

REHABILITATION GAZETTE

INTERNATIONAL JOURNAL OF INDEPENDENT
LIVING BY PEOPLE WITH DISABILITIES



SPECIAL FEATURES:

AGING SUCCESSFULLY

Survival Notes
at 50-Plus

Long Term Care '88

UNDERVENTILATION

1987 ■ VOLUME 28, NUMBER 2

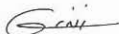
From the Editor

New emphasis on aging successfully. Long ago — back in 1958 — when I started this *Gazette*, many of you were in your late 20's or early 30's. Now, you are "50 Plus" and learning to cope with aging as well as you learned to cope with disability. In this issue, you share your wisdom and life experiences and point the way for *Gazettes* of the future to reflect your needs by emphasizing: aging successfully, the late effects of polio and other disabilities, and long term care for people of all ages.

G.I.N.I. plans for the future. The Gazette International Networking Institute (G.I.N.I.) is preparing for the future with a Five-Year Plan and the gradual addition of more Board members, staff, and volunteers with disabilities.

Our new G.I.N.I. Board president. I'd like to introduce you to our new Board President, and my long-time friend, Jack Quigley. Jack has been a part of the *Gazette* community for 14 years, ever since he returned to St. Louis following three years as business manager for Cesar Chavez' United Farm Workers in California and became a neighbor. Before that he had headed the Inter-religious Center for Urban Affairs developing low-income housing here in St. Louis. Since 1974, he has been a pastoral counselor with an independent psychotherapy practice. Some of you will remember him for his participation in several of our conferences, or for his article on Depression in the *Gazette*, Vol. 19, 1976.

Jack is an energetic leader who is currently helping the G.I.N.I. Board of Directors reorganize to meet the challenge of expanded G.I.N.I. programming in the future. And he is helping us on the staff move into the computer age. We are glad he is with us now, officially.



Gini Laurie

Dear Friends,

I am delighted and proud to be more closely associated with Gini Laurie and the G.I.N.I. Board now. Over the last six months, the Board and staff, with the help of Monte C. Throdahl, retired Senior Vice-President of Monsanto, have completed a Long Range Plan for the future development of G.I.N.I.

Our future, as we now see it, will build on the two defining characteristics of G.I.N.I.: we have always been and will continue to be a network of real people helping each other, and we have always done that best when we share vital, practical information.

Our future will, most certainly, see us continuing to focus a lot of energy on anything and anyone related to polio. We will also continue to develop and disseminate information about living with ventilators. We will continue to support and promote independent living among, and the dignity of people with all kinds of significant disabilities.

What will be new for us will be the way we will begin to use the computer and telecommunications in service of our objectives. We hope to transfer all of the vast G.I.N.I. library to electronic media over the next several years. We will make it available to all of you through a multiuser Bulletin Board System. We will also enhance our own information database with as much information as we can get from other sources. Most especially, we will develop the sharing and storing of our own experience and ideas for immediate retrieval, and person-to-person communication, until the G.I.N.I. BBS grows into the most vigorous and systematically developed disabilities information system available.

But it is also clear that this information system will not be one thing in one place. If our movement is anything, it is a *network* of people and organizations. The G.I.N.I. information system will, in fact, be our information linked to your information. So part of what we hope to do is assist in developing a vigorous on-line network within and among any organizations that want to participate. We hope that will naturally lead to some greatly increased advocacy among us all.

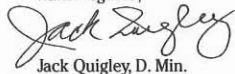
But, finally, our vision for G.I.N.I.'s future doesn't have to do with computers or databases. It has to do with the several hundred letters that arrive at the G.I.N.I. office each day, many of them requesting help for the first time. We will continue to answer each letter with the best information available. I am impressed that WE, who are disabled, are many more in number than we sometimes realize, that there will never be an end to the need to share, and that we all can be most productive and most fulfilled when we work together to help each other.

I remember poignantly that the first source of information about living with my disability, and the first real source of hope that I could do virtually anything I wanted to, was the 1964 issue of the *Gazette* that a PT gave me at Rehab in West Haverstraw, N.Y. Every major idea about coping since has in some way come from the *Gazette*. We hope we will continue to be that primary source of information and energy for anyone who needs us.

I don't know how we are going to realize this vision financially. We are talking about a quantum leap in our organizational budget. Anyone who wants to contribute to the vision will be more than welcome to do so. We also have a never ending need for financial support for our ongoing publishing program. We have several more topical booklets that we want to publish if only we could.

I hope you enjoy and benefit from this issue of the *Gazette*. Aging with our disabilities is a very current topic with many of us, and a process that none of us will escape.

Warm regards,



Jack Quigley, D. Min.





REHABILITATION GAZETTE

International Journal of Independent Living by Individuals with Disabilities

Volume 28, No. 2, 1987

Rehabilitation Gazette (formerly *Toomey j Gazette*) has been published since 1958. Its aim is to reach, to inform, and to dignify individuals with disabilities throughout the world. The Gazette reaches about 40,000 readers in 87 countries. It has been translated into five languages and is currently available in Japanese.

Editors: Gini Laurie, Joe Leone

Proofreader: Richard Deverell

Design/Production: Sheryl Prater, Prater Graphics

U.S. Advisors: *Susan Armbricht, Mickie Martin Cammerer, Penny Chrisler, *Ruth Davis, *Jack Genskow, PhD, Gloria Gerich, *Dick Goodwin, Marion Greene, *Joan Headley, *Doris Jones, *Mickie McGraw, *Mary Jane Owen, *Jack Quigley, D.Minc., Oscar Schwartz, MD

International Advisors: *Pierre Garipey (Canada), *Kathy Jagoe (South Africa), *Audrey King (Canada), *Erich Krell (Australia), *Masao Nagai, MD (Japan), *Ethna O'Dowd (Ireland), *Adolph Ratzka, PhD (Sweden), *August Ruggeberg (W. Germany), *Eileen Van Albert (Mexico), *Gertrud Weiss (W. Germany), *Ala Wokoun (Czechoslovakia)
*Disabled

Cover: Mary Jane Owen, a national advocate for understanding, cooperation, and interchange among people with all types of disabilities and of all ages.

Membership in G.I.N.I.:

\$25 per year for individuals

\$35 per year for institutions

(Dues include subscription to *Rehabilitation Gazette*)

Single Copy: \$8

Back Issues: 1/\$4, 2/\$3.25, 3/\$2.50, 1 complete set/\$60 (See center pages for topical Index)

Advertising: Rate cards available on request

©1987 Gazette International Networking Institute (G.I.N.I.)

ISSN 0361-4166

Published by:

Gazette International
Networking Institute (G.I.N.I.)
4502 Maryland Avenue
St. Louis, MO 63108 U.S.A.
314/361-0475

2 Special Feature: Aging Successfully

Survival Notes at 50-Plus by *Mary Jane Owen*

Marriage After 24 Years of Correspondence by *Robert Sudheimer*

Home Care: Humane, Cost-effective Healer by *Basil Chenevert*

Long Term Care '88

Living with a Spinal Cord Injury for 17½ Years

by *Robert J. Throckmorton, PhD*

English SCI Research by *Gerry Zarb*

A Triad of Venerable Polio Survivors

by *Dessie Brooks, Lenna Furgerson, Y'vonne L. Greatwood*

16 Coping

Accounting on a Computer by *James R. Carlisle*

Coping with Progressive Muscular Dystrophy is an Art

by *S. Hacham-Zadeh, MD*

Saga of a Writer by *Theodore Solomon*

Employment Wanted by *Wallace Dowe*

Bargain Sale of *Rehabilitation Gazette* Back Issues

25 Sexuality

We also Exist Beneath our Necks by *Kalle Könkkölä*

Life After Quadriplegia by *Matt Green*

28 Friends Around the World

32 Travel

Danish Ventilator User's Tour of the U. S. West by *Bente Madsen*

The Land of the Bible by *David R. Morton*

October 1988 Israel Tour

34 Equipment Ideas from Readers

Wheelchair Gardening by *Joan Hughes*

Wheelchair Hydroponic Gardening by *A.G. Garris*

Leg-Operated Wheelchair by *Richard L. Weiler*

Rehabilitation Engineering by *Keith Sofka*

36 General Periodicals for People with Disabilities

37 Potpourri

40 Photo Page

41 Underventilation: A Warning by *Richard L. Weiler*

Reproduction permission. All editorial matter in *Rehabilitation Gazette* is copyrighted. No specific permission is required to photocopy or reproduce a limited number (100 or less) of a complete article as it appears in *Rehabilitation Gazette* if the reprints are for free distribution within an organization or classroom. Permission for any reproduction or other distribution of copied articles must be obtained from the editors.

AGING SUCCESSFULLY

Survival Notes at 50-Plus

by Mary Jane Owen

Mary Jane Owen has been involved in many aspects of the disability movement since losing her sight in 1972. Since that time, various additional limitations lead her to laugh and say: "You get three for the price of one." She is now a wheelchair user and has lost both the hearing and balance in one ear.

"Our evaluation is that it will be best for you not to waste your resources on rehabilitation efforts. We can send you home and arrange for essential services to be delivered you there. We are sure you'll be a lot more content with that arrangement."

I wasn't expecting the harshness of the judgment, but the physical therapist's words forced recognition that I had passed too far beyond what was considered potentially salvageable.

It was all so professional and precise. I couldn't find the strength to react. I sat quietly, gripping the arms of the rickety wheelchair, trying to force my mind to quiet the loud hammering in my head and the dizzy careening through space which followed every movement. Out of the confusing noise of the therapy room came the tones I recognized as "transport" and I intensified my grasp on the chair in preparation for the lurching rush to clear the door jam of the clinic and accelerate into the hospital corridor.

The confusion of voices, equipment, and unidentifiable sounds changed their cadence as we moved at breakneck speed toward my room. I had lost my sense of space, direction, and gravitation with the irrevocable surgical removal of my inner ear. Several weeks earlier my radar system was still excellent. I had spent over a year in a rehabilitation center for the blind learning to "hear" open doors, poles and corners in my path. I had moved through my surroundings with grace based on rigid attention to other than visual cues. But the surgeon's drill had assaulted both the hearing and balance mechanisms.

No need to ask for a more sedate pace: nobody had the time to pause and listen. Pell-mell was followed by the sudden stop which meant I was not expected to throw myself out into the void of space, hopefully to land back in my bed. Giving up my hold on the questionable safety of the wheeled chair, I fell forward, found the edge of the mattress, and with a vise-like grip, pivoted awkwardly in the general direction of the bed. Terror accompanied those movements but there could be little compassion for such an unrealistic fear in a hospital ward where life and death were the critical balance points. The challenge of high stakes in the medical game left little time to consider altering predictable and clinically appropriate patterns of behavior.

I couldn't have seemed a less likely candidate for rehabilitation. There I was, a middle-aged female without benefit of those little tricks and aids we all learn to use to cover the accumulating flaws which passage of time brings. Slumped over in my wheelchair and unresponsive, dressed in a too short hospital gown, over which was stretched a dressing gown which had seemed rather glamorous over a colorful negligee in my own apartment, gave evidence of inappropriate effect. In this setting, the flimsy robe added a touch of drama to the picture of incompetence. I was immodestly exposed to cool clinical examination.

I had learned to cope with blindness, but now all sound came to me in flat confusion. In trying to explain to a friend, I suggested following the sense of a verbal statement was

rather like searching for a kernel of corn in a dish of cornmeal mush. My tactile and proprioceptive sense had been eroded by an early childhood bout with meningitis and several spinal injuries, followed by surgical fusion in later years, had continued the movement toward modest but bothersome neurological limitation. The loud ringing and hissing in my ears, to which I had become relatively adjusted, was now joined by a continuous clang rather like a metal hammer blow on an anvil. I was unsure if words I could make out from this din were directed toward me or someone else.

Small wonder young physical therapists, fresh out of training, with their lists of specific physical limitations and medically prescribed solutions, viewed me as "not appropriate." My only salvation lay in being looked at as an individual rather than a category, as unique instead of a part of a clinical classification.

As I lay back against the bed, I could feel the plastic of the mattress as it bent to accept the shape of my body. Sinking into its surface, the terror which movement brought slowly gave way and the Mary Jane of a month before rose to confront me.

During the Christmas season of 1986 I was that other person. Now, in mid-February, I seemed to have lost track of that competent and self-assured person. Where had she gone?

Slowly the depression was displaced with frustration and rage. I pushed the button to call a nurse anticipating the extended wait which the more chronic patients learn to expect. Some hours later the physical therapist and I were again face-to-face. But now I felt safer and less vulnerable. I did not have to worry about falling into a black bottomless pit if I breathed too hard and my room was quiet. I had tapped into that knowledge I shared with all other successful disabled people: recognition of the value of using the energy of anger in countering depression and apathy. How did those experts dare to judge me, not knowing what I had been or could

become! I had been trained not to let *anything* defeat me.

My words were uttered in rage and they issued from my mouth as if fashioned into spears and arrows. They were not polished into careful epistles to persuade but were like the warnings of a cornered animal, frightened but fighting to be taken seriously. They were meant to shock and wound. The rush of gutter words slowed, the storm of rage began to move on and a more rational self-interest began to operate. Had this "care-taker" taken her leave? Was she going to strike back? This unequal battle took place on her professional turf and it was she who would have to win in the end.

There was a terrible pause. Through tears of frustration, fear, and shame of how "un-professional" I had just behaved, I quietly added: "I think you'd really like me if we had met under different circumstances. I'm really a witty and bright woman with a lot of compassion and sympathy for others. I know you're not my enemy, but I can't be discounted — I *do* still count."

I waited as she struggled through her identification with the clinical judgment she had made. My professional cap again on my unkempt hair, I joined her in grappling with my actions and her desire to agree to my demands. When she left, we were both relieved by our consensus: she would be my physical therapist and would work with me every day until my discharge from the hospital.

This young woman's eventual evaluation allowed me to enter a rehabilitation facility where I endured the judgments of a medical model of function for slightly over five months. Because of years of training and background in human services and a decade as an advocate in the disability movement, I knew too much to be comforted by the experts' insistence they were in the best position to judge what were proper goals, devices, and treatment modalities for me and they did not want or need my active participation in that evaluative process.

The rigidity of the medical mindset frustrated me and prevented any

consistent action in my own behalf. There was conflict and growing awareness of a love-hate relationship which still awaits the writing of the final chapters. I *needed* help and in the early days of my rehabilitation process, I was content to rely upon their clinical knowledge base. With the passage of time, it would have been beneficial to move from the role of "patient" to that of "student" or "client" or even "peer." I look back on some of the battles fought over equipment and priorities, wishing I had been allowed to play a meaningful role in the final decisions.

The walls of medical facilities are often not open to the realities of what exists beyond them. Too many disabled people and their families are blocked from future options by choices which are made by professionals acting "in their best interest" without any accountability for the "future" they have created. But one does not bite the hand which rescued one from the edge of a precipice.

I reconstruct my memories and form the suggestions for change which await an appropriate time for sharing. That time *will* come because the outmoded mindsets are too costly and inefficient, too many of us are lost and swept out of our places on the planet. Too many of us never recover our drive to choose our own goals and priorities and to wrestle with life to fulfill our dreams.

My favorite Monty Python movie, which I believe is called "In Search of the Holy Grail," includes a scene in which a resolute knight is determined to prevent passage of a transgressor. Outnumbered, he stands there, sword at the ready. When his strong right arm is lopped off, the weapon is transferred to his left. With the loss of one leg, he hops about on the other; deprived of that one, he remains firmly balanced on his trunk brandishing his blade with the remaining arm.

By the time this last appendage is forfeited, the audience is roaring with laughter. What can the intrepid warrior do now? Of course, he will never be conquered. He will butt

those who are attempting to subjugate him. He cannot be defeated and the theater is filled with howls. Who is the victim? Who the victor?

Nowhere have I seen a better example of what absurd human desire to survive — to struggle and endure. And we laugh with joy and tears in our eyes in recognition of that noble, yet eventually foolish,

endeavor. We are survivors until the last moment. And those of us who survive with the normal "afflictions" of the human species are playing out the desire to prevail "in spite of" what the living process demands of us.

I fully intend to live to be 100 years old. I expect to croak from that last bed: "Keep your damn hands off

that plug, sonny, I'll pull it myself, if and when I decide my life isn't worth the effort."

福

Address: Mary Jane Owen, Director, Disability Focus, Inc., 2032 Belmont Road, NW #226, Washington, DC 20009.

Interchanging the Words of Disability and the Words of Aging

by Mary Jane Owen

Increasing numbers of us are caught between the edges of two systems which can increase options in our lives. We talk toward similar goals, but discussions too often lead to confusion and frustration among potential allies. As we try to form coalitions, we use words which sound almost foreign in their meaning.

An advocacy friend returned to his hometown upon learning of his mother's stroke. He saw her through transfer from a hospital where many friends dropped by to a nursing home where no one visited. He thought all she needed to return home was an "attendant." He railed against a heartless community which wouldn't meet his mother's needs. By chance, not reason, he eventually fell into the right system and was taught the essential substitute language: "home health care."

An informal taskforce of individuals from the National Council on Aging, Disability Focus, Inc., Gazette International Networking Institute, and Gray Panthers is developing a draft lexicon for presentation during a workshop at the National Conference on Independent Living in May, 1988. Your suggestions and examples are essential. Send them to G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108 or Mary Jane Owen, 2032 Belmont Rd., NW, #226, Washington, DC 20009.

Marriage After 24 Years of Correspondence

by J. Robert Sudheimer

"Independent living can be reached at any age in life, if one believes, and works."

I was born in 1921, on a farm in the southern part of Missouri, the youngest of 10 children.

The farm where I grew up was quite isolated. We lived three miles from the closest post office, two miles from the closest school. Our closest neighbor was more than half a mile away.

Since I was injured at birth and never walked, my growing up years were very lonely, despite a large number of brothers and sisters.

At age 10, I entered Shriners Hospital for Crippled Children in St. Louis. Although the doctors there were unable to help me, the school teacher who taught us younger children did! She awoke in me an interest in reading and a love for books.

Because of my disability and the remoteness of my home, I was never able to attend public school. Except for two hours a day, during the 10 months I spent at Shriners, my only education was that furnished by my parents, both of whom had only eighth grade educations.

However, both my parents were dedicated to teaching me the best they could. Many times I recall my father saying to me, "Son, simply because you can't walk doesn't mean you have to grow up a 'block-head.'"

When I was 23, my father bought a used typewriter. How I loved that old Underwood #5!

Because I have always been a "quad," writing by hand has been a slow, difficult process for me. Although I had no tutoring, and have always typed with one finger, that first typewriter opened up a whole new world to me: the world of penpals! I've no idea how many penpals I have corresponded with over the years, but the number was large, and of many ages and in different parts of the U.S.

In 1957 I began corresponding with a young lady in Buckfield, Maine. This person was also disabled. Later that same year, 1957, this lady in Buckfield "swapped" penpal names and addresses with a disabled young lady in Bangor. The young lady in Bangor sent me a brief note of introduction, describing how she had gotten my name and address. I answered her note and thus began a correspondence that was to span 23 years, thousands of pages, and four typewriters!

