SAINT LOUIS, MISSOURI – The Research Fund of Post-Polio Health International (PHI) has awarded its fifth grant to a team of researchers from the University of Insubria Medical Center, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology. The $25,000 award, funded by PHI’s Post-Poliomyelitis Research Grant, is for work to be completed in 2009-2011.

Dr. Antonio Toniolo

members of the research team include: dr. toniolo; andreina baj, md, phd; giuseppe maccari, ms; and angelo genoni, bs. participants for the study will be selected from two clinics that treat post-polio patients – the university of verona medical center, headed by salvatore monaco, md, and the rehabilitation hospital “villa beretta,” costamasnaga, italy, headed by franco molteni, md.

research funds to specifically study post-polio problems are hard to find,” says joan l. headley, executive director of post-polio health international. “generous donations from phi’s members over the last decade have helped us fill the gap, so research can help answer the questions that affect them in a very personal way. dr. toniolo’s team wisely has combined the phi funds with funds from several other sources. we will update the post-polio community periodically of the progress of the two-year study.”

the study, entitled “persistent noninfectious fragments of poliovirus in pps patients: virus detection and susceptibility to antiviral drugs,” will complete the sequencing of the genome of persistent fragments of poliovirus strains and compare them to wild-type polioviruses. the last year of the study will test the susceptibility of the persistent fragments of poliovirus in vitro to antiviral drugs.

phi’s board president, lawrence becker, phd, comments, “the application from the team in italy impressed the panel as having real promise for tracking down the etiology of post-polio syndrome. and if it turns out that these viral fragments play a major causative role, the study will not only help develop an important diagnostic tool, but may point the way toward an effective treatment.”

we are also particularly proud of conducting part of the study with prestigious investigators of the columbia university.”

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2 $25,000 Grant Awarded to Advance Noninfectious Virus Detection in Polio Survivors

PHI’s Board of Directors recently approved the funding of its fifth grant, which was selected from a group of eight applications. Rahnuma Wahid, PhD, the lead investigator of the 2007 grant team at the University of Arkansas for Medical Sciences (UAMS), has finished her work at UAMS, but the rest of the group has applied for funds from NIH.

3-6 Rehab for Incontinence Solves Two Problems

Linda L. Bieniek candidly discusses her long-time struggles with incontinence and constipation, and describes her success in finding solutions.

7 The ADA Amendments Act of 2008 was passed with relative ease recently, especially for those of us who wrote many letters, articles and attended rallies in the late ‘80s. The article explains why the ADA of 1990 was amended.

8 The New Books page features the story of a polio survivor who has used “Seven Wheelchairs” and a new offering from The Hesperian Foundation, publisher of the popular “Where There is No Doctor.”

9 Learn about a unique program – Polio Wonder Welders – in Tanzania that provides opportunities for survivors.

10-11 Support for PHI’s Activities: A reminder that PHI is member supported and so is The Research Fund. Won’t you give the form on page 11 to a non-member and ask them to join? This fall, it seems prudent to revise page 11 to ask you to contribute to The Research Fund instead of bearing the expense of a separate mailing.

12 See you in Warm Springs in April of 2009.

Inside this Issue ...

Joan L. Headley, Executive Director, PHI
have suffered from urinary incontinence (UI) for more than ten years. This condition, often uncomfortable to discuss, disrupted my life and distressed me. Recently I have gained incredible relief from UI – about an 80% reduction of symptoms – by participating in the Pelvic Rehabilitation Program at Loyola University Medical Center in Maywood, Illinois. As a surprise bonus, I also have resolved constipation problems that I had struggled with since childhood. I hope that the positive results I have achieved will motivate other polio survivors with UI and bowel problems to pursue treatment that can improve their lives.

A SLOW START

Studies claim that women usually do not seek medical intervention for UI until three years after the problem begins. Unfortunately, I beat that record. My incontinence problems started around 1995, but I did not consult a urogynecologist until 2000. At that time, Linda Brubaker, MD, prescribed physical therapy for “stress and urge incontinence.” Regretfully, I never followed up because I was too busy. By 2005, I had “urge incontinence” that made me void every 15-20 minutes in the mornings. But I still did not revisit Dr. Brubaker.

