PHI Awards Research Grant to University of Arkansas Team

Post-Polio Health International (PHI) awarded a \$25,000 research grant to a team from the University of Arkansas for Medical Sciences (UAMS), Little Rock. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.

PPS is a slowly progressive neurodegenerative disease that occurs many years later in individuals previously affected by paralytic poliomyelitis due to the poliovirus infection. The causes of PPS are unknown but it is characterized primarily by new muscle weakness that negatively affects the quality of life of survivors.

"Although the research is in its very early stages ... a biomarker for post-polio syndrome that can be potentially measured in an individual's blood should enable a more rapid and more definitive diagnosis," states Rahnuma Wahid. PhD. Marie Chow, PhD, **Professor, Departments** of Microbiology and Immunology, and Pathology, and Katalin Pocsine, MD. **Assistant Professor of** Neurology, are part of the research team.

Biomarkers are biological measures found associated with specific diseases. They are useful because they can assist in disease diagnosis or provide a means of monitoring disease development and progression.

The researchers at UAMS recently detected the increased presence of a distinct immune cell population in the blood of individuals with PPS but not healthy individuals, although the number of donors examined was small. The detected cells represent a recently described subtype of T cells, known as regulatory T cells (Tregs).

The research award will fund a small pilot study that will determine whether development of PPS is associated with increased numbers of Tregs, and whether the Tregs found in individuals with PPS have unusual properties as compared with those in healthy individuals.

"We are very grateful to PHI for their support of this research. Although the research is in its very early stages and our initial results need to be rigorously tested in a much larger group of individuals with PPS, a biomarker for PPS that can be potentially measured in an individual's blood should enable a more rapid and more definitive diagnosis of this debilitating disease," said Principal Investigator Dr. Rahnuma Wahid, Postdoctoral Research Assistant, Microbiology and Immunology Department, at UAMS.

"A definitive diagnosis of PPS is difficult because it is based on past history, which may be lost or incomplete, or dependent on recall. The diagnosis is complex and unreliable because many symptoms of PPS overlap those of other diseases including osteoarthritis, fibromyalgia, hypothyroidism and a number of neurological conditions. Available treatments are limited, so finding a definitive test for PPS would not only help with a diagnosis but would also help develop potentially more effective therapies," said Joan L. Headley, Executive Director of Post-Polio Health International.



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Special thanks ...
Nancy Baldwin Carter
Judith R. Fischer

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To be sure you receive email updates from PHI, set your spam filters to allow messages from info@post-polio.org and news@post-polio.org.

Inside this Issue ...

Pages 4 and 5

Gastroesophageal Reflux Disease

Nancy Baldwin Carter, Founder and former director, Nebraska Polio Survivors Association (NPSA), Omaha, Nebraska, writes about GERD. Is GERD more prevalent in polio survivors? We don't know of a bona fide survey



that says "yes," but conditions such as scoliosis, problems with swallowing, and difficulties due to lower body weakness can make us likely candidates.

Pages 1 and 3

The Research Fund of Post-Polio Health International

When the family of Thomas Wallace Rogers sent word to PHI (then Gazette International Networking Institute) through his physician, Oscar A. Schwartz, MD, that he wanted us to start a Research Fund, we accepted the offer, established our aims and began to raise additional funds.

Pages 6 and 12

We list new books about polio each quarter. Some are published by noted houses; some are self-published. Is there more to say about polio and post-polio? We are preserving our collective history, and, individually, we are "coming to terms."

Pages 7 and 8

As polio survivor Arnold Snyder, West Palm Beach, Florida said, "We are getting older and weaker, but that does not mean we don't want to go out and enjoy life." Members share what works for them. Diane Kirlin Murphy relates a travel nightmare and what she did about it.

Page 9

Acute poliomyelitis cases are increasing in some parts of the world. See the latest statistics.

Page 10

Meet the newly elected Board of Directors and Officers of Post-Polio Health International.

-Joan L. Headley, Executive Director of PHI

Research

The Research Fund Exceeds Half Million: Past Grants Fulfill Aims

he Research Fund of Post-Polio Health International (PHI) surpassed \$500,000 in 2006. Begun in 1995 with a generous bequest from polio survivor Thomas Wallace Rogers, Moline, Illinois. The Research Fund continues to grow and allows PHI to fund projects from its earnings that are relevant to the lives of polio survivors. The major aim of The Research Fund is to improve the lives of people with neuromuscular conditions.