After spending the first 56 years of my life with members of my family, first my parents and then with one or the other of two married brothers, in 1977 I went into a medium care nursing home in a small town in Missouri. There I found complete physical care, and absolutely NO personal freedom!

Over the years, my friend, Cynthia, in Bangor, and I had occasionally, over the years, discussed the idea of marriage. However, because we were both quads, and far apart, the discussion of marriage had never gone beyond the "wouldn't it be nice if . . ." stage.

However, in June 1978, I wrote to Cynthia and asked her if we could locate a suitable place to live, and if I came to Maine, would she consider becoming my wife?

Sending a letter through regular mail, and receiving an answer required about eight working days. To my delight and, I must confess, to my surprise, she said "Yes!"

Then we began the slow process of trying to locate a place. We needed not only a reasonably accessible apartment, but also an agency that would provide twice-a-day, seven-day-a-week care in our home.

My next step was finding a way to "escape" from the nursing home. After many letters and other methods of gaining information, I found the name of an apartment complex in St. Louis, Missouri, that was for disabled tenants only.

That was in April, 1978, and the apartment complex called "The Boulevard" was scheduled to open in August.

In May, began the busiest 12 months of my life. First I learned that by becoming a client of Vocational Rehabilitation I could receive funding of \$420 per month to pay a personal care attendant, so long as I remained a client of Vocational Rehabilitation.

At the same time I was trying to become a Vocational Rehabilitation client, I was also writing many other letters and making phone calls in an effort to get one of the apartments at The Boulevard. At first I received only discouragement. But Missourians are not likened to wiles without good reason! Finally, after countless letters to both Missouri senators, my district congressman and the governor, I was given an interview with the agency in charge of renting the Boulevard Apartments.

During most of the time from May to September, 1978, I was being assisted by a young lady working for the Outreach Program in our county



Robert and Cynthia Sudheimer

seat town. Shortly after this young lady started her efforts on my behalf, she met Gini Laurie. With the help of many fine, caring people, not the least of whom was Gini Laurie, on September 29, 1979, I moved into my very own apartment at The Boulevard. As a client of Vocational Rehabilitation I was placed on a Work Adjustment Training program in the accounting department of Goodwill Industries in St. Louis.

In November or December, I attended a meeting of the St. Louis Chapter of the National Spinal Cord Injury Foundation. There I met Gini Laurie for the first time.

About a week later, I called Gini and asked her if she would do some research for me. When she agreed, I asked her to find a place, preferably in Maine, where there was subsidized accessible housing, along with twice-a-day, seven-days-a-week personal care, which Medicaid would pay for.

Only a few days later, Gini called me and told me a man in Portland to write to. I wrote to this man, Kim Matthews, in South Portland, Maine. Kim and his excellent secretary, Suzy, not only found the care I needed in Portland, but an apartment as well.

Can anyone reading this grasp my feelings when, on May 5, 1980, I boarded a TWA 747 in St. Louis bound for Boston and then on, by Delta, to Portland? When I bid "farewell" to my minister friend and my attendant that morning I believe I felt a little the way Columbus must have felt when he set sail! When I allowed the skycaps to lift me from my motorized wheelchair and into the narrow boarding chair, I knew my future was entirely in the hands of total strangers. The plane might never become airborne! It might crash enroute! It might be hijacked! I might be murdered and robbed! I might be stranded in Boston!

Not only was my future survival in the hands of strangers, I had only the written word of a stranger that I actually had an apartment. I had only the promise of a man I had never met that he would meet me at the Portland airport with new batteries for my chair and a lift-equipped

van and transport me to my apartment on State Street in Portland.

Although I had a power wheelchair, I could not take the batteries along. Therefore, it was necessary to wheel my chair into the air terminal. It was a great deal of relief to see this rather large, bearded man sitting in a wheelchair and smiling.

My second moment of relief came when I found that all my luggage, including my Hoyer lift, had arrived with me.

Kim and Suzy drove me, bag and baggage, to Longfellow Commons where my apartment, along with considerable furniture I had shipped, was waiting.

Kim Matthews was director of what was, at that time, the Maine Chapter of the National Spinal Cord Foundation, later to become ALPHA 1, Adaptive Living for Physically Handicapped Americans. Soon after we arrived at the apartment, a man from Vocational Rehabilitation and another young lady from Kim's office arrived at my apartment to help get me unpacked and settled in. At 7:30 that evening, Monday, May 5, 1980, a nurse from Community Health Services of Portland arrived to put a tired, happy Missouri hillbilly to bed.

About two weeks before I came to Maine, Cynthia called and informed me she had been offered an accessible apartment just across the hall from mine. The only difficulty was the apartment manager insisted that, upon my arrival, I look at this apartment and decide if Cynthia would accept it. Although both these apartments were in the basement, mine next to the trash room, Cynthia's next to the elevator, and both were dark, we were ready to move in.

Next incident of consequence was Monday, May 12 — the day Cynthia Giles and I met for the very first time! I truly wish it were possible to describe my emotions when the day arrived that Cynthia was to come to Portland to meet me! There was the realization of the wishes and dreams of many years, well seasoned with fear that I would disappoint her, or that she would dislike me on sight! In short, all the mixed emotions one might expect to feel.

Cynthia and I met, she did NOT leave screaming. Four weeks after our first meeting, she moved into the apartment across from mine where she lived until September 5, 1981 at which time we were married.

In December we moved to Newport, Maine, where we lived until April 1982. On the latter date we moved into our present home, a fairly comfortable two-bedroom apartment, ground level, in a family housing project, close to a small shopping center, where we live with our Siamese/Tiger cat named "Gaspar." Gaspar is the family name of one of Cynthia's Portuguese ancestors.

At the present time, Cynthia is working 25 hours a week as Community Services Coordinator for ALPHA 1 Center for Independent Living in Brewer, which involves: advocacy, case-management, skills training, and peer counselling. I am chief cook, in addition to working part-time as an accessibility reviewer for the State Handicapped Accessibility Directory under the direction of Maine Independent Living Center in Augusta, Maine.

Cynthia and I have had our share of problems. We still do. But we have had our moments of victory as well. We were privileged to help advocate for the enactment of Maine's excellent Home-Based Care Program, which was made into law in 1981, shortly after we were married. And here in Bangor, we helped to found the Maine Action Coalition for Disabled Persons (M.A.C.), a non-profit organization providing transportation and advocacy for persons with all types of disabilities. We have each served a term as president of M.A.C.

We are not uncommon people, just a couple who found that dreams can and do come true, if we work hard, pray hard, and trust in God and our fellow human beings. Independent Living can be reached at any age in life, if one believes, and works. 福

Address: J. Robert Sudheimer, 194 Griffin Road, Apartment 301, Bangor, Maine 04401.

Home Care: Humane, Cost-Effective Healer

by Basil Chenevert

"Fortunately, there is a growing awareness that home care can be a viable, humane, and economical alternative . . . I have no doubt that home care is responsible for marked improvement in my physical condition and attitude."

In early 1979, I was diagnosed with amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease. I have lived beyond the average predicted survival for those with ALS, and this period of my life has been given comfort and meaning by home care.

Home care has had a dramatic impact in several ways. Shifting my care from a hospital ward to familiar surroundings gradually changed my depression and despair to hope and determination. Returning to limited participation in life with those who were most important to me made every day meaningful. I also found that these changes had a powerful therapeutic effect that reduced many of the medical problems I had been experiencing before I went home.

Unquestionably, a person's access to high-level medical skill and sophisticated life-saving equipment that hospitals offer is critical at certain stages of any serious illness. Progressive hospitals now recognize that when a patient's illness is stabilized and recovery begins, this recovery can be accelerated if the patient's recuperative powers work with family support in familiar surroundings. Physicians are also aware that, despite elaborate precautions, hospitals present a higher risk of cross infection than exists in an average home.

For terminally ill patients, progressive hospitals also recognize that, when the end result can no longer be changed, it is cruel to continue institutional confinement. The quality of whatever life remains to me is more important than easy access to medical skills.

Fortunately, there is a growing awareness that home care can be a viable, humane, and economical alternative. The hospital responsible for my care encouraged and effectively promoted home care. They organized regular visits by special nurses and therapists. My physician made house calls when needed and had the flexibility to allow experimentation in my care, even accepting suggestions from me.

The dramatic improvement in my condition included the following: my

appetite improved and I regained normal weight; constipation and gas attacks decreased; kinking of my intestine became less frequent and ultimately ceased; and I discontinued sleeping pills and pain killers.

I have no doubt that home care is responsible for this marked improvement in my physical condition and attitude. The key factor is the freedom and flexibility that home care provides. No such leeway could have been allowed in a hospital where rigid procedures are dictated by specialization and a heightened awareness of malpractice vulnerability. Of course, the ultimate freedom is the freedom that permits continued interaction with my family.

My good fortune is highlighted by a decision my wife and I made in 1978. At that time, my employer offered employees the opportunity of switching from conventional hospitalization coverage to a health maintenance organization (HMO). We changed only because our regular doctor had retired and the new plan automatically made doctors from a large medical center available. The only treatment a conventional plan would have paid for in my case was hospital care—any attempt to finance home care ourselves would have quickly wiped out our savings.

Home care offered me the freedom to make a number of changes that not only improved my health, but also allowed me to reduce the frustration of complete dependency on others. The healing effects of home care that helped my comfort and survival will also benefit other home care patients.

福

Address: Basil Chenevert, 819
Winchester, Lincoln Park, MI 48146.

Long Term Care '88

Copyright 1988, Paralyzed Veterans of America by permission of *Paraplegia News*.

"Long-term care is an issue of concern not only for the elderly but for disabled individuals of all ages... and their families!"

The Paralyzed Veterans of America has joined forces with the American Association of Retired Persons (AARP), the AFL-CIO, and more than 100 other health care, disability, religious, and advocacy groups to promote a nationwide educational campaign on the need for a government policy for long-term care protection. The cooperating organizations have a combined membership of over 60 million. The campaign is called Long Term Care '88 (LTC'88).

The lack of a comprehensive long-term care policy is a critical issue facing Americans of all ages, yet is has not received major public attention. More and more Americans are faced each day with the staggering impact and cost of catastrophic disability and illness. Current government programs fall far short of providing protection to meet these needs.

Long Term Care '88 is using the presidential primaries as a springboard to launch the campaign. Presidential candidates were asked to participate in a series of forums held in Iowa and New Hampshire during October and November 1987 to discuss their positions on long-term care and the needs of disabled persons of all ages. Similar events were planned in the southeastern United States prior to Super Tuesday

— March 8, 1988. LTC'88 plans to launch, as well, an impressive media campaign in certain parts of the country.

The campaign is completely non-partisan. It is not designed to promote any individual candidate but to bring forward an idea for all candidates to support. Likewise, the campaign is not endorsing or saying that there is one specific legislative proposal or policy initiative to address long-term care needs. LTC'88 is merely calling on those seeking elective office and those who elect them to recognize that a serious national problem exists. Collectively, we ought to have the wisdom, the compassion, and the foresight to seek a solution to this crisis. The US is one of two industrialized nations (South Africa is the other) not to have filled the long-term care gap.

PVA's advocacy role for health care, compensation, pension, and rehabilitation programs provided by the Veterans Administration (VA) gives some protection for many of its members. However, even VA programs do not provide full protection for all veterans and are not immune from budget cuts, reduction, and attack. The real need for long-term care goes far beyond PVA membership; it is a family issue. Disability can strike at any age, and the impact and cost of disability can affect every generation within a family.

The stark facts reveal the staggering human, emotional, and financial cost that catastrophic illness and disability have brought to thousands of American families. Each year, an estimated one million Americans become impoverished due to the costs associated with long-term illness. Of this group, nearly one third are catastrophically disabled individuals under the age of 65. More than 4 million Americans are hospitalized each year and require therapy as a result of accidents; nearly half a million of these are left permanently disabled.

Medicaid provides significant assistance for nursing homes and other long-term care expenses.

However, the rules of eligibility have been so restrictively structured that these benefits are available to fewer than half of those with incomes below \$11,000.

Private insurance for long-term care coverage can be part of the solution for some, but the costs associated with this coverage would preclude most American families. The cost of nursing home care ranges from \$15,000 to \$70,000 and averages approximately \$25,000 per year. Coverage for home care and personal care services for disabled individuals of all ages is largely nonexistent.

Current catastrophic health care initiatives for Medicare provides significant improvements in coverage of acute care, hospital bills, and some extraordinary doctor and drug costs — but primarily for those over age 65. Eighty percent of true catastrophic health care expenses are for long-term care provided outside hospitals. These bills are not covered.

PVA, as a cooperating organization in Long Term Care '88, is going beyond the initial presidential primary focus of the campaign to seek a broader constituency. PVA's goal is to state clearly that long-term care is an issue of concern not only for the elderly but for disabled individuals of all ages — and their families!

PVA's National Legislation Office is coordinating briefings and seminars for members of Congress and their staffs on Capitol Hill. Over the next ten months PVA is planning to distribute campaign materials among disability and health groups and elected officials and candidates at the national, state, and local levels. At the same time PVA is encouraging its chapters and its membership to join this effort.

A national long-term care policy will not materialize from the top down or from the White House alone, no matter who is President. Health policy is directed from many levels in the American political spectrum. Many cooperating organizations plan to promote Long Term Care '88 with their member-

ships and with elected officials at conventions, forums, town meetings, and the like. Some even plan to go door-to-door in primary states.

If any organization or PVA chapter knows of an appropriate occasion or event on your schedule in which the goals of the campaign might be

promoted or information distributed, please let the National Legislation Office know. PVA has a list of a variety of campaign materials, briefing papers, and brochures that can be suitable for any occasion.

福

For more information on Long Term Care '88 contact: Paralyzed Veterans of America, National Legislation Program, 801 Eighteenth Street, NW, Washington, DC 20006.

Highlights: the American public views long-term care

The foundation for Long Term Care '88 is a nationwide poll and two targeted polls commissioned by the American Association of Retired Persons (AARP) and the Villers Foundation, an organization that supports a variety of health care issues. The surveys revealed that six out of seven American voters want some government actions on long-term care. A significant majority of those polled said they would even be willing to pay more taxes to finance long-term care coverage.

In corroborating polls conducted in New Hampshire and Iowa (October and November 1987), more than eight out of ten of those persons contacted responded that long-term care coverage should not be just for the elderly but for disabled individuals of any age.

Long-term care is a problem with universal impact.

- Over 60 percent of respondents have had some experience — in their own families or through close friends — with the need for long-term care.
- More than one in two of those without experience anticipate facing a long-term care problem in their immediate family within the next five years.

Long-term care is a major financial concern for families.

- Ninety percent agree that having a family member who needs long-term care would be financially devastating for most working and middle-income families.
- By more than a four-to-one ratio, voters feel that nursing home costs would be "impossible to pay" or would constitute "a major sacrifice."
- Four in ten of the families who have sought paid help in providing long-term care at home have experienced difficulty in paying for that care.

Government should get involved in long-term care.

- More than six of seven respondents believe it is time to consider some government program for long-term care. This is true of 92 percent of Democrats, 82 percent of Republicans, 87 percent of Democrats who voted for Ronald Reagan in 1984, and 86 percent of Super Tuesday voters.
- Support for a government program is overwhelming across age groups, income levels, and political ties.

Americans are willing to pay increased taxes for a government long-term care program.

- By a five-to-two margin, respondents express a willingness to tax themselves at rates that correspond to their income to pay for long-term care for everyone 65 and older.

Americans favor a candidate who supports long-term care.

- A majority of respondents (including those residing in Super Tuesday primary and caucus states) said they were "more likely" to vote for a presidential candidate who made developing a long-term care program a major part of his campaign.

Long-term care advocacy carries a positive image.

- Support for a long-term care program carries an immensely favorable image for a candidate, especially in terms of "leadership and vision."
- By a three-to-one margin, respondents rejected the idea that favoring long-term care brands a politician as a "big spender."

This survey was commissioned for Long Term Care '88 by AARP and the Villers Foundation and was conducted by R.L. Associates of Princeton, New Jersey. It is based on telephone interviews conducted in early July 1987 with a nationally projectable random sample of 1000 registered voters.

Living with a Spinal Cord Injury for 17½ Years

by
Robert J. Throckmorton, PhD

"Today, a person with a SCI can expect to have a normal life span providing he/she has proper care, follows a daily regimen for living, and has no other health deficits."

At present (1987), anyone living in the United States has a 1:8000 chance of receiving a spinal cord injury (SCI) which will result in paralysis — a chance which is of the same order as hitting a jackpot on a slot machine in Las Vegas, Nevada. Thus, in a U.S. population of 258 million people as many as 32,000 persons per year might receive such SCI that result in paralysis. The few statistical studies which have been done on the SCI indicate that 56% of the injuries are caused by vehicular accidents — mostly automobiles, 20% from falls, 12% from gun shots, 9% from sport activities, and 5% from all other causes.

Before 1945, the prognosis for the majority of persons with a SCI was "death within a year" even with the best of care. However, with the discovery of penicillin and medical techniques developed during World War II that all changed. Today, a person with a SCI can expect to have a normal life span providing he/she has proper care, follows a daily regimen for living and has no other health deficits.



Robert J. Throckmorton, PhD (C7 incomplete), retired elementary school principal, and his friend, Auna Van Otton

Over the past 17½ years, the author of this article has found the following behaviors and habits positive for survival and health:

- Don't smoke because of reduced breathing capacity;
- Avoid alcoholic beverages;
- No chocolate;
- Reduce consumption of soft drinks;
- Increase consumption of water and fruit juices;
- Drink milk or eat milk products early in the day to help reduce kidney malfunctions;
- Reduce calorie intake by 500 to 1,000 calories;
- Sleep on a sheepskin;
- Learn to sleep on one's stomach;
- Reduce salt intake;
- Dress with loose-fitting clothing;
- Reduce amount of beef and pork in diet;
- Increase amount of fish, chicken and turkey;
- Make carrots, parsley and yellow vegetables a staple in one's diet to improve the tone of the skin and reduce further the chance of developing a pressure sore;
- Eat ice cream and desserts infrequently and preferably early in the day;
- Eat the bulk of one's food at breakfast and lunch and end the day with snacks, soup or liquids;
- Drink water on a 24 hour basis — have a carafe of it by the bedside.

The price of my survival as a SCI is to follow a regular daily routine.

福

Address: Robert A. Throckmorton,
1267 Douglas Dr., Las Vegas, NV
89102.

Ageing and Support Services for Living Independently

by Gerry Zarb,
Research Officer,
Thames Polytechnic

"Physical ageing is a normal and natural process; the important question concerns the effects of normal ageing when they are combined with long standing physical impairment."

It has been suggested, both by professionals and spinal injured people themselves, that spinal cord injury can lead to "premature ageing." A figure commonly quoted is that, 20 years with SCI adds 10 years to a person's "physical age." Early observations from the study seem to offer fairly strong evidence to support this notion of premature ageing. It is important to point out, however, that many of the problems reported are not unique to spinal cord injury. Physical ageing is, of course, a normal and natural process; the important question to be explored concerns the effects of normal ageing when they are combined with long standing physical impairment.