The next year, after an unrelated surgery and months of catheter use, my problem escalated. Certain activities, such as suctioning my tracheostomy or pouring liquids, triggered stress incontinence. I felt the urge to void more frequently. Although I always wore a maxi-pad, at times, the leakage was excessive. I could not go out without fear I might have an embarrassing accident in public.

PHASE 1: Assessment & Diagnosis

In 2007, I finally returned to Dr. Brubaker at Loyola University Medical Center for another consultation. Fortunately, she understands post-polio syndrome and has treated other polio survivors. Before meeting with her, I completed paperwork that asked about my experiences with UI, bowel functioning and sexual activity problems. On one form I prioritized the problems by how severely each interfered with my functioning, and also, by the order in which I wanted to resolve them.

During the consultation, Dr. Brubaker first tested to see if I emptied my bladder when I urinated. I had no problem with that. Then she performed an internal examination of my pelvic muscles to assess their strength and check for problems such as a tumor that could cause incontinence. Determining that my pelvic muscles were weak, she referred me for pelvic muscle therapy and prescribed Ditropan® (oxybutynin chloride), an older, inexpensive drug, to help with the urge incontinence.

PHASE 2: Physical Therapy

After I scheduled physical therapy appointments at Loyola University’s Pelvic Rehabilitation Program, I received information clearly outlining the various treatment options of this program. When I arrived at the clinic,
I completed a comprehensive medical history and answered questions about my incontinence patterns.

After reviewing my data, the physical therapist, Heather, explained each step of the treatment process. She began by internally examining the strength, flexibility and control of my pelvic floor muscles, and then, manually stretched them. Initially, the stretching process was painful, but the pain subsided with each subsequent session.

Heather taught me exercises for strengthening my pelvic muscles. I learned how to contract them for a set amount of time and slowly release them to control the flow of urine. Each week, she also gave me paperwork to complete.

PHASE 3: Bladder & Bowel Assessment

My homework was to track the liquids I drank, the food and fiber grams I ate, days and times I voided and had bowel movements, and the texture of my bowel movements based on a form identifying five different textures. In assessing my paperwork, Heather found that I ate plenty of fiber, but needed to drink more water. She gave me a list of liquids and foods that trigger urinary urges, such as coffee, tea and tomatoes, but she did not think that drinking two cups of tea each day was the cause of my excessive urges.

Noting that I experienced frequent constipation, Heather explained that my bowels could be pressing on my bladder, contributing to my UI. I realized that I had struggled with constipation since I had contracted polio as a child. I remembered that while I was in the hospital encased in a full-length body cast and undergoing surgeries, I dreaded receiving enemas even though they relieved the discomfort from being constipated. As an adult, I ate prunes in addition to a high-fiber diet and sometimes used herbs, but I was inconsistent in managing my bowels.

PHASE 4: Another Door Opens

During the weeks that Heather stretched my pelvic muscles, I practiced the pelvic floor exercises and
took Ditropan®. As I still had UI symptoms after the four treatments allowed by Medicare, she referred me to Judith Meredith, OTR, who uses biofeedback training as part of the Pelvic Rehabilitation Program.

**PHASE 5: Conquering Constipation – The Miracle of Miralax®!**

After reviewing my worksheets, Judith focused first on my constipation problems and recommended that I take Miralax® (polyethylene glycol), which previously required a doctor’s prescription, but now is available over the counter. She described how it works in the digestive system and emphasized the importance of taking it daily; she also explained the negative aspects of the herb senna that I had been taking.

Since following Judith’s advice, I am astounded by the improvements in the ease, frequency, quantity and texture of my bowel movements. Until I had started using Miralax®, I had lost significant time and energy and endured a great deal of discomfort during most of my life because of constipation. Now, I never miss a night of taking Miralax®. In addition to reducing my incontinence problems, it has decreased the frequency and intensity of irritable bowel attacks, and has relieved pressure on my diaphragm, which helps my breathing.

