

POST-POLIO HEALTH

SAINT LOUIS, MISSOURI

WWW.POST-POLIO.ORG

Transition from a Metal/Leather Leg Brace to a Plastic/Metal Hybrid

Richard J. Feltes, Lisle, Illinois (rfeltes@refco.com)



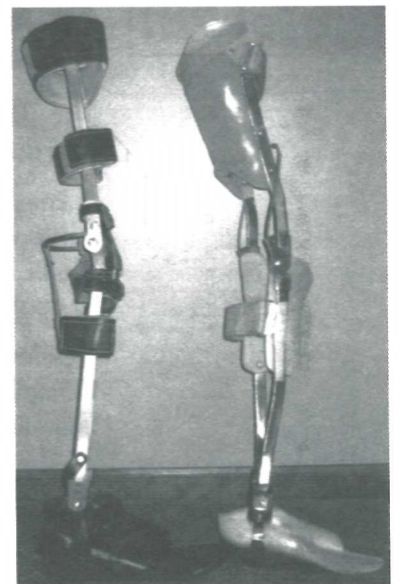
Richard Feltes

Shortly before my first birthday, I contracted polio in both legs. Only one leg required a full-length leg brace known as a Knee Ankle Foot Orthosis (KAFO). My brace, prescribed for me in the early 1950s, consisted of stainless steel uprights joined by leather-covered steel bands, a leather pad to stabilize the knee, and a shoe attached to the steel uprights. Periodically, I asked my orthotist about advances in leg brace technology, but he was reluctant to recommend a plastic leg brace because of my history of frequent breakdowns and the general difficulty in changing bracing systems for long-time post-polio people. I had used mine for over 50 years.

In 2001, I visited an old friend and fellow college wheelchair athlete, who was elated over his new plastic/metal hybrid orthosis crafted by Beverly Hills Prosthetics & Orthotics, Inc., in Van Nuys, California. His enthusiasm was contagious, and within a few months, I had secured the necessary insurance approval and was on my way to California.

The fitting process of a plastic/metal hybrid orthosis begins by taking a mold of your leg, which is then filled with plaster to create a model used for shaping the polypropylene shells and metal components. (Fiberglass is used by some orthotists.) The next phase of the process, fitting and adjustments, requires patience, trust, commitment, persistence and plenty of positive attitude by the polio survivor and the orthotist. The transition will be expedited if your orthotist can duplicate the position and elevation of the foot as closely as possible with your original orthosis.

My new brace consists of a molded polypropylene shell, stainless steel uprights, a titanium knee joint with spring-loaded cable release, a plastic pretibial shell, and a molded polypropylene foot plate with a double action ankle joint. Springs in the posterior aspect of the double action ankle joint prevent my "drop foot" from dragging. The anterior channels of the ankle joint have steel pins that stop the leg from going forward during ambulation, which helps stabilize the knee. Beverly Hills Prosthetics used the top-of-the-line stainless steel uprights and the Otto Bock™ wedge lock titanium knee joint to eliminate the breakage that plagued my aluminum brace. Some insurance carriers will not pay for a titanium joint, but I'm very glad I chose it. The extra security and longevity of the joint has been well worth the additional expense.



Major modifications should be tackled before moving on to minor adjustments. Then start wearing your new orthosis for 1-2 hours a day. Keep scheduling appointments with the orthotist (or returning by UPS) until a reasonably accurate fit is achieved.

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After completing all the necessary adjustments on my new brace and enjoying the many advantages of a modern KAFO, I decided to order a back-up leg brace. If you think you might be interested in ordering a back-up brace, make sure the orthotist saves your leg/foot cast.

I have experienced fewer breakdowns than with my traditional brace, and I believe preventative maintenance is very important. Sheering of copper rivets is the only problem I've encountered thus far. Ask your orthotist to secure both the tibial and thigh shells to the uprights with stainless steel rather than copper rivets. I have my brace checked twice yearly for a thorough inspection of all working parts.

The benefits of my new brace include greater comfort, improved stability and a better fit under my pant leg. The brace is easier to put on and take off, and is considerably lighter. The advantages of my new leg brace more than compensate for the multiple fittings, added expense and temporary discomfort during break-in.

Going to California won't be an option for most of you. Consider giving this article to your orthotist and ask him/her if they are experienced with fabricating plastic/metal KAFOs, if they are willing to incorporate an Otto Bock™ titanium knee joint, if they will work with you until a comfortable fit is achieved, and if they will stand behind their work.

Have confidence that your leg will adjust to the new orthosis as you wear the brace. Within a few weeks you'll be enjoying a superior bracing system and wondering why you didn't make the change earlier. ●

FAQ of PHI

Q: My physician just told me I couldn't have post-polio syndrome because I have the knee jerk reflex. What is the knee jerk reflex and is he correct?

A: The knee jerk reflex is the sudden kicking movement of the lower leg in response to a sharp tap on the patellar tendon, which lies just below the kneecap.

A knee jerk is a normal reflex which requires an intact nerve loop between the sensory nerve which detects the "tap" at the quadriceps tendon below the kneecap, and an intact motor nerve in the spinal cord that sends the reflexive message to the quadriceps muscle to contract and straighten out the knee with a kicking movement.

If polio survivors had involvement of the quadriceps muscle, they usually lost the knee jerk. If they had no lower limb involvement, or specifically quadriceps involvement, then the knee jerk was not lost.

Consequently, you cannot use a single test, like a knee jerk, as indicating the presence or absence of polio involvement overall — or of post-polio syndrome. All that can be said is that if it is absent in a polio survivor, probably that person had involvement of the quadriceps muscle, the muscle that straightens out the knee.

Frederick M. Maynard, MD, Upper Peninsula Rehabilitation Associates,
Marquette, Michigan

FLYING TO NORWAY

Richard Flickinger, Anacortes, Washington (rcflickinger@msn.com)

As a polio survivor with limited vital capacity*, I have used the BiPAP® S/T (Respironics Inc., www.respironics.com) for about 10 years. I need ventilatory support when sleeping or just lying down. I traveled extensively with the BiPAP but, at age 82, as my strength (and most importantly, that of my wife and helpmate) declined, the weight of the BiPAP became a major factor in planning future airplane travel.

The inability to tolerate low airplane cabin pressure, as my breathing became further impaired, also deterred longer airplane flights, particularly for those longer than a few hours. If I remained seated, not reclined, I managed on short flights. But when I ate a meal or exerted myself in any way, my oxygen saturation dropped and my heart rate jumped.