At this stage, however, it is very difficult to assess how prevalent the kinds of problems reported will be amongst the SCI population generally. This will be one of the aims of the second stage of the research which will consist of interviews with a representative sample of older lesions drawn from former patients at Stoke Mandeville and (possibly) a spinal unit in the North of England. What follows should, therefore, only be regarded as a very tentative indication of what some of the effects of ageing with SCI might be.

The most commonly reported effect of ageing has been a generalised reduction in physical strength and energy. This is, of course, part of the normal ageing for old lesions due to the extra strain placed on particular parts of the body. Also, because of the reliance on the limbs and joints which remain working, further reduction in physical functioning may have particularly significant consequences for older lesions.

For example, several people have reported difficulty in transferring, turning, and standing without assistance. This is usually attributed to reduction in strength and energy, but sometimes also to weight gain. The physical consequences of these problems are varied. The most common problem appears to be damaging shoulder joints whilst transferring; falls have also occasionally led to fractures or dislocations. Some people have also reported problems with pressure sores, often after several trouble-free years. This may also be partly a result of reduced mobility; the tendency for skin to be more easily damaged amongst older persons is also a factor. What is quite clear, however, is that the problem of turning certainly makes the management of pressure sores more difficult once they develop.

Similar difficulties have been reported regarding routine skin care. Some people have found that they are no longer able to check their skin for marks as often as they would like. Even if this has not actually led to skin damage, the situ-

ation is a source of anxiety for some people. As will be discussed further below, the reduction in energy and mobility has led to some qualitative changes in life styles. People have reported having to find different ways to get in and out of wheelchairs and cars, or on and off the toilet, etc. Most recognise a need for more personal and domestic assistance than previously required.

Several other specific problems are worth noting. Arthritis has been frequently mentioned. This is not surprising since arthritis is the single most common cause of impairment amongst older persons generally. Once again, however, the effects of arthritis combined with spinal cord injury can be wide ranging since the affected joints — usually hands, wrists and shoulders — have to take an extra load.

The common problem of poor circulation makes control of body temperature that much more difficult. This may be a particular problem for high lesions who may experience extreme variations in body temperature and/or blood pressure as they get older.

Some older lesions are increasingly prone to thrombosis and embolisms. Again, this is not uncommon amongst older people generally, but may be exacerbated by increased difficulties in maintaining previous levels of movement which require some older lesions to spend more time in bed or in their wheelchairs. Several people have mentioned that they feel that they would benefit from more assistance with physiotherapy to compensate for reduced mobility and to improve circulation. Unfortunately, however, they have often been told that this is unavailable.

Finally, some people have reported a noticeable increase in pain as they have got older. Sometimes this is attributed to a specific cause, eg persistent pressure sores or arthritis. More often, however, no specific cause has been identified.

Whilst it is necessary to obtain some "hard facts" about ageing, it is equally important to understand

what ageing means at the more subjective level.

It has become obvious during the early part of the research that people tend to evaluate their present experiences against what has gone before. For example, nearly everyone contacted so far has experienced noticeable common difficulties with activities of daily living. How this affects the way they view their lives is, however, extremely varied. For someone who has been used to living independently on their own for perhaps 30 or 40 years, the inability to carry on with formerly simple tasks like washing up, grooming, writing a letter, etc., is a source of great frustration. For someone who has been used to assistance with these kinds of activities, the personal and emotional consequences will not necessarily be as intense.

Furthermore, even people who have reported getting depressed about problems they have experienced with ageing have often said that this was only temporary. As they have become used to the changes they have experienced, people have regained a new sense of equilibrium. However, the observations made by a few of the people we have contacted also suggest that prolonged periods of individually minor problems can have a highly significant effect on how people view their lives. In some cases, this may lead to the decision to make major qualitative changes in life style — eg looking for a live-in care attendant, moving into sheltered accommodation, or even into a residential home.

Regardless of whether or not major changes in life styles or living arrangements are contemplated, nearly everyone contacted so far has reported some qualitative changes in how they feel. The most commonly reported changes are related to a noticeable reduction in energy. Usually this is a gradual, almost imperceptible, process; occasionally, however, a particular event (eg a period of illness) has led to a fairly rapid decline leaving the individuals concerned feeling significantly weaker than before.

Whilst loss of energy is essentially a physical problem, its significance in subjective personal terms can be much wider than simply feeling physically tired.

Frustration is one common reaction which has already been mentioned; many people have reported a general feeling of constant tiredness which makes everything they do seem slower than before. Some people have also mentioned that they have become increasingly irritable and less motivated to get out or socialise. This in

"The extent to which ageing will actually affect changes in life style will also be very much influenced by what kind of support will be available."

turn can lead to feelings of loneliness — particularly for people living alone. A few have experienced varying degrees of depression.

Often these kinds of experiences do not only affect how people feel about their present situation; several have also reported feeling anxious about the future. This kind of comment is usually made in the context of the individuals concerned realising that they will need more personal assistance as time goes on. Most often, however, it is not so much the increased need itself which concerns people, but doubts about whether their needs will be met. For some, this is because their usual carers are themselves experiencing the effects of ageing, making it more difficult for them to cope. For others, their anxieties stem from a lack of confidence in existing care support services and/or a fear of residential care.

It is obvious, therefore, that the extent to which ageing will actually affect changes in life style will also be very much influenced by what kind of support will be available, and

whether or not this is compatible with how older lesions wish to organise their lives. This question will be a central aspect of later stages of the research.

Most of the people contacted so far have expressed an awareness that their need for support either has or will increase as they get older. A central aim of the research is to examine the resources which are, or could be, available to older lesions in order for them to live independently. In this context, living independently simply means that individuals should have the resources to live their own lives, in the way they want and, in a residence of their own choice.

Current debate about 'community care' as it relates to the ageing disabled population is centrally concerned with enabling people to remain in their own homes for as long as possible by the provision of suitable domiciliary care support. This approach is fine as far as it goes. However, it is also necessary to remove the assumption that care in the community will only be maintained 'for as long as possible'. For community care to be compatible — even in principle — with older lesions' definition of living independently, adequate resources and services would have to be provided for as long as particular individuals want them. As one person interviewed put it; — "When I say I want to stay living in the community, I mean more or less until I die ... and if I can't, I'm going to kick and scream."

The increased need for personal care assistance reported by many old lesions is, to a great extent, a reflection of the physical consequences of ageing. However, it is also important to stress that, an increased need for such support is often just as much a consequence of social and material factors. For example, adequate housing design has a direct bearing on whether an individual's home environment can offset any physical effects of ageing, or, add further obstacles to living independently.

It is also important to note that

an increased need for care support often results from the effects of ageing on an individual's normal career — usually a spouse or other relative. Unfortunately, the need for support to ageing careers is often overlooked completely in the planning and delivery of support services.

After personal care assistance, the most important aspect of support for many older lesions concerns adequacy and choice in housing.

The problem of care attendants and other services (eg community nursing, home helps etc.) not being available at times to suit peoples' needs could, to a great extent, be overcome by increased resources. However, an equally important obstacle which would have to be addressed concerns the assumption that people do not mind how such assistance is organised as long as it is available in some form or other. This is simply not acceptable to most older lesions because it denies basic choice and control over how they organise their daily activities.

Clearly, there is an urgent need for care support and housing services which are both adequately financed as well as capable of meeting individual needs defined by older lesions themselves.



ED: Excerpted, with permission, from *SCI Injuries Association Newsletter* 43 & 44, 1987. The SIA newsletter is an excellent resource. To subscribe, write: SIA, Yeoman House, 76 St. James's Lane, London N10 3DF.

The research report, *Personal and Social Implications of Spinal Cord Injury: A Retrospective Study* by G. Creek, M. Moore, M. Oliver, V. Salisbury, J. Silver, G. Zarb is published by Thames Polytechnic and available from SIA for \$14 including postage.

Spinal Cord Injury

Syringomyelia Support Group

G.I.N.I. is acting as the catalyst to promote the organization of a support group for individuals with syringomyelia. If you would be interested in joining, send your name and address to Gini Laurie, G.I.N.I., 4502 Maryland Ave., St. Louis MO 63108.

Paraplegics Wanted

"I would like to hear from anyone who is interested in a self-help book for paraplegics and their families. My research is based not only on my own experiences but on those of other paraplegics, doctors, counselors, therapists, and other professionals involved. I especially would like to hear from any paraplegics and their family members who are interested in being interviewed for the book." Lena Ennis, 918 New Ballwin Road, Ballwin, MO 63021.

U.S. SCI Groups United

The National Coordinating Council on Spinal Cord Injury (NCCSCI) held its first meeting in September 1987 at Atlantic City, New Jersey. The Council

established priority issues: cure and rehabilitation research, public education, prevention, and promotion of care and training.

Member organizations include: American Association of Spinal Injury Nurses, American Paralysis Association, American Paraplegia Society, American Spinal Injury Association, The Daniel Heumann Fund for Spinal Cord Research, Inc., Help Them Walk Again, National Spinal Cord Injury Association, Paralyzed Veterans of America, Shake-a-Leg, Inc., Stifel Paralysis Research Foundation.

The president is Jack Powell, Paralyzed Veterans of America. The corporate offices of the Council are at 801 Eighteenth St., NW, Washington, DC 20006. The administrator is Mary Field and her phone is (202) USA-1300.

Paraplegia News

This monthly publication is an excellent source of information and should be required reading for all who are spinal cord injured. The subscription is \$12 a year in the USA, and \$18 outside the USA. *Paraplegia News*, 5201 North 19th Ave., Suite 111, Phoenix, AZ 85015.

1989 CONFERENCE

Mark your calendars for another great gathering.

Our Fifth International Polio and Independent Living Conference will be at the Sheraton Hotel in St. Louis on May 31 to June 4, 1989.

As an added attraction, the Midwest EXPO is scheduled at the same time at the Convention Center across from the hotel.

A Triad of Venerable Polio Survivors

Dessie Brooks

"I had polio at age six... I am now in a wheelchair. At this 93-year age, I don't mind it... I live a normal life staying happy with my 'disadvantage.'"

I am 93 years old now and well do I remember that time so long ago when I had polio at age six. I was stricken at school with a fever of 105 degrees! I went to bed for one whole year. The only medication the doctors gave me was Syrup of Pepsin, and the only treatment was alcohol rubs.

The damage polio left was a half inch shortness in one leg. I lived.

Lenna Furgerson



Tom and Lenna Furgerson, married for 60 years

I did normal hard work. I married and bore two perfect children.

Then, when I was 70, I developed a curvature of the spine. It's painless, but I am now in a wheelchair for the rest of my life. At this 93 year age I don't mind it. The pain is not acute any more and I have no stiffness in any joints. I haven't had a headache or cold for 60 years. My mastectomy was painless. My cataract implants were painless. Doctors say I heal up like a 16-year old. The only medicine I take is Ecotrin (enteric coated aspirin) for my heart, which is normal. I weigh only 80 lbs.; I'm on a sensible diet and I drink six glasses of water each day which keeps my tissues lubricated. I have no facial wrinkles and still have all my own hair. My blood pressure stays the same — 180/40 — but I do have hardening of the arteries. My stomach has moved to the right side under my arm, but that does not cause me any trouble. I do all my own housework in my wheelchair which is run by hand.

I was paralyzed from the hips down and on the left side in 1908 (at age 3). The doctors did not know what it was and they said I had only an hour to live. But I came out of that and they said it was infantile paralysis.

I was treated at the McLain Orthopedic Hospital in St. Louis. The first time, I was there for six months. Later, I went for three months. They had nine or ten different exercise machines and they made braces. I wore shoe braces, sandal braces, and back braces.

I was taught to be strong and independent. My therapist put me on a horse as soon as I was able to stay on. I am a native Texan and I always had a horse to ride because my



Mrs. Dessie Brooks, age 93

Occasionally, I have a boutique in my apartment in this rest home and I sell the crafts I make for recreation. I do needlepoint, crocheting, and origami. I hope my experiences will encourage somebody about polio. I live a normal life staying happy with my "disadvantages."

福

Address: Mrs. Dessie Brooks, 1840 Park Avenue, Apartment 109, Costa Mesa, California 92727.

father thought that was the best exercise in the world.

I can do almost any kind of handwork or art and I was trained as a musician, both piano and voice.

I am a member of Daughters of Nile, Eastern Star. I have devoted most of my life to Shriners Childrens Hospital, especially to getting ramps and wheelchairs.

I use a wheelchair which I push myself because it makes my arms strong. I find crawling the best therapy.

On August 27, 1987 my husband, Tom, and I celebrated 60 years of marriage.

福

Address: Lenna Furgerson, 2848 N.E. 14th Drive, Gainesville, FL 32609.

Y'vonne L. Greatwood

"Other students' journeys as a teacher were not like mine. Mine was slow motion. I succeeded as a substitute, but success was not a guarantee of security."

I took poliomyelitis or infantile paralysis, as it was called, at three months of age on October 4, 1910. My father was a railroad man, my mother was a teacher. We lived in an immigrant neighborhood in Buffalo, New York, beside railroad tracks.

At eight years of age, I received six months of treatment at the McLain Sanitarium in St. Louis, Missouri, which consisted of exercising my paralyzed muscles in machines with weights. After 4-1/2 months I walked without a brace for the first time in my life. For five years the improvement continued. I danced.

Adolescence reversed the picture. My paralyzed foot dropped. Surgery failed. I walked with a cane and a brace. I fought to overcome my handicap by intellectual recognition. Having won a New York State Regents Scholarship to college, a principal ruthlessly made me give it up. In 1929, as a final effort to restore my ability to walk without a brace or cane, I spent six months at the Reconstruction Home for Infantile Paralysis at Ithaca, New York, in bed with my feet in casts. Modeled after Warm Springs, Georgia, the program was called "muscle reeducation." I left the "home" severely weakened, scarcely able to walk around our little block on two canes.

With no hope for a medical cure, I prayed. In 1932, I entered Canisus College, a Jesuit institution in Buffalo, to prepare to become a teacher in a public high school. In

spite of the repeated warnings of a New York State Rehabilitation representative, "You'll never be passed as a teacher," I went on preparing. I tried the City Examination in 1937 and was marked 0% physically and 0% orally.

I took a second college degree. Other students' journeys as a teacher were not like mine. Mine was slow motion. I succeeded as a substitute but success was not a guarantee of security. In the school year 1944-45, after seven years of being on the substitute list, a period of six months came with scarcely a call. I froze. I was called for one day during a severe epidemic of the polio isolation annex of the Children's Hospital on Delaware Avenue. That day changed my focus. My concern widened to include all students who are disabled. I broadened my knowledge in these special fields.

In 1945, when the City Examination for Teachers of Secondary School English was given again, I passed first on the eligibility list and was appointed a probationary teacher. In 1948, I received a permanent contract. Overworked, my strength failed.

I prayed. Unexpectedly, I was "called" to be the Director of Religious Education at St. Paul's Cathedral in Buffalo, where I had been taken as a child to a great healing service. I accepted "the call." Three years later, I was told by the dean, "I knew from the first day you were the wrong person." I went on to study at Union Theological Seminary in New York City, one of the four large, ecumenical seminaries of the world. Having graduated, I taught Bible at National Cathedral for Girls in Washington, D. C. A so-called failure again, I was "called" to be the Director of Religious Education at the Lewinsville Presbyterian Church in McLean, Virginia, one of the fastest growing areas in the United States.



Y'vonne Greatwood, age 77

In 1961-62, I studied for a year in Scotland at the Divinity School of the University of Edinburgh and traveled as far as the Holy Land to "think things over." At 53 years of age, I returned to the Buffalo Board of Education to teach English at South Park High School where I once was a student. I came in contact with the world. And then I came in contact with teaching in a public school again.

福

Address: Y'vonne L. Greatwood, 1515 Great Falls Street, Apt. 403, McLean, VA 22101.

Accounting on a Computer

by James R. Carlisle

"... the computer age has opened up the world ... My Apple II Plus system allows me to ... operate an accounting office, although I have very limited physical and vocal abilities because of a severe cerebral palsy condition."

Keying in on life through a computer terminal might seem impersonal to some people, but to me, the computer age has opened up the world. My Apple II Plus system allows me to control the lighting and appliances in my home, to dial a telephone and communicate with friends, and even to operate an accounting office although I have very limited physical and vocal abilities because of a severe cerebral palsy condition.

Born in 1936 when this sort of technology was far in the future, I was destined to institutional living. Fortunately, my mother saw more potential in my abilities. She, being a teacher, pioneered the concept of special education for the disabled by tutoring me through the 8th grade. And my father, using his mechanical training to adapt equipment for me, was one of the first rehabilitation engineers.

In spite of my parents' efforts, they were never able to teach me a practical handwriting style. Also, for a long time, only my immediate family understood my distorted speech; and even now, just my close friends and working associates understand me. During high school, the one teacher who tutored me in all subjects learned to distinguish my spoken words, and my parents finally allowed me to peck away at a manual typewriter.

My freshman year in high school was a breeze since the school administration, not believing my mother's grading of her son even though it was conservative, gave me the simplest courses with the minimum credits. But by my senior year, I was being challenged to the maximum with math and science classes. My success was due in large part to a resourceful teacher who modified the program to my special needs. Most of his tests were oral which saved me the time and effort of typing.

After graduating from high school with honors, the Division of Vocational Rehabilitation gave me a used IBM typewriter, a mechanical adding machine, and a correspondence course in accounting which I could have taken five years to complete. I finished the necessary assignments in nine months and went on for another year taking advanced accountancy training. I was then ready for employment, but DVR was unable to sell my services.

Since I needed an office, my parents moved into a different home, which was a former parsonage, so that I could use the pastor's study to set up practice. This was my place of business for many years while I slowly accumulated clients.

During my early career when I had time to spare, I volunteered to be my church's financial secretary. This



James R. Carlisle

turned into a paying job after a few years and it also brought in some other clients from the congregation. My past reputation in high school gave me a good share of work preparing income tax returns for school administrators and teachers. With their word of mouth advertising, my practice eventually grew.


My limited prosperity afforded me an electronic calculator and two IBM correcting Selectric typewriters. Although the two machines did cut down on the paper shuffling somewhat, it was very time-consuming to type figures on the records, to total these amounts by keying them into a calculator, and then to transfer the sums back to the typewritten sheets again.

Thus, when the age of personal computers arrived, I decided a computerized office was a necessity. As I began exploring the computer world, I was impressed with the way the multi-key functions that I often used could be performed by pushing just one command key and how bookkeeping figures need to be keyed in only once. With this single input operation, all information could be totaled, balanced, and stored. Such one-time data entry saves me many hours of work.

Having a computer as a partner, my abilities to serve a growing clientele increased to a point where I needed to rent commercial office space and to employ additional office staff, thus contributing to the community's economy. I recruited employees from the office education class of the local high school, which gave me the opportunity to teach young people about accounting as well as about working with the disabled. Some of these students

have continued to work for me many years after graduation, while others have pursued different business careers, hopefully with a good attitude toward hiring the physically challenged.

Now I am kept so busy solving other people's accounting and taxation problems that I do not have time to worry about my own impairments. For one who has been physically dependent all his life, it is certainly a pleasure to be called

upon by able bodied individuals for professional guidance in securing their financial independence. 

Address: James R. Carlisle, Carlisle Accounting Service, 3480 Upper 149th St. W., Rosemount, MN 55068.