Another aim is to provide seed money to talented young researchers as they study unexplored areas and unanswered questions. Claire Kalpakjian, PhD, from the University of Michigan, is an excellent example of that success. Kalpakjian, recipient of PHI's second \$25,000 grant, has had five articles published in peer-reviewed journals related to her research about menopause and women who had polio; several more publications are planned for 2007.

Kalpakjian is in her third year of a \$470,000 career development award from the National Center for Medical Rehabilitation Research at the National Institutes of Health. This award supports junior investigators in further training and experience to become principal investigators. Successful awardees typically have some experience independently leading a small study, such as Dr. Kalpakjian did with PHI's grant. Her current research focuses on menopause in women with spinal cord injury using her previous work in women with post-polio as a springboard.

The third recipient, Noah Lechtzin, MD, MHS, Johns Hopkins University, recently reported on a retrospective study of patients with amyotrophic lateral sclerosis (ALS). It concluded that survival from time of diagnosis was nearly a year longer in the group who started noninvasive positive pressure ventilation (NPPV) use when their forced vital capacity (FVC) was 65% of predicted.

When asked if early use of NPPV could benefit polio survivors, Lechtzin responded, "This is a challenging question. The time to start NPPV in ALS is better defined than in other neuromuscular conditions, but even in ALS it is not clear-cut. My feeling is that until more definitive information is available, this question should be approached clinically.

"I do not think there is any absolute value of FVC or other pulmonary function test that will determine if any individual with post-polio syndrome will benefit from NPPV.

"However, if individuals have shortness of breath (dyspnea), need to sleep sitting up (orthopnea), fatigue, hypersomnolence, or difficulty sleeping, NPPV may be beneficial."

The first award given in 2001 was for a qualitative study of ventilator users' perspective of life with a ventilator. The final report – "Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life" is one of the more frequently accessed documents on PHI's website, www.post-polio.org.

How to Contribute

Contributions to The Research Fund can be sent to: PHI, 4207 Lindell Blvd., #110, Saint Louis, MO 63108. Checks should be made payable to Post-Polio Health International, with "The Research Fund" on the memo line.

Together we can improve the lives of polio survivors worldwide.

Gastroesophageal Reflux Disease

Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

"It was the peach pie that did it. Not long after I devoured a hearty slice of this scrumptious dessert. my insides began to feel like a volcano - hot, roiling eruptions, ugly, painful pressure. This was no delicate dyspepsia. This was a major assault on my esophagus. Lots of antacid over the next few hours finally settled me down, and I decided it was time to start paying attention to my GERD."

Although estimates vary, between 7-10% of the US population experiences GERD. The percentage markedly increases after age 40.

The Problem

GERD is gastroesophageal reflux disease, a chronic condition that some people think of as heartburn. Often it feels like that, a burning sensation in the chest. What's actually happening is that acid (or sometimes bile) from the stomach is backing up into the esophagus.

When we eat, food and liquids go down the esophagus to a muscle at the bottom called the lower esophageal sphincter (LES). The LES loosens its hold on the esophagus to allow what we've consumed to continue into the stomach. Then it tightens again, closing the passage from esophagus to stomach. When the sphincter doesn't function properly, because it's too weak to hold the esophagus shut, then stomach acid can wash back up (reflux) into the esophagus. A stomach that is slow to empty can produce the same problem. Eventually this can cause the esophageal irritation and inflammation known as GERD.

As individuals age, all parts of their bodies begin to show wear and tear, so it's possible for acid reflux to develop or worsen. Certain physical changes caused by polio may contribute to the chance of experiencing GERD. For example, scoliosis, swallowing problems, or lower body weaknesses may play a role in this scenario.

Common symptoms of GERD include chest pain (which always needs to be checked out, since this is easy to confuse with a heart problem), persistent coughing, a sore throat or hoarseness caused when the acid refluxes to the area of the larynx (voice box) and pharynx (throat), and even asthma. A sour taste in the mouth and belch-

ing can also be signs to watch for. We're advised to seek professional advice if we experience acid reflux several times a week or if it takes repeated doses of antacid to stop it.

Certain conditions can add to the probability of having GERD because of the various effects they have on the stomach particularly, but also the LES and esophagus. Some examples of these are obesity, diabetes, hiatal hernia, peptic ulcer and connective tissue disorder. Your doctor will be able to identify others.

