

POST-POLIO HEALTH

SAINT LOUIS, MISSOURI

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Ralph: The Home Assistant

Debbie Hardy, Whittier, California

Do you ever wish you had a personal butler, valet or concierge at your beck and call? The reality is you may be able to purchase one in the form of an automated technology system for your home. The system, known as Ralph, is a voice-commanded control, monitoring and supervisory system. It uses voice recognition to take commands from the home's occupants and talks back to them with speech synthesis. For those who prefer not to use the voice command system, a pushbutton control is available. Ralph helps people live independently in their own homes by doing small things they cannot do for themselves.



He decided to automate things in the house that needed to be done on a daily basis, and created a "digital companion" that could talk as well as respond to verbal commands.



Don Holbert with nearly invisible "friend," Ralph.

PHOTOS COURTESY OF RANDY KIRBY

The system was originally developed to help Don Holbert. Don, who is paralyzed below the waist (*See Don's Story, page 2.*), unable to adjust the thermostat or open the drapes, thought his only options were to either sell his home or hire someone to stay with him. He was unhappy with these choices, so his friends came to the rescue and remodeled his house, making it more accessible for him.

One of those friends, Greg Corpier, a computer consultant and engineer, also decided to automate things in the house that needed to be done on a daily basis and created a "digital companion" that could talk as well as respond to verbal commands. Don named his companion "Ralph."

Ralph was installed in Don's home in 2001. Except for the monitor, keyboard, tiny speakers and motion detectors mounted on the walls, Ralph remains invisible and is multi-talented. He opens and closes drapes, blinds and doors, and controls lights, ceiling fans, and TV, VCR, DVD and stereo systems. Ralph can answer the door and telephone and can act as an answering machine. He reminds Don when to get up, take medication and eat. Ralph can make a shopping list, control thermostats for air conditioning and heating, and operate small appliances. He turns on a recirculator pump enabling Don to be able to walk into a dry shower on his crutches (lessening the chance of a slip and fall) and have instant warm water. Ralph acts as a personal motion monitor and is able to call specific people for help if Don falls and is unable to get up. Ralph advises of weather conditions, reads the newspaper aloud, types and reads email, and acts as a home security system. He has given Don peace of mind by being a 24-hour-a-day personal assistant – always ready, willing and able to help.

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Although this automated technology system was originally designed to help people with disabilities, it is available for purchase by anyone who would like to have such a system. Ralph can be customized for your individual needs and sized to fit any home from a cottage to a mansion. For more information, contact Greg Corpier (866-315-6967, greg@ralphmyfriend.com) or visit www.ralphmyfriend.com. ●

Don's Story (donh1@swbell.net)

In 1949, shortly after my fifth birthday, I was diagnosed with polio. After spending 4½ months in the hospital, I returned home wearing braces on both legs and using crutches to help me walk.

I attended a special school in Kansas City, Missouri, for physically disabled students that offered both physical and occupational therapy as part of our regular school day.

At age 22, I married and we had three children. After 15 years, we divorced and I retained custody of the children. Though busy raising three children and working full-time, I managed to find time for a relationship and remarried. In 1981, my middle daughter was involved in athletics and I began volunteering with the Special Olympics. My volunteer service progressed from chaperon to coach to the state board to an employee as a director covering sixteen counties in Mid-Missouri.

In 2001, my wife became ill and died. I was alone and depressed. In addition to missing her love and companionship, I realized all of the little things my wife had done to make life easier for me. If it hadn't been for my family and friends, and the installation of a home-automated technology system known as Project Ralph (See cover article, "Ralph: The Home Assistant."), I might have given up.

In 2003, a woman on the Governors Council of Disabilities came to my home to assess the Ralph system. Later, I learned that in addition to checking out Ralph, she was also checking me out. A year later, we were married. She has made me feel alive again and, even though we both have limitations, we are very happy to have a new start at life together.

NEW BOOK

Aging with a Disability: What the Clinician Needs to Know

Published by The Johns Hopkins University Press.
Edited by Bryan J. Kemp, PhD, and
Laura Mosqueda, MD.