ED: Reprinted with permission from *The Disabled Challenger*, Vol. 2, No. 4 (Winter 1987-88), Lake Kisseick, Jr., Editor, 1615 So. 4th St., #M-3210, Minneapolis, MN 55454. "See Potpourri, Publications, New," for subscription information.

Coping with Progressive Muscular Dystrophy Is an Art

by S. Hacham-Zadeh, MD

"It is my credo that I, or any disabled adult, can understand his own needs better than anyone else, including physicians and rehabilitation personnel. So I learned not to be deeply concerned with the prognosis of physicians."

When we write about our own life experiences and how to cope with the problems facing us, it proves helpful to learn from each other.

I am a medical doctor (MD) with limb-girdle muscular dystrophy (MD). I was born in Iran and graduated from the University of Teheran Medical School, then settled in Israel, where I completed my residency in dermatology. Now, I am a staff physician at the Department of Dermatology, Hadassah University Hospital. Among my routine duties are patients' treatment, teaching, and research.

The first symptoms of muscular dystrophy were manifested at age of eight and the disease has progressed to a stage where, today, I use a powered wheelchair and require assistance for personal care.

Hopefully, my own experiences in coping with the problems of my disease, will help others, strengthen their own physical and mental reactions to disabilities.

There is no question in my mind that one of the most important factors in shaping my personality and my ability to cope, was the fact that my upbringing and education took place within my own family and in normal schools, among healthy

students. My achievements were measured against the expectations from normal students. Therefore, I was able to enter a career among normally functioning professionals.

To achieve what my colleagues without disabilities achieve, my disabilities placed numerous and daily problems in my way. These had to be continuously solved, and problem solving has become second nature to me. For instance, even a proper and comfortable sitting and writing setup at home and at work required me to design a special table, back supporters, strapping, and auxiliary equipment.

In Iran and even in Israel automated and sophisticated rehabilitation equipment is either non-existent or priced beyond my means to purchase it.

As a matter of fact, normal facilities, in almost all aspects of daily life, are not custom-built for the disabled. To adapt normal facilities for the disabled is a special achievement, and gained only after much struggle. The healthy seem reluctant to expend the time, the effort and the cost, to give us disabled people, the opportunity to compete on an even basis.

However, self-confidence, a firm



S. Hacham-Zadel, MD

belief in the possibility of overcoming obstacles, persistence, patience, stubbornness, optimism, and the empathy and understanding of many people around me, helped. Strangely enough, I somehow really never felt disabled; I was often surprised and astounded by the people around me who thought I could never achieve my goals.

It is my credo that I, or any disabled adult, can understand his own needs better than anyone else,

including physicians and rehabilitation personnel. So I learned not to be deeply concerned with the prognosis of physicians.

It became natural for me to concentrate on the things that I could do and not worry too much about the things that I could not do. This too, became second nature and I developed the habit of permitting my mind to guide my weakening muscles, rather than having my muscles dictate to my mind.

Of course, I love and value my family, in whose midst I live, and from whom I receive warm support. Of course, I appreciate my colleagues at work, who always treat me as an equal and valuable human being. Despite all that, I think it is most important to be independent and to strive for successive achievements, even though they may be small and turn out to be only temporary.

These successive achievements can build a pattern of behavior, which is extremely important in overcoming new and increasing problems, which will surely arise almost daily. So, the integration of a disabled person into a normal society depends on two parts: the strong willpower of the disabled to face difficulties and, equally, on the persistent, positive support, and empathy of the surrounding society.

Under such circumstances, an *able* human being can evolve from one who is disabled.



Address: S. Hacham-Zadeh, MD,
Senior Lecturer in Dermatology,
Hadassah University Hospital,
p.o.b.12000, il-91 120 Jerusalem,
Israel.

Inventory Clearance Sale



We are cutting the prices on Back Issues of the Gazette 50% and more. Instead of paying \$8.00 per issue, you now can have each issue for \$4.00 or LESS.

We are hoping that our need to reduce inventory will fit your wish to obtain the Back Issues of the *Gazette* that you don't have.

To help you determine which issues to buy, we've organized a TOPICAL INDEX to all the Back Issues which follows. Look up topics you want to know more about and order your copies NOW.

For as long as supplies last, you can purchase Back Issues at the following prices:

Single Issue	\$4.00 each plus \$1.00 postage
Two Issues	\$3.25 each plus \$1.00 postage
Three (or more) Issues	\$2.50 each plus \$1.50 postage
Complete Set (23 Issues)	\$60.00 plus \$8.00 postage

*We look forward to hearing from you. Tell your friends.
Let your Rehab Center know. Order today.*

REHABILITATION GAZETTE 1962-1987

A

- Acupuncture, Vol. 17, 1974
- Adoption, Vol. 23, 1980; Vol. 24, 1981
- Adoption & Marriage, Vol. 6, 1963
- Aging with Disability
 - ALS, Vol. 27, No. 1, 1986
 - Muscular Dystrophy, Vol. 27, No. 1, 1986
 - Polio, Vol. 23, 1980; Vol. 27, No. 1, 1986; Vol. 28, No. 2, 1987
 - Special Feature, Vol. 27, No. 1, 1986; Vol. 28, No. 2, 1987
- Amerind
 - Indian Sign System, Vol. 21, 1978
- Amputees, Vol. 16, 1973
- Amyotrophic Lateral Sclerosis (ALS), Vol. 16, 1973; Vol. 26, 1985; Vol. 27, No. 1, 1986
- Home Care, Vol. 28, No. 2, 1987
- Art
 - Artists & Pianists, Vol. 15, 1972
 - Mouth & Foot Painting Artists, Assoc., Vol. 9, 1962
- Aspirator
 - Self, Vol. 5, 1962

- Association of Mouth and Foot Painting Artists, Vol. 9, 1966
- Attendants, Vol. 5, 1962; Vol. 22, 1979
- Approach, Unique, Vol. 28, No. 1, 1987

B

- Biofeedback, Vol. 17, 1974
- Biomedical Engineering, Vol. 8, 1965
- Blind
 - Typing, Vol. 19, 1976
- Businesses
 - Homebased, Vol. 11, 1968

C

- Camping, Vol. 6, 1963
- Cerebral Palsy
 - Challenges, Vol. 25, 1982
 - Charcot-Marie-Tooth, Vol. 17, 1974
 - Chess by Mail, Vol. 13, 1970
 - Citizens Band Radio, Vol. 10, 1967
- Communication
 - Word Board, Vol. 18, 1975
- Community Service Projects, Vol. 13, 1970
- Computer, Accounting on, Vol. 28, No. 2, 1987
- Computers, Vol. 26, 1985; Vol. 28, No. 1, 1987
- Coping, Special Feature, Vol. 28, No. 2, 1987
- Programming Training, Vol. 22, 1979
- Correspondence Courses, Vol. 5, 1962

D

- Depression
 - Coping, Vol. 19, 1976
- Dialysis, Vol. 16, 1973
- Diets: SCI & MS
 - Special Feature, Vol. 22, 1979
- Disabled People's International, Vol. 23, 1980; Vol. 28, No. 1, 1987
- Disabled Veterans
 - Special Feature, Vol. 16, 1973
- Driving
 - Ellsworth Envoy, Vol. 26, 1985
 - Foot Controls, Vol. 22, 1979; Vol. 27, No. 1, 1986
 - Pushbutton, Vol. 22, 1979
 - Quad Drivers, Vol. 8, 1965
 - Quad, Equipment, Vol. 11, 1968

E

- Education, Vol. 8, 1965
 - Correspondence Courses, Vol. 5, 1962
 - Higher Education of Quads, Vol. 5, 1962
 - Quads at College/Work, Vol. 10, 1967
 - Telephone, by, Vol. 5, 1962
 - Vocational Rehabilitation and, Vol. 9, 1966
 - Education & Employment, Vol. 12, 1969; Vol. 21, 1978; Vol. 17, 1974

Employment, Vol. 9, 1966
Disabled Women, Vol. 20, 1977
Homebased Businesses, Vol. 11, 1968
Quad, Vol. 19, 1976
Quads at College/Work, Vol. 10, 1967
Quads, 101 Employed, Vol. 18, 1975
Writing, Vol. 28, No. 2, 1987
Employment of Disabled Women
Special Feature, Vol. 20, 1977
Employment & Education, Vol. 12, 1969
Equipment
Alert Systems, Vol. 23, 1980
Automated Urinator, Vol. 22, 1979
Bath Lifts, Vol. 13, 1970
Bathroom Aids, Vol. 12, 1969
Battery Chargers, Vol. 20, 1977
Camera Mount, Vol. 28, No. 1, 1987
Camper-Pickup with Lift, Vol. 20, 1977
Chair, Vol. 28, No. 1, 1987
Ceiling Hoists, Vol. 24, 1981
Computers, Vol. 28, No. 1, 1987
Cushions, Wheelchair, Vol. 6, 1963;
Vol. 13, 1970
Driving, Quad, Vol. 11, 1968
Electric Drawing Board, Vol. 28,
No. 1, 1987
Engineering, Rehabilitation,
Vol. 28, No. 1, 1987
Foot Control, Vol. 22, 1979
Handcycling, Vol. 23, 1980
Hoist, Electric, Vol. 20, 1977
Iron-Lung, Fiberglass, Australian,
Vol. 6, 1963
Legbag Controls, Vol. 22, 1979
Lifts, Vol. 24, 1981; Vol. 8, 1965
Lifts & Ramps, Vol. 25, 1982;
Vol. 18, 1975
Mouthsticks, Vol. 25, 1982
Page Turners, Vol. 25, 1982
Photography, Quad, Vol. 18, 1975
Portable Iron Lung, Vol. 21, 1978;
Vol. 27, No. 1, 1986
Portable Rocking Bed Plans, Vol. 25,
1982
Pushbutton Driving, Vol. 22, 1979
Ramps, Vol. 8, 1965; Vol. 12, 1969;
Vol. 15, 1972
Reading Aids, Vol. 5, 1962
Remote Controlled Typewriter, Vol. 9,
1966
Remote Controls, Vol. 11, 1968; Vol. 19,
1976; Vol. 17, 1974; Vol. 16, 1973;
Vol. 10, 1967; Vol. 15, 1972
Respiration, Vol. 21, 1978
ROHO Cushion, Vol. 19, 1976
Self-Operating Electric Hoist,
Vol. 20, 1977
Shoes, Vol. 23, 1980
Step-Vans, Vol. 19, 1976; Vol. 18, 1975
Suspension Arms, Vol. 21, 1978
Tailgates, Hydraulic, Vol. 13, 1970
Talking Eyes, Vol. 15, 1972
Typing Aids, Vol. 12, 1969
Urinary, Vol. 28, No. 1, 1987
Van Conversion, Vol. 28, No. 1, 1987
Vans & Lifts, Vol. 16, 1973; Vol. 17, 1974
VA-Tested Van Lifts, Vol. 24, 1981
Ventilators, Vol. 25, 1982
Wheelchair Accessories, Vol. 12, 1969
Wheelchair Lifts, Vol. 20, 1977

Wheelchair Loader, Vol. 19, 1976
Wheelchair Pilots, Vol. 15, 1972
Wheelchairs, Vol. 8, 1965; Vol. 9, 1966;
Vol. 11, 1968
Wheelchairs & Accessories,
Vol. 15, 1972
Wheelchairs, New, Vol. 17, 1974;
Vol. 16, 1973
Wheelchair, Chin-Controlled,
Vol. 10, 1967
Wheelchair, Curb-Climbing,
Vol. 10, 1967
Wheelchair, Leg-Operated,
Vol. 28, No. 2, 1987
Word Board, Vol. 18, 1975

K

Families
Quads and Their Families, Vol. 6, 1963
Fishing, One-Armed, Vol. 13, 1970
Friends Around the World, Regular
feature in all volumes
Frog Breathing, Vol. 10, 1967;
Vol. 25, 1982
Quads Vol. 19, 1976

G

Gardening, Wheelchair,
Vol. 28, No. 2, 1987
Gardening, Hydroponic,
Vol. 28, No. 2, 1987
German Breathing Treatment,
Vol. 17, 1974
Grief, Helping with, Vol. 19, 1976

H

Ham Radio, Vol. 15, 1972
Hearing-Impaired Adults
Oral, Vol. 22, 1979
Higher Education of Quads
Special Feature, Vol. 5, 1962
Hobbies, Vol. 9, 1966; Vol. 17, 1974
Home Care, Vol. 28, No. 2, 1987
Homebased Businesses, Vol. 11, 1968
Homemaking, Quad, Vol. 11, 1968
Housing, Vol. 8, 1965; Vol. 9, 1966
Independent Living, Vol. 19, 1976
Housing & Home Services, Vol. 15, 1972

I

Independent Living, Vol. 22, 1979
Attitudes & Lifestyles, Vol. 24, 1981
Centers, Vol. 24, 1981
Europe, Vol. 23, 1980
Housing, Vol. 19, 1976
Independent Living by Quads
Special Feature, Vol. 13, 1970
Independent Living vs.
Institutionalization
Special Feature, Vol. 26, 1985
International Post-Polio Conference I
Special Feature, Vol. 24, 1981
International Post-Polio Conference II
Special Feature, Vol. 25, 1982

Iron Lung
Portable, Vol. 21, 1978
IRS Regulations
Attendants, Vol. 18, 1975

K

Kidney
Dialysis, Vol. 16, 1973

L

Legislation
Rehabilitation Act of 1973, Vol. 17,
1974
Rights, Vol. 21, 1978
"504 Demonstrations" of 1977, Vol. 28,
No. 1, 1987
Long Term Care, Vol. 28, No. 2, 1987

M

Marriage, Vol. 28, No. 2, 1987
Marriage & Adoption, Vol. 6, 1963
Mexico
Travel & Living, Vol. 12, 1969
Mouth Intermittent Positive Pressure, Vol.
24, 1981
Mouthstick Typing, Vol. 13, 1970
Multiple Sclerosis, Vol. 18, 1975
Muscular Dystrophy, Vol. 27, No. 1, 1986;
Vol. 28, No. 2, 1987
Myasthenia Gravis, Vol. 25, 1982

N

Navajo Nation
Rehabilitation in, Vol. 20, 1977
Nutrition
Polio Survivors, Vol. 28, No. 1, 1987
Nutrition: SCI & MS
Special Feature, Vol. 22, 1979

O

One-Handed Typing, Vol. 10, 1967
Oral Positive Pressure, Vol. 24, 1981; Vol.
25, 1982; Vol. 26, 1985

P

Parenting
Adoption, Vol. 24, 1981; Vol. 23, 1980
Adoption & Marriage, Vol. 6, 1963
SCI Mother, Vol. 26, 1985
SCI Pregnancy & Delivery, Vol. 26,
1985; Vol. 27, No. 2, 1986
Photography
Quad, Vol. 12, 1969
Polio
Aging Problems, Vol. 23, 1980
Polio Support Groups
Guidelines, Vol. 26, 1985
Polio Survivors, Vol. 26, 1985; Vol. 28,
No. 2, 1987
Nutrition, Vol. 28, No. 1, 1987

Polio Survivors 25 Years Later
Canada & U.S., Vol. 25, 1982
Polio & Independent Living Conf., I,
Vol. 23, 1980; Vol. 24, 1981; II, Vol. 25,
1982; IV, Vol. 28, No. 1, 1987
Positive Pressure Ventilation
English Views, Vol. 5, 1962
Post-Polio Aging Problems
Special Feature, Vol. 23, 1980

Q

Quad Artists & Pianists
Special Feature, Vol. 15, 1972
Quad Homemaking, Vol. 11, 1968
Quads
Employment, Vol. 18, 1975;
Vol. 19, 1976
Higher Education of, Vol. 5, 1962
Quads and Their Families
Special Feature, Vol. 6, 1963
Quads at College/Work
Special Feature, Vol. 10, 1967
Quads in their Communities
Special Feature, Vol. 12, 1969

R

Reading Aids, Vol. 5, 1962
Recreation
Artists & Pianists, Vol. 15, 1972
Camera Mount, Vol. 28, No. 1, 1987
Camping, Vol. 6, 1963
Chess by Mail, Vol. 13, 1970
Citizens Band Radio, Vol. 10, 1967
Gardening, Wheelchair, Vol. 28,
No. 2, 1987
Ham Radio, Vol. 15, 1972
Hobbies, Vol. 9, 1966; Vol. 17, 1974
One-Armed Fishing, Vol. 13, 1970
Painting, Mouth & Foot Artists,
Vol. 9, 1966
Photography, Quad, Vol. 12, 1969;
Vol. 18, 1975
Tennis & Skiing, Vol. 19, 1976
Rehabilitation
in the Navajo Nation, Vol. 20, 1977
Music, through, Vol. 11, 1968
Woodrow Wilson Center, Vol. 15, 1972
Rehabilitation Act of 1973, Vol. 17, 1974
Religion, Vol. 21, 1978
Yoga, Zen & Sufism, Vol. 16, 1973
Religion & Disability, Vol. 26, 1985
Religion & Rehabilitation, Vol. 23, 1980
Respiratory Rehabilitation, Vol. 23, 1980
Rights
"504 Demonstrations" of 1977,
Vol. 28, No. 1, 1987
Legislation, Vol. 21, 1978
Rehabilitation Act of 1973,
Vol. 17, 1974
Vocational Rehabilitation, Vol. 20, 1977

Rehabilitation Gazette ORDER FORM

Make checks or money orders in U.S. dollars payable to:
Gazette International Networking Institute (G.I.N.I.).
Mail to: G.I.N.I., 4502 Maryland Avenue, St. Louis, MO 63108 U.S.A.

Subscription:

\$15 for individuals \$ _____
 \$20 for institutions \$ _____
(Add \$3 postage outside U.S. & Canada) \$ _____

Current Issue: \$8.00, plus \$1 postage

Vol. 28, No. 2, 1987 \$ _____

Back Issues:

<input type="checkbox"/> Vol. 28, No. 1, 1987.	<input type="checkbox"/> Vol. 17, 1974.
<input type="checkbox"/> Vol. 27, No. 1, 1986.	<input type="checkbox"/> Vol. 16, 1973.
<input type="checkbox"/> Vol. 27, No. 2, 1986.	<input type="checkbox"/> Vol. 15, 1972.
<input type="checkbox"/> Vol. 26, 1985.	<input type="checkbox"/> Vol. 13, 1970.
<input type="checkbox"/> Vol. 25, 1982.	<input type="checkbox"/> Vol. 12, 1969.
<input type="checkbox"/> Vol. 24, 1981.	<input type="checkbox"/> Vol. 11, 1968.
<input type="checkbox"/> Vol. 23, 1980.	<input type="checkbox"/> Vol. 10, 1967.
<input type="checkbox"/> Vol. 22, 1979.	<input type="checkbox"/> Vol. 9, 1966.
<input type="checkbox"/> Vol. 21, 1978.	<input type="checkbox"/> Vol. 8, 1965.
<input type="checkbox"/> Vol. 20, 1977.	<input type="checkbox"/> Vol. 6, 1963.
<input type="checkbox"/> Vol. 19, 1976.	<input type="checkbox"/> Vol. 5, 1962.
<input type="checkbox"/> Vol. 18, 1975.	