**PHASE 6: Biofeedback Training – Another Miracle!**

Next, Judith began using biofeedback to help me strengthen my pelvic floor muscles. First, she applied electrodes (as used for an EKG) to specific places on my body and then inserted a small sensor into my rectum (another option is the vagina), connecting these to a computer program. She showed me how the program graphed my pelvic muscle contractions and releases on the computer monitor. My exercises involved rotating periods of contracting and releasing the pelvic muscles with the goal of reaching a certain point on the graph. After three biofeedback sessions and practicing the exercises at home, I gained significant strength in my ability to contract, control and release my pelvic muscles. Judith was extremely pleased with how quickly I achieved results, noting that most people usually require more sessions.

By participating in this program I have reduced both urge and stress incontinence incidents by an estimated 80%. I rarely have any leakage; most days I do not even need to wear a maxi-pad. Instead of needing to void every 15-20 minutes in the morning, I can wait 45-60 minutes between voids. And I have not had any more accidents. I continue to take Ditropan® twice a day because I feel it also helps.

**Research Findings**

Most studies cited on the Internet have concluded that using biofeedback in addition to pelvic floor therapy and exercises has improved patients’ outcomes. Based on the findings of independent studies, Medicare reimburses covered charges for pelvic rehabilitation physical therapy and biofeedback treatment when properly documented to meet Medicare protocols. However, Blue Cross Blue Shield has used other findings to justify refusing reimbursement for biofeedback.

Pelvic rehabilitation treatment often is prescribed for UI experienced by women after pregnancy or during continued, page 6
menopause; by men after prostate treatment; and by both genders after surgery, a stroke or for neurological conditions such as multiple sclerosis.

**Treatment Providers & Coverage**

In making treatment recommendations, urologists and urogynecologists at major medical centers are most likely to have access to Pelvic Rehabilitation Programs and to refer their patients to physical and occupational therapists trained in providing services such as manual therapy and biofeedback for UI. Otherwise, polio survivors need to do research to find local professionals skilled in providing such services. The Association for Applied Psychophysiology and Biofeedback (AAPB) and the Biofeedback Certification Institute of America (BCIA) websites identify professionals trained in providing biofeedback, but their lists are limited.

Another challenge for polio survivors is learning whether their health insurance will reimburse for pelvic rehabilitation services such as manual therapy and biofeedback. If it does, a physician’s referral always requires proper documentation to justify the medical necessity of the service.

**Recommendations**

I highly recommend that polio survivors with UI pursue treatment options such as pelvic rehabilitation by taking the following steps:

- Identify your urinary patterns and problems by tracking them for a period of time.
- Consult a urologist or urogynecologist who specializes in UI for a thorough assessment and treatment referrals.
- Inquire about whether pelvic rehabilitation therapy, including biofeedback, is an option for reducing your symptoms.
- Find out if your health insurance will reimburse for pelvic rehabilitation services including biofeedback.
- Commit to working with therapists and doing the exercises and homework required.
- Track your bowel movement patterns and seek assistance to resolve any constipation or diarrhea problems.

As polio survivors, we cannot change many aspects of our physical health. We can, however, seek treatment for reducing UI symptoms. I hope polio survivors will make getting help with this distressing condition a priority.

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**REFERENCES**


To understand what the ADAAA means, it’s important to understand why the ADA needed amending in the first place. When it was passed back in 1990, the ADA had a definition of disability that was based on the definition used in the Rehabilitation Act of 1973. An individual with a disability has a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or is regarded as having such an impairment. Congress used the same definition because it had worked well.

The Supreme Court, in 1999, started to narrow the definition of disability in unexpected ways. In a case called Sutton v. United Air Lines, the court said that, when you determine whether an individual has a disability under the ADA, you have to consider the effects of mitigating measures – such as corrective lenses, medications, hearing aids and prosthetic devices – when deciding an impairment is substantially limiting. The Court did one other thing in Sutton. It essentially overturned an old Rehab Act case, School Bd. of Nassau County v. Arline. Arline had broadly viewed the part of the definition of disability that mentions having a “record of” an impairment. The Court in Sutton required a more restrictive view of that part of the definition, which practically eliminated it.