Kemp and Mosqueda are director and co-director, respectively, of the Rehabilitation Research and Training Center on Aging with a Disability at Rancho Los Amigos National Rehabilitation Center in Downey, California. (2004. \$55 hardcover, #0-8018-7816-0. \$24.95 paperback, #0-8018-7817-9. 328 pp, 20 illustrations.) The chapter on post-polio syndrome in the book is written by Jacquelin Perry, MD.

With advances in medical care, technology and rehabilitation, people with disabilities are now living longer. Many have near-average life expectancies. Research has shown that the changes and problems associated with aging often occur 10–20 years earlier in the lives of people with disabilities than in the lives of people without disabilities.

Aging with a Disability provides clinicians with a complete guide to the care and treatment of persons aging with a disability. This book first addresses the perspective of the person with a disability and his or her family. Chapters in the second section address the physiological and functional changes people will face as they grow older, and how these changes may affect quality of life and caregiver requirements. In the third part, contributors discuss treatment considerations such as maintaining employment and managing pain and fatigue. The book's fourth section focuses on specific conditions: spinal cord injury, polio, cerebral palsy, and developmental disabilities.

The concluding section presents research needs and discusses policy issues for future consideration. ●

From the Inside Out

David Florian, Palo Alto, California

To look at me, no one would ever guess that I almost died twice before I was 8 years old, or that I was once paralyzed and had to learn to walk again. I was diagnosed with bulbar polio in 1947 at age 6. Two months in the hospital, four more in bed at home, close monitoring for a year or two, and I recovered completely. Or, that's what I thought. As I grew up, it never occurred to me that there might be physical limitations, much less psychological ones.

Over the years I have come to realize that the trauma I experienced as a child in that hospital so long ago has permeated nearly every facet of my life to such an extent that it is difficult to wrap my mind around it all. Even now, at age 63, I still discover new ways that it has "crippled" me, colored my thinking, or affected my attitudes and relationships with people and the world. It's not that I am unhappy with the person I have become, because I'm not. But surely the path my life has taken would be significantly different had it not been for having had polio.

The first real inkling of trouble came when I met the woman I wanted to marry. I was 29, and my problems manifested themselves very quickly in terms of sexual dysfunction. We were living in Los Angeles and I remember driving to the university to teach an evening class. I was distraught, crying, barely able to see the road. I had an overwhelming desire to pull over and curl up in a ball in the back seat of my car. It was the closest I ever came to feeling as though I was "going crazy."

The sexual problems had come to the fore in the months preceding our wed-

ding. It had nothing to do with any physical cause, nor was it a question of impotence. The machinery clearly worked just fine, but it would just turn off at the very last, possible moment. Vanish, in an instant! Stretched over a period of time, that sort of recurring event tends to wreak havoc with one's self-esteem and self-worth.

After Post-Polio Health International published a series of articles about healing polio memories in 2002-03, a member sent us an account of how psychotherapy helped him discover that early polio experiences had impacted his sexuality, self-esteem and ability to express his true feelings.

His story is valuable because it provides evidence that our early life experiences can have long-lasting effects on how we think, feel and physically react to present-day situations. His story reveals how our minds, emotions and bodies affect each other. These insights are important for finding solutions to problems such as anxiety attacks, or an inability to concentrate, complete tasks or follow up with medical recommendations.

Determined to resolve his difficulties, Florian worked with a therapist to guide him through a process of discovery. Uncovering memories safely requires a trusting relationship with a therapist who has vast experience, an enormous range of skills, and deep sensitivity to how past experiences affect a client's responses in therapy. A competent professional will teach clients important skills for managing their intense reactions to situations stemming from their past as well as strong feelings that may surface.

Regardless of the depth of a person's pain or of a person's age, making positive change is possible, and David Florian's story is about powerful possibilities. What is most important is that we know we have choices and that we find ways to address our needs. With David's permission, we publish his story.

I went to a psychiatrist who told me that therapy would help. After surviving our honeymoon, I began to see him regularly and continued for the next six years. The therapy sessions came back again and again to childhood images of hospitals, nurses, doctors and procedures. But the years of therapy didn't result in a "cure" for my problem; that goal proved more elusive and more time-consuming than expected. The therapy provided valuable tools and an understanding of the situation that allowed me to put it all into perspective and to lead a normal life in every respect but that one.

