by 1995.

◆ Pakistan organized its first national immunization days in April of this year. Syria and Iran also conducted highly successful national immunization days. Despite civil unrest on the island of Mindanao a special cease fire for children was held, so national immunization day activities could occur unimpeded by the threat of violence.

◆ Provisional data suggest that only about 9,600 cases of polio will be reported in the entire world for 1993. Note that reporting is weak, especially in the developing countries and World Health Organization (WHO) estimates that there are ten times as many paralytic cases as reports received. So the probable global incidents of polio in 1993 is 100,000 cases.

### THE BENEFITS

◆ Smallpox eradication in 1960s and 1970s offers a clear example of the financial and humanitarian benefits which accrue to the world community following total eradication of a disease.

Since the last case of smallpox was detected in Somalia in 1977, more than two billion dollars has been saved in the United States alone. There is no budget for smallpox in the United States.

There is no program for smallpox at CDC.

◆ In the United States alone more than two hundred and thirty million dollars will be saved annually in polio vaccine and administrative costs when polio eradication is achieved and vaccinations can be stopped.

◆ The global polio program has brought together organizations, governments, and the private sector. It was realized that more vaccine could be provided to China if it were made in the vaccine factory in Beijing, China, at two cents a dose rather than paying the global prices.



\*Mopping up is the term used when additional vaccination is provided regardless of the vaccination status of children younger than five years in areas where there is low vaccination coverage or reported cases of polio.



## THE COSTS

◆ Rotary International has raised over \$240,000,000 to buy vaccines and to pay other costs of this program and has mobilized volunteers to provide manpower and community support. Despite these impressive efforts much more needs to be done. WHO estimates that fifty to seventy million will be needed annually during the next five years.

◆ Although governments and United Nations organizations do not always have a reputation for spending money wisely, funds for polio eradication are spent effectively. The involvement of Rotary International has strengthened the overall management of the program.

## TO HELP END THE STORY

Contributions may be made to the following:

Task Force for Child Survival and Development, TFCSO — Polio Eradication Fund, 1 Copenhill, Atlanta, GA 30307. The TFCSO can best use funds intended for technical and operations support of the polio eradication program, particularly support for medical and laboratory experts, procurement of equipment and supplies, etc. The TFCSO is a non-profit organization and donations are tax deductible to the full extent permitted by law.

United Nations Children's Fund (UNICEF), U.S. Committee for UNICEF, 333 E. 38th St., New York, NY 10016. UNICEF can best use funds intended for the purchase of polio vaccine for special polio eradication activities such as national immunization days in polio-endemic countries. The U.S. Committee for UNICEF is a non-profit organization and donations are tax deductible to the full extent permitted by law. Please specify that donations are intended for the purchase of polio vaccine for the polio eradication initiative. ■

### ***If you are moving ...***

Please remember to send both your old and new addresses to:

International Polio Network  
5100 Oakland Ave., #206  
St. Louis, MO 63110-1406.

*Polio Network News* will not be forwarded by your post office.

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## PARTICIPATE IN THE U.S. HEALTH CARE REFORM DEBATE

Presently the United States House and Senate leaderships are discussing and compromising to ready a health care reform bill for a vote before the November election.

As health care is being discussed, many groups are using their vast resources to influence the outcome of the final health care bill to best meet their constituency's needs. Polio survivors are not all alike physically, psychologically, philosophically, and are not all aligned politically. However, polio survivors need to become involved in the health care reform debate, so the issues relating to having a disability are not slighted or, worse yet, ignored.

The Consortium for Citizens with Disabilities (CCD)

has identified five principles against which health care proposals can be measured.