In 2002, in a case called Toyota v. Williams, the Supreme Court focused on the word “substantially” from the definition of disability, and said that it means “considerably” or “to a large degree.” The Court also narrowed the scope of “major life activity,” stating that it must be something that was of central importance to most people’s daily lives.

Eventually, the definition of disability was narrowed to such a degree that most cases became more about whether a person met the definition of disability, rather than focusing on access or accommodation. The EEOC had regulations that defined “substantially limits” as “significantly restricts.”

The ADAAA has new rules for the definition of disability. They include:

- The definition of disability is construed in favor of broad coverage to the maximum extent permitted; and
- The term “substantially limits” is to be interpreted consistently with the ADAAA; and
- An impairment that substantially limits one major life activity need not limit other major life activities to be considered a disability; and
- An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active; and
- Mitigating measures shall not be a factor when determining whether an impairment substantially limits a major life activity. The only mitigating measures that can be considered are ordinary eyeglasses or contact lenses that fully correct visual acuity of eliminate refractive error.
- People who are regarded as being disabled are not entitled to reasonable accommodations or modifications. Previously, courts had debated whether the ADA required having to accommodate a disability that didn’t actually exist.

The ADAAA is not some revolutionary new law. It simply attempts to bring the law back to what Congress intended it to be when it passed the ADA in 1990.
Seven Wheelchairs: A Life beyond Polio
Gary Presley

Gary Presley’s book has been described as “sardonic and blunt’ and “bitingly honest” and a “moving story of how the love and care of his parents and later his wife helped him enjoy life seated in his wheelchairs.”

In this unique memoir, Presley, who is a ventilator user, compels the reader to relive and understand his transformation from a seventeen-year-old farm boy to his late ’60s “gimp” self who refuses to allow himself to be invisible.

Presley was born in 1942 in Long Beach, California; he now lives and writes in Springfield, Missouri. Visit his website at www.garypresley.com.

Seven Wheelchairs is available from bookstores ($25.95 cloth) or directly from University of Iowa Press (800-621-2736; www.uiowapress.org; www.eurospangroup.com/bookstore).

Excerpt from Seven Wheelchairs: A Life beyond Polio...

“I pity you for being in that wheelchair.”
What can I say in response?
“I pity you for not being able to understand that this wheelchair sets me free.”
But it’s all so damned confusing, that murky line between compassion and pity, sympathy and condescension. I only know one thing as dead certain as the polio-killed nerves in my spine. Pity is objectification. Count on that.
And I know when I’m being pitied.
Why? Because I cringe at the idea of being robbed of my conception of the person I have constructed in this decades-long building project. Sincere sympathy may be a little better, but I don’t want it. Whatever warmth it provides you, it is of no value to me. Empathy, silent empathy, that unvoiced assumption of our commonality, I suppose is best of all. Empathy does not ask me to decide if I am worthy. Empathy simply recognizes we all ride this world together, and, like mine, all of your conceptions about life, death and disability are mere smudge marks on a dull gray sliding scale. I cannot find a place to mark off where knowledge ends and faith begins. I suppose you cannot either.

New from The Hesperian Foundation ...

A Community Guide to Environmental Health

This comprehensive guide has 23 chapters which break down the broad overview of environmental issues and concerns into specific examples of how they affect peoples’ health, and how communities have organized to improve their environment and thus their own lives. These chapters include: Promoting Environmental Health; Environmental Rights and Justice; Protecting Community Water; Building Toilets; Mining and Health; Solid Waste: Turning a Health Risk into a Resource; Preventing and Reducing Harm from Toxics; Sustainable Farming; and Clean Energy.

Hesperian’s open-copyright policy grants permission to interested organizations to translate/ adapt its materials, so long as they do so on a not-for-profit basis. If you or anyone you know has the interest to take on such a translation effort, please contact their International Publications Associate, Tawnia Litwin, at tawnia@hesperian.org.