Single Issue \$4.00 each + \$1.00 postage

Two Issues \$3.25 each + \$1.00 postage

Three Issues \$2.50 each + \$1.50 postage
(or more)

Complete Set \$60.00 + \$8.00 postage
(23 copies) \$ _____

I enclose an additional donation
to support G.I.N.I.'s work.
(Donations are tax deductible.) \$ _____

Total \$ _____

Enclosed is my check or money order.

Bill my institution.

Name _____

Name of Institution _____

Address _____

City/State/Zip _____

Phone (_____) _____

Please send information on the 1989 International
Polio and Independent Living Conference.

S

- Self-Aspirator, Vol. 5, 1962
Sex and the Disabled, Vol. 10, 1967
Sex & Disability, Vol. 16, 1973
Sign System Indian
 Amerind, Vol. 21, 1978
Social Security
 Disability Benefits, Vol. 27, No. 1, 1986
 SSI, Vol. 18, 1975
Spinal Cord Injury, Vol. 28, No. 2, 1987
 Centers, Vol. 21, 1978
 English Research on SCI Aging,
 Vol. 28, No. 2, 1987
Sports
 Tennis & Skiing, Vol. 19, 1976
Syringomyelia
 Special Feature, Vol. 28, No. 1, 1987

T

- Telephone Services, Vol. 18, 1975
Ten Years in the Gazette House
 Special Feature, Vol. 11, 1968
Tracheostomy Speaking Valve,
 Vol. 27, No. 1, 1986
Travel
 Denmark, Vol. 28, No. 1, 1987
 France, Vol. 28, No. 1, 1987
 Israel, Vol. 28, No. 2, 1987
 Mexico, Canada & Europe, Vol. 17, 1974
 Quads, Vol. 8, 1965
 Train, Vol. 27, No. 2, 1986
 Vacations, Vol. 6, 1963
 Ventilator & Wheelchair, Vol. 17, 1974
 Ventilator, Europe, Vol. 28, No. 1, 1987;
 Vol. 23, 1980
 Ventilator User, USA, Vol. 28,
 No. 2, 1987
 Warnings for Ventilator Users,
 Vol. 27, No. 1, 1986
 Wheelchair, Vol. 19, 1976; Vol. 22, 1979;
 Vol. 25, 1982
Travel & Living
 Mexico, Vol. 12, 1969
Travelling Quads
 Special Feature, Vol. 8, 1965
Twenty Years in the Gazette House
 Special Feature, Vol. 21, 1978
Typing
 Teaching the Blind, Vol. 19, 1976
 One-Handed, Vol. 10, 1967

U

- Urination
 Pissing Cross Country, Vol. 21, 1978
Urinator
 Automated, Vol. 22, 1979

V

- Vacations, Vol. 6, 1963
Van Conversion, Vol. 28, No. 1, 1987
Ventilator/Ventilators
 Adapting to Ventilation Changes,
 Vol. 27, No. 1, 1986

Advice to People with Polio or Other

- Neuromuscular Diseases,
 Vol. 23, 1980
Aspirator, Self, Vol. 5, 1962
Frog Breathing, Vol. 10, 1967;
 Vol. 19, 1976; Vol. 25, 1982
German Breathing Treatment,
 Vol. 17, 1974
Homemade Cuirass Shell, Vol. 24, 1981;
 Vol. 25, 1982
Iron Lung, Fiberglass, Australian,
 Vol. 6, 1963
Iron Lung, Portable, Vol. 21, 1978;
 Vol. 27, No. 1, 1986
Learning to Use a Portable Volume
 Ventilator, Vol. 25, 1982
Mouth Intermittent Positive Pressure
 Ventilation for Sleep, Vol. 24, 1981
Oral Positive Pressure, Vol. 24, 1981
Oral Positive Pressure Adaptations,
 Vol. 26, 1985
Portable Rocking Bed Plans,
 Vol. 25, 1982
Positive Pressure, English Views,
 Vol. 5, 1962
Respirators/Ventilators — Face Mask,
 Mouthpiece, Vol. 25, 1982
Respiration Equipment, Vol. 21, 1978
Respiratory Rehabilitation, Vol. 23,
 1980
Tracheostomy Speaking Valve,
 Vol. 27, No. 1, 1986
Travel Ventilator User, USA, Vol. 28,
 No. 2, 1987
Ventilator Users, Warnings for,
 Vol. 27, No. 1, 1986
Ventilator and Wheelchair,
 Vol. 17, 1974
Ventilator, Europe, Vol. 23, 1980;
 Vol. 28, No. 1, 1987
Underventilation: A Warning,
 Vol. 28, No. 2, 1987

- Veterans
 Disabled, Vol. 16, 1973
Vocational Rehabilitation
 Rights, Vol. 20, 1977
Vocational Rehabilitation & Education
 Special Feature, Vol. 9, 1966
Vocations for Quads, Vol. 19, 1976
Vocations & Avocations for Quads
 Special Feature, Vol. 19, 1976

W

- Wheelchair & Ventilator Travel in Mexico
 Special Feature, Vol. 17, 1974
Women with Disabilities
 Employment Experiences, Vol. 20, 1977
 Intermittent Self-Catheterization, Vol.
 27, No. 2, 1986
 Special Feature, Vol. 27, No. 2, 1986
Woodrow Wilson Rehabilitation Center,
 Vol. 15, 1972

X-Y-Z

- Yoga, Zen & Sufism, Vol. 16, 1973

G.I.N.I. Publications

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors. Edited by G. Laurie, F. Maynard, MD, D.A. Fischer, MD, J. Raymond. 48 pages. Easy-to-read dictionary format. The "bible" of commonsense information on symptoms and treatment. \$6 U.S./Canada. \$8 overseas. (75¢ postage.)

Proceedings of G.I.N.I.'s biennial International Polio and Independent Living Conferences. Topics include symptoms, treatment, research, and psychological adaptations of the late effects of polio; ventilators and ventilator assisted living; support services; and independent living worldwide.

1983. \$16 U.S./Canada. \$18 overseas. Includes postage.

1985. \$16 U.S./Canada. \$18 overseas. Includes postage.

1987. \$16 U.S./Canada. \$18 overseas. Includes postage.

Ventilators & Muscular Dystrophy by N. Schock, A. Colbert, MD.

40 pages. Handbook of longterm mechanical ventilation of persons with Duchenne muscular dystrophy. \$6 U.S./Canada. \$8 overseas. Includes postage.

G.I.N.I. Memberships

International Polio Network (IPN)

IPN links more than 200 polio support groups and 55 polio clinics throughout the US. Membership benefits include the quarterly newsletter, *Polio Network News*, and the annual directory of US and international polio support groups and clinics.

ANNUAL DUES:

- \$8 Polio Survivors.
- \$15 Health Professionals.
- Overseas, add \$3 postage.

International Ventilator Users Network (IVUN)

IVUN is a worldwide network of ventilator users and health care professionals experienced in home mechanical ventilation. Membership benefits include the biannual newsletter, *IVUN News*.

ANNUAL DUES:

- \$5 Ventilator Users.
- \$15 Health Professionals.
- Overseas, add \$3 postage.

Saga of a Writer

by Theodore Solomon

"Very little success comes easy. But there are other rewards to writing: self-discovery and self-therapy . . . and learning to respect and love the language."



Theodore Solomon

Ever since I can remember I knew I was different from others. I had polio when I was a year old and learned to walk with braces and crutches. I couldn't run, play football or baseball like the other kids, but my brother, Morris, taught me the "law of compensation." I decided I would excel in other ways.

At home and in Feilbach School for the handicapped, I spent my spare time making electrical gadgets. Of course, I also studied the basic courses of English, math, and history — and learned to type. I wrote my first poem at Feilbach.

During my four years in a mainstream high school I often led a very lonely life, because I was self-conscious about the way I walked. In addition to my usual studies, I read and wrote verse and had a poem accepted for a national anthology of high school poetry.

I attended the University of Toledo and decided I would be a writer. It was at this time that I studied the art of poetry in earnest.

Then I developed tuberculosis and spent 20 months in a sanitarium. I also lost much of my hearing from doses of streptomycin. Oddly enough, my confinement had a positive effect. It was here that I began to write plays, using many of the hospital experiences, but also exercising my imagination.

This was apprentice stuff. When I left the hospital I plunged into the new field of television, wrote a couple of scripts, and sent those around. I had already received a number of rejections for poetry, and now I "earned" some more. I knew I would not earn a living at writing, so I studied bookkeeping and went to work. I wrote plays and short stories. For all of my labors I received what Ernest Hemingway called "the most savage of all reprimands, the printed rejection slip."

I moved to San Francisco and worked for awhile and wrote a few short stories. After a year and a half, with all my worldly goods piled in my car with its handbrake and left-foot accelerator, I drove back to Toledo.

Living on unemployment compensation, I settled in a one-room apartment and worked at writing fulltime. I turned out several short stories and a children's novel — all of which were rejected — along with a three-act play that was written earlier and was currently making the rounds. By now I had enough rejection slips to paper the wall.

But my money ran out and I went back to work for Goodwill Industries — which was my second job there.

Eventually, I got a job with the Ohio Department of Public Welfare. I stayed there for 13 years and worked my way up to the position of clerical

supervisor. During this time I wrote at night and weekends, though not consistently. I managed to complete several stories and a science fiction novel during the next ten years. These made the rounds but never found their way to print. Was I discouraged? Yes, but by now I became more or less used to the idea of rejection slips. I was earning a good living and saving money.

I met a lot of nice people at work, and I also bought a computer. I managed to operate this new gadget and even learned BASIC language. I had a great time composing a program, working at night and comparing notes during the day. I never forgot writing, though; like Mark Twain's smoking, I quit hundreds of times. I did quit smoking, but in the matter of writing I was an incurable junkie and kept up my daily "exercises."

The years of writing were not merely a matter of knocking my head against a stone wall. To be sure, I made lots of mistakes and continued to remake some of the same ones. But, I also knew that I was learning. I read, I wrote, I stumbled about, but I knew I was improving. I learned to have faith in my ability. So with that knowledge, and a determination to write seriously, and enough money in savings, I quit my job and returned to the lonely retreat which has been the other half of my life.

Armed with experiences of the years, I would learn to write science fiction stories. I read how-to books and other writers' stories. It is the same process I had gone through many times before — with short stories, plays and poetry. During the next year I wrote six science fiction stories and had one accepted for publication. At the age of 57 my first fiction was published. But even before this happened, I began writing another novel. First came the preparation. I spent five months reading and studying more than 25 books that I needed for technical background and ended up with three or four hundred pages of notes, which included outlining and character studies.

I formed a strict discipline of writing a minimum of a thousand words a day, got up early every morning and was at my desk by 7:00. The story is moving slowly but steadily with much rewriting — a lesson learned a long time ago from a playwright who once said, "plays aren't written — they're rewritten."

I have to admit none of it comes easily. Often, the hardest part is a lapse of self-confidence. It's a recurring problem known as "writer's block." The problem arises in trying to bridge the gap between a "good idea" and fleshing it out so that characters come alive and the action is filled with suspense. This almost always takes many steps, and the

first drafts of a story are usually pretty bad.

As a writer it is sometimes hard to see the finish of a story or the light at the end of the tunnel. But faith helps. And I begin to see the light now. So stay tuned. I may yet turn out to be the "Grandpa" Moses of the literary world.

If all this sounds like a long trail to fame and fortune or even earning a living, in most cases that's the way it is. Very little success comes easy. But there are other rewards to writing: self-discovery and self-therapy that comes from setting your thoughts and feelings on paper, developing all your senses while observing other people and the

world around you, and learning to respect and love the language.

Over the years I've come across many bits of advice from other writers, but one of my favorites is that of George Bernard Shaw: "You learn to skate by falling down and making a fool of yourself. Indeed, in all things you learn by falling down and making a fool of yourself."

So pick up your pen or tap the keys and take up the game. As J.D. Salinger wrote: "Raise high the roof beams, carpenter!"

福

Address: Theodore Solomon, 2023 Marlow Road, Toledo, OH 43613.

Employment Wanted

by Wallace Dove

"Being unemployed hasn't been easy, but I'm not about to give up. I'm 50 years old and I've made my own way since age 10."

I was born with cerebral palsy and battled polio at age 13. After graduating from high school, I applied to college in Riverside, California, which wouldn't accept me because I couldn't pass the written entrance exam. I'd gotten straight A's in Algebra, B's in Trigonometry and C's in English, but I couldn't get into college because they refused me an oral exam.

I went to the Division of Vocational Rehabilitation and asked for an oral exam. The DVR counselor recommended Hotel Management School instead of college, where I maintained a 93 average, earning

a degree in hotel management. I worked as an expeditor for a major manufacturer, managed hotels and resorts and became a nursing home administrator.

Returning to Vocational/Technical School in 1974, I received certification as an assessor and building inspector. For the past nine years, I was City Assessor and Zoning Administrator in a small Wisconsin city until they replaced my job with two part-time employees. I'm unemployed now, and looking for the next exciting adventure. I'd like to get back into the hotel management field. And I'm studying for my licensure exam in nursing home administration just in case I find an opening in that field.

Being unemployed hasn't been easy, but I'm not about to give up. I'm 50 years old and I've made my own way since age 10, never having to ask anyone for money. Public assistance is out of the question. My problem is that sometimes I'm told I'm overqualified, and underqualified for other things. I'm at that stage in life where my three daughters are grown and I want to work more for the joy of work; I don't have to support a family anymore. I'd like to do something where I can help other people with a service. I've learned

through the years to be aggressive and adventurous, to take risks because of my cerebral palsy. I had to. I'd like to share that and challenge others. My disability is not really a handicap; it has taught me to be loving and tolerant of other people's attitudes and actions.

I have also done volunteer work most of my adult life. I've visited hospitals and talked with disabled kids. I put together and produced a television show for children called "It's Great To Be Different." I've taught Bible stories in costume about Elijah, Moses, and Paul in my church, and produced puppet shows, even playing Santa Claus in the local department store.

My ability to supervise, foster teamwork, overcome obstacles, and employ common sense in decision-making are attributes I've worked hard to develop. My commitment to learning and creativity are valuable assets. I hope that my abilities will strike a responsive chord in some of the *Gazette* readers. I can be reached at (414) 982-5899 for an interview.

福

Address: Wallace Dove, 1110 Robin Street, West London, Wisconsin, 54961.

We Also Exist Beneath Our Necks

by Kalle Könkkölä

Kalle Könkkölä, who is disabled by respiratory polio, is a Member of Parliament in Finland.

The UN declaration concerning the rights of the disabled person gives the following definition of the word, disabled: "a person who on account of congenital defects or other physical or mental characteristics is unable to satisfy his or her requirements in respect to a normal individual and/or social life."

The disabled person is cared for and rehabilitated, but he or she is not approached as an entirely whole and complete human being. It is my experience that one never, in connection with the rehabilitation, mentions anything to do with sex. That we are sexual beings implies that we have the same sexual requirements as do other people — requirements that vary for each individual.

We must not set sexuality apart, as if it were independent of the rest of the personality. Sex is inseparable from being human, and the sexual requirement is necessary for loving and being loved. Society wishes to deny or forget the sexuality of persons with disabilities. Experts, as well as parents and other near associates of disabled persons, are guilty in this respect, and even we who are disabled often deny our own sexuality when we too easily concur with the attitudes of other people.

It is far easier to speak about the difficulties of disabled persons than

of their possibilities. Our culture is severely encumbered with hysterical attitudes in connection with male and female sexuality. We should realize that there are no normal or abnormal positions, that virility does not depend on the size of the penis or the size of the breasts. It is not "unmanly" to be passive; it is not "unwomanly" to be active.

We who have disabilities should remember that questions concerning sexuality are not as simple and free from problems as for nondisabled individuals. As in the field of sexuality, everyone assuredly experiences difficulties sooner or later; some manage them and others do not.

Impediments to a happy life may take the form of various psychological factors such as prejudice, ignorance, complexes, etc. In addition to problems that are common to all, disabled persons have particular problems of their own. Of these, the primary problem is the experiencing of one's own body and the feeling and acting by its means, added to which is the extra pressure of society and one's immediate surroundings.

Our society suffers on one hand from a faulty sexuality and on the other from denial of sexuality. Many of us endeavor to be some kind of James Bond or Marilyn Monroe. This is destructive. People develop faulty behavior patterns — gentleness and love are suffocated by the concept of "super sex." Nevertheless, it continues to be more important to be able to love and be loved. Acrobatics in bed do not of themselves make anyone happy. Many severely disabled couples have found a happy and harmonious life together. It is important to be able to live together with the person one loves — above all, to be able to live together freely. Inseparable from this is a rich sex life.

Disabled persons should have the right to take responsibility for themselves. It is our obligation to do so.

It often happens that nondisabled persons decide what is good for disabled persons. It is easy to crush dawning sexuality under the pretext of protecting disabled persons. It is easy to try to condemn a disabled person's plans of marriage as "foolishness." It is easy to say to a disabled person that it is madness to have a child because it would be impossible to look after it properly.

Yet a person grows and develops exclusively through his or her own experiences, and to these necessarily belong the unsuccessful ones. The disabled person is the best judge of whether a permanent relationship with another person is a wise choice. I am convinced that a disabled person considers decisions with respect to marriage and children more seriously than does the average individual.

A severely disabled person is dependent on the physical assistance of others. This physical dependence may lead to a psychic dependence as well. This may take place in institutional or home surroundings. Even when fully grown, a disabled person is bound by this sort of control.

Nor should it be forgotten that the physical environment with its many drawbacks may also be a cause of great sexual difficulties. Many disabled persons have difficulty getting around and so lack the possibility of meeting other people with whom they can form close friendships.

We must live every moment and not waste our lives. We must acquire knowledge wherever possible. We must educate ourselves and remember that we exist beneath our necks. We must overcome warped sexual roles. We can discuss sex openly, especially with our partners. There is nothing to be ashamed of. If difficulties arise, attempts must be made to solve them together. We must learn gentleness. We must work hard, so that conditions will be changed. We must speak, demand, and act to the best of our abilities.

福

Address: Kalle Könkkölä, Wecksellintie Bay, 00150 Helsinki 15, Finland.

Life After Quadriplegia

by Matt Green

"Do you want detachable arms?"

"Yes, I think so. I don't know."

"How about a reclining backrest?"

"Sounds OK."

"You'll have to have detachable leg rests."

"Whatever."

"What color do you want the upholstery?"

What color do I want the upholstery! That was more than I could bear. "Black," I said, and then muttered to myself, "It'll match my mood." I couldn't believe the salesman was asking me to choose a color for wheelchair upholstery. I didn't want a wheelchair in the first place, and picking a color for it was like accepting the fact that I would have to use the unholy thing. I was still assuring myself that this condition was only temporary. I was going to walk out of that hospital on my own two legs.

On a blowy March day I lost control of my car on an exit ramp. Because I wasn't wearing a seat belt I shot out of the seat and hit my head on the roof as the car rolled.

I woke up wedged between the seat and the driver's door and looked through the shattered glass at some people who were looking in at me, asking if I were all right.

"Sure," I said. "I'll be out in a minute. I'm OK. Thanks." "Should we call an ambulance?" "No. No need. You go on."

But I couldn't move my arms or legs. I blacked out again and next remember my wife looking down at me as I lay on a stretcher in the emergency room. I still couldn't move.