*"The CCD believes that any ultimate solution to the health care crisis must be based on the principle of non-discrimination ensuring that people with disabilities of all ages and their families have the opportunity to fully participate. The CCD would define a successful health care system as one that offers a comprehensive array of health, rehabilitation, personal, and support services, as well as a system that ensures that these services are appropriate in that they are provided on the basis of each individual's need, personal choice, and situation. In addition, any truly effective solution must be equitable ensuring that no group of individuals bears a disproportionate burden. Finally, the CCD asserts that an effective and accessible health care system must be efficient ensuring that system resources are utilized to meet health care needs. The CCD strongly supports the right to health care for all persons regardless of income or health status."*

Many polio survivors do not have health insurance because of preexisting condition exclusions. Many survivors who have been high users of health care in the past can no longer afford the higher premium they are charged by private insurers. If they have insurance, many survivors are unable to find a physician knowledgeable about the late effects of polio and appropriate treatment options. In fact, as they continue to age, it is becoming more difficult to find a physician who remembers polio from personal experience or medical school.

When a knowledgeable physician is found many survivors in managed systems are financially prevented from receiving that physician's care, appropriate testing, and appropriate therapy and equipment. This is especially distressing as many polio survivors, through

Continued on page 10

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## INTERACTION WITH TIME

*The Spring issue of Polio Network News (Vol. 10, No. 2) asked for comments regarding "Reliving Polio" a two-page article featured in TIME March 28, 1994. The following letters and comments are representative of responses we received.*

### **To TIME:**

"It was a relief to see an article related to post-polio syndrome (March 28). This condition had been ignored by both the media and the medical profession for a long time. It was disappointing however to read of your most negative and depressing outlook for this condition. It is not true that 'not much' can be done or that 'the most effective therapy seems to be no therapy at all.'

"Physical therapists work closely with patients with this condition. Because many of us accept the 'wear-and-tear theory' for the etiology we no longer advocate a 'use it or lose it' approach. However, patients respond successfully to guidance and advice in fashioning their lives to conserve energy and preserve function. The use of appropriate exercises and outside supports such as light-weight braces and motorized scooters have enabled many people to continue their usual and very productive lives. Many physical therapists have knowledge and training in this syndrome and are sought out to evaluate and educate patients in an appropriate energy conservation program. We and our patients feel that something CAN be done.

"Your negative approach only reinforces the difficult emotional burden these patients are facing. Because of the prevalence of this hopeless attitude, some insurance companies are not reimbursing for needed care and equipment which will help maintain the very useful lives these people have worked so hard to develop. This is a gross disservice." **Susan F. Fish, PT, NY**

"Dear Ms. Fish: Thank you for writing in response to the March 28 Health article, 'Reliving Polio.' In stating that little can be done to combat post-polio syndrome we wanted only to suggest that the attending discomforts could not simply be made to disappear, that daily activities must be adjusted to accommodate a certain level of neuromuscular stamina. We did not mean to disregard the positive steps that can be taken to confront the condition, and we regret if we left readers with the impression that the syndrome must be endured without the benefit of any ameliorating treatments. We nonetheless appreciate your taking the time to comment on our efforts, and although your letter was not published, it was circulated among the appropriate editors for their consideration."  
**Robert Cushing, TIME, New York.**

"Thank you for bringing the issue of the post-polio syndrome to the attention of the general public. I would like to clarify some points from your March 28, 1994 article. It has not been proven that the post-polio syndrome is due to a reactivation of the poliomyelitis virus. Consequently, it is an overstatement to say that a person with the post-polio syndrome has had polio again.

"In addition, there is fortunately a great deal that can be done to help individuals with the post-polio syndrome. They can be instructed in appropriate lifestyle modifications to minimize the symptoms of the post-polio syndrome. They can receive appropriate mobility and activity of daily living aids, as well as appropriate physical, occupational, and if necessary, speech therapy to optimize function and minimize pain. They can benefit from counseling to help them best deal with their disabilities.

"It should also be pointed out that there are other medical problems which can masquerade as the post-polio syndrome and an individual that feels that he or she may have this syndrome should be assessed by a properly trained physician to rule out other causes for their new symptoms be it inordinate fatigue, further loss of strength, new aches and pains, and/or compromise of swallowing and breathing."