If left untreated, GERD can be serious. Scar tissue that forms when cells in the esophagus are damaged by repeated assaults from acid may narrow the food pathway, causing food to get caught, making swallowing difficult. Or an esophageal ulcer can form when acid erodes tissue that lines the esophagus, causing pain and bleeding and swallowing problems. Occasionally a cellular change occurs over time after frequent acid refluxes. This is known as metaplasia, and it can mean an increased risk of esophageal cancer.

What We Can Do

We can take steps to try to keep GERD from getting worse. Certain lifestyle changes can make a big difference. Here are some common suggestions:

Stop smoking – Smoking encourages stomach acid, belching and reflux.

Stay away from acid reflux "triggers" — Food and drink such as alcoholic beverages, coffee, caffeine, carbonated drinks, orange juice, grapefruit juice, chocolate, tomatoes and food made with tomatoes, fried foods, fatty foods, spicy foods, garlic, onions and even mint (never mind that antacids

are often flavored with mint). If a certain food or preparation method causes problems, avoid it.

Weigh less and eat less – Being overweight can push up on the stomach, which forces acid into the esophagus. Eating too much at one time can also pressure the LES to open, causing acid reflux.

Take the pressure off – Give food a good chance to get to its destination: wear clothes that don't bind at the waist. Resist lying down after eating, as well as doing jobs that require stooping and bending, such as gardening. Eat at least three or four hours before going to bed.

Let gravity help – Raise the head of your bed six-eight inches with cement or wooden blocks, or place a wedge (sold at most pharmacies) between the mattress and box spring.

Mellow out - Stress can be a factor.

Check with your doctor – It's possible for certain medications such as tranquilizers, calcium channel blockers, and sedatives to make GERD worse.

Treatment

There are many ways of treating acid reflux, depending upon its severity. Over-the-counter antacids such as Tums®, Mylanta®, Maalox® and Rolaids® (which neutralize acid) are what most people reach for first. *H-2-receptor blockers* such as Zantac®, Tagamet® and Pepcid® (which reduce acid production) and proton pump inhibitors such as Prilosec® (which block acid production) can now be purchased at an over-the-counter strength.

For those who have more than a little heartburn now and then, prescription-

- The role of hiatal hernia in GERD continues to be debated and explored. It is a complex topic because some people have a hiatal hernia without having reflux, while others have reflux without having a hernia.
- Much research is needed into the role of the bacterium *Helicobacter pylori*. The ability to eliminate *H. pylori* has been responsible for reduced rates of peptic ulcer disease and some gastric cancers. At the same time, GERD, Barrett's esophagus, and cancers of the esophagus have increased. Researchers wonder whether having *H. pylori* helps prevent GERD and other diseases. Future treatment will be greatly affected by the results of this research.

National Institute of Diabetes and Digestive and Kidney Diseases www2.niddk.nih.gov

strength medication may be necessary. Again, there are many options.

Stronger versions of H-2-receptor blockers include Zantac®, Pepcid®,
Tagamet® and Axid®. Prevacid®,
Nexium®, Prilosec®, Protonix® and
AcipHex® are examples of prescriptionstrength proton pump inhibitors. A thorough discussion about symptoms and side effects will help find the right medication.

If medications are ineffective or cannot be tolerated, there are certain medical procedures available, though they are seldom needed because medications usually handle the situation. Various types of fundoplication are possible. One is laparoscopic surgery, which "tucks up" the LES to tighten it. Another restructures the LES to give it the strength it needs to resist reflux.

Other procedures can be done endoscopically. Individuals should discuss these surgeries carefully with their doctors if one of them is recommended. Risks accompany all surgery, and some of these can be greater for certain polio survivors. For instance, survivors with pulmonary problems and those who use ventilators need to take great care in arranging the details of their surgical experience.

In the end, the smart thing for people like me to do is to make a thorough list of symptoms, discuss them with their doctor/gastroenterologist, pay attention to treatment choices, and then follow the plan the two have laid out together.

Resources

About GERD, International Foundation for Functional Gastrointestinal Disorders, www.aboutgerd.org.

Calmes, Selma Harrison, MD, Chairman and Professor, Anesthesiology Department, Olive View/UCLA Medical Center, Sylmar, California.

The Facts about Acid Reflux Disease, TAP Pharmaceuticals, Inc., Lake Forest, Ilinois.