The neurosurgeon arrived and took over.

"How long has it been since you went to the bathroom?" "Don't know. What time is it?" "Eight." "About four hours."

So the doctor ordered a catheter and that was my introduction to the world of wheelchairs and cystograms and rehab centers and PT's and OT's and leg braces and finger splints and conservation of energy.

Conservation of energy. When I first heard my occupational therapist use that phrase, I thought she must not know me. I don't have to conserve anything, least of all energy. I could do anything. I learned fast that I had to learn a lot, not the least of which was how to conserve my energy.

"I am blessed with a good wife . . . She loved me as well and in the same ways with my disability as she had before. I am happier now — seventeen years later — than I ever have been in my life."

When I left work that blustery March day, I had been teaching for four years; I was doing a good job. I was also the Chief Negotiator for the teachers' association. It was like having a second eight hour a day job for all the time and concentration it took. I went from being very busy to having all the time in the world in a matter of a few seconds.

My first reactions were probably typical. I wished I had died in the crash. I could not bring myself to even consider the possibility of using a wheelchair. It just wasn't me. I spent most of my time in the first week after the accident cursing my fate and everything else that popped into my head or crossed my path. I am thankful that that phase was short-lived.

I am blessed with a good wife. A saint, my mother called her. And she was. At the hospital every day. Always supportive. Not thinking of



Catherine, Matt (C5-6 incomplete), and Virginia Green

her loss as much as mine. She was the main reason I was able to change my mindset, to decide to make the most I could of my life. I discovered that there was life after quadriplegia. I discovered that there were laughs and good times and genuine, deeply felt happiness and joy for the disabled. She loved me as well and in the same ways with my disability as she had before.

I am happier now — seventeen years later — than I ever have been in my life. But I am getting ahead of myself.

Two years going to the Rehabilitation Center at St. John's Mercy Medical Center in St. Louis County helped me immeasurably. My physical therapist helped me get my fingers moving and then my arms and then my toes and then my legs. But more than that she too helped me see that I could be happy and that there was more that I could do than what I couldn't do. She was irrepressibly positive while I was struggling to regain control of my body. It was what I needed.

It wasn't a picnic by a long shot. There were many traumas and sad moments. The worst was the exchange my wife and I had with the urologist. We asked the normal questions about adjustments I might

need to make in my routines. But there was one area that we were especially concerned about.

"What about sex," I asked. "You'd better not think too much about that," he shook his head sadly.

But we didn't accept his sentence. I refused to see myself as an asexual being.

And there were also others who, however unintentionally, seemed bent on discouraging me. I remember well a conversation with a well-meaning nurse. I looked at her through the boards of the guard rails of my hospital bed as she talked about my plans for the future.

"What did you used to be?" "I am a teacher." "But what are you going to do now?"

"I am a teacher," I repeated. And I intended to return to my job. It did not occur to me that I would do anything else. I know that she meant

"In 1974 our first daughter was born . . . Our second daughter was born in 1986."

to help me, but the effect of her comments was devastating. She only wanted to make me aware of the excellent services of the Division of Vocational Rehabilitation.

I returned to my high school and my teaching four months later, on a part-time basis. Within a year I had resumed all my duties as a fulltime teacher and have been employed as a teacher on a regular basis since then.

At the time of my accident I was just about finished with a master's degree in education. I wanted to complete the degree requirements as soon as possible, but I wasn't sure I could manage getting around campus in a wheelchair. I had let myself start thinking negatively. So that I could finish the last two courses, my wife went with me every day to the campus and sat waiting patiently while I attended classes. Without her help and encourage-

ment I could never have got my first master's degree.

Shortly after that I applied for the job of Chairman of the Foreign Language Department of my high school. And I found that I could do that job from a wheelchair too. I also wanted to learn more about the teaching of writing and so decided to get a second master's. This time I promised myself that I would not have to ask my wife to accompany me every day. With the aid of an electric wheelchair lift in a van, I found that it could be done.

When I finished that degree I went to work part-time at the local community college teaching composition while still working fulltime at the high school.

I also ran for the Board of Directors in my suburban St. Louis city. I lost the race by seventy five votes and it turned out to be the best thing that could have happened because shortly after the election the mayor appointed me to a seat on the Architectural Zoning and Planning Commission. It was perfect for me because from that position I was able to work toward making some of the businesses of the city accessible to people with disabilities.

As the years rolled by my wife and I found ourselves really wanting to have a family. We tried every angle we could think but were initially unable to have or adopt a baby.

In 1974 our first daughter, Catherine, was born. That may have been the proudest, happiest moment of my life. It transformed our lives. Although we often said that we would be happy with or without children, neither my wife nor I can imagine what our life would be without them. I say "them" because our second daughter, Virginia, was born in 1986.

I recently finished the coursework and the exams for my PhD. I look forward to writing the dissertation — if I can find the time. I recently started an independent computer consulting service and business is booming.

It's been a balancing act between dependence and independence. There is nothing I have done that I

did by myself. I needed help — a lot of it — along the way. But I have discovered that most people are willing to give it and that there is nothing wrong with accepting it happily and graciously.

"It's been a balancing act between dependence and independence. There is nothing I have done that I did by myself."

A friend of mine recently got a new wheelchair. It's a beauty: canary yellow, with black trim, super-light-weight and very maneuverable. I want one just like it.

福

Address: Matt Green, 1221 Tahiti Drive, Crestwood, MO 63126.



Josephine and Virginia Green

FRIENDS AROUND THE WORLD

Memories of a Czechoslovakian Tropical Sea

by Āla Wokoun, PhD

In 1935 the spa Janske Lazne became the first European special institute for the treatment of polio. It was named "Warm Springs" in honor of President Franklin D. Roosevelt and a great portrait of him hangs in the central building.

The second day after my arrival at Janske Lazne I was transported to an interior thermal pool with a tropical temperature. I imagined that I was in the Caribbean. But if I struck against something under the water, it was no coral barrier, but a sunken therapy couch. If something wreathed my legs, it was no sea snake, but only a rubber tube with which the massages were made.

I enjoyed that small "tropical sea" where I felt no gravity, no paralysis, and lived warm dreams. So I was sad when the time approached for me to return home. Then I was in a wheelchair and my family's apartment on the fourth floor would have been a prison for me.

At the last minute an elephant saved me from isolation in Prague. I had drawn a cartoon of an elephant making a subaquatic massage with a stream of water from his trunk instead of from the usual rubber tube. It caught the fancy of the head physician and she exhibited it at a regional exhibition and hired me as her secretary when she found out that I could type as well as draw.

Although typing was not my professional ideal, it was a good living solution for a wheelchair user

because I worked, lived, and ate in the same building. It was especially advantageous in winter when the deep snow blanketed the mountains.

There was another advantage. During the lunch time I was allowed to bathe in the massage pool while the masseurs had their lunch.

One day, a little after noon, one of the masseurs let me finish the subaquatic massage treatment of a young boy so he could go to lunch. While I was working with him the administrator appeared at the pool unexpectedly. I was horrified. He knew I was no qualified masseur. Nevertheless, he beamed with joy and asked me to give a massage to a healthy skier.

The lady appeared immediately and jumped into the pool. She weighed at least 120 kilograms (264 pounds) so she was not completely submerged on the massage couch. Her thighs, abdomen, and convex beauties were like islands on the sea. This brought problems because the subaquatic massage should be below the water level. When I learned that she had never had an underwater massage, I told her that she would be treated with an experimental massage.

I managed to cover up my lack of experience until the perfidious tube tripped my unstable leg and I squirted the lady's curled hair. It hung limply like seaweed on a dry rock. I expected thunder and lightning but she was so dazed by my



adventurous massage that when we finished she even thanked me and wanted to give me a tip.

After that experience I studied the massage rules of the upper body and its anatomy. Shortly afterwards, two masseurs left and the administrator offered me the job of massaging children.

I worked there until the masseurs became professional physiotherapists and then special Kenny therapists after the visit of Sister Kenny. Because I had no professional training I had to leave my beloved massage pool. From my wheelchair, I learned to work at a "dry" table testing and stimulating children's muscles.

Eventually, I qualified for another profession and "graduated" to high crutches. But I shall never forget and never regret my life in that small artificial "tropical sea" where, thanks to that brave and stout lady skier, I had the opportunity to help many polio children with the empathy of a polio survivor.

福

Address: Dr. Āla Wokoun, Chararoviccka 1333, 182 00 Prague 8, Czechoslovakia.

Our late friend, Jurgen Weise

"Jurgen Weise passed away on November 15 during a tour through Israel with his wife, Renate. Both were just visiting a park near Tiberias. He was so happy to see big bushes in full bloom with which we are familiar here only in small flower pots. He suffered a sudden cardiac arrest. A few minutes later they arrived in the hospital — but he had already died.

"On November 17, Renate returned to Munich. At night she called me. Since that telephone call we have been meeting or talking on the phone very often. The funeral was on one of the last November days in Rosenheim, just one day before winter started with snow, so I was able to attend.

"The other day she brought the copy of *Rehabilitation Gazette* (Vol. 28, No. 1) to show me the picture of the Weise family on page 30 and asked me to translate the text. The *Gazette* had arrived the same day when she returned from Israel and she told me that it had meant comfort to her to find the picture."
Gertrud Weiss, Ebersbergerstr. 33, 8200 Rosenheim, West Germany

East German independent living hopes

"I have broken my neck at C5 when I had just finished the eleventh class at school. Those eleven years at school and some dark and lonely years at my parents are my only training. I attempted to paint by mouth. So I discovered this talent. And I got in touch with Viola Henne of Vancouver, Washington, who is a mouthpainter and one of the readers of the *Rehabilitation Gazette* ... In October 1985 I met Tine at the ministry for disabled people and we decided to live together. In November 1986 we moved to Waase on the island of Rugen in the Baltic Sea ... Tine is working as Christian so-



Andreas Franke, Thomas, Stefan, Marlen, and Angela, East Germany

cial worker at the Greifswald County Church. I am also studying Christian social work, but as a guest so I will get no diploma but I want to learn to help other people better. I believe that independent living is the direction to go. It is very encouraging to know that we all look for a way in the same direction. The *Rehabilitation Gazette* is an encouragement because it broadens my mind in search of my way ... We have traveled with a group of disabled and nondisabled to Potsdam and to Hungary ... I would like information about reading by mouthstick and about page turners. And Tine wants to know what is the situation of disabled who belong to minorities, especially of American Indians."
Andreas Franke, Am Focker Strom 1, Waase, 2331, German Democratic Republic.

O.T. student in Iran

"I am a senior student majoring in occupational therapy at the School of Rehabilitation Sciences. I would like information on the newest appliances and techniques in foreign countries and would appreciate having catalogues." *R. Gazor, School of Rehabilitation Sciences, 33 Farnaz St., Sh Zamacni Sq., Mirdamad Bolu, Tehran, Iran 15875-4391.*

Myasthenia gravis and multiple sclerosis

"The *Rehabilitation Gazette* is a vital link to my communication with the outside world ... I am especially interested in reaching other people who also have myasthenia gravis and multiple sclerosis ... I like to read, enjoy music, photography, love dogs. I'm very interested in building accessibility and advocacy issues for the disabled." *Bobette Figler, 7782 West Bruno, Apt 4, St. Louis, MO 63117.*

Taiwanese wants penpals

"When I was 22 years old, during my senior year in the National Chengchi University, I was afflicted with a serious illness. CVA caused by artery-vein malformation left me with my left side paralyzed ... After nine years of combat, I am winning. Now, I can walk and work and have only a mild weakness remaining ... I am working as TA of Management Information Systems at the University. However, I am ready to take another step into an advanced degree. I would like to have some penfriends." *Miss Bih Rong Huu, P.O. Box 1-305, Mucha, Taipei, Taiwan, Republic of China.*



Nick Iwuozor, Nigeria

Nigerian wants help

"I don't want to be a useless person in this world. I want to pursue my schooling in surveying at the polytechnic school but the distant relation who was paying my school fees has died. I beg with prayer that you grant me a scholarship or invite me to come and finish my studies in the U.S.A. ... If it is also possible to employ me in business, I will learn any handwork which will earn me a living. I was born in 1965 and disabled in 1976. I have only one hand and I write with and do everything well with it." Nick Iwuozor, Amauku Orod, Mbitoli L.G.A., Owerri-Imo State, Nigeria, West Africa.

Polio in the Philippines

Polio support groups in the U.S. and Canada may wish to "adopt" one of the following agencies and exchange letters and send books, clothing, or whatever is needed. The *Rehabilitation Gazette* and International Polio Network will publicize the responses you receive to encourage others to become involved in sharing.

"I have been working here as a prosthetist for the Philippine Band of Mercy for nine and a half years. It is hard to believe that we remain the only resource for polio in the Philip-

ines. I find it simply incredible that about one out of 200 kids in the elementary grades appears to have mild to moderately severe post-polio paralysis.

"We make more and more braces every year and at the lowest cost we can manage. Wherever possible I avoid double long leg braces as folks here just don't eat as well as the average American family and lack energy reserves.

"Jennifer now walks with a single forearm crutch. If we don't brace kids like that they move around on their bottoms and hands. There is no terrain here for wheelchairs. In the U.S., you complain about architectural barriers. Well, thank God for some architecture. Here natural barriers look like the U.S. three hundred years ago.

"Children's polio here in Mindanao is as common as when I was a kid in Milwaukee during the 50's. But Rotary International with their inoculators is doing something at last." Ralph F. Kienzle, Jr., P.A.L.M., Jasaan, Misamis Oriental, Philippines 84111.



Jennifer, Philippines

"At our Lady of Victory Training Center we try to give physical and occupational therapy, nutrition, compassion, and dignity to the disabled poor of Davao City.

"Our Center bustles with business enterprises. We raise puppies which will bring in about 800 pesos (\$40). If we can sell just a couple, we can get some patients through surgery.

"Our bakery employs 20 people who work in two shifts. In wheelchairs, they do a marvelous job. Boys from the clinic work as carpenters and welders.

"Our chickens are a very good source of income for the kids who can't read or write. You can have 12 boys working together plucking, preparing, and making the poultry presentable for market.

"Our Sisters became involved in this work by accident. In 1981, I found a young man named Rudy near death. He had fallen out of a coconut tree and was paralyzed, so I put him in a hospital for treatment. That cost 8,000 pesos. But after he was discharged he had no place to go. I knew that if I just sent him back to his shack, he would die. So Sister Maria del Rey and I rented a house for three months.

"At the end of two days we had four other disabled youths living with us. By the end of the month we had 20. Maryknoll wasn't too anxious to get involved in this project at first, so the Jesuits helped us with the rent for a year. After that we were supposed to move on, but I didn't have the heart to tell these kids to get lost because we can't take care of them. Thank God, we Sisters are on the same wave-length — we agree there is always room for one more.

"Close to 700 patients have been helped in the house at the new facility which opened in 1983. Someone has donated a hectare of land near the airport. We want to develop that for long-term disabled and their families. Out there they can do farming or small business, something like a kibbutz. They will enjoy some degree of independence and can lead happier lives." Sister Cecile Wood, M.D., Maryknoll Sisters (SASA), PO Box 62, Davao City, 9501, Philippines.

ED: Reprinted, with permission from Maryknoll, Vol. 82, No. 2, February 1988.

Polio in Taiwan

"For four months this year I was in the United States to attend the Annual Meeting of the President's Committee on Employment of the Handicapped in Denver, the International Polio Network's 4th Polio and Independent Living Conference in St. Louis where I made a presentation, and a training workshop at McCarron-Dial Systems in Dallas.

"Living in Taiwan helps me to appreciate all the advantages I left at home. Every visit to the States also makes me appreciate all the fine things of living and working in Taiwan.

"During the year, Operation De-Handicap (ODH) sponsored two events for families with children who have Duchenne muscular dystrophy. In April over twenty families with their children enjoyed a group outing to a dairy ranch. In October forty parents attended a seminar and their children's muscles were checked by some volunteer physical therapists. Each of these occasions was a valuable chance for the parents to exchange ideas and to encourage each other.

"In September, 43 disabled went on a three-day excursion by plane, board, and bus to the Pescadore Islands off the coast of Taiwan.

"We are still active in helping those who are experiencing new effects of polio. With the help of the Tienmu Rotary Club we published a Handbook for Polio and how to deal with the post-polio effects. It won a first prize for the Rotary Club for social service in Taiwan. Over 7,600 copies have been distributed and it will soon have to be reprinted.

"In January we held a seminar about scoliosis for polio survivors, since that is a problem that many of them have to face. 2,500 questionnaires were sent out to polio people concerning another problem faced by persons who use crutches, namely injury to their hands from the constant gripping of the crutch handles.

Ignatius Huang and Davis Chi and Dr. Chen Chiu-Fen were interviewed on the radio a couple of times. Many telephone calls and letters have been received by ODH about these problems.

"We spent more money this year than last because of increased activities. Nearly half of the money we need is presently being donated right here on Taiwan, but we still require the assistance of our friends abroad.

"May 1988, the Chinese Year of the Dragon, bring you all that you hope and pray for. May peace and job be your inseparable companions."

Fr. Bob Ronald, SJ, Operation De-Handicap, PO Box 7-553, Taipei (10610) Taiwan, Republic of China.

Amjad A. Saddique, Pakistan

Peripatetic paraplegic Pakistani

"I was paralyzed from the waist down after a car accident several years ago. After rehabilitation, I resumed a normal life, working as a telex operator at Arab National Bank and driving a car. To show people what someone with self-confidence and desire can do and to research the lives of disabled persons in other countries I went on a 45-day mission. I visited 48 rehabilitation centres in the United States, Canada, United Kingdom, France, West Germany, Italy, Austria and nine other European countries I would appreciate any information so I can start an information centre to give hope to those who are presently overlooked and who do not know how much they can do." *Amjad A. Saddique, PO Box 41095, Riyadh 11521, Kingdom of Saudi Arabia.*



Danish Ventilator User's Tour of the U.S. West

by Bente Madsen

After the 1987 G.I.N.I. International Poilo and Independent Living Conference in St. Louis last year my two attendants and I rented a car and drove west. We went first to a very little town called Clarksville at the riverside of Mississippi and stayed there for a couple of days to relax. One day we rode a skylift to an old Indian overlooking point about 600 feet above the river only using the ventilating bag. I have never ridden a skylift before so it was a very funny experience.

While we were driving along the Arkansas river we saw some people panning gold and Klaus and Peter got the gold fever at once. They talked about gold all the time and when we came to Boulder in Colorado they bought pans for goldwashing. I have never seen them so concentrated before as when they were looking in their pans for gold. We met a real gold-washer and his family and he gave me a tiny piece of gold so I was the only one who really got gold and without standing in the cold water of the Arkansas river.

We spent a few days in Colorado Springs and one day we rode a cogwheel train to Pike's Peak which is 14,100 feet high. I have never been in such a thin air before but I felt quite well. It was a very beautiful trip with a lot of hairpin bends and snow on the top of the mountain.



On our way from Colorado Springs to Las Vegas we found both true and tourists' ghost towns and one day we decided to ride a preserved railway line from Durango which is a town in the south of Colorado to a tourist ghost town called Silverton on the other side of the pass and along the way the rails were placed on the extreme edge of the cliff. The cliff went vertically down to the river about 10 feet below. I tell you I was nervous but I forced myself to look out of the window and down at the river.