**Martin B. Wice, MD, St. Louis, MO**

"Dear Dr. Wice: ...we appreciate your suggesting that, as no conclusive evidence has yet identified the poliomyelitis virus as the cause of post-polio syndrome, it is, strictly speaking, an overstatement to say that someone with the condition has polio again. We used that phrasing simply to indicate the recurrence of polio symptoms, to acknowledge that those with the syndrome are reacquainted with the initial pain, fatigue, and hardship caused by polio. Further into the story, however, we were sure to distinguish the syndrome from polio by noting the decreased severity of the symptoms and the dubious role of the virus in their reappearance.." **Robert Cushing, TIME, NY**

### **To JOAN:**

"I've been meaning to write you about the article in TIME (March 28, 1994), "Reliving Polio." I feel that the general public reading this article will get the wrong impression.

"In commenting on Roberta Simon's finally correct diagnosis, the writer states, 'She had polio. Again.' Those of us actively involved in the network know that is not true. We did not come down with polio — again. A statement like that scares people, particularly polio survivors who still don't know what is happening to them.

"Most of us accept the theory that states 'wear and tear on the nerves is to blame.' We realize that we

have overused. We now know that the old saying 'no pain, no gain' is incorrect. We must listen to our bodies and pace ourselves. Those of us leading support groups stress this to all polio survivors who contact us.

"It's also true that there is no 'cure' for us. But we can help ourselves by learning to make life-style adjustments, i.e., again getting into braces, using canes or crutches, getting into wheelchairs or scooters. I disagree with Renah Shnaider's last sentence in the article, 'It's important for people with post-polio to face their experience and allow themselves to feel sad.' Yes, we do have to face what is happening to us and accept it. However, we cannot afford to feel sorry for ourselves as that is a sure way to self-destruct."

Barbara Goldstein, Ormond Beach, FL

## RESPONSES FROM ROBERTA AND RENAH

*Editor's note: When TIME called and asked for polio survivors to interview I suggested six individuals whom I knew had varying experiences with polio and post-polio. They interviewed four of the six and quoted two ladies I know personally and who were unfairly represented. I publish their comments as a way to help set the record straight.*

"I am writing in response to the *TIME* magazine article on the late effects of polio. First, I would like to say that I did not say that I had polio again. Second, I would like to apologize to those who believed I did. I know better and have gone out of my way many times to dispel that idea. What I did say was that once I was rehabilitated from my original illness I did not think I would ever hear from polio again. To me it was the same as having measles or any other illness in childhood. Once you recovered, it was over!

"I also take exception with the statement that there is no treatment for the problems related to the late effects. There is no cure at present because the exact cause of our difficulty — is unknown. (Should that change in the future, perhaps there will be a cure.) There are, however, many treatments. These include bracing, physical therapy, occupation therapy, medications, and various other conventional and unconventional treatments that are working and making a difference.

"I've always been a proponent of conservative medicine involving any issue. And, I am an advocate for conservation of muscles, because we are uncertain if overuse is causing our nerve sprouts to die back. If we use strengthening exercise to build up our muscles, we may in the long run cause irreversible harm to ourselves.

"When I agreed to this interview, I hoped to make some statements regarding ventilation assistance which has been of great concern to me. In the mid 1980s, I began hearing stories from people who had not been on ventilation assistance with their original

bout of polio but who were now having difficulty sleeping and breathing. The problems of underventilation in individuals such as this must be addressed and each and every time I have a listening ear I try to get the message out. Incidentally, when I first made this my mission I had no idea I would be involved personally. I have used a ventilator at night for over three years. Like any other brace it has improved my quality of life.

"The article was good in that it created awareness of our problem even though some of the facts were erroneous. I guess we have to accept the good, thank them for their concern, and chalk the rest up to experience." Roberta Simon, RN, Darien, IL

"As a person who was interviewed and quoted in the March 28, 1994, *TIME* issue about the late effects of polio, I would like to share my response.