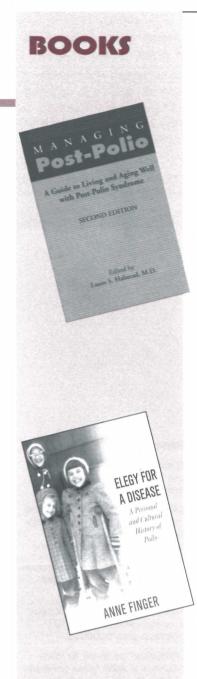
Heartburn/GERD, MayoClinic.com, www.mayoclinic.com/health/heartburn-gerd/DS00095.

LPR Reflux, The Center for Voice Disorders of Wake Forest University and The Department of Otolaryngology, Bowman Gray School of Medicine.

Milone, Mark J., MD, Gastroenterologist, Bergan Doctors Building, Omaha, Nebraska.

Orr, W.C. Night-time gastroesophageal reflux disease: prevalance, hazards and management. *Eur. J. Gastroenterol. Hepatol.* 17, 113-120 (2005).

The Word on GERD, American College of Gastroenterology, www.acg.gi.org/patients/gerd/word.asp.



Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition, 2006)

Edited by Lauro S. Halstead NRH Press, Washington, DC

Lauro S. Halstead, MD, in conjunction with National Rehabilitation Hospital (NRH), Washington, DC, and NRH Press, offers a new, fully revised Second Edition of Managing Post-Polio (1998). Edited by Halstead, the book provides a comprehensive overview dealing with the medical, psychological, vocational and the many other challenges of living with post-polio syndrome. The majority of the 15 contributing health professionals are polio survivors themselves.

The 304-page, 6 x 9 (ISBN 0-9661676-6-X) paperback with index retails for \$13.95. Shipping is \$4.25 for one book, and \$7.50 for two or more copies. Orders should be mailed, called or faxed to NRH Press, National Rehabilitation Hospital, Publications Office, 102 Irving Street, NW, Washington, DC 20010-2949; 202-877-1776; 202-829-5161 fax. Discounts are available for larger orders by calling NRH Press.

In addition to announcing the release of this book, NRH announced the appointment of Elizabeth Kilgore, MD, as Co-Director of its Post-Polio Clinic that celebrated its 20th Anniversary in 2006. Kilgore sees patients at the main hospital on Irving (202-877-1620) and at the NRH Regional Rehab Centers at Bethesda and Olney. Dr. Halstead sees patients at the Irving address outpatient clinic.

Elegy for a Disease: A Personal and Cultural History of Polio (2006)

Anne Finger

St. Martin's Press, New York (www.stmartins.com)

Finger interweaves the story of poliomyelitis with her history of having the disease. She admits distancing herself from other disabled people until the early '80s. She writes of very shadowy memories of having polio at age three and relates "memories of memories" or "memories about stories our family told." Finger believes the intensive rehabilitation gave her a strong sense of "never give up," which she thinks is simultaneously her best and worst characteristic.

The 289-page (ISBN 0-312-34757-X) hardcover retails for \$25.95 USA; \$34.95 Canada. Check with your local or online bookstores.

Finger, who now lives in Oakland, California, taught creative writing at Wayne State University in Detroit and at the University of Texas in Austin. She was president of the Society for Disability Studies and continues to be active in the disability rights movement.

Polio: A Dose of the Refiner's Fire -- Surviving Polio (2005)

Jeane L. Curev Dille

AuthorHouse, Bloomington, Indiana (www.AuthorHouse.com)

Many polio stories are written by people who had polio as a child, but Dille had bulbar polio in 1952 at the age of 28. She was a wife, a mother of two and, within a year of returning home with both arms in slings, was forced back into the work force to save her home.

The softcover 6 x 9 book (ISBN 9781420803938) can be ordered from AuthorHouse (800-839-8640) for \$10.25 plus s&h.

polio: A Dose of

the Refiner's Fire

Surviving Polio

Jeane L. Curey Diffe

Networking
From Our Members

Do you have a special device or trick that helps you live independently? Have you located a talented shoemaker, back brace or corset maker, or other specialist? Send your solutions to editor@post-polio.org or to PHI, 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930 USA.

Making life easier ...



"The One Touch™ Automatic Can
Opener works like a charm and can be purchased for around \$28 by calling 800-742-2263
or online at www.haband.com." Jane Dummer,
Baltimore, Maryland (dummersings@hotmail.com)



"The UpLift Seat Assist helps me get up from various chairs around the house. It uses a hydro-pneumatic mechanism; no electricity or batteries. I had to use it a while to have confidence in it. You can order it from Uplift Technologies, Inc., 11 Morris Drive, Unit 125, Dartmouth, Nova Scotia, B3B 1M2 Canada (www.up-lift.com; 800-387-0896)."