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It would be wonderful if the story ended there, or perhaps, more appropriately, *started* there. But, unfortunately that was not the case.

It's EMDR (Eye Movement Desensitization and Reprocessing) that I credit with finally curing my sexual problems 22 years after I started seeing a psychiatrist. Over a period of maybe two months – a period that straddled the winter holidays, so there was some down time included – something of a miracle happened and in a rush of bewildering speed, all of the inhibitions, the self-doubts, the inability to fully experience sexual release, all vanished! For the first time in my life, at age 52, I was able to experience what most of the rest of the world takes pretty much for granted.

My feeling, all my life, was that the real David Florian, the *feeling* David Florian, was locked away in a little black box at the core of my being. To me, that image was very real and very powerful. Through EMDR, the doors to that little black box flung open and released feelings and emotions that I never had before.

It would be wonderful if the story ended there, or perhaps, more appropriately, *started* there. But unfortunately that was not the case.

Because an irregularity was detected during a physical examination, my primary care physician, a short eight months after my "release," suggested I have a sonogram of my prostate. While being examined, an the intern said that he needed to take a biopsy and gave me a choice to do it right then or to come back at a later time. Foolishly, I decided to do it on the spot to get it over with. There was no anesthetic. They generally take six samples, and by the third puncture, I was sweating ... shaking ... and trying to tell myself that this was going to be OK. It wasn't.

While on the table, I saw – and I mean "saw" in a very literal way – the doors of that little black box I envisioned inside of me slamming shut with each jolt of the needle. I was trying frantically to tell myself that all of this was *not* related to the pain I experienced in my childhood, but my argument apparently was not very convincing. And that's where I am today.

My wife and I recently celebrated our 33rd anniversary. We have a happy marriage that we never take for granted. When we met, it was love at first sight and after these many years we're still in love today. We prefer to spend our free time together; we actively enjoy each other's company. And our "problem?" Yes, it remains unresolved. But, there was that brief interlude.

And yet, perhaps surprisingly, my story is not about negativity and gloom. With the love and support of my wife, I've grown into a generally upbeat, productive adult who is happy, and relatively satisfied with my life as it is. Because this difficulty manifested itself so early in our life together, and because we both felt that our love for each other was worth rescuing, instead of driving us apart, it drove us closer to each other. We bonded early on in a way that might not have been possible if the circumstances were otherwise.

Was it always easy? Of course not. But, ultimately, it turns out that my story is really about a lifetime of continuing, positive discovery and learning ... and it seems that we have more learning yet to do. ●

To link to articles about polio memories and to see the extensive "Treatment Approach Options Chart" log on to www.post-polio.org/ipn/pnn18-4A.html or call 314-534-0475 and request a copy.

Strategies for Living Well: Theme of Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living

Conference Co-Chairs, Audrey King, Toronto, Canada, and William Wischmeyer, Saint Louis, Missouri, along with Post-Polio Health International's Board of Directors and Staff have been busy crafting the program for the June 2005 meeting. The ninth gathering since 1981 of polio survivors and ventilator users and their families, along with the health professionals who treat them, will begin with a luncheon at 11:30 am on Thursday, June 2, 2005. The conference, located at Marriott Saint Louis Downtown, will conclude at 4:30 pm on Saturday, June 4, 2005. Daily and half-day registration will be offered.

Because we know what the problems are, this meeting will focus on *Strategies for Living Well*. The conference will offer over 45 practical and participatory sessions. Participants will be able to select from diverse topics such as:

- ◆ New Bracing: The Challenge and the Payoff
- ◆ Planning Ahead to Stay in Your Home When Getting Older
- ◆ What about Nutraceuticals?
- ◆ Analyzing Your Gait: The Roles of Exercise, Bracing or Surgery
- ◆ Analyzing Your Sleep: Is It Apnea, Hypoventilation – or Both – or Something Else?
- ◆ Research: What is Being Done? What Needs to Be Done?
- ◆ Disability Insurance: Buying It and Securing It
- ◆ Anesthesia Precautions for People with Neurological Conditions
- ◆ Expressing Sexuality: What Works for Me
- ◆ Option if a Post-Polio Clinic Is Not an Option
- ◆ Experience Yoga, Reiki, Acupuncture, etc.
- ◆ Considering Exercise: What Steps to Take
- ... and many, many more.