A recent trip to Norway occurred because of two factors: the use of a lightweight bilevel unit and the newly available 110V power in the airplane cabin. The KnightStar® 330 (Puritan Bennett, www.puritanbennett.com) weighs only 2.7 lbs, with dimensions of 3.75"H x 8.25"W x 5.62"D.

I flew SAS from Seattle to Copenhagen nonstop, a 9½ hour flight, on the Airbus 330, followed by an 80-minute flight to Bergen, Norway. **The Airbus 330 features 110V power at the business class and "economy extra" seats.** The latter is a new category that costs less than business class but still considerably more than economy/coach. I felt it was worth the extra cost to have the power available. The power was installed primarily for the convenience of computer users, but the out-

lets can fulfill the electrical requirements of some ventilators.

I placed the KnightStar on the floor in front of me and plugged it into an outlet in the armrest. The increased seat pitch (five inches more than in economy class) added a little more floor space. I used my Mirage® nasal mask (ResMed Corporation, www.resmed.com) because its hose connection can point directly to the floor. I had purchased a manual resuscitator bag – just in case – but decided it was too bulky to carry and my need for it unlikely.

Preliminary communications with the SAS Medical Department were necessary to approve my use of the KnightStar. Their Copenhagen home office consulted with Puritan Bennett, the manufacturer, about machine specifications and other engineering details. I obtained a letter of approval from the SAS Medical Department, even though I was informed that it wasn't necessary because the approval would be entered in my flight record.

When I boarded the plane, the cabin personnel asked to see the unit and to show it to the Captain. They were most helpful in making certain that I had the correct plug-in adapter and that the machine operated properly. (I received the impression that SAS, and probably other airlines, has a list of ventilatory equipment that is pre-approved for use in the cabin, but the KnightStar hadn't been included yet.)

It is encouraging that some of these new technological developments make travel easier for ventilator users. Our Norwegian journey was successful. ●

***Vital Capacity (VC):**
Maximum amount
of air expired after
maximal inspiration.

Activities of the Post-Polio Program in Johnstown, Pennsylvania

Research

Conemaugh Health System has completed a preliminary outcome study evaluating the benefits of Hatha yoga and meditation in people with post-polio syndrome.

The cardinal characteristic of post-polio syndrome is new onset of weakness that cannot otherwise be explained. Many survivors also experience significant fatigue. It has been shown that mild, less extreme forms of exercise may improve muscular strength and fatigue^{1,2} leading some experts to suggest that the most viable treatment presently available involves management of one's day-to-day activities and non-fatiguing exercise.³

Twenty-three polio survivors, accompanied by their significant others, participated in a five-day retreat in Johnstown, Pennsylvania. The protocol included training in Hatha yoga and mindful meditation, a chronic disease self-management workshop and group support. The participants were then followed for twelve weeks while they utilized a Hatha yoga video specifically developed for this study. Seven outcome measures were used to assess the individuals' responses to the interventions and to compare reliability among the scales used. Participants were assessed at three time periods: baseline (first day of retreat), last day of retreat and twelve weeks after the retreat.

The polio survivors showed significant improvement in areas of fatigue, weakness and pain and continued to practice their skills. At the end of the twelve-week program, individuals averaged

45 minutes of exercise and stress management a day including week-ends. The results of this clinical trial will be used to develop a longitudinal data collection effort integrated with ongoing care and education.

Ongoing research at the John P. Murtha Neuroscience & Pain Institute at Conemaugh Health System includes fatigue issues, osteoporosis and respiratory management.

REFERENCES

1. Einarsson, G. (1991). "Muscle conditioning in late poliomyelitis." *Arch Phys Med Rehabil*, 72, 11-14.
2. Spector, S.A., Patricia, L.G., Yildiz, E., et al. (2001). "Effect of strength training in patients with post-polio syndrome: A preliminary report." *Ann NY Acad Sci*, May 25 1995, 753, 296-302.
3. Dalakas MC. (1999). "Why drugs fail in postpolio syndrome: Lessons from another clinical trial." *Neurology*, 53, 1166-1167.

SOURCE: DeMayo, W., Singh, B., Duryea, B., & Riley, D. (2004). "Hatha yoga and meditation in patients with post-polio syndrome," *Alternative Therapies*, 10(2), 24-25.



Carol Yoder, master trainer and leader of "Healthy Living with a Chronic Condition." Eight classes have been presented as a result of the August 2002 training held in Johnstown. Courses have been offered to polio survivors in Arizona, Florida, Michigan, Oregon and Pennsylvania.



Post-Polio Clinic Directors Meet Monthly on Conference Calls

William M. DeMayo, MD, Director of the Post-Polio Program, moderates monthly conference

calls of Post-Polio Clinic Directors. Past topics include exercise, pain syndromes, bracing and the use of statin drugs in the post-polio population.

During the latter discussion, Dr. Carol Vandenaeker (University of California-Davis Medical Center, Sacramento, California) presented a case study of a polio survivor with high cholesterol, a risk factor for heart disease, who was on Lipitor® (atorvastatin calcium), plus other medications. The survivor reported considerable muscle pain and wanted to determine if it was due to his post-polio syndrome, or to the Lipitor®, which lists new pain and weakness as “serious muscle side effects.”

Dr. Vandenaeker ordered a blood test called a CPK, which measures the amount of creatine phosphokinase in the blood. CPK, an enzyme found predominantly in the heart, brain and skeletal muscle, leaks into the bloodstream when a muscle is damaged, and determining which specific form of CPK is elevated will help determine which tissue has been damaged. The gentleman's CPK was over 500. In the first month off the Lipitor®, his CPK was 327 and finally down to 175. Most importantly, he continued to see his cardiologist and take Zetia® (ezetimibe) to help control his cholesterol.

Ezetimibe is in a class of lipid-lowering compounds that selectively inhibits the intestinal absorption of cholesterol and related phytosterols.

The incorrect information that statin drugs should not be taken by polio survivors continues to be disseminated throughout the polio community. As a result, a number of survivors prescribed statins by their primary physicians to help control their cholesterol refuses to take them.

The Directors recommended that survivors with cardiology risk factors follow their cardiologists' instructions and try the statins while carefully monitoring their symptoms. The Directors acknowledged that an increase in pain and/or weakness could reduce the ability of a survivor to function and thus have an impact on quality of life. They further noted that people are not going to die from muscle pain, but the scientific evidence for the benefits of cholesterol-lowering drugs, including the statins, is significant and taking them can save lives.

The medical literature does not recommend routine monitoring of CPK levels, and none of the Directors routinely check CPK levels in their post-polio patients, but all do use the test when symptoms appear to necessitate it. ●

Post-Polio Clinic Directors who are not receiving the meeting reminders are urged to call Barbara Hull, John P. Murtha Neuroscience & Pain Institute, at 814-269-5232.