"First, the phone interview lasted forty-five minutes over a two day period. We talked at great length about a number of polio related issues. I emphasized that the post-polio syndrome was not polio the second time around.

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## International Polio Network

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ISSUED QUARTERLY

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## INTERACTION WITH TIME

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"When I saw the title and the byline I was outraged and shocked. When I started the support groups in the Bay area in 1982, we spent many hours trying to demystify the late effects emphasizing that it was not polio again. I am disappointed that 12 years later we are still having to do this!

"My statements were taken totally out of context. I consider myself a fairly positive person and could not and still cannot believe what the reporter chose from our conversation. The article described me as a person who 'lives in my wheelchair.' That comment is a definite indication of the reporter's general lack of awareness and sophistication about people with disabilities.

"The article was uncomfortable and embarrassing for me. Many new people have phoned me (and that's o.k.) but most of them phoned with great fear that they are experiencing polio the second time around. With a great sigh I apologized for the article and tried to calm them down." Renah Shnaider, Oakland, CA

### OTHER COMMENTS UNDER "I DON'T WANT TO TAKE ON TIME MAGAZINE, BUT..."

"They interviewed me extensively and then misquoted me."

"I have been trying to convince my extended family I need to pace myself. They called to tell me about the article in TIME showing a gentleman lifting weights."

"We have been trying to convince our insurance company that post-polio syndrome is not a pre-existing disease so they will pay for a scooter. An article referring to 'getting polio again' does not help our argument."

"I can honestly understand why individuals experiencing the post-polio syndrome are so concerned about getting the message out, but I ask them to consider those of us who are not experiencing post-polio syndrome and who are in the workplace. I may be paranoid, but I sense my employer is constantly scrutinizing me to see if I can still do the job. My being promoted is being jeopardized." ■

### October is National Disability Employment Awareness Month.

This year's theme is "Ability + Diversity = Economic Strength." For a program planners kit contact: President's Committee on Employment of People with Disabilities, 1331 F St., N.W., Washington, DC 20004

## Readers Write

"I would like to remind your readers that Nordstrom sells mismatched shoes for the price of one pair."  
Betty, UT

"I am a 70 year old survivor and the doctor is recommending knee replacement surgery. I would like to hear from survivors close to my age who have had this type of surgery." Shirley, NM

"I would like to hear from polio survivors regarding any treatment they have found helpful for bladder/bowel problems." Rachel, PA

"I am writing to ask permission to circulate an article on Accessible Worship by Elizabeth Reeves in *Polio Network News* (Vol. 8, No. 4). I would like to send it to 80 churches in our district. The executive of the presbytery has finally listened to me on the subject and agreed." William, OH

An excellent resource is "That All May Worship; An Interfaith Welcome to People with Disabilities" available for \$10.00 postpaid from National Organization on Disability, 910 16th St., N.W., Suite 600, Washington, DC 20006 (202/293-5960).

"Tips on Shopping for a Scooter, *Polio Network News* (Vol. 10, No. 2) should be exceedingly valuable for newcomers to post-polio syndrome. I had to learn these matters by myself, and it took me a good part of the year to feel knowledgeable enough to make the decision. A major problem that cannot be gotten across in any article is that someone losing the ability to walk and/or stand for any length of time, has to bite the bullet as early as possible and accept that he/she needs to get a scooter." Donald, IL

"I would recommend that polio survivors looking for motorized equipment rent a scooter for a few months, and then a power chair for a few months, before purchasing. It has been my experience that over the years some individuals become disenchanted with the scooter and wish they had purchased the wheelchair originally." Joe, MO

"I would like to connect with polio survivors in the Greenwich/Norwalk, CT area." Denise, CT

"I contracted polio in 1954 and received therapy at California Rehabilitation Center in Santa Monica. The therapist taught me to walk again with Kenny sticks. For all of these years I have nursed two pairs by replacing only the leather strap. Six months ago, one half of one pair broke, and I almost fell. Since that time I have been trying in vain to find another pair but it seems they are no longer being made. I have tried every resource, including having them made, with no success. Is there anyone who can help me?" Lois, CA