Dan Hindle, Saint Louis, Missouri



"My husband and I both had polio. It is very difficult for him to transfer now, and I can't help like I used to. We have installed a lift from SureHands® Lift & Care Systems, Pine Island, New York (www.surehands.com: 800-724-5305). Ours is from the HM 2500 series and is rather expensive, but we saved for this possibility." Mary Ann Buckingham, Worth, Illinois

Searching for ...

"I have people stopping me all the time asking where I got my arm supports. They were made for me at Warm Springs. Is there any place that makes a device like this today? If so, contact PHI." Jean Davis





"Does anyone remember the Gordon Brock Belt?

It has stays like a corset and laces up the back. In the front, an oval-shaped soft pad fits directly over the chest cavity, with the bottom over the diaphragm. It is spring-loaded on the front so that every time one inhales, this activates the spring, which then pushes on the diaphragm to help with exhaling." Joe Roberts, Valley, Nebraska (lojorob@cox.net or 402-359-2446)

Advocacy

Nightmare in San Francisco

Below are excerpts from a letter Diane Kirlin Murphy wrote to the Transportation Security Administration (TSA), followed by excerpts from their response. If you would like to read the letters in their entirety, go to www.post-polio.org or call PHI.

Diane Kirlin Murphy, Erdenheim, Pennsylvania

"My point in documenting this incident is not to protest the fact that it will take longer to 'clear' me any time I fly. ... I just need some sort of clarification." "I am a polio survivor and have been paralyzed since childhood which requires me to wear two long leg braces (KAFOs), walk with forearm crutches and always use a manual chair when I travel. Last August I flew from Philadelphia to San Francisco ... and breezed through the security checkpoint after a body pat-down and an inspection of my wheelchair.

"On the way home, I was told to wait for a female security screener ... while my belongings went through the metal detector. After a full body pat-down, I was told that I would not be cleared to fly until I submitted to further inspection of my legs and braces. ... I was told to drop my pants, while they offered to hold up a sheet to prevent onlookers from seeing what was going on!

"It was at this point I refused. I cannot physically stand and drop my pants while maintaining my balance. Never mind the absurdity of disrobing behind a sheet The TSA would not give me my crutches or my handbag because I had not been cleared. I was then told that I could not fly that day if I did not submit to the search and ... that I could not go to the bathroom until I was cleared. This was getting out of control. By now I was swelling with outrage and in tears. I had no choice but to submit to the humiliating and demeaning strip search by two female security officers. They reluctantly agreed to allow the search to be conducted in an adjoining ladies room, and ... then I was allowed to use the bathroom, and fly home."

Sandra Cammaroto, Disability Programs Division, Office of Civil Rights and Liberties, TSA

"Although every person and item must be screened before entering each sterile area, it is the manner in which the screening is conducted that is most important." "At the outset, please accept my sincere and deepest apology An investigation of this incident with Transportation Security Officers (TSO) management in San Francisco revealed that they applied the wrong procedure, explosive trace detection (ETD) sampling, to your metal leg braces

"Whenever a person wearing a support appliance alarms the walk-through metal detector, they must undergo additional screening. A visual inspection should be conducted on the exterior accessible area of the support appliance, the areas that can be assessed by a person lifting his/her pant leg, shirt sleeve, or raising a skirt to knee-level. If no area can be assessed, a limited pat-down will be conducted to ensure that no prohibited items are being concealed. At no time during the process, should you be required to remove your support brace for additional screening or remove your clothing.

"... The exact screening procedure depends on whether the individual can stand and walk, only stand or not stand at all. TSOs are taught to offer a private screening for the pat-down inspection. A companion/assistant may accompany the passenger to the area after he/she clears screening to provide assistance

"Walkers, crutches, and canes that can fit through the machine must undergo x-ray screening TSOs should have allowed you to have your cane [Murphy's letter referred to crutches] once it had cleared to assist you during the screening process; however, ... your handbag cannot be given back to you until you have cleared the screening process.

"Regarding use of the restroom once a passenger enters the screening process, he/she cannot exit it until screening is complete."

For more information on the screening process geared for people with disabilities, visit tips for "Travelers with Disabilities & Medical Conditions" located at www.tsa.gov under "Our Travelers."