April 12, 1955 ...

An important day in the history of poliomyelitis

On April 12, 1955, Dr. Thomas Francis, Jr., director of the University of Michigan's Poliomyelitis Vaccine Evaluation Center, announced the results of the Salk polio vaccine trials at the Rackham Auditorium, University of Michigan, Ann Arbor. Starting at 10:20 a.m., Francis meticulously laid out the scientific evidence gathered from more than 1,829,916 children in 217 areas of 44 states. Francis spoke for an hour and forty minutes before "he made it clear that the Salk vaccine has been proved an effective weapon...."

Exhibit at the Smithsonian

The Smithsonian's National Museum of American History will mark the 50th anniversary of the polio vaccine with a new exhibition – "Whatever Happened to Polio?"

Scheduled to open on April 12, 2005, the year-long display will tell the story of the polio epidemic in the United States, the vaccine development, current world efforts to stop polio transmission and the story of survivors and the influences they have had on American society. The exhibition also will explore some of the changes in American medicine in the 20th century and the impact a disease can have on society as a whole. The show draws upon the themes of community activism, human resilience, the development and use of medical technologies and medical science, and competition and rivalry in science.

The exhibition is designed according to principles of Universal Design, a design aesthetic of seven principles with roots in the disability accessibility movement, and will exceed current federal standards for accessibility.

A companion website will be available in April:
<http://americanhistory.si.edu/polio>

Other commemorations by post-polio organizations

International Rehabilitation Center for Polio at Spaulding Framingham, Massachusetts, is sponsoring *Celebrating Life: A Reception for Polio Survivors* on April 9, 2005, 2:30-5:30 pm. RSVP to Anna Rubin, agrubin@partners.org or 508-872-2200, ext. 241.

Polio Survivors Association (Richard@polioassociation.org), Downey, California, is working with a shopping center company near Rancho Los Amigos, one of the original respiratory polio wards, to mount an exhibit in several centers during the month of April.

Polio Survivors and Associates (raytaylor@mindspring.com), a fellowship of Rotary International is planning a float in Rotary International's Centennial Parade to be held in Chicago, June 18, 2005.

Ontario March of Dimes (KDowds@dimes.on.ca) is planning several events on April 12th and a special nationwide commemoration on May 8th. This date is distinctive in Canadian polio history because it is the 50th anniversary of the decision by Paul Martin, Sr. (Minister of Health) to continue the vaccinations in his country after the Cutter incident in the US. The vaccine,

Post-Polio Health International remembers the survivors of polio.

To commemorate the 50th anniversary of the development of the Salk vaccine, Post-Polio Health International chose to honor those for whom the vaccine was too late. Since its inception in 1958, the organization has focused its resources and efforts on improving the health and independence of polio survivors and ventilator users and is committed to continuing this practice.

Artist Deborah Goodwin and polio survivor Mickie McGraw teamed up to create a visual reminder that millions of polio survivors are citizens of the world community who are in need of information, advocacy and research.

The nautilus shell represents an external stillness and static mobility. Contained and protected within is a rich and active life force that radiates outward from the central creation point of its spiral to reach beyond the limits of its boundaries.

The butterfly depicts the ephemeral, unique beauty of each life that begins encased within a cocoon and emerges in its time, transformed, to color the world and give wings to the future.

Together they celebrate our human potential to transcend limitations. They commemorate the 50th anniversary of the development of the Salk polio vaccine, which forever changed our lives and our future.

The design, in shades of blue and yellow, and the text have been printed on note cards. To help PHI remind the world of this anniversary and to support our work, order your set of 10 note cards for \$13.50 (s&h included). Order online at www.post-polio.org or send \$13.50 to PHI, 4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915.



made at Cutter Laboratories in California, had caused, not prevented, polio, and the US halted all production and immunization on May 7th. The senior Martin is the father of the current Prime Minister of Canada and polio survivor, Paul Martin, Jr.

The Ontario March of Dimes is coordinating "Polio Vaccine: The First 50 Years and Beyond," a conference of the International Association for Biologicals (www.iabspolio.com) to be held in Toronto, June 5-7, 2005. ●

PHI will post a calendar of commemoration events on www.post-polio.org. Send details to webmaster@post-polio.org.

Watch for news from the following groups planning commemoration activities.

University of Michigan School of Public Health, the site of the historic announcement (www.sph.umich.edu/about/polioannouncement.html)

University of Pittsburgh, the location of the laboratory of Jonas Salk, MD (www.pitt.edu)

Salk Institute for Biological Studies, founded by Jonas Salk, MD, in the 1960s to explore questions about the basic principles of life (www.salk.edu)

March of Dimes, the major source of funds for development of the vaccine (www.marchofdimes.com/polio)

Rotary International, the worldwide service organization that has committed \$600 million dollars and thousands of volunteer hours to make the world polio-free (www.rotary.org)

In Appreciation

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

In honor of...

Augusta Alba, MD	Joan Headley
Bobbie Bartels	Beth Kowall
Linda Bieniek	Patricia Ann Chase Laird
Gary Dean	Tony Lu, MD
Gina Demos, ADTR	Sairam Parthasarathy, MD
Judith Fischer	Niles Mielke
Barbara Goldstein	Michael Minieka, MD
Georgia Griffin, DO	Myles Sheehan, SJ, MD
Ed Hamilton	Margaret Stein
Jim & Judy Headley	

In memory of ...

Donna Lee Chase	Ellen Martini
Tanner Chrisler	Ona Mills
Lorna Eby	Henri Powers Minette
Daniel Ezydorski	James Odell
Mary Ann Farrington	Effie Louise Otto
Hugh Gallagher	Margaret Pfrommer
Anne Gawne, MD	Cornelia Posey
Violet Gormly	Barney Ross
Evelyn Gruben	Robert Ruyle
Jerry Hazel	John Scalise, Jr.
Clela Headley	Elise Seligman
Harold Heath	Joyce Siegfried
Martin Hokamp	Linnea Elmborg Sindoni
Jack Kaplan	Margaret Stein
Shari Kimura	Peggy Strohmeier
Gini Laurie	John Westbrook
Wilbur Lippert	Donald Willfong
Elizabeth Lloyd	Corley Wright
Robert Lohse	Ronnie Zenk

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

In honor of...

Bobbie Bartels	Debra Hansen
Linda Bieniek	Judy Whitehead

In memory of ...