Moderators Needed: The committee is looking for a limited number of polio survivors and ventilator users to serve as moderators. We invite you, including our international friends, if you plan to attend to contact Joan L. Headley (director@post-polio.org) if you are interested in being considered. Sessions in need of a moderator include: nutraceuticals, pulmonary health, pedorthic solutions, tracheostomy, exercise and orthopedic surgery.

Catalogue of Resources for Post-Polio Health and Ventilator-Assisted Living

Post-Polio Health International, including International Ventilator Users Network, will prepare a "Catalogue of Resources for Post-Polio Health and Ventilator-Assisted Living" for the conference participants and to be distributed online after the meeting. If you provide any product that assists polio survivors and ventilator users in living well and would like to learn how your company or organization can be included and support the work of PHI, please email info@post-polio.org with "Catalogue of Resources" in the memo line or call 314-534-0475.

Program and registration details will be available in January 2005. Members of Post-Polio Health International, including International Ventilator Users Network, will be notified by mail or email.*

*Please note that PHI wants to communicate with you in the most cost-effective way, and we will contact you periodically by email if you provide it. Please adjust your spam filter to receive emails from news@post-polio.org.

Activities of the EFNS Task Force on Post-Polio Syndrome

The Task Force on Post-Polio Syndrome, under the auspices of the European Federation of Neurological Societies (EFNS), was established in January 2003 to clarify and define the various terms used for the disabilities experienced by previous paralytic polio patients, and propose a common understanding and definition of the term "post-polio syndrome" in Europe; to give a brief review of the proposed mechanisms behind late polio deterioration; and to set up guidelines for health care interventions for this patient group.

Current Project: The Task Force is working on the "EFNS Guidelines on diagnosis and management of post-polio syndrome" to be submitted to the *European Journal of Neurology* by January 2005. The manuscript will then undergo the ordinary referee evaluation as a part of the publishing process.

EFNS Task Force on Post-Polio Syndrome

NORWAY: Prof. Nils Erik Gilhus (chair) and Dr. Elisabeth Farbu, Department of Neurology, University of Bergen, Bergen.

POLAND: Prof. Józef Opara, Repty Rehabilitation Centre, Tarnowskie Gory.

SWEDEN: Prof. Kristian Borg, Department of Rehabilitation Medicine, Karolinska Hospital, Stockholm; Prof. Erik Stålberg, Department of Clinical Neurophysiology, University Hospital, Uppsala.

THE NETHERLANDS: Prof. Marianne de Visser, Department of Neurology, and Dr. Frans Nollet, Department of Rehabilitation Medicine, Academic Medical Center, University of Amsterdam, Amsterdam; Mrs. Anita Driessen, Baarn.

UNITED KINGDOM: Dr. Robin Howard, Department of Neurology, St. Thomas' Hospital, London; Prof. Michael P. Barnes, Academic Unit of Neurological Rehabilitation, Hunters Moor Hospital, Newcastle-upon-Tyne.

To contact the EFNS Task Force, contact Elisabeth Farbu, Department of Neurology, Haukeland University Hospital, Bergen, Norway. (elisabeth.farbu@helse-bergen.no)

Recent Articles by Members:

Post-polio syndrome and total health status in a prospective hospital study by E. Farbu, T. Rekand and N.E. Gilhus, was published in the *EFNS European Journal of Neurology* 2003, 10:407-413. Eighty-five patients referred to the Department of Neurology, Haukeland University Hospital, Bergen, aged 47-91 years with mean of 61 years, were examined prospectively. The most common complaints were pain (44%), muscular weakness (27%) and fatigue (16%). Post-polio syndrome was diagnosed in 26% of the patients. Polio-related loss of function including cervical and lumbosacral radiculopathies, mononeuropathies and degenerative joint disease were found in an additional 53%. Eleven patients (13%) had distinct non-polio-related disorders that caused new loss of function. The remaining 8% had a stable condition.

Postpolio syndrome by F. Nollet and M. de Visser, was published in the *Archives of Neurology*, July 2004, 61:7, 1142-4. They review the early literature reporting cases of late-onset weakening following poliomyelitis from 1875 to 1954, because it provides insight for understanding PPS today. The authors question whether nonparalytic polio really exists. During acute poliomyelitis there was a continuum of paresis with severe amounts less prevalent than moderate amounts.