Global Poliovirus Weekly Update

Data as of 9 January 2007

| Total cases | In 2006 | Compared to same period in 2005 |
|--------------------------|---------|---------------------------------|
| Globally | 1902 | 1802 |
| In endemic countries | 1783 | 808 |
| In non-endemic countries | 119 | 994 |

Case breakdown by country

| Country India | Cases 641 | Compared to same period in 2005 63 | Date of onset of most recent case 5 December 2006 |
|-------------------------|--------------|------------------------------------|---|
| Pakistan | 39 | 26 | 30 November 2006 |
| Afghanistan | 31 | 7 | 28 November 2006 |
| Nigeria | 1072 | 703 | 21 November 2006 |
| Somalia | 34 | 153 | 17 November 2006 |
| Kenya | 2 | 0 | 13 November 2006 |
| Ethiopia | 17 | 20 | 7 November 2006 |
| Bangladesh | 17 | 0 | 4 November 2006 |
| DRC | 12 | 0 | 25 October 2006 |
| Niger | 11 | 9 | 23 October 2006 |
| Cameroon | 1 | 1 | 22 August 2006 |
| Nepal | 2 | 4 | 1 August 2006 |
| Angola | 1 | 9 | 27 June 2006 |
| Namibia | 19 | 0 | 26 June 2006 |
| Indonesia | 2 | 297 | 20 February 2006 |
| Yemen | 1 | 478 | 2 February 2006 |
| | | | |

Source: Global Polio Eradication Initiative (www.polioeradication.org)

Assistance for Purchasing Bracing/Shoes

Post-Polio Health International received a grant to assist individuals who had polio in purchasing new bracing or custommade modified shoes.

The funds of \$3,000 from Special People in Need, Chicago, Illinois, will be given based on need. The maximum amount available to one polio survivor is \$500.

Polio survivors living in Missouri may apply for funds (\$500 maximum) for bracing/shoes from the Gilbert Goldenhersh Memorial Tribute Fund.

To receive an application for either, call Maria at 314-534-0475, or email her at maria@post-polio.org. 🔺

Special Thanks to Our Supporters

Recent contributions to The Research Fund ...

In honor of Linda Bieniek Debra Hansen

Ruth Zimmerman

In memory of

Jim Chapin Jack Genskow

Professor Peter L. Hammer Catherine Murray Hencmann Verdie B. & Erlyne Pope Presley

Daniel Karol Yasko

Recent contributions to PHI's educational, advocacy and networking activities ...

In honor of

Lawrence & Charlotte Becker Morton Freilicher Jim & Judy Headley William B. Krieg Viola Malmgren Eugene Smith

In memory of

Dail Woodward Brown Nat Chrisler Preston Covey, Jr. Cleo Marie Fowler Professor Peter L. Hammer William B. Harford Donald Wilfong Lyn Wolf Bob Zondler

Margaret Zonnevylle



Post-Polio Health International Board of Directors Met for Strategic Planning in October

(Front row)

President/Chairperson: Lawrence C. Becker, PhD, Fellow of Hollins University, Professor of Philosophy Emeritus, College of William and Mary, Roanoke, Virginia Vice President: William G. Stothers, The Center for an Accessible Society, San Diego, California

Allison "Sunny" Roller, MA, Mary E. Switzer Distinguished Research Fellow, Ann Arbor, Michigan

Assistant Treasurer: Saul J. Morse, Legal Counsel, Brown Hay & Stephens, LLP, Springfield, Illinois

(Back row)

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Richard W. Hokamp, Attorney-At-Law, Saint Louis, Missouri

Assistant Secretary: Gayla Hoffman, Public Relations Consultant, Saint Louis, Missouri Executive Director: Joan L. Headley, Saint Louis, Missouri

The following Board members joined the planning sessions via conference call: Selma Harrison Calmes, MD, Chairman and Adviser, Anesthesiology Dept, Olive View/UCLA Medical Center, Sylmar, California

Judith E. Heumann, MPH, Lead Consultant, Global Partnership for Disability and Development (GPDD), World Bank, Washington, DC

Daniel J. Wilson, PhD, Muhlenberg College, Allentown, Pennsylvania

The PHI Board met in Saint Louis to review strategic plans for serving its members whose needs are increasing as they age. PHI is committed to serving its core constituency and is exploring ways to best reach and address the needs of polio survivors around the world, particularly in countries where polio has only recently been eradicated. Several initiatives are being considered, and details will be forthcoming as they are available.