*International Polio Network has received several requests lately regarding "documentation that accidents (traffic, falling) can precipitate post-polio syndrome." Individuals and health professionals with information and experience, who are willing to speak with others, should contact our office.*



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## CASE HISTORY

By Charlotte Gollobin, MS, LN, CNS

Sixty-one year old male had contracted polio at the age of 22 while in military service in Newport, Rhode Island. Polio was generalized (but not bulbar). Recovery after a ten-month hospitalization and six-month convalescence was almost complete, except for fibrotic anterior tibialis of right leg and weakness in upper quadriceps of the same leg. There were no symptoms for many years except for some weakness in right leg.

The subject began experiencing pain in 1964, presenting in area of right knee. A diagnosis was made that the pain was of psychosomatic origin.

In the early to mid-1980s, it was noted that leg was getting weaker and subject complained that it was harder to get up a flight of stairs. In 1985 or 1986 pain in right knee returned when swimming. By this time patient had knowledge of the existence of post-polio syndrome and discontinued swimming. The pain ceased but subject gained 20 pounds. Within the next few years he developed what was referred to as "heroic snoring" which were breathing problems not diagnosed as sleep apnea until 1991.

From 1985 onward, subject noticed progressive weakness in leg as a function of time. He felt there was no way to objectively measure the change, though the right leg was getting weaker. He noted developing weakness in the left leg, but not to the same extent. Pain in area above and around both knees was sufficient to wake him during sleep by 1992 or 1993. It was an aching pain, reminding him of growing pains as a child.

September 20, 1993 subject complained of aching pain in left elbow and right shoulder, with tingling in arms. Recommendation was made for daily supplementation of 100 mg vitamin B6. Within six (6) days all muscular pain (side, above, back and below) around knee cap had disappeared. Subject remained pain-free.

On April 18, 1994, subject discontinued vitamin B6. Pain returned on April 29, 1994, 11 days after experiment began. On May 3, 1994 subject complained of

tingling in hands when gripping automobile steering wheel, as well as aches and pains in both knees plus shoulder discomfort.

May 12, 1994 subject complained of aches and pains in knees and other areas in high and thigh. He resumed daily supplement of 100 mg vitamin B6 on this day. May 24, 1994 subject reported pain in knees disappeared within "a couple of day" of resuming 100 mg vitamin B6. Subject reported occasional pain in gluteus maximus after exercising, but May 31, 1994 reported pain had disappeared.

June 1, 1994 subject again discontinued use of vitamin B6.



The subject gladly agreed to participate in this experiment. He was initially skeptical about the effects of vitamin B6, but when it relieved his pain so completely, he was willing to discontinue its use in an attempt to determine if the pain would return. It did. He was convinced that the vitamin B6 had a positive effect on the muscular pain when, upon resumption of the vitamin, the pain again disappeared. He has agreed to discontinue it again, which he did on June 1, 1994. If the pain returns, he will resume supplementation to determine if it eliminates the pain once again.



Vitamin B6 is a water-soluble vitamin. Alone and in conjunction with vitamin B2 it can provide beneficial effects on carpal tunnel syndrome (1, 2, 3) a painful neuropathy which affects many PPS survivors. There are numerous references in the literature to this effect.

It is involved in neuromuscular function and protein metabolism — aminotransferase reactions, decarboxylation reactions (synthesis of polyamines, serotonin, tyramine, histamine and GABA), synthesis of choline and phosphatidylcholine and in sphingolipid biosynthesis. It is involved in carbohydrate metabolism and heme biosynthesis (4). Neuromuscular function is a major concern for PPS survivors. Energy metabolism is also of importance for possible beneficial effects on fatigue. Heme biosynthesis is necessary for transport of oxygen for energy.