Members Borg and Farbu presented at the 8th EFNS Congress in Paris, France in September 2004. Their abstracts are reprinted with the permission of the EFNS [European Journal of Neurology, 11 (Suppl. 2)].

Immunopathogenesis of the post-polio syndrome

K. Borg¹, H. Gonzalez¹, T. Olsson²

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²Centre of Molecular Medicine, Karolinska Hospital, Stockholm, Sweden

Many polio patients experience new or increased symptoms decades after the acute infection, a condition known as the post-polio syndrome (PPS). An inflammatory process has been described in some studies but has not been found in others. In the study by Gonzalez et al (2002) we found a chronic inflammatory process in the CNS of PPS patients by means of studying cytokine expression of mononuclear cells in the cerebrospinal fluid. The levels of cytokine expression were comparable with those of patients with multiple sclerosis. The cytokine levels were down-modulated to normal values by means of treating the patients with intravenous gammaglobulin (Gonzalez et al 2004). In order to study if the decrease of cytokine levels was followed by a clinical improvement with a gain of function, a multi-centre, double-blinded and placebo-controlled study was performed. The results of this study are at the moment not finally analyzed. It is, thus, concluded that there is an inflammatory process in the CNS of patients with PPS. The inflammation may play a role in the pathogenetic mechanism of PPS. The inflammation is down-modulated by intravenous gammaglobulin. If this is followed by a clinical improvement it leads to new therapeutic strategies for the treatment of patients with PPS.

Post-polio syndrome (PPS) treated with intravenous immunoglobulin

E. Farbu¹, T. Rekand¹, E. Vik-Mo¹,

H. Lygren², N.E. Gilhus¹, J.A. Aarli¹

¹Department of Neurology, Haukeland University Hospital, Bergen, Norway

²Department of Physical Therapy, Haukeland University Hospital, Bergen, Norway

Patients with previous poliomyelitis can after many years develop new atrophy and new muscle weakness, known as the post-polio syndrome (PPS). The cause for this progression is not known. The patients have increased expression of mRNA for the inflammatory cytokines TNF-alpha, IL-10, IL-4 and IFN-gamma in their CSF. This suggests an ongoing inflammatory process. Intravenous immunoglobulin may be a therapeutic option for these patients. The study is a placebo-controlled, double-blinded prospective study, independent of any pharmaceutical company. 20 patients with PPS with mean age of 61 years were included. After randomisation, they were given either intravenous immunoglobulin at dose 2g/kg body weight during two days, or placebo (saline). They were evaluated clinically with neurological examination, muscle strength assessment with CarolusTM, with Fatigue Severity Scale, Disability Rating Index, and with Patient's Global Impression of Change. Evaluation was performed prior to treatment, after one week, one month, three months and six months. All included patients have received treatment and no serious side effects have occurred. Clinical results will be presented after the code for randomisation has been opened in July 2004 and will be published in 2005. ●

My Experience with Human Growth Hormone (hgh)

Chris Cash, Carrollton, Texas



I contracted polio in 1951 when I was nine months old. My residual was paralysis of the right leg. I regained mobility in about six months and subsequently had four surgeries for my right foot. I wore a knee-length brace until I was 13. My right leg is about a half-inch shorter than my left and my right foot is two sizes smaller than my left. I was always strong, however, and managed to do everything I wanted with the exception of ice skating. This failure bothers me to this day.

I was diagnosed with post-polio syndrome in 1997 and was given the standard advice: Don't exercise too much or too hard; conserve your energy; take naps; take these pills for sleep; take these pills for pain; take these pills for muscle twitches. I became depressed as I saw my future before me ... in a wheelchair and dependent on others.

For five years, I lived a sedentary lifestyle. I gained weight and felt lethargic, weak and hopeless. I was frustrated at the support group meetings I attended where it seemed everyone was following the simplified warning of "use it *and* lose it." I stopped going when the speakers consistently tried to sell something and nobody talked about alternative research or treatments.