Yvonne Albi	J.D. & Claudia Gray
August Christman	Doris Lee
Joseph Cronin	Douglas Schultz
June Fortezzo	Robert Warnock

Special Thanks

Post-Polio Health International received a generous donation from the Roosevelt Warm Springs Foundation to upgrade our computer hardware and software to meet the increased demand for our information and services.

Post-Polio Health International received a generous donation of \$10,000 from the Edouard Foundation for our Research Fund.

Post-Polio Health International Awards Third Research Grant

Post-Polio Health International awarded a \$25,000 research grant to a team from Johns Hopkins University. The researchers propose to determine whether early use of noninvasive positive pressure ventilation (NIPPV) prolongs survival in people with amyotrophic lateral sclerosis (ALS) and to relate their findings to other neuromuscular diseases including polio and its late effects.

ALS, also known as Lou Gehrig's disease, is a progressive neurodegenerative disease that attacks nerve cells in the brain and spinal cord, resulting in muscle weakness. The respiratory muscles are invariably affected, and respiratory failure is the most common cause of death. NIPPV is an increasingly common treatment for people with chronic respiratory failure, and observational studies suggest that NIPPV prolongs survival, but it is not known whether it modifies disease progression or simply provides support in the terminal stages of the disease. Currently, guidelines recommend starting NIPPV when a patient's forced vital capacity (FVC) – a measure of breath exhalation – falls below 50 percent of the predicted value.

The Johns Hopkins study aims to determine whether NIPPV is more beneficial in prolonging survival if it is started earlier in the course of ALS. The study will also attempt to determine if a point can be identified at which survival is maximized.

"If our study demonstrates prolonged survival in patients who begin using NIPPV earlier than currently recommended, it will have profound implications for how patients with ALS and other neuromuscular diseases are managed," said Principal Investigator Dr. Noah Lechtzin (nlechtzin@jhmi.edu), instructor of medicine in the Division of Pulmonary and Critical Care Medicine at Johns Hopkins University. "It will suggest that a more proactive approach is beneficial. This study could alter this passive approach to patient care."

"We believe that the results will apply to a majority of the people we serve with post-polio syndrome, as well as to those with other neuromuscular diseases such as muscular dystrophy, spinal muscular atrophy and multiple sclerosis," said Joan L. Headley, executive director of Post-Polio Health International. ●

Join Post-Polio Health International and International Ventilator Users Network in Saint Louis in June!

Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: **STRATEGIES FOR LIVING WELL**

For polio survivors, ventilator users,
families and friends, health professionals,
organizations and companies

WHEN? Thursday-Saturday, June 2-4, 2005

- Thursday opens with an 11:30 am luncheon, followed by afternoon and twilight sessions.
- Friday offers 24 diverse sessions.
- Saturday has 17 more presentations focusing on STRATEGIES FOR LIVING WELL, concluding at 4:30 pm.

(Daily and half-day registration is available.)

WHERE? Marriott Saint Louis Downtown
Saint Louis, Missouri

WHY?

- To learn personal STRATEGIES FOR LIVING WELL
- To provide information and support to families and friends of polio survivors and ventilator users
- To exchange ideas with polio survivors and ventilator users
- To exchange ideas with health professionals
- To contribute to the worldwide activities supporting the improved health and independence of polio survivors and ventilator users
- To renew old acquaintances and make new friends

*Interested in exhibiting? Want to be listed
in the Catalogue of Resources for
Post-Polio Health and Ventilator-Assisted Living?*
CALL 314-534-0475!

Program for Thursday, June 2, 2005

Program subject to change.
www.post-polio.org for updates

9:00 am – 6:15 pm/REGISTRATION

2:30 am – 5:30 pm and

8:30 pm – 9:30 pm/EXHIBITS OPEN

11:30 am- 1:00 pm

OPENING LUNCHEON

Post-Polio Health International
Board President

Frederick Maynard, MD

U.P. Rehabilitation Medical Associates,
Marquette, Michigan

Conference Co-Chairs

Audrey King

Toronto, Ontario, Canada

William Wischmeyer

Saint Louis, Missouri

1:30 pm – 2:45 pm

SESSION I (PLENARY)

THE PAST, THE PRESENT, THE FUTURE

The Vaccine Story

Christopher Rutty

Health Heritage Research Services,
Toronto, Ontario, Canada

The Rotary Story

Ray Klingensmith

Rotary International Foundation,

Kirkville, Missouri

Ray Taylor

Polio Survivors & Associates,

Pinehurst, North Carolina

The Unfinished Story

Daniel Wilson, PhD

Muhlenberg College,

Allentown, Pennsylvania

2:45 pm – 3:15 pm/BREAK

3:15 pm – 4:30 pm

SESSION II OPTIONS

ANESTHESIA PRECAUTIONS FOR PEOPLE WITH NEUROLOGICAL CONDITIONS

Selma Calmes, MD

Olive View-UCLA Medical Center,

Sylmar, California

Erik Jacobsen, MD

Chief Anaesthetist (Retired),

Copenhagen, Denmark

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POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Blvd #110, Saint Louis, MO 63108-2915 USA

314-534-0475, 314-534-5070 fax

info@post-polio.org

www.post-polio.org

INTEGRATIVE MEDICINE APPROACH TO POST-POLIO SYNDROME MANAGEMENT IN PRACTICE

William DeMayo, MD
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain
Institute, Conemaugh Health System,
Johnstown, Pennsylvania
Reactor: Sue Harris
Canton, Massachusetts

TRAVEL TIPS

Taking Cruises

Linda Priest
Atlanta, Georgia

Surviving Not Driving:

Getting Around without a Car

Susan Borgman
Black Coffee Creative,
Wyoming, Michigan

And, If You Use a Vent

Angela King, BS, RRT, RPFT, NPS
Pulmonetic Systems, Inc.,
Minneapolis, Minnesota

EMOTIONAL EATING

My Story

Marge Torre
Bradenton, Florida
Robert Thayer
Clinton, Mississippi

What Is It and What to Do About It

Linda Bieniek, CEAP
La Grange, Illinois
Reactor: Stephanie Machell, PsyD
International Rehabilitation Center for
Polio, Framingham, Massachusetts

DISABILITY INSURANCE: BUYING IT AND SECURING IT

Moderator: Saul Morse
Springfield, Illinois
Mark DeBofsky
Daley, DeBofsky and Bryant,
Chicago, Illinois

LEAVING A LEGACY

The Polio Oral History Project

Anna Rubin
International Rehabilitation Center
for Polio, Framingham, Massachusetts

Documenting Polio Stories: Learn from the Canadian Experience

Sally Aitken
Polio Québec, Québec, Canada

4:30 pm – 6:15 pm

DINNER (On Your Own)