Vitamin B6 deficiency can result in electroencephalographic abnormalities, seizures, impaired immunity and depletion of lymphocytes (5, 6). B6 is increased during exercise which has been shown during a recent conference (7) to be quite beneficial to PPS survivors. At this same conference, it was suggested that the

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**Charlotte Gollobin holds a Masters degree in Nutritional Science from the University of Maryland. A former president of the American Nutritionists Association, she is a consultant in private practice who also lectures and writes on topics of nutrition.**

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## CASE HISTORY

Continued from page 9

female sex is a risk factor for PPS. Estrogen depletes B6 and may, therefore, add to symptoms over time.

There are many reasons to study the effects of vitamin B6 on PPS patients. We hope that controlled research studies will be undertaken to determine these effects in a scientific way. The first step in a scientific experiment is "observation" and this case history is such an observation. ■

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7. *The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment*. Bethesda, Maryland, April 27-30, 1994.

**The Proceedings of the New York Academy of Sciences meeting, April 27-30, 1994, The Post-Polio Syndrome: Advances in the Pathogenesis and Treatment, will be available no sooner than Spring of 1995. For more information contact New York Academy of Sciences, Marketing Department, 212/838-0230, Ext. 346.**

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## PARTICIPATE IN HEALTH CARE REFORM

Continued from page 5

appropriate rehabilitation, did become teachers, physicians, accountants, truck drivers, president of the United States, i.e., employed and productive tax-paying citizens with families. Today, these same polio survivors, with their late effects, require restorative therapies as well as assistive devices such as customized braces, scooters, wheelchairs, and ventilators to maintain the function that will allow them to continue being productive and paying members of society.

Another issue important to survivors who are aging is the availability of long-term care. Many survivors need personal assistance and some will need more. Polio survivors who have been depending on their parents, siblings, and spouses for assistance are finding that these long-time caregivers are less able to assist them and, in many instances, are in need of assistance themselves. Any reform needs to address the availability of home and community-based long-term care.

These four issues — preexisting condition exclusions, access to knowledgeable health care professionals, affordable access to assistive devices and therapy for the long-term, and access to personal assistance services or long-term care — are concerns of polio survivors regardless of their persuasions.

As the debate continues it is urgent that polio survivors express their concerns to their legislators. Contact your senators and representatives in Washington now, and when they are "back home" during the August recess. The general telephone number for the Capitol switchboard is 202/224-3121.

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## THE NATIONAL ORGANIZATION ON DISABILITY (NOD)

commissioned Louis Harris and Associates to conduct the NOD Survey of Americans with Disabilities. (NOD published a 1991 Harris Survey of "Public Attitudes towards People with Disabilities.")

This most recent survey is based on in-depth interviews of 1,021 non-institutionalized adults with disabilities. The survey measured quality of life, employment and social opportunities, financial status, and lifestyles of adults with disabilities. Two thirds of Americans with disabilities between the ages of 16 and 54 are not working. This number shows no improvement since 1986. Two in 10 (20%) are working full time, and 11% are working part time.

An encouraging finding states that three in four adults with disabilities have now completed at least a high school education, compared with only three in five disabled adults in 1986.

To receive a complete copy of the 175-page report (\$95), contact NOD, 910 16th St., NW, Suite 600, Washington, DC 20006 (202/293-5960). ■

## Calendar

To publicize your conference in *Polio Network News*, send appropriate information in writing. Yearly deadline dates are: January 15, April 15, July 15, and October 15.

❖ **1994 National Conference, Auckland,** New Zealand, September 23-25, 1994. Contact: Ramon Chandler, P.O. Box 51 641, Pakuranga, New Zealand (0-9-534 6151).

❖ **Controlling PPS: The Key to Wellness,** Ocala, FL, November 5, 1994, 8:00 a.m. — 4:30 p.m. Contact: Carolyn Raville, 7180 S.W. 182nd Court, Dunnellon, FL 34432.

❖ **International Symposium and Exhibition on Orthopedic and Paralysis Sequelae Rehabilitation,** Beijing, China, October 16-20, 1995. Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICCST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China.