In 2002, I learned about the benefits of human growth hormone (hgh) from a friend (not a person who had polio). hgh is an anti-aging product, popular with some baby-boomers because hgh levels begin falling in our 20s. hgh has been called the "fountain of youth in a shot" because research suggests that it builds muscle, decreases body fat, increases energy, enhances sleep, and

thickens your hair and skin. I decided to see if it would help my the post-polio symptoms. For me, nothing ventured, nothing gained.

I started taking 4 mg of injectable hgh five days per week in May 2002. Along with the hgh, my doctor (who also had polio and was taking hgh himself) suggested I use a topical testosterone cream to enhance the hgh. Three weeks later, I went to see my physician and before I knew it, I was at the top of the stairs without using the usual upper body strength to get up those stairs.

I lost 18 pounds within nine months, began to swim, and fairly quickly got up to a half mile with short breaks. I slept well, my energy was high, and my outlook on life improved 100%.

It is now 22 months since I have been on hgh and testosterone. The same 18 pounds are still off, I swim five days per week, and I have tons of energy. I have occasional joint pain (which I have always had) and a bit of weakness in my left hand.

I have had no side effects with hgh except for some edema in my legs in the first week which went away and has not returned.

(Editor's Note: Reported side effects include an increase in blood pressure, fluid retention, carpal tunnel syndrome and joint pain. The use of growth hormone has also been tied to an increase in insulin resistance, which leads to diabetes.)

Little research has been done with polio survivors and hgh. Doctors Shetty, Gupta and Rudman (deceased) from Milwaukee did a few studies in the early '90s. They found that folks with

post-polio syndrome have impaired growth hormone secretion compared to non-polio people in the same age group.* My level was very, very low.

hgh is very expensive and can be \$1,000-\$2,000 a month or more. I purchase mine through www.drugstore.com, but there are buyers groups where you can get it for less. The *only* type of hgh that works is the injectable form. Anything taken internally will break down before it has any effect.

At this time, insurance will cover only hgh for those who are HIV-positive, have a pituitary condition or are children who are not growing as expected.

I do not know if everyone, or anyone, will benefit from this treatment. But, this is my experience. Please email me (chriscash2002@msn.com) if you have any questions or comments. ●

*Editor's Note: In this study of six individuals, the majority of muscle tests showed little or no change after three months of hormone treatment. [Human growth hormone was administered subcutaneously at 0.0075, 0.015 or 0.03 mg/kg (full replacement dose) of ideal body weight, three times weekly for successive periods of one month.]

Post-Polio Health International

maintains an extensive website at www.post-polio.org. One section, called "What Works for Me" (www.post-polio.org/whatwks.html), contains messages from polio survivors and ventilator users about their personal experiences, ranging from finding shoes to trying hgh as Cash has done. PHI welcomes your contributions to the site and reserves the right to edit the information.

Send "What Works for Me" to editor@post-polio.org or submit your information in the form provided on the web page.

"I am not sure how many polio survivors, especially men, are aware of the relationship between post-polio and osteoporosis. This connection has been brought to my attention when a colleague of mine, who also has the late effects of polio, fell and broke his femur. The major cause was osteoporosis. Following his suggestion, I had a bone density scan, and, sure enough, my density level is at 85% of the norm despite the fact that my daily diet includes healthy portions of yogurt, cheese and milk. Nonetheless it is obviously not enough. I have now added the intake of 1500 mg of calcium and 400 mg of vitamin D."

Zeke, Los Angeles, California

* * * * *

Recently, a group of researchers from Montréal, Canada, completed a cross-sectional study involving a chart review of available clinic charts of patients at a university-affiliated hospital post-polio clinic. They wanted to determine the frequency of osteoporosis and osteopenia of the hip, and the association of lower-extremity muscle strength with bone density.

The occurrence of osteoporosis and osteopenia of the hip was: 20/62 (32%) and 29/65 (45%) in men (mean age, 58 years); and 18/67 (27%) and 23/67 (34%) in postmenopausal women (mean age, 63 years), respectively.

In men, there was a significant correlation between hip bone density and hip flexor strength, and strength sum score (hip flexors, knee extensors, ankle dorsiflexors) in the same extremity where bone density was done.

In postmenopausal women, there was a significant correlation between hip bone density and same hip flexor strength, strength sum score in the same lower extremity and strength sum score in both lower extremities.