6:15 pm – 8:30 pm

TWILIGHT SESSION OPTIONS

6:15 pm – 8:30 pm

THE LATEST IN VENTILATORY EQUIPMENT

Moderator: Larry Kohout
Edina, Minnesota
Representatives of ventilatory
equipment and manufacturers

6:15 pm – 8:30 pm

SPIRITUAL HEALTH

Strategies for Living in Peace with Polio

Robert Ronald, SJ
Kuangchi Program Service,
Taipei, Taiwan ROC

The Art of Making A Difference in Your Own Life

Scotty Foglesong, MA, PhD (Theology)
Marina, California

6:15 pm – 8:30 pm

GETTING TO KNOW YOU: POST-POLIO SUPPORT GROUPS

Moderator: Beth Kowall, MS, OTR
Greenfield, Wisconsin
Johan Bijttebier
PostPolio België, Antwerpen, Belgium
Harald Hasle

International Post-Polio Support
Organization, Braskereidfoss, Norway
Ray Taylor
Polio Survivors & Associates, Pinehurst,
North Carolina
Other support group leaders who
are in attendance

6:15 – 7:15 pm and
repeated at 7:30 – 8:30 pm

EXPERIENCE ACUPUNCTURE

Sue Harris
Canton, Massachusetts

6:15 – 7:15 pm and
repeated at 7:30 – 8:30 pm

EXPERIENCE YOGA

David Riley, MD
Editor-in-Chief, *Explore: The Journal
of Science and Healing*, Santa Fe,
New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain
Institute, Conemaugh Health System,
Johnstown, Pennsylvania

6:15 – 7:15 pm and
repeated at 7:30 – 8:30 pm

EXPERIENCE REIKI

Stephanie Machell, PsyD
International Rehabilitation Center
for Polio, Framingham, Massachusetts

6:15 – 7:15 pm and
repeated at 7:30 – 8:30 pm

EXPERIENCE WATSU

Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center,
Saint Louis, Missouri

6:15 – 7:15 pm

THERAPEUTIC USE OF MUSIC: EXPERIENCE MUSICAL ACUPUNCTURE AND MUSICAL BIOFEEDBACK

Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

6:15 – 7:15 pm

SERVICE DOGS FOR PEOPLE WITH NEUROMUSCULAR CONDITIONS AND THOSE WHO USE VENTS

Joanne Kocourek, RN, CCRC,
with Annalies and Kristen
Worth, Illinois
Susan Borgman
Black Coffee Creative,
Wyoming, Michigan

7:30 – 8:30 pm

THERAPEUTIC USES OF THE NATIVE AMERICAN CEDAR FLUTE

Janalea Hoffman, RMT, MA
Rhythmic Medicine, Olathe, Kansas

7:30 – 8:30 pm

EXPERIENCE MYOFASCIAL RELEASE

Nancy Caverly, OTR/L
Cedar Ridge Wellness Center,
Bland, Missouri

8:30 pm – 9:30 pm

MEET FOR HEALTHY TREATS

Program for Friday, June 3, 2005

Program subject to change.
www.post-polio.org for updates

8:00 am – 1:30 pm/REGISTRATION

8:30 am – 9:00 am/
CONTINENTAL BREAKFAST

8:30 am – 3:30 pm/EXHIBITS OPEN

9:00 am – 10:15 am

SESSION I OPTIONS

ASSISTANCE FROM ALLIED HEALTH PROFESSIONALS

Falling: Fear, Risks, and Practical Strategies

Kristine Legters, DSc,PT,NCS
Gannon University, Erie, Pennsylvania

What OTs and PTs Can (and Can't) Do for Polio Survivors

Maria Cole, OTR/L
Laura Ryan, OTR/L
Kristeen Muldoon, MSPT
International Rehabilitation Center
for Polio, Framingham, Massachusetts

COMPUTERS AND THE INTERNET

What a Computer Can Do for You TBA

NCPAD Website: A Friend to Polio Survivors

Sunny Roller, MA
University of Michigan,
Ann Arbor, Michigan

PLANNING AHEAD TO STAY IN YOUR HOME WHEN GETTING OLDER

Moderator: Beth Kowall, MS, OTR
Greenfield, Wisconsin
Stephanie Malench, MSW, LCSW
Full Living Services, Saint Louis, Missouri

WHAT ABOUT NUTRACEUTICALS?

Moderator: Bruce K. Stampley,
PhD, BCH
Albuquerque, New Mexico
Tony Lu, MD
Medical Director, Integrative Medicine,
La Grange Park, Illinois

INTIMACY AND SEXUALITY: MIND, BODY, AND HEART CONNECTIONS

Linda Bieniek, CEAP
La Grange, Illinois
Hannah Hedrick, PhD
Mountain View, Hawaii

CLARIFYING CHOICES

Moderator: Lawrence Becker, PhD
Roanoke, Virginia

The Right Ventilation at the Right Time

Tony Oppenheimer, MD
Pulmonary Medicine (Retired),
Los Angeles, California

Non-Invasive Ventilation for a Tracheostomized Polio-Patient

without Intubation Tube
Grethe Nyholm Olesen (RN)
Respiratory Centre East, Copenhagen
University Hospital, Copenhagen,
Denmark
Birgitte Brandt Lassen (RN)
Copenhagen, Denmark
Lottie Lotte Mortensen (RN)
Institutionen for Respirationspatienter,
Copenhagen, Denmark

10:15 am – 10:45 pm/BREAK

10:45 am – 12:00 noon

SESSION II OPTIONS

ANALYZING YOUR GAIT: THE ROLES OF EXERCISE, BRACING OR SURGERY

Mary Ann Keenan, MD
Orthopaedic Surgery, University of
Pennsylvania, Philadelphia, Pennsylvania
Alberto Esquenazi, MD
Gait & Motion Analysis Lab,
Moss Rehabilitation Hospital,
Philadelphia, Pennsylvania

RESEARCH I: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Moderator: Lauro Halstead, MD
National Rehabilitation Hospital,
Washington, DC

Results of a NHIS Survey: How Info Might Prompt New Research and Care

Nancy Myers, PhD, RN CPHQ
Northeastern Ohio Universities College
of Medicine, Rootstown, Ohio

Update on Growth Factors Used in Mouse Model

Burk Jubelt, MD
Department of Neurology, SUNY Upstate
Medical University, Syracuse, New York

Update on Modafinil Study

Col. William Campbell, MD
Chairman of the Department of
Neurology, Uniformed Services University,
Bethesda, Maryland

UPDATE FROM MEDICARE

Moderator: Jean Csaposs
New Jersey Polio Network,
Martinsville, New Jersey

Prescription Drug Cards

Bill Hunot
Social Security Administration,
Saint Louis, Missouri

Payment for Durable Medical Equipment and Staying in Your Home: What Medicare Can Do for You