I celebrated my birthday in Grand Canyon crossing the Canyon in a single prop plane. I will never forget this flight, because it was such a fantastic experience to see the canyons from the sky. I do not know why, but I like very much to fly, and in small planes too.

It was hot in Arizona. Really hot! I have never drunk so much coke in my whole life as during the days we were there. We spent almost a week going around in Arizona and visited Monument Valley, the Meteor Crater, and Petrified Forest where we met two Danes who were the only other people in the desert beside us. It was a strange experience to meet two Danes in the desert of Arizona. We saw some old Indian dwellings and crossed Indian reservations and deserts bigger than the eye could reach.

Klaus, Peter, and Bente Madsen

I bought a beautiful Indian carpet to hang on the wall.

In Las Vegas, Peter and I decided to spend \$5 each on the slot machine. Klaus did not want to spend his money on a slot machine at all — he wanted a cold beer instead which he got. Peter won \$30 and I lost my \$5 but it was funny to be a gambler in Las Vegas for an hour.

After almost a week in the desert it was wonderful to see the palms and the Pacific Ocean and to taste the fresh seafood again.

We had not any problems with my respiratory equipment at all. (I use a ventilator by trach fulltime because of muscular dystrophy.) It was a wonderful trip and everybody told us that we had made the impossible. It is easy to be a disabled tourist in the United States because of the kind and helpful people, elevators, parking spaces for disabled, and the very suitable motels everywhere. It was easy to visit all the tourist attractions — much more easy than in Denmark.

福

Address: Bente Madsen, Betty Nansens Alle 61, 7th, 2000 Frederiksberg, Denmark 99.

The Land of the Bible

by David R. Morton

Flavian Dougherty, CP, National Director of Stauros, an ecumenical, non-profit organization, conceived the idea of a Bible study tour to enable persons, with various disabilities, to receive three hours of continuing education. He persuaded the Catholic Theological Union to offer this Bible study tour as a part of its curriculum.

Two years of planning preceded the tour which was scheduled from August 31 thru September 13, 1987. Father Dougherty had the assistance of Donald Senior, CP, professor of New Testament, Jennifer Corbett, OSF, a registered nurse, and Carl Hand, CP, a maintenance expert.

Judy Benson, who is paraplegic and works in the Stauros office as a resource person, made the travel arrangements with Pan Am Airline. She had to resolve many logistical problems of flying 17 individuals with various disabilities, ranging from mobility impairment and blindness to deafness, and their attendants. For example, Benson was confronted with Pan Am's policy of permitting only four wheelchairs per flight. After negotiations, Pan Am agreed to load our seven wheelchairs and three Amigos. The airline furnished a separate luggage container for storing our equipment. The container was easily transferred from O'Hare in Chicago to JFK in New York to Charles De Gaulle in Paris to Lod in Tel Aviv. Despite the excellent arrangements, the inaccessibility of the plane's lavatories presented a problem for persons with mobility impairments. Thus, the use of urinals became as common as breast feeding.

Sister Jennifer had chosen our accommodations a year in advance of our arrival with the assistance of Hallelujah Tours, an Israeli-based company. Neve Ilan Hilltop Resort

was our main base of operations. Despite the pleasant surroundings and the warm hospitality of the staff, accessibility was a problem because most bedrooms had narrow bathroom doorways.

"Trust me, it's relatively easy" became the rallying cry of Don Senior as our tour progressed. His words bounced in our heads as we singlefiled along the cobbled streets of old Jerusalem, on the rocky beaches of the Sea of Galilee, and as our bus threaded its way through a large orange grove where we had become lost. Another time we held up traffic in Cana just as the Moslems headed to their evening prayers.

Before Don came forth with his famous quote, Sister Jennifer would scout our next site for the best accessible path to arrive at the destination. She located the most accessible restrooms and the best spots for our picnics along our route. Her choices for picnicking places ranged from the shore of the Dead Sea to the top of Mount Tabor. Also, Sister Jennifer preceded us to obtain tickets for the areas requiring an entrance fee.

Carl Hand's mechanical and electrical skills were constantly demanded. He rode with the bus during the day and he made repairs on the Amigos and tightened screws on wheelchairs and crutches late into the night. Our group would have "come apart" very quickly, if Carl had not accompanied us.

We now know that "setting the wheel" upon the land should not be attempted with Amigos and electric wheelchairs as the rough terrain takes its toll upon them and that three teams should be alternated daily for loading and unloading the bus.

Despite these problems, access to the Land of the Bible was a successful and enjoyable tour. The cooperation of all the participants was its crowning achievement. Israel can be accessible!



Address: David R. Morton, 4545 Forest Park, Apt. 309, St. Louis, MO 63108.

October 1988 Israel Tours

Lois Bonanni, director, Accessible Tours, learned accessibility from her son, who is paraplegic. She has directed tours to Israel for wheelchair users as well as for visually impaired and blind persons. She uses a deluxe bus with a ramp and tie-downs for 8 wheelchairs and a regular driver. The 15-day tour in October '88 starts with three days at a hotel in Tel Aviv. Five days are spent at a hotel in the Sea of Galilee region with visits to Nazareth, Mount of Beatitudes, Capernaum, Tabgha, Saffed, Mt. Meron, Golan Heights, and a kibbutz. Six days in Jerusalem include visits to the Mount of Olives, Garden of Gethsemane, Church of the Holy Sepulchre, Hadassah's Chagall windows, Bethlehem, Dead Sea, Wailing Wall, Mount Zion, the Citadel, etc. Write to Lois Bonanni, Accessible Tours, 344 Main St., Mt. Kisco, NY 10549.

The experienced Flying Wheels travel agency plans a similar accessible tour from October 19 to November 1, 1988. In addition to the usual sights listed above, the tour includes visits to Haifa, Caesarea, and Jaffa. Write to Flying Wheels Travel, Inc., PO Box 382, Owatonna, MN 55060 or call toll free 1-800-533-0363.

English Tours of Israel

Tours planned by an English travel agency are booked in 5-star hotels, including Hiltons in Tel Aviv and Jerusalem, which have rooms large enough for a wheelchair and bathrooms with toilet rails, and the Ein Gedi kibbutz which has chalets specially adapted for wheelchairs and a spa for treatment of arthritis and psoriasis. Information from Travel Supreme Ltd., Tara, Vicarage Gardens, White Waltham, Maidenhead, Berks. SL6 3J3, England.

Wheelchair Gardening

by Joan Hughes

Before I used a wheelchair, I had been a keen gardener. With the help of my husband, I have been able to maintain that interest.

My husband reorganized the garden completely. He obtained a variety of large containers and brought as much of the garden as possible up to wheelchair level. We toured junk shops, salesrooms, and jumble sales for suitable containers and picked up an old, solid chest of deep drawers. Removing the drawers, he raised each one on a platform to my level; in those drawers I have successfully grown peas, runner beans, lettuce, cauliflowers, courgettes, and outdoor tomatoes. I have a raised deep drawer under my kitchen window that I have made into an herb patch with mint, chives, thyme, sweet basil, and sage.

We found a large old-fashioned stone sink, which again was raised on concrete bricks. At each end, I made a pretty miniature garden. In other containers there are roses, various flowers, and shrubs.

In a sheltered corner of the garden, I have a sturdy old kitchen table. On it I do all my potting, planting, and fashioning of hanging baskets. Incidentally, I find that an old tablespoon and one of the big old-fashioned forks are far easier for planting than are the conventional garden tools.

I have just acquired a large, deep aluminum cold frame with a sliding top in which to raise my cuttings.

This has been brought up to my level by putting legs onto a large old door and covering this with roofing felt. Under the table is an old bread crock containing my potting compost.

This type of gardening need not be expensive. What you save on growing vegetables will cover the modest outlay. You can pick up suitable containers from many sources. Watch for items discarded from a bonfire; you can often negotiate a cheap purchase. Whatever container you buy, make sure that holes can be drilled for drainage in the base. I make my own pots from the sturdier type of plastic container by cutting the top off the bottle type and piercing the base for drainage holes with a hot skewer. (Warning: never attempt to convert any spray or pressurized container.)

The garden means more to me now than when I was fully active because I have accepted the challenge. I have the pleasure of knowing I can plan, design, and, if lucky, harvest the fruits of my labor. *Joan Hughes, 27 Manchester Old Road, Bury, BL9 0TR, Lancashire, England.*

Adaptive Garden Equipment.

Booklet of adaptations for ordinary gardening tools and ideas for making gardening accessible. 20 pgs. \$2.50 from Craig Hospital, Materials Management Dept., 3425 S.Clarkson St., Englewood, CO 80110.

Wheelchair Hydroponic Gardening

by A.G. Garriss

Hydroponics is a system of growing plants in nutrient solutions with or without an inert medium to provide mechanical support. There are many systems, but I have used only two — the wick and the pump systems.

The wick system uses natural phenomena to draw up the nutrient to the plant roots. The growing area is placed over a reservoir of nutrient in which the wicks reach down from above and draw up the nutrients. The wick system seems to produce larger root systems than the pump method.

The pump method uses a small pump to bring up the nutrient, which drains slowly back into the reservoir. The reservoir should be closed to light to prevent the buildup of algae. Because the pump pressures are low, the plastic pipes need to be only pressure fit and not glued. This makes it easy to remove the pipes in the unlikely event of a blockage. The drains should have an adjustable "standpipe" (one pipe with another inside to slip freely up and down so the rate of drain can be controlled and running over can be prevented). In addition, small holes are used at the bottom of the standpipe for slow drainage.

A timer with 30-minute intervals is used to turn the pump on and off twice a day. After planting there is little to do but visually inspect

Rehabilitation Engineering

As a rehabilitation engineer, I act as a mediator between science and the individual who has encountered an obstacle at work or at home.

The more I know about the person and what he/she wants to do the easier it is for me to recommend an existing product or to design a special solution.

The evaluation process is unique for each individual and begins with a personal interview. The purpose is to gain an understanding of the nature of the problem, assess the social and physical environment, and explore the individual's motivation and experience with adaptive devices. If applicable, the interview occurs at the site of the obstacle. Extensive notes, videotape, and photographs may be used to document the obstacle and, if appropriate, a job analysis may be performed. Research may include computer data base searches, telephone networking, and a review of literature.

I generally consider the following points: What is the simplest solution? Is a device commercially available? Is there available an adaptive device? Is the only choice to design and fabricate a one-of-a-kind accommodation?

Not only is this simple-to-complex approach cost effective, but experience indicates that it is the most successful. Individuals are more likely to use devices which are simple and familiar.

I also consider how easily the device can be repaired since time lost due to repairs may be a serious hardship.

In some instances, I must research, design, and fabricate a unique solution, drawing from fields seemingly unrelated to rehabilitation, such as using the mechanical advantages of levers to enhance the strength and range of motion of a physically disabled counselor so she could operate a tape recorder for the purpose of writing reports.



A.G. Garriss and 19" burpless cucumber

whether the system is working. Instead of soil, the supporting media can be many inert substances. I use peasized gravel and sponge rock. I add peat moss at the top to help starting seeds. Sometimes I add a growing mixture, which the experts say is a "no no." It may attract unwanted soil insects.

I have successfully grown the following plants: cucumbers (burpless type), string beans, corn, radishes, swiss chard, beets, lettuce, onions, tomatoes, snow peas, peppers, etc. I have avoided plants that require sandy soil, such as peanuts, potatoes, long white radishes, and asparagus. The pea gravel would make it difficult for those crops. In our mild California winters I grow beets, chard, and radishes.

Change the nutrient once a month by pumping out the old solution on the lawn. Renew the water that evaporates every day or two.

If the outlets in the growing area are screened, the pump will not get clogged as often. Back flushing with a hose should remove any obstruction.

My two units are about four feet square and the growing area about 10 inches deep. The growing bins should be raised for wheelchair users and accessible from all sides, if possible. The reservoir for the nutrient is underneath, but it can be anywhere. Do not worry about getting the exact mixture in your nutrient. Nature has soils of varying amounts and plants still grow.

Your plants will grow about one-fourth faster than plants in the ground. The system can be used indoors with light from a southern exposure and a growing light. In a mild climate you can grow most things outdoors, but plants grow slower in the winter.

The nutrient will rust most metal containers. Fiberglass is used over wood with plastic pipes. The pump is one often used in yard fountains and has a rotating impeller that is sufficient if the nutrient does not have to be lifted far. A valve on the nutrient tank would be useful for saving the solution in the event that the pump has to be removed.
A.G. Garriss, 16238 Georgia Ave.,
Paramount, CA 90723.

Calculated against other report writing methods previously used, this device paid for itself within the first report writing period (one month) by reducing her report writing time by two thirds. Within one week of using the device she was generating reports at a faster rate than her nondisabled co-workers and, for the first time, with complete independence.

Well designed equipment or modifications are easier for everyone to use and a change that eases the work of a person with a disability eases the work for everyone else.

Individuals with disabilities, employers, and rehabilitation personnel should utilize the skills of rehabilitation engineers to enhance independence and productivity. *Keith Sofka, 2314 Louisiana St., St. Louis, Missouri, 63104.*

Leg-operated Wheelchair

The picture shows some of the detail of the guidance system that Professor Ross Young of the University of Missouri (now retired) designed for me. Basically, he took the normal Everest & Jennings control box with the "joy" stick and repositioned it under the seat of the wheelchair. Utilizing a mechanical device, he then connected the control stick to a clamp which fits around the calf of my left leg and a wire rod which attaches to a tongue extending from the back of a platform under the left foot. This platform is mounted on a hinge which allows me to move my foot up and down by pressing down or letting up with the muscles in my left foot. By moving the foot up or down and moving the leg left or right, I am able to control all forward or backward functions of the chair. Pressing against the platform under the right foot allows me to turn the power on and off.

This particular setup allows me to utilize the strongest muscles



Richard L. Wieler's leg-operated wheelchair

available, those in my left leg and foot, to operate the chair. At the same time, since the device is mechanical in nature, I have experienced very few breakdowns. I have utilized this chair and this guidance system for over four years now with very little damage to walls, colleagues, or myself. *Richard L. Wieler, 2401 West Broadway #904, Columbia, MO 65203.*

General Periodicals for People with Disabilities

Accent on Living. P.O. Box 700, Bloomington, IL 61702.

Achievement. 925 N.E. 122nd St., North, Miami, FL 33161.

American Rehabilitation. Rehabilitation Services Administration, 330 C St., S.W., Washington, DC 20201.

Breaking New Ground. Dept. of Agricultural Engineering, Purdue U., West Lafayette, IN 47907.

The Bumblebee. 412 Woodward Blvd., Pasadena, CA 91107.

CDR Reports. Council for Disability Rights, 343 S. Dearborn, Chicago, IL 60604.

COPH Bulletin. 1814 Welwyn, Des Plaines, IL 60018.

The Disabled Challenge. 1615 So. 4th St., #M-3210, Minneapolis, MN 55454.

Disabilities Studies Quarterly. Dept. of Sociology, Brandeis University, Waltham, MA 02254.

The Disability Rag. Box 145, Louisville, KY 40201.

Itinerary. P.O. Box 1084, Bayonne, NJ 07002.

Journal of Rehabilitation. National Rehabilitation Association, 633 S. Washington St., Alexandria, VA 22314.

Kaleidoscope. 326 Locust St., Akron, OH 44302.

Mainstream. 2973 Beech St., San Diego, CA 92102.

NAPH National Newsletter. 221 W. Douglas Rd., #19, Fort Collins, CO 80524.

New World for the Physically Disabled. P.O. Box 1965, Reseda, CA 91335.

Paraplegia News. 5201 N. 19th Ave., Suite 108, Phoenix, AZ 85015.

Rehabilitation Gazette. Gazette International Networking Institute, 4502 Maryland Ave., St. Louis, MO 63108.

Sports 'N Spokes. 5201 N. 19th Ave., Suite 108, Phoenix, AZ 85015.

Word from Washington. UCP Association, Inc. 66 E. 34d St., New York, NY 10016.

Artists

1988 Harmarville International. Art exhibit for artists with physical disabilities. October 28 to November 18. Entries in the following categories: painting, drawing, ceramics, sculpture, graphics, collage, fiber, photography, and poetry. Entries should be submitted in slide form and are due by May 18, 1988. Details and entry forms from: Harmarville Rehabilitation Center, Box 11460, Guys Run Road, Pittsburgh, PA 15238.

Attendant Care

Attending in America. Report of survey of attendant services in US. For copies, write: World Institute on Disability, 1720 Oregon St., Suite 4, Berkeley, CA 94703.

Barrier-Free Design

The Barrier-Free Design Centre in Toronto provides consultation, education, information, and library services for a fee or free to professionals and individuals: 150 Eglinton Ave. East, Suite 400, Toronto M4P 1E8, Canada.

Charcot-Marie-Tooth Disease

C-M-T volunteers have organized a national organization for research and self-help support groups. For information, write to National Foundation for Peroneal Muscular Atrophy, University City Science Center, 3624 Market St., Philadelphia, PA 19104.

Children

Disabled Village Children by David Warner. Clear, simple information on most common disabilities. Suggestions for low-cost aids. 4,000 drawings. 200 photos. \$9. The Hesperian Foundation, PO Box 1692, Palo Alto, CA 94302.

National Information Center for Handicapped Children and Youth (NICHCY). Free information service. Publishes newsletters. To be put on mailing list: NICHCY, P.O. Box 1492, Washington, DC 20013.

The accessible home: renovating for your disabled child. By Heather Snell, 1983. Is Five Press, 467 Richmond Street East, Toronto, Ontario M5A 1R1, Canada.

Clothing

The September 1987 issue of *Paraplegia News* published a comprehensive survey of manufacturers of clothing for people with disabilities: "The Clothes Line" by Susan Robbins. \$2 from PN, 5201 N. 19th Ave., Suite 111, Phoenix, AZ 85015.

Computers

In the Chips. How to use your computer to make money. By Anne Cardoza and Suzee J. Vik. 304 pages. Paperback. \$10.95. Simon & Schuster, Inc. Rockefeller Center, 1230 Avenue of the Americas, New York, NY 10020.

Technical Aids and Assistance for the Disabled (TADD). One of 10 centers in the National Special Education Alliance, a project of Apple Computer, Inc. Directed by Margaret Pfrommer, it evolved from COPH-2. Provides both information and training. Located in Illinois Children's School and Rehabilitation Center, 1950 West Roosevelt Road, Chicago, IL 60608. Phone: 312/421-3373.

Center for Computer Assistance to the Disabled. Provides customized computers and adapted software. C-CAD, 2501 Avenue J, #100, Arlington, TX 76006.

IBM/Easter Seals have created a joint program to enable persons with disabilities to purchase adapted computers. The project, located in 10 cities, includes training and telephone support. Ed Porter, The National Easter Seal Society, 2023 W. Ogden Ave., Chicago, IL 60612.