The researchers of the post-polio clinic concluded that osteoporosis of the hip is a common occurrence. And, that hip bone density is associated with muscle strength in the same lower extremity.

SOURCE: Poster 160: Osteoporosis in a post-polio clinic, Muriel Haziza, MD (University Montreal, Montréal, Quebec, Canada); Richard Kremer, MD; Andrea Benedetti, MSc; Daria A. Trojan, MD, MSc. *Archives of Physical Medicine & Rehabilitation*, 2004; 85(9):E36.

Special Thanks

We thank our supporters for their contributions to our work ...

In honor of ...

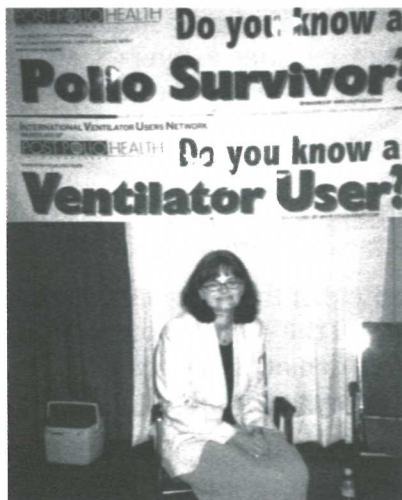
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Justine Craig-Meyer, Membership Services Coordinator of PHI, at the Assistive Technology Consumer Fair 2004, Saint Louis, Missouri.

Special thanks to Thomas Fetterman, Inc. (www.crutchguy.com) and J.H. Emerson Company (www.coughassist.com) for underwriting the cost of the banners.



The Post-Polio Support Group of Southwest Community Center, Worth, Illinois, has contributed funds to Post-Polio Health International to purchase a video camera. The goal is to use the camera to create videos of topics of interest that can be sent to support groups to inform or to initiate discussion.

Other groups wishing to donate should email director@post-polio.org or call 314-534-0475.



PHOTO BY ANNE GROEBNER

Third Annual Curt Kettner Post-Polio Syndrome Golf Tournament at Show Low Golf Club in Show Low, Arizona, yielded over \$2,000 for The Research Fund of Post-Polio Health International. Curt, a polio survivor who currently holds a 20 USGA handicap and always plays one-handed, led 32 players in a format that required all participants to use the same technique.

We thank our supporters for their contributions to The Research Fund ...

In honor of ...

Dorothy Arnold	Joan Headley
Lucille Bean	Daniel Huguenin
Carl Danielson	Jacquelin Perry, MD

In memory of ...

Samuel Berry	Clela Headley
Edie Elterich	Wilbur Lippert
Lewis Gumerman	Mary Jane Nygaard

Good news from The Research Fund 2003 researchers: In September, University of Michigan Investigators Dr. Claire Z. Kalpakjian, PHI's 2003 awardee of \$25,000 to study menopause and polio survivors, and Dr. David R. Gater, Medical Director of Spinal Cord Injury Medicine, were awarded a 3-year, \$450,000 Field Initiated Research Award from the National Institute of Disability and Rehabilitation Research (NIDRR) to study the menopause transition in women with spinal cord injury. This multi-site project will begin in November 2004.

Thanks to the generosity of Mrs. Lew Gumerman and Mrs. Ronald Collins, Post-Polio Health International has two PLV-100s and six exsufflation belts with bladder (medium) to give away. PHI asks that the recipients agree that the equipment is accepted "as is," absolve the donors and PHI, and pay shipping charges. For more information, contact ventinfo@post-polio.org.

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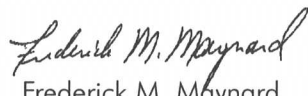
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THE MISSION OF POST-POLIO HEALTH INTERNATIONAL, including International Ventilator Users Network ... is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

Members of Post-Polio Health International,

We thank you for your compliments, your suggestions and your continued financial support that allows us to fulfill our mission.

We extend our best wishes for personal good health and success with your life's endeavors.


Frederick M. Maynard
President, Volunteer Board
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Joan L. Headley
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Contact Justine Craig-Meyer at 314-534-0475 or info@post-polio.org with your new address to make sure your newsletter moves with you!

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