Diana Brady
CLAIM, Columbia, Missouri

TRAUMA TREATMENT: WHAT IS IT AND WHAT ARE THE BENEFITS

Stephanie Machell, PsyD
International Rehabilitation Center
for Polio, Framingham, Massachusetts

CAN WE TALK ABOUT IT? BEING PREPARED FOR MEDICAL CRISES, ADVANCE DIRECTIVES, LIVING WILLS

Moderator: Lawrence Becker, PhD
Roanoke, Virginia
Allen Goldberg, MD, FRACP
Chicago, Illinois
Kristi Kirschner, MD
Rehabilitation Institute of Chicago,
Chicago, Illinois

EATING BETTER FOR BETTER HEALTH WITH YOUR FAMILY AND FRIENDS

Jann and John Hartman
Baltimore, Maryland

12:15 pm – 1:15 pm/LUNCHEON

1:30 pm – 2:45 pm

SESSION III OPTIONS

SOLUTIONS FOR OVERUSE AND DISUSE WEAKNESS

Moderator: Glee O. Helms, RN, NP
Novato, California
Frans Nallet, MD, PhD
Rehabilitation Medicine, University
of Amsterdam, Netherlands
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas

continued on page 12

ANALYZING YOUR SLEEP

Moderator: Bill Stothers
San Diego, California

Is It Apnea, Hypoventilation ... or Both ... or Something Else?

Brenda Butka, MD
Vanderbilt Stallworth Rehabilitation
Hospital, Nashville, Tennessee

Sleep Hygiene

William DeMayo, MD
John P. Murtha Neuroscience & Pain
Institute, Conemaugh Health System,
Johnstown, Pennsylvania

SPINAL BRACING & NEW TECHNOLOGY IN LOWER EXTREMITY ORTHOTICS

Mark Taylor, MLS, CPO
Ammanath Peethamaran, MS, CO
University of Michigan,
Ann Arbor, Michigan
Reactor: Alberto Esquenazi, MD
Gait & Motion Analysis Lab,
Moss Rehabilitation Hospital,
Philadelphia, Pennsylvania

SUMMARIES OF SELECT THERAPIES: YOGA, WATSU, REIKI, MYOFASCIAL RELEASE

David Riley, MD
Editor-in-Chief, *Explore: The Journal
of Science and Healing*, Santa Fe,
New Mexico
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain
Institute, Conemaugh Health System,
Johnstown, Pennsylvania
Kathleen Christ, LMT, NCMBT
Saint Louis Aquatic Healing Center,
Saint Louis, Missouri
Stephanie Machell, PsyD
International Rehabilitation Center
for Polio, Framingham, Massachusetts
Nancy Caverly, OTR/L
Cedar Ridge Wellness Center,
Bland, Missouri

EXPLORING STRATEGIES: QIGONG AND ACUPUNCTURE

Tony Lu, MD
Medical Director, Integrative Medicine,
La Grange Park, Illinois
Sue Harris
Canton, Massachusetts

PHI'S WEBSITE: WHAT IT CAN DO FOR YOU AND WHAT YOU CAN DO FOR IT

Sheryl Rudy
Webmaster, Post-Polio Health
International, Saint Louis, Missouri

2:45 pm – 3:15 pm/BREAK

3:15 pm – 4:30 pm SESSION IV OPTIONS

PAIN AND POLIO: PITFALLS, MYTHS AND REALITIES

Moderator: Selma Calmes, MD
Olive View-UCLA Medical Center,
Sylmar, California
Julian Lo, MD, FRCPC
Physical Medicine & Rehabilitation,
West Park Healthcare Centre,
Toronto, Ontario, Canada

FINDING TECHNOLOGY TO MAINTAIN INDEPENDENCE

David Gray, PhD
Program in Occupational Therapy,
Washington University
School of Medicine, Saint Louis, Missouri
Maria Cole, OTR/L
Laura Ryan, OTR/L
Kristeen Muldoon, MSPT
International Rehabilitation Center
for Polio, Framingham, Massachusetts

HOW SELF ASSESSMENT CAN HELP YOU IN OBTAINING BETTER CARE FROM HEALTH PROFESSIONALS

Hilary Hallam
Denise Carlyle, BA, MA, PhD, LRAM
Mary Kinane, BA, PGCE
Lincolnshire Post-Polio Network,
Lincolnshire, United Kingdom
Reactor: Carol Vandenakker, MD
Physical Medicine & Rehabilitation,
University of California Davis
Medical Center

PHI SECOND RESEARCH AWARD: WOMEN WITH POLIO AND THE MENOPAUSE STUDY-PRACTICAL ADVICE BEHIND THE DATA

Claire Kalpakjian, PhD
Sunny Roller, MA
University of Michigan,
Ann Arbor, Michigan

MAINTAINING PULMONARY HEALTH

Monitoring and Preventing: What You Can Do

Tony Oppenheimer, MD
Pulmonary Medicine (Retired),
Los Angeles, California

The Importance of Cough

Augusta Alba, MD
Rehabilitation Medicine (Retired),
Coler Goldwater Specialty Hospital
and Nursing Facility, Roosevelt Island,
New York

IMPROVING BALANCE AND STAMINA VIA PEDORTHIC SOLUTIONS

Edith James, C.Ped.
Michael Lukowsky
Comfort Shoe Specialists,
Saint Louis, Missouri
Dennis Janisse, C.Ped.
National Pedorthic Services, Inc.,
Milwaukee, Wisconsin

6:30 pm – 8:45 pm
Post-Polio Health International's
Awards Dinner & Entertainment

Program for Saturday, June 4, 2005

Program subject to change.
www.post-polio.org for updates

8:00 am – 1:30 pm/REGISTRATION

8:30 am – 9:00 am/
Meetings of Medical and
Consumer Advisory Committees
CONTINENTAL BREAKFAST

8:30 am – 1:30 pm/EXHIBITS OPEN

9:00 am – 10:15 am
SESSION I OPTIONS

THE TRACHEOSTOMY OPTION

What, Why and When

Tony Oppenheimer, MD
Pulmonary Medicine (Retired),
Los Angeles, California

Management of Neuromuscular Breathing Problems:

The Danish Way

Jesper Qvist, MD
Respiratory Centre East,
Copenhagen, Denmark

RESEARCH II: WHAT IS BEING DONE? WHAT NEEDS TO BE DONE?

Moderator: Lauro Halstead, MD
National Rehabilitation Hospital,
Washington, DC

Inflammation of the Central Nervous System: A Treatable Cause of PPS?