Individual copies of the book are available for $28, plus shipping and handling. They can offer a 20% discount on orders of five or more copies of this book. It’s also available on CD for $18, and the two together are $36, a savings of $10 off the retail cost of each if purchased separately. There is also a digital version available for free at www.hesperian.org/publications_download.php.
Are you in the mood to purchase a new sculpture to display in your home or office? How about a new pair of earrings, a wooden toy or perhaps some handcrafted paper products or candleholders? If so, you might want to view the merchandise offered by the Wonder Workshop.

Founded in 2004 in Tanzania, the Wonder Workshop is a welding workshop established to teach local polio survivors to create welded art using recycled scrap metal. Soon, individuals who originally had no other means of support other than begging in the streets were crafting beautiful welded art sculptures that were sold locally enabling them to support themselves and their families.

The metal art sculptures are amazing and intricately detailed. There is a wide variety of subjects and if you don’t find something that piques your interest amid the animals, insects, boats, birds, bicycles or masks currently available. The artists will be happy to commission an original piece in any image that you desire.

After the initial establishment of the organization, Heather Cummings, an artist from Scotland whose creations are known worldwide, offered a two-month training session to help the local artists perfect their craft.

Today, with a full-time staff of more than 40, the NGO (non-governmental organization) also offers handmade recycled paper cards, bookmarks, photo albums and picture frames. There is a wide assortment of wooden toy cars, trucks and animals made of the finest Tanzanian hardwoods and polished with coconut oil, and a wide variety of lovely recycled glass jewelry made from broken bottles and window panes.

The NGO, originally started by Paul Hicks of Blue Mango Photography with the help of a small grant from the Dar es Salaam Charity Goat Races and donations of scrap from large companies across Dar, hopes to continue to expand and employ more polio survivors while continuing to produce world-class art.

To view all of the items produced by these talented artists and learn more about this artistic organization go to www.wonderwelders.org.
Funds Utilized

“I am a post-polio survivor lady and a disability activist in Uganda. I am Chairperson of Lira District Disabled Women Association, part of Action on Disability and Development, and an Honorable Councilor representing persons with disabilities in the council of Lira District. I serve on several other committees and work with individual polio survivors to assist them in getting an education, etc.

“It is not easy for a poor person with a disability at the grassroots level to purchase orthopedic appliances in Uganda.

“I requested funds from PHI for purchasing a bending caliper, a knee cap, surgical boots and a pair of crutches. My request was approved and Gulu Regional Referral Hospital in Northern Uganda made my new appliances. These appliances will now help me carry out my activities effectively.”

Florence Adong, Lira, Uganda, florenceadong@yahoo.com

Funds Available

Post-Polio Health International has funds to help polio survivors in purchasing braces or modified shoes. To assist the greatest number of survivors, the maximum funds available per individual is $500.

To receive an application, call Brian Tiburzi at 314-534-0475 or email him at info@post-polio.org.

Applicants from any country may apply. There is no deadline for applying and payments will be disbursed as eligible applicants are reviewed.

Donations in Recognition of Others

Post-Polio Health International thanks the many friends and family members who contributed in support of its mission.

Contributions to PHI’s educational, advocacy and networking activities ...

In Memory of
Stanley P. Baldwin
Edie Elteritch
Katheryne P. Tate Evans
Honey Formica
Dr. Vincent N. Fornango
Harry B. Guarino
D. Rose Huffaker
Delores Mansfeldt
Jeanette Slobodin
Dan Taylor

In Honor of
Kenneth & Shelah Michael
Ron Kunitz

PHI acknowledges the following special contributors ...