Rehabilitation Gazette plans to feature specialized computer technology, emphasizing personal experiences. Computer users with disabilities are invited to share experiences and knowledge. G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

Employment

Using Private Rehabilitation Vendors: Selection Criteria and Performance Standards to Ensure Quality by G.E. Schwartz and M.E. Carbine. A concise, well presented 48-page workbook of value to private rehabilitation agencies and independent living centers as well as employers interested in return-to-work strategies and training. Missyay R. White, 102 Irving St., NW, Washington, DC 20010.

Equipment

Cane Winterizer. An attachment with a five-point steel ice spike fits any wood or metal cane. Flips out of the way when not needed. #1554. \$9 plus \$2 shipping from Thos. Oak & Sons, 901 Main St., Salem, VA 24156.

Equipment Loans

New York State Department of Social Services provides low interest loans for purchase of adaptive equipment and aids. Loans from \$500 to \$2,000. Write Equipment Loan Fund for the Disabled, New York State Department of Social Services, P.O. Box 1935, Albany, NY 12201.

50 Plus

AARP. As soon as you are 50, we suggest that you become a member of the American Association of Retired Persons (AARP). For \$5 you will receive the publication *Modern Maturity* and be eligible for many free booklets and services. The address is AARP, 3200 E. Carson St., Lakewood, CA 90712.

National Eye Care Project makes referrals to volunteer ophthalmologists who provide examinations and treatment (not eye glasses), without charge, to people over 65 who have no insurance coverage, or will accept Medicare of other health insurance as payment in full. Call: 1-800-22-EYES.

Ourselves Growing Older. By P.B. Dorress and D.L. Siegel. Considers the special physical and emotional health concerns of midlife and older women. \$15.95. Simon & Schuster, Inc. Rockefeller Center, 1230 Avenue of the Americas, New York, NY 10020.

Friedreich's Ataxia

Espoir. 36-page quarterly journal of Association Francaise de l'Ataxie Friedreich, 19, rue Vincourt, Jouy-le-Moutier, 95000, Cergy, France.

Income Tax Deductions

Certain capital expenditures that do not increase the value of a personal residence generally do not increase the value and thus generally are deductible in full as medical expenses: ramps, handrails, widening of doors, lowering of cabinets, adjustment of electrical fixtures, porch lifts, grading of ground, etc. (See K-2120 and Rev Rul 87-106, 1987-43 IRB 13). Only "reasonable" costs can qualify.

International

The next world Congress of Disabled Peoples' International will be in Bogota, Columbia, in November, 1989. DPI, General Secretariat, Box 360 33, S-100 71 Stockholm, Sweden.

DPI/USA has been reorganized and renamed Disability International, U.S.A. A general membership meeting will be convened during 1988. Information from: Gordon H. Mansfield, President Designee, Paralyzed Veterans of America, 801 Eighteenth St., NW, Washington, DC, 20006.

International study fellowships. Brochure from Diane Woods, World Rehabilitation Fund, 400 E. 34th St., New York, NY 10016 or Judy Heumann, World Institute on Disability, 1720 Oregon St., Berkeley, CA 94703.

Multiple Sclerosis

Symptom Management in Multiple Sclerosis. By R.T. Schapiro, MD. Understandable and practical. 128 pages. Softcover. \$10.05. Order from Demos Publications, 156 Fifth Ave., Suite 1018, New York, NY 10010.

Muscular Dystrophy

Ventilators and Muscular Dystrophy. By Nancy Schock and Agatha P. Colbert, M.D. Discusses the management of longterm use of mechanical ventilation for persons with Duchenne muscular dystrophy. \$6 (plus \$1 postage) G.I.N.I., 4502 Maryland Ave., St. Louis, MO 63108.

Polio "Bible."

If you are a polio survivor, you can keep yourself informed about the latest on the late effects by joining the International Polio Network (IPN) and getting a copy of the "bible" on the subject, the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. (For details, send a self-addressed, #10 stamped envelope to IPN, 4502 Maryland Ave., St. Louis, MO 63108.)

Polio Conference 1989

Mark your 1989 calendars for International Polio Network's Fifth Polio and Independent Living Conference. It will be in St. Louis again, at the Sheraton St. Louis Hotel from May 31 to June 4. At the same time, Abilities Expo-Midwest will be at the adjacent

convention center. Write to Joan Headley, IPN, 4502 Maryland Ave., St. Louis, MO 63108.

Publications, Free

Rehab Briefs. Excellent 4-page summaries of selected topics in rehabilitation, sociological, and medical fields. Important resource for both health professionals and persons with disabilities. Request from: PSI International, Inc., 510 North Washington St., Falls Church, VA 22046.

Ableware. 96-page catalog of devices for living independently. Request from: Maddak, Inc., Pequanock, NJ 07440.

Publications, New

The Disabled Challenger. Quarterly newsletter dedicated to helping people with disabilities lead fuller, more positive lives. Ideas and resources submitted by readers with disabilities to assist others in independent living. \$6 for people with disabilities; \$10 others. Cassette edition at same prices. Lake Kissick, Jr., editor. Kissick's Consultants, Inc., 1615 So. 4th St., #M-3210, Minneapolis, MN 55454.

Rights

Disability Rights Guide by Charles D. Goldman, JD, LLD. Legislation and problems related to accessibility, education, employment, and transportation. Clearly written. Practical. 172 pages. 6" x 9", paper, 1987. \$14.95. Media Publishing, 2440 O St., Ste. 202, Lincoln, NE 68510.

Self-Help Directory

Directory of National Self-Help/Mutual Aid Resources. Information on 900 organizations, clearinghouses, and toll-free hotlines. \$20. Barbara Giloth, American Hospital Association, 840 N. Lake Shore Dr., Chicago, IL 60611.

SSI Changes

The July 1987 amendments to Section 1619 of the Social Security Act provide incentives which encourage blind and disabled recipients, under age 65, to work, without losing Medicaid benefits. Check with your local office.

Sports

Products to Assist the Disabled Sportsman. By Judy Pachner. 36-page catalog of fishing adaptations for all types of fishing and disabilities. A few other adaptations for camping, hunting, and boating. J. L. Pachner, Ltd., PO Box 93, Lake Zurich, IL 60047.

Disabled Outdoors. Quarterly publication for fisherman, hunters, and campers. \$8 year. Disabled Outdoors, 5223 South Lorel Ave., Chicago, IL 60638

Vermont Handicapped Ski Foundation, PO Box 261, Brownsville, VT 05037. Specialized ski instruction located at Ascutey mountain resort.

Sports/Recreation

Access to Recreation. Free catalog of imaginative and practical equipment compiled by Don Krebs, who is quadriplegic because of a water skiing accident. Write to Access to Recreation, Inc., 2509 E. Thousand Oaks Blvd., Suite 430, Thousand Oaks, CA 91361.

Stroke

The Road Ahead: A Stroke Recovery Guide. A comprehensive guidebook. \$14.50 postage paid. National Stroke Association, 1420 Ogden St., Denver, CO 80218.

Travel

Cruise Guide for the Wheelchair Traveler lists accessibility or non-accessibility of 50 cruise ships. Free from Cruise Line International, 17 Battery Place, Suite 631, New York, NY 10004.

Rental cars adapted to all types of disabilities. Monsieur Dupuis, 15 rue du 11 November 45130 Charsonville, France. Phone: 38.74.28.40. Telex: 782 441.

Consumer hotline for complaints of airlines travelers: 1-800-FAA-SURE. Operates 8 am to 4 pm, Eastern time, weekdays. More information: Fred Pelzman, Manager, Community and Consumer Liaison Division, APA-200, Federal Aviation Administration, Washington, DC 20591.

Canadian Rehabilitation Council for the Disabled: Travel Guide. Free guide to nationwide services available to persons with disabilities. Information Services, C.R.C.D., 1 Yonge St., Suite 2110, Toronto, Ontario M5E 1E5, Canada.

Airline Lavatory Access. The following airlines have added a narrow wheelchair for use in reaching the lavatory: Air France, British Airways, Scandinavian Airlines, United, and Quantas. Check at the time of making reservations.

HANDI-TRAVEL: A Resource Guide for Disabled and Elderly Travellers. \$12.95 plus \$1.50 postage. (Canadian or U.S. funds only.) Order from: Canadian Rehabilitation Council for the Disabled, Suite 2110, One Yonge St., Toronto, M5E 1E5, Canada.

A World of Options. Guide to International Educational Exchange. Community Service and Travel for Persons with Disabilities. 1985-1986. By Susan Sygall, a knowledgeable and enthusiastic traveler. 192 pgs. Softbound. \$11. (Add \$2 outside USA.) Order from: Mobility International USA, PO Box 3551, Eugene, OR 97403.

Travel, Wilderness Trips

From May to December *Wilderness Inquiry II* leads trips out of Minneapolis. They include canoe trips to the Upper St. Croix, and Northwestern Canada, kayak trips to British Columbia and Lake Superior, and bike trips (tandems and armchairs furnished) in Minnesota and Wisconsin. Trips include nondisabled

people as well as those with disabilities. Brochure from Wilderness Inquiry II, 1313 Fifth St., SE, Suite 327, Minneapolis, MN 55414.

Vogageur Outward Bound School runs similar trips with courses in canoeing, and compass and map navigation, etc. 8-day trips about \$700. Write to the school at 10900 Cedar Lake Rd., Minnetonka, MN 55343.

Blue Spruce Lodge and Guest Ranch offers a wide variety of activities including sledding, river raft and canoe trips, sailplane and fishing trips, and art seminars. The lodge was built for wheelchair users (three staff members are spinal cord injured). Daily rates (\$75 single, \$125 double). 7- and 10-day packages include meals, lodging, and outings. Write to Russ Milleson, Blue Spruce Lodge, Route 3, Box 114, Trout Creek, MT 59874. (Guests can be picked up at the Spokane, Washington airport, the Missoula airport, or at the train station in Sandpoint, Idaho.)

Ventilator Users

Frogbreathing videotape: \$50. Order from Mrs. Doreen Kelsey, Respirator Therapy Supervisor, Aberhart Center, U Of Alberta Hospitals, 8440-112 St., Edmonton, Alberta, T6G 2B7 Canada.

Writing

A Readers/Writers' Guide to Periodicals in the Disability Field. New edition. U.S. and international periodicals. Detailed information for writers. Bibliography. \$10. Prof. J.L. Baird, Chairman, CPWDS, English Dept., Kent State University, Kent, OH 44242.

Manuscripts sought for anthology of short prose with theme of disability. Fiction, autobiography — all types except the excessively sentimental or superficially religious. Send manuscripts to Prof. J.L. Baird, Address above.)



Ruth Davis, the Gazette's correspondent with the United Kingdom for almost 30 years



Adolf Ratzka, PhD, and Doro Riedel of Sweden were married in Stockholm on 6 February 1988.



Dick Goodwin, executive director of IMPACT, the Alton, Illinois independent living center, and a G.I.N.I. Board member



Two G.I.N.I. Board members, Joe Leone, Secretary and a Gazette editor, and Penny Chrisler



Nancy and Jack Quigley, G.I.N.I.'s new president of the Board

Photos 1987

WARNING

TO ALL WHO WERE WEANED FROM AN IRON LUNG BACK IN THE 1950's:

If you have trouble sleeping and morning headaches and feel tired and unjoyous, show this article to your physician.

Underventilating is insidious. You may be "alarmingly ignorant."

Underventilation: A Warning

by Richard L. Wieler

Central Alveolar Hypoventilation Syndrome — my doctor's description of a condition which was slowly destroying me and of which I was alarmingly ignorant.

I am a polio survivor (1955) who relied on mechanical ventilation for approximately a year after the disease struck, six weeks in an iron lung and the remainder of the time in a chest cuirass or shell and a rocking bed. After this, it was decided that I could breathe adequately without mechanical ventilation and, at the age of sixteen, I began to cope with the severe paralysis which remained, a process which has taken a lifetime.

After six months at the Georgia Warm Springs Foundation, I returned home to Nebraska to complete high school. After that, college and law school at the University of Missouri, Columbia. Since 1968, I have been employed by the State of Missouri, currently with the Attorney General's office.

It is hard to remember when the first symptoms of breathing difficulties began to appear, but it was well before any public discussion of "post-polio syndrome." I began to experience difficulty in sleeping at night, I started having vivid dreams and sometimes nightmares, and I seemed to wake up often. This, of course, led to fatigue during the day.

Six years ago, my local doctor became concerned about continued high blood pressure readings and I started taking blood pressure medication. Approximately four years

ago, I woke up in the middle of the night with a tremendous ache in my chest and stabbing pains down the left arm. Fearing a heart attack, I was rushed into the emergency room of the local hospital. Tests disclosed no damage to the heart but my breathing difficulties at night were noticed. Upon my physician's advice, I started using the chest cuirass or shell for breathing assistance at night.

Although the chest shell provided some relief for the next several years, the problem started accumulating again. My sleep patterns became very erratic (I would sleep heavily for an hour or two and then spend the rest of the night awake or in a shallow dream stage), I had morning headaches, tiredness during the day (at times I could not keep my eyes open), and at times I was not mentally alert. Sinus conditions from allergies aggravated the condition and made life miserable. At times I would be so tired at the end of the day that I could barely speak audibly.

Finally, in the fall of 1987, a doctor suggested a sleep test. Results indicated that the symptoms were caused by a carbon dioxide buildup because of inadequate ventilation at night. The doctor recommended a return to the iron lung at night. He suggested that daytime use might be necessary also in the future.

This was a real shock for me. My health had reached a point where continued employment seemed in jeopardy. Now the doctor was telling me that the cure might also make it impossible to continue employment. I decided to seek a second opinion from someone more knowledgeable on post-polio problems. After soliciting information from various sources available to me, I decided to contact Dr. Oscar Schwartz in St. Louis. Dr. Schwartz called me to discuss my condition and followed up with

a letter. As a result, I checked into a hospital in St. Louis in early December, 1987.

I have heard weight lifters say "no pain, no gain." That describes my five day stay in the hospital under the supervision of Dr. Schwartz. They took so many blood samples that I think I am qualified for a Red Cross pin. I was introduced to positive pressure ventilation using a nasal mask which promptly blistered my nose. However, the gain was tremendous. The first night I used the nasal mask and positive pressure, I slept better than I had in years. By the end of five days the nasal mask no longer felt alien and I was sleeping soundly through the entire night.

I now wake up in the morning refreshed with plenty of stamina for the entire day. The morning headaches have receded and the periods of mental fatigue have disappeared.

The change has been obvious to all those around me. For the first time in a long time, I am enjoying myself both at home and at work. Even the blood pressure problems have disappeared. After evaluating the situation, Dr. Schwartz discontinued all of the blood pressure medicine.

Any polio survivor who required ventilatory support in the past, or whose current ventilation system is not allowing sound sleep, should seek the advice of a knowledgeable medical specialist. If you are not sure who that might be, contact the Gazette International Networking Institute (G.I.N.I.), 4502 Maryland Avenue, St. Louis, Missouri 63108. I will bet my last dollar that Gini Laurie can provide you with the necessary information.

Address: Richard L. Wieler, 2401 West Broadway, #904, Columbia, MO 65203.

Gazette International Networking Institute (G.I.N.I.)

Reaching, informing, and dignifying people with disabilities throughout the world.



Origin

Rehabilitation Gazette, an international journal for independent living by individuals with disabilities, was started by Gini Laurie in 1958 for polio survivors in iron lungs to share their information and experiences.

The *Gazette* grew from a local newsletter to a renowned international journal and evolved to include other physical disabilities and the aging of all persons with disabilities.

In 1983, the *Gazette* celebrated its 25th year as a journal and information service, and was reorganized to expand its services. The new organization was named Gazette International Networking Institute (G.I.N.I.).

G.I.N.I. is incorporated as a non-profit [501(c)(3)] organization. Donations are tax-deductible.

Publications

Published since 1985, *Rehabilitation Gazette* embodies and reflects the imaginative, practical, down-to-earth life experiences of its readers with disabilities.

It is a form of peer counseling and therapy by mail, an invaluable source of ideas, inventions, and adaptations that have been tried and found useful by others. Personal experiences in the *Gazette*'s articles motivate other readers to live full and independent lives.

The *Gazette* is an invaluable tool for creative rehabilitation, providing health care professionals with additional insight into the interests and needs of individuals with disabilities. Readers include doctors, nurses, therapists, social workers, rehabilitation counselors, government officials, educators, and the relatives and friends of persons with disabilities.

The *Gazette* reaches 30,000-50,000 readers in 87 countries with translations in five languages. It is read by people who are disabled by ALS, amputation, arthritis, cerebral palsy, head injury, multiple sclerosis, muscular dystrophy, polio, spinal cord injury, and stroke.

In 1986, G.I.N.I. began offering membership in the G.I.N.I. organization. Membership benefits include a subscription to *Rehabilitation Gazette*, G.I.N.I.'s information service and library, and discounts on G.I.N.I. conferences and membership events.

Other G.I.N.I. publications include the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors* and the proceedings of G.I.N.I.'s polio and independent living conferences. Order forms are available from G.I.N.I. and on the center pages.

Polio Network

G.I.N.I. has maintained a worldwide polio network since 1958. Consequently, when an increasing number of polio survivors began to report new symptoms of pain, fatigue, weakness, and breathing difficulties, G.I.N.I. took the lead in organizing the first coordinated look at the problems with its 1981 polio conference.

G.I.N.I.'s subsequent biennial polio conferences continue to educate physicians, promote research, and provide information and psychological support to polio survivors.

In 1985, G.I.N.I. formally established the International Polio Network (IPN) to link polio survivors and to encourage the formation of post-polio support groups.

G.I.N.I. publishes the *Polio Network News*, a quarterly bulletin for IPN members and coordinates and maintains the national and international directory of post-polio support groups, clinics, and physicians.

IPN membership forms are available from G.I.N.I.

Ventilator Users Network

Polio survivors who started using home mechanical ventilation in the 1950s formed the nucleus of G.I.N.I.'s International Ventilator Users Network (I.V.U.N.).

I.V.U.N. links ventilator users with each other and with medical personnel interested in home mechanical ventilation. These ventilator users include

infants, children, and adults disabled by neuromuscular diseases or injuries affecting the respirator system.

I.V.U.N.'s members receive a biannual newsletter featuring ventilator equipment and adaptations, glossopharyngeal breathing techniques, psychosocial aspects of long-term ventilator use, sleep disorders, organizations concerned with ventilator users, travel, etc.

I.V.U.N. Membership forms are available from G.I.N.I.

Information Service and Networking

G.I.N.I. is a primary source of specialized information and do-it-yourself equipment, independent living, polio, spinal cord injury, and ventilators.

The library, with materials amassed over 35 years, is a special collection of books, periodicals, monographs and reports, pamphlets, clippings, and case histories.

Using the library's unique resources, G.I.N.I. answers questions on disability-related subjects, such as architectural and attitudinal barriers, civil rights, housing adaptations, wheelchairs, vans and lifts, etc. Questions about coping with disability are answered by referrals among G.I.N.I.'s international people network.

Independent Living

Gini Laurie is well known as the historian of the independent living movement. She has watched and encouraged the growth of the independent living centers since the last 1970s.

The lives of disabled individuals as role models are chronicled in the pages of the *Gazette* and parallel the involvement of the independent living movement.

G.I.N.I. provides information on all aspects of independent living including attendants, education, employment, equipment, family life, sex, sports, and travel.