Kristian Borg, MD
Karolinska Hospital, Stockholm, Sweden

Update on Stem Cell Research for Neuromuscular Disorders

David Gottlieb, MD
Washington University School of
Medicine, Saint Louis, Missouri

Update on Research at USU

Olavo Vasconcelos, Jr., MD
Physician Research Coordinator,
Uniformed Services University,
Bethesda, Maryland

EXERCISE, PART 1: A DEBATE ABOUT THE DEBATE

Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates,
Marquette, Michigan

Clinical predictors of electromyographic findings of remote polio in "unaffected" limbs of patients with a history of acute paralytic poliomyelitis

Chanda Mayo, MD
Physical Medicine & Rehabilitation,
National Rehabilitation Hospital,
Washington, DC

Opinion of an Experienced PT

Holly Wise, PT, PhD
Medical University of South Carolina,
Charleston, South Carolina

Opinions from Polio Survivors

Jane Atkey
Toronto Peel Post-Polio Community,
Toronto, Ontario, Canada
David Kelly
South Lake Tahoe, California

SCOOTERS AND POWER CHAIRS

The Care and Feeding of
a Scooter or Power Chair
John and Jann Hartman
Baltimore, Maryland

Choosing and Funding a Scooter or Power Chair

Jean Csaposs
New Jersey Polio Network,
Maywood, New Jersey

PREVENTING AND MANAGING SECONDARY CONDITIONS FOR POST-POLIO HEALTH

Alexa Stuijbergen, PhD, RN, FAAN
Tracie Harrison, PhD, RN, MSN, FNP
University of Texas, Austin, Texas

NEW BRACING: THE CHALLENGE AND THE PAYOFF

Marny Eulberg, MD
St. Anthony's Family Medical Center
West, Denver, Colorado
Marmaduke Loke
Dynamic Bracing, Encinitas, California
Reactor: Mark Taylor, MLS, CPO
University of Michigan, Ann Arbor,
Michigan

10:15 am – 10:45 am/BREAK

10:45 am – 12:00 noon SESSION II OPTIONS

OPTIONS FOR MANAGING THE MULTIPLE CAUSES OF FATIGUE

Martin Wice, MD
Physical Medicine & Rehabilitation,
St. John's Mercy Medical Center,
Saint Louis, Missouri
Alexa Stuijbergen, PhD, RN, FAAN
University of Texas, Austin, Texas

EXERCISE, PART 2: WHAT STEPS TO TAKE

Moderator: Frederick Maynard, MD
U.P. Rehabilitation Medical Associates,
Marquette, Michigan

Suggestions from ...

Mary Klein, PhD
Director, Post-Polio Project,
Moss Rehab Research Institute,
Philadelphia, Pennsylvania
Barbara Duryea, RN
John P. Murtha Neuroscience & Pain
Institute, Conemaugh Health System,
Johnstown, Pennsylvania
Holly Wise, PT, PhD
Medical University of South Carolina,
Charleston, South Carolina

Reactions from Polio Survivors

Jane Atkey
Toronto Peel Post-Polio Community,
Toronto, Ontario, Canada
David Kelly
South Lake Tahoe, California

VENTILATOR USERS: GETTING YOUR ACT TOGETHER AND TAKING IT ON THE ROAD

Audrey King
Toronto, Ontario, Canada
Barbara Rogers
Respiratory Resources, Inc.,
New York, New York
Sponsored by Pulmonetic Systems, Inc.

CHOOSING TO FLOURISH: WHAT WORKS FOR ME

Linda Wheeler Donahue
The Polio Outreach of Connecticut,
Southbury, Connecticut
Dorothy Woods Smith, PhD, RN
Houses of Healing, Portland, Maine

LONG-TERM CARE: BUYING IT AND SECURING IT

Moderator: Saul Morse
Springfield, Illinois
Matt McCann
Darien, Illinois

12:15 pm – 1:15 pm/LUNCHEON

1:30 pm – 2:45 pm SESSION III OPTIONS

OPTION IF A POST-POLIO CLINIC IS NOT AN OPTION

Moderator: Mary Louise Dickson
Toronto, Canada
Carol Vandenakker, MD
Physical Medicine & Rehabilitation,
University of California Davis Medical
Center, Sacramento, California
Reactor: Armand Zilioli, MD
Bay Pines VA Medical Center,
Saint Petersburg, Florida

EXPRESSING SEXUALITY: WHAT WORKS FOR ME

Moderator: Linda Bieniek, CEAP
La Grange, Illinois
Panel: TBA

INTERFACES: NEW, TRIED AND TRUE, AND CUSTOM

Barbara Rogers
Respiratory Resources, Inc., New York,
New York
Sponsored by Pulmonetic Systems, Inc.
Diana Guth RRT
Home Respiratory Care, Los Angeles,
California

COLLABORATION WITH PHI AND WITH EACH OTHER

Moderators:
Beth Kowall, MS, OTR
Greenfield, Wisconsin
Joan Headley
Post-Polio Health International,
Saint Louis, Missouri
Representatives of post-polio
organizations

BREATHING TRAINING: DEVELOPING A USER- FRIENDLY BODY

Betsy Thomason, RRT
Park Ridge, New Jersey

2:45 pm – 3:15 pm/BREAK

3:15 pm – 4:15 pm SESSION IV (PLENARY)

TRANSLATING GOOD IDEAS INTO PRACTICE, WHAT ABOUT TOMORROW?

Kristi Kirschner, MD
Rehabilitation Institute of Chicago,
Chicago, Illinois

4:15 pm – 4:30 pm
CLOSING SESSION

GENERAL INFORMATION

Hotel Information

Space is reserved at the Marriott Saint Louis Downtown, 1 Broadway, Saint Louis, MO (Missouri) 63102 (314-421-1776). The Marriott Saint Louis Downtown is located just north of Busch Stadium on Broadway (one-way, southbound) between Market Street (two-way with median) and Walnut Street (one-way, eastbound, between the Marriott and Busch Stadium).

If you are interested in sharing a room, contact PHI for a list of potential roommates.

Make reservations online at https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=18966, or call 800-266-9432.

Shower benches and commode units will be made available as modifications in regular rooms. If you have need of either modification or an accessible room, you should call 314-421-1776 and ask for Sandy or Kay to make a reservation.

Some accessible rooms have been reserved at the Adam's Mark Hotel, Fourth & Chestnut (www.adamsmark.com/stlouis). Call 800-444-ADAM (2326) for reservations. Ask for the Post-Polio Health International meeting. A credit card number is required. The Adam's Mark Hotel is two blocks from the Marriott Saint Louis Downtown.