April 1 - September 30, 2008

Bronze ($250)
Lawrence Becker
William Groening, Jr.
Mendel Plumbing & Heating, Inc.
Saul Morse
Janice Flood Nichols
Michael Pavelich
Post-Polio Awareness & Support Society of British Columbia
Post-Polio Support Group of Ireland
Alison (Sunny) Roller
Chris & Anita Russell

Silver ($500)
Norman & Marie Donner
Judith H. Johnsen
Victoria Keenan
Andrew E. Withrow

Gold ($1,000)
Helen H. Ford
PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

- $30 Subscriber
  Quarterly newsletter of your choice:
  - Post-Polio Health OR Ventilator-Assisted Living
- $55 Subscriber Plus
  Both quarterly newsletters:
  Post-Polio Health AND Ventilator-Assisted Living
- $100 Contributor
  ALL the benefits of Subscriber Plus AND
  Post-Polio Directory AND
  Resource Directory for Ventilator-Assisted Living;
  discounts on special publications
  and meetings sponsored by PHI
- $150 Sustainer
  ALL the benefits of Contributor AND
  One additional complimentary gift membership to:
  - Person of your choice (include name and address) or
  - Person who has expressed financial need to PHI

Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications:

- $250 Bronze Level Sustainer
- $500 Silver Level Sustainer
- $1,000 Gold Level Sustainer
- $5,000 Platinum Level Sustainer
- $10,000 Gini Laurie Advocate

Here’s an opportunity for each of us to invest in the future! PHI invites members and groups to play an important role in closing the gap on discovering reliable post-polio diagnoses and treatments. Promising research brings us closer every year to the elusive answers we seek. Will you help?

As post-polio researchers uncover more and more exciting possibilities, we realize the urgent necessity for these solutions. Will we soon know what's causing post-polio syndrome? Will this deliver us to thresholds allowing that burst of treatment knowledge all of us hope for? What will we learn for tomorrow that we don’t even know enough to dream about today?

Our goals are so close – we simply must push harder to reach them soon. You can help by donating any amount, large or small, to PHI’s Research Fund. Your group can help, too – as well as relatives and friends. Complete the form below or mail a check with “research” in the memo line to PHI, 4207 Lindell Blvd. #110, Saint Louis, Missouri 63108-2930.

**Donation to PHI’s Research Fund**

Name______________________________

Affiliation__________________________

Address____________________________

City_________________________ State/Province________________________

Country_________________________ Zip/Postal Code____________________

email____________________________

Phone (include area/country code)_________________

Fax (include area/country code)_________________

**Please accept my donation in the amount of ...**

- $30
- $50
- $100
- $250
- $500
- Other $_________________

- I am enclosing a check made payable to “Post-Polio Health International.” (USD only)

- Charge my donation to this credit card:
  - VISA
  - MasterCard
  - Discover

Card No.______________________________

Exp. Date_________ Card Verification # (3 digits on back of card)________

Name on Card________________________

Signature____________________________

Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
314-534-0475   314-534-5070 fax

PHI has given $120,000 for research.

Rates Effective July 2007
PHI has posted the comprehensive three-day program online at www.post-polio.org. The sessions start on Thursday, April 23, 2009 at 1:00 pm and end Saturday, April 25, 2009 at 4:00 pm. Designed to address the varying needs of polio survivors, ventilator users and health professionals, there are 40-plus sessions from which to choose. Details about the pre-conference Post-Polio Wellness Retreat are also online.

Roosevelt Warm Springs Institute for Rehabilitation (RWSIR), our host, is an historic, pretty and peaceful site. In addition to the educational sessions, conference attendees will be able to tour the RWSIR campus, the Little White House Historic Site, and the Historic Pools Museum.

The information online describes the many options for lodging and for transportation to and from the Hartsfield-Jackson Atlanta International Airport (ATL).

Full registration, which includes Continental Breakfast and the evening meals, ranges from $120 (individual)–$180 (individual plus family member/attendant or health professional).

Members who do not have access to the Internet are invited to call 314-534-0475 and request a copy of the program and registration materials.

“We are very excited to be hosting such a prestigious lineup of speakers,” stated RWSIR Executive Director Greg Schmieg. “Warm Springs was synonymous with polio treatment for much of the 20th Century, and I’m confident FDR’s famous ‘spirit of Warm Springs’ will be very much in evidence when survivors from all over the country gather on our campus next April.”

“By meeting at this historic location, we are able to add a whole new dimension to the dialogue,” said Joan L. Headley, Executive Director of PHI. “The program offers a wide range of sessions for survivors and their families and health professionals. Attendees will participate in serious discussions – and fun. It will be an experience of a lifetime.”