Tabor Challenge Grant Met by PHI Members

Robert Tabor, Emporia, Kansas, a longtime PHI member, chose to honor newly-elected PHI Board Chair, Lawrence C. Becker, Roanoke, Virginia, who was a "classmate" from polio rehabilitation in Omaha, Nebraska, in the 1950s (see photo below), by issuing a challenge grant to PHI Members.

The challenge of matching a \$10,000 gift was immediately met by:
Gwen Babcock
Lawrence C. Becker
Clark S. Callahan
Jerome S. Grady
Judith E. Heumann
Frederick M. Maynard, MD
Marshall Payn
Sam L. Sanders

"Bob had a lot of great ideas when we were roommates at the rehab center, too. Most of those got us in trouble. This one, though, has been a terrific benefit to PHI. If anyone else wants to honor their own old roommate, or put out a challenge on behalf of a particular rehab center, let us know!" -Larry Becker



Larry Becker (left) and Robert Tabor with friend Sally in 1954.



Support Post-Polio Health International's educational, research, advocacy and networking mission.

*Active members are sent reminders when their Membership is due.

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Membership Application

Name

on card ____ Signature

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ULTIMATE DIAGNOSIS OF 1000 SUSPECTED POLIOMYELITIS ADMISSIONS

| S.W.P.R.C. (Five-year Period) | Number | Per Cen |
|--|--------|-------------------|
| Non-Poliomyelitis Non-Paralytic Poliomyelitis° Paralytic Poliomyelitis | | 15% 26% 59% |
| Total | | 100% |

PHI periodically receives calls from individuals who thought they had polio but are now told they did not. These pages are excerpted from Treatment of Acute Poliomyelitis (Third Edition), which was published in 1956 by Charles C Thomas, Springfield, Illinois, Written by William A. Spencer, MD, the Medical Director of the Southwestern Poliomyelitis Respiratory Center (SWPRC), Jefferson Davis Hospital, Houston, Texas, the charts show that in a fiveyear period, 15% of suspected cases received a non-poliomyelitis diagnosis. Spencer attributes the original misdiagnoses to the complexity of diagnosing polio and pressure from an apprehensive public.

Polio History

FINAL DIAGNOSIS OF NON-POLIOMYELITIS

78 CNS INFECTIONS TOTAL 151

- 27 encephalitis etiol. not det.
- 6 mumps encephalitis. l pertussis encephalitis.
- 1 post-vaccinal encephalitis. I herpes zoster encephalitis.
- I post-rabies vaccinal encephalitis. 10 pyogenic meningitis.
- 5 lymphocytic choriomeningitis. 3 tuberculous meningitis. I herpes simplex meningo-
- encephalitis. 1 arachnoiditis.
- 4 cerebral abscess.
- l acute pyogenic cerebritis. 1 CNS syphilis.
- 11 infectious neuronitis.
- 3 Coxsackie virus infection? 1 tetanus. 16 OTHER CNS DISORDERS

- 4 brain tumor. 4 cerebral vascular accident.
- l idiopathic epilepsy. l infantile hemiplegia.
- I acute cerebellar ataxia. 2 acute meningo-myelitis etiol.
- 1 spinal cord neoplasm. general muscular rigidity.

26 MISCELLANEOUS INFECTIONS

- 3 pneumonia.
- 2 influenza. 2 U. R. I.
- 2 roseola. 3 otitis media. 1 tonsilitis.
- 1 sinus infection.
- 2 gastroenteritis. 1 infectious mono
- 9 infection etiol. unknown. 1 serum sickness.

31 OTHER

- 2 rheumatoid arthritis. l arthralgia.
- 1 rheumatic fever. 1 sprain-lumbar muscles.
- 1 trauma-left arm. 1 neuropathy.
- I cervical adenopathy. 1 tenosynovitis. 2 infantile scurvy.
- 1 post-partum post L. P. headache. 12 not determined. l angioneurotic edema.

The above diagnoses were those made on patients admitted to the hos-The above diagnoses were those made on patients admitted to the nos-pital following outpatient admission screening in most instances. It is apparent that many disease entities mimic poliomyelitis so that careful historical and sharing assumptions are model to identify religious/elitic. pparent that many cusease entities mimic ponomyenus so that curerin istorical and physical examinations are needed to identify poliomyelitislike disorders.



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