## POST-POLIO BIBLIOGRAPHY

**"Post-polio Syndrome: An Update."** Burk Jubelt, MD; Judy Drucker, ANP. *Seminars in Neurology*, September 1993; Vol. 13, No. 3, pp. 283-290.

The second in-depth review of post-polio syndrome centering on recent advances in pathophysiology, etiology, and treatment of the muscle weakness. The article outlines all aspects of post-polio syndrome. For details about topics briefly mentioned the reader is referred to the 1987 in-depth review by B. Jubelt, MD and Neil Cashman, MD — **"Neurological Manifestations of Post-Polio Syndrome."** *Critical Reviews in Neurobiology*, 1987, Vol. 3, Issue 3, pp. 199-220.

**"Fractures in an Aging Population of Poliomyelitis Survivors: A Community-Based Study in Olmsted County, Minnesota."** Jean B. Goerss, MD; Elizabeth J. Atkinson, MS; Anthony J. Windebank, MRCP (UK); Michael O'Fallon, PhD; and L. Joseph Melton, III, MD. *Mayo Clinic Proceedings*, April 1994; Vol. 69, pp. 333-339.

These data indicate that survivors of poliomyelitis do not have an unusual risk of fracture except in affected limbs.

## WANTED

Men or women for  
a 20-minute,  
confidential telephone  
interview regarding  
new treatment  
in development  
for post-polio  
syndrome.

Have you seen a physician and been diagnosed with post-polio syndrome? (or)

Have you previously had paralytic poliomyelitis and are currently experiencing any combination of the following symptoms?

- muscle weakness • muscular atrophy
- muscle pain • joint pain • fatigue

If you answered yes to either of these questions, you may qualify for a market research survey currently being conducted.

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Please call Jennifer collect at (708)825-8017 for more information. Please call early, number of participants is limited.

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## USEFUL RESOURCE NUMBERS

International Polio Network.....	314/534-0475	FAX 314/534-5070
National Organization on Disability.....	202/293-5960	TDD 202/293-5968
National Council on Disability.....	202/272-2004	TT 202/272-2074
President's Committee on Employment of People with Disabilities.....	202/376-6200	TTD/TTY 202/376-6205
Job Accommodation Network .....		800/JAN-7234
Disability Rights Education and Defense Fund (DREDF) <i>resource for civil rights and ADA</i> .....		202/328-5185
Regional Disability and Business Technical Assistance Centers <i>resource for ADA</i> .....		800/949-4ADA
Social Security Administration .....		800/772-1213
Natl. Catholic Office for Persons with Disabilities.....		202/529-2933
Breaking New Ground Resource Center <i>for farmers and ranchers with disabilities</i> .....		800/825-4264
American Academy of Physical Medicine and Rehabilitation (AAPM&R) <i>a list of physiatrists in your state</i> .....		312/922-9366
ABLEDATA • <i>data base of assistive technology and rehabilitation equipment</i> .....		800/227-0216
Yes I Can • <i>resource for equipment</i> .....		800/366-4226
Aequitron Medical Inc. ....		800/497-4979
LIFECARE International (USA).....	800/669-9234	LIFECARE Europe ..... 49/8152-93060
Respironics .....		800/345-6443
Prescription Footwear Association <i>for board certified pedorthist in your area</i> .....		800/673-8447
National Vaccine Information Center .....		800/909-SHOT
CDC's Immunization Voice Information System (automated).....		404/332-4553
Access to Recreation • <i>a free catalog</i> .....		800/634-4351
Wheelers Accessible Van Rental <i>rent adapted minivans through AVIS</i> .....		800/456-1371
Wheelchair Getaways • <i>rent adapted vans</i> .....		800/642-2042
Flying Wheels Travel.....		800/535-6790
Travelin' Talk • <i>resource</i> .....		615/552-6670
Ford Mobility Motoring Program .....		800/952-2248
Physically Challenged Resource Center at Chrysler Motors .....		800/255-9877