Information about Saint Louis and Other Hotels

Contact the Saint Louis Convention & Visitors Bureau at 800-888-3861 or visit www.explorestlouis.com. (Note: The Saint Louis Cardinals will not be in town.)

Parking

At the Marriott, valet parking is available at the Broadway entrance (\$21/day). Parking is also available in the Stadium Park East garage, across Broadway, for \$19/day.

Transportation from the Airport

www.lambert-stlouis.com/index/ground.html

METROLINK: MetroLink is Saint Louis' light rail system. It is located on the upper level of the Main Terminal at Exit MT1 and the East Terminal through the parking garage on all levels. Operating daily from 5 am until midnight, with tickets priced at \$3 for an adult one-way trip from the airport, less for seniors and children under 12. There is no charge to ride between the East and Main Terminals. Disembark at Busch Stadium, the closest station to Marriott Saint Louis Downtown (about two blocks).

TAXIS: Board at Main Terminal, Exit MT14 (yellow level of garage) or East Terminal, Exit ET12. Approximate cost one-way \$32.00. Harris & Eagle Para-Lift Service, 314-535-5087, \$49 one-way, recommends at least one day's notice in advance.

GEM SHUTTLE/TRANS EXPRESS

TRANSPORTATION: Provides shared van service to downtown hotels (including Marriott Saint Louis Downtown). Purchase tickets and board at: Main Terminal, Exit MT12; East Terminal, Exit ET12. Tickets are \$13.00 one way, \$21.00 round trip.

For their lift-equipped van service, call 800-844-1985 a few days in ahead.

Advanced reservation limousine/van services are available for transportation to your destination in Saint Louis and surrounding Missouri/Illinois locations. Phone 314-427-3311.

Scooter and Wheelchair Rental

Individuals wanting to rent a scooter should contact Scootaround, Mobility Product Rentals (www.scootaround.com/rentals/postpolio or call 888-441-7575).

Personal Assistance Services

Individuals wanting personal assistance services may contact Lari Calder, Assistant Director of Independent Living and Housing, Paraquad (314-567-1558).

NOTE: Smoking will not be permitted in the conference meeting rooms.

Available at the Conference:

Many of the sessions will be audio taped, with tapes being available on site. Attendees will receive a Program Book with summaries of the sessions and a Catalogue of Resources for Post-Polio Health and Ventilator-Assisted Living. All three resources will be available after the meeting on www.post-polio.org and in future issues of *Post-Polio Health*.

Name _____ Date _____
First Middle Initial Last Degree(s)

Institution/Organization (if applicable) _____

Address (Check one.) ☐ Home ☐ Business _____

City _____ State/Province _____ Zip/Postal Code _____

Country _____ email _____

Phone (Check one.) ☐ Home ☐ Business _____ Fax _____
Include Area/Country Code Include Area/Country Code

PHI Member ID Number (if known): _____

For program accessibility, list special needs (i.e., interpreter, braille, etc.): _____

FULL DAY REGISTRATION includes "Meet for Healthy Treats" on Thursday evening and Continental Breakfasts on Friday and Saturday.

SINGLE DAY REGISTRATION includes "Meet for Healthy Treats" with Thursday registration and Continental Breakfasts with Friday or Saturday registration. See "MEALS" (below) for lunch and dinner information.

FULL REGISTRATION

Individual with disability:

Prior to May 2

After May 2

☐ \$170

☐ \$190

Individual with disability and one attendant/family member:

☐ \$240

☐ \$260

Name of attendant/family member: (for badge) _____

Health Professional and Others:

☐ \$250

☐ \$270

SINGLE-DAY REGISTRATION

Individual with disability: ☐ Thursday ☐ Friday ☐ Saturday

\$65/day \$ _____ \$70/day \$ _____

Individual with disability and one attendant/family member:

☐ Thursday ☐ Friday ☐ Saturday

\$85/day \$ _____ \$90/day \$ _____

Name of attendant/family member: (for badge) _____

Health Professional and Others: ☐ Thursday ☐ Friday ☐ Saturday

\$90/day \$ _____ \$95/day \$ _____

Thursday Evening Twilight Session & "Healthy Treats" (\$25/session & treats)

How many? _____ \$25/ea. \$ _____

Cancellation: 85% of the registration fee will be refunded if cancellation is made by written notice and received by PHI before May 2, 2005. The registration fee cannot be refunded after May 2, 2005.

Minus discount for Contributor or Sustainer Members

(-\$10/day or -\$40 for full registration): \$ _____

Registration Subtotal: \$ _____

MEALS Please indicate quantity of meal package(s) or individual meal(s):

___ Complete Meal Package (includes all four meals listed below) \$115/each package

___ Thursday lunch \$25/each

___ Friday lunch \$25/each

___ Friday dinner \$40/each

___ Saturday lunch \$25/each

(Vegetarian options available at every meal.)

Meals Subtotal: \$ _____

TOTAL AMOUNT DUE: \$ _____

Payment of Fees: ☐ Check or Money Order enclosed (US dollars only, payable to "Post-Polio Health International")

☐ MasterCard ☐ VISA ☐ Discover Card Number _____ Exp. date _____

Name on Card (please print) _____ Signature _____

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	C	CC		

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.

Correction

In the last issue of *Post-Polio Health* (Vol. 20, No. 4), on page 8, second column, first full paragraph, the first sentence should read "I started taking .4 mg of injectable gh five days per week in May 2002."

New Support Group

Polio survivor Bruce K. Stampely, PhD, announces the formation of Polio Survivors, Inc. (PSI) for polio survivors in New Mexico. Contact PSI, 8220 La Mirada, Suite 300, Albuquerque, NM 87109 (505-944-2406; PSIDoc@comcast.ent) for details.

Post-Polio Directory 2005 will be available after March 1, 2005 and will be mailed to those who subscribed. It is free online at www.post-polio.org/ipn/locate.html or for \$8 (USA); \$10 (Canada & Mexico); \$12 (Overseas Air). The *Post-Polio Directory* is a benefit of Contributor and Sustainer Memberships in PHI.

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SPECIAL THANKS TO ...

Richard Feltes

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HOW TO CONTACT US ...

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314-534-0475, 314-534-5070 fax

info@post-polio.org, www.post-polio.org

Sponsored in part by



The Winter 2005 issue of *Post-Polio Health* features ... Metal/Leather Leg Brace to Plastic/Metal Hybrid ... Flying to Norway... April 15, 1955, An important day in the history of poliomyelitis ... Program & Registration Info for STRATEGIES FOR LIVING WELL ... and more!

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
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