

PHI's mission is supported by its Membership.

\$100,000 Grant Announced at 11th International Conference

Joan L. Headley, PHI Executive Director, St. Louis, Missouri

Antonio Toniolo, MD, FAMH, University of Insubria, Varese, Italy, accepted the Post-Polio Health International two-year grant award of \$100,000 (\$50,000 each year) at the organization's 11th International Conference on May 31, 2014. The announcement at the opening dinner of the conference by Research Committee Chair, Daniel J. Wilson, PhD, represents the eighth award year. PHI/IVUN has given nine awards between 2001-2014 totaling \$295,000. (Two awards were granted in 2011.)



Antonio Toniolo, MD, FAMH

Dr. Toniolo's proposal, "Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with antiviral antibodies and drugs," was selected from 11 proposals reviewed by the expert Review Panel and approved by PHI/IVUN's Board of Directors. Proposals were submitted from researchers representing seven different countries.

Dr. Toniolo also received PHI's \$25,000 award in 2009. He and team member

Andreina Baj, also at the University of Insubria, conducted an observational study of post-polio syndrome in a cohort of polio survivors and consenting family who were attending Northern Italy Hospitals for neuromuscular problems over the last four years.

In humans, the only evidence for persisting poliovirus infection has been found in

individuals with deficiencies in B lymphocytes and low or absent immunoglobulins.

Results of virology studies (detection of poliovirus genome and virus activity) show that a persistent low-level infection is associated with post-polio syndrome (PPS). So far, however, the Italian group has been unable to demonstrate that the persisting virus does play a role in the development of post-polio syndrome, a progressive disorder.

The data

In the investigated cohort, 97/107 individuals have been shown to have developed PPS 15 or more years after the acute attack. Family members of PPS patients (n=45) were also studied, together with a control group represented by healthy blood donors and controls with neurologic disorder other than PPS (n=47). Specimens included: cerebrospinal fluid, peripheral blood leukocytes, live cells of duodenal mucosa, skeletal muscle and peripheral nerve.

Poliovirus genomes were detected in 82/97 patients with PPS (85%) and in 3/92 controls (3.3%). Type 1 poliovirus was the most prevalent (61% of cases), followed by type 2 and type 3 (12% and 9%, respectively). Some cases (18%) could

WE'RE STILL HERE!

October 12-18, 2014
www.post-polio.org

Help PHI proclaim to the world that WE'RE STILL HERE!

Carol K. Elliott, polio survivor and contributing editor to Polio Place and PHI, Downers Grove, Illinois

PHI's annual awareness campaign will run October 12-18 in 2014. You can contribute by sharing experiences. Why? How?

Why? We have the opportunity to leave a written legacy with pictures/scans or artifacts that recalls the past and educates and encourages the international community of polio survivors. The internet makes this possible and PolioPlace is your web site! Whether we are retired, semi-retired or currently working — we are all “living with polio” and have contributions to make. Let’s record our achievements, recall our important memories, share the lessons learned and help ourselves and the younger generation of polio survivors who will be living in a world without polio.

How? Go ahead! Pick a topic and include at least one picture/artifact representing the memory from your past and write a short piece (250-400 words) about that piece of equipment, letter, etc., telling other survivors how you were influenced by it as a polio survivor. Or, write about your personal experiences and achievements reflecting how you are “living with polio” – share your ideas!

These questions will help you pick a topic.

- Did you find getting a job difficult? If so, what helped in getting employment?
- Was obtaining the appropriate education or advanced degree you needed easy or difficult?
- Did you find securing a job challenging? How did you overcome the challenge?
- Did you feel you had to settle for something less just to become employed?
- How did your polio shape or define how and what you chose as your job or career?
- If you are still working, what hints do you have for others?
- What was your experience raising your children?
- How have you made your home accessible to your needs?
- What care-providing challenges does your spouse or life partner face? How have they been resolved?
- How do you live with post-polio syndrome on a daily basis as you face your “new normal”?
- Do you take the time for relaxation and hobbies, and if so, what are they?

For examples, visit www.polioplace.org and look at “Artifacts” and “Living With Polio” sections. There are contributions on many topics: Aging, Breathing, Education, Exercise, Health and Wellness, Ideas to Manage Fatigue and Pain, Mobility, Relationships, Retirement, Self Help/Mutual Aid, Travel, Ventilator Users, Worship, Workplace. If you have questions before you submit your contribution, send an e-mail to polioplace@gmail.com. ■

Your contributions will be posted on Polio Place (www.polioplace.org) to remind the world that WE'RE STILL HERE! ■



Plan Ahead for a Great Travel Experience

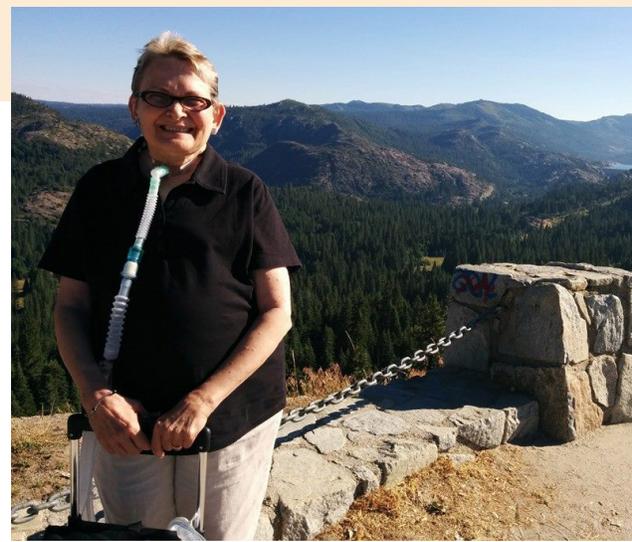
Carol Meyer, Ankeny, Iowa

Traveling to the Post-Polio International Conference in St. Louis this spring was amazing and a joy! I met so many other polio survivors, listened to very interesting presentations and learned a lot! It was no small feat for any of us polio survivors to attend, but I was really surprised to learn that my presence there was especially unique because I am trached and hooked up to a vent 24/7. But before I get into that, here is a little bit of my polio story.

My brother, sister and I had seen a movie about the Little Rascals going camping the night before, and that Sunday afternoon in September 1952, we were reenacting the movie in our yard. One minute I was playing and having fun, and the next minute I felt cold and tired. I wrapped up in one of the blankets we were playing with and fell asleep in the grass. This was an immediate red flag for my mother because I was the kind of kid who couldn't be bothered with naps. She was so alarmed and frightened that I might have polio that she took me to the doctor the next day, but he didn't think that I had it.

The following day I couldn't swallow the orange juice that Mom gave me to drink and when I tried to walk across the room, my legs collapsed and I fell to the floor. At that point, Mom picked me up and drove me to the hospital in Mason City, Iowa, where a spinal tap confirmed her worst fears. Because all of the major hospitals in Iowa were filled with polio patients, I was admitted to Mercy Hospital in Mason City with spinal and bulbar polio. Both of my legs were paralyzed and I had trouble swallowing food.

The paralysis left my legs and I was discharged. I worked hard at all of the exercises that I was given, and I was able to join my classmates in second grade yet that fall. By the time I was in fourth grade, my scoliosis was beginning to be visible and my doctors at Children's Hospital in Iowa City thought that I should start wearing a body brace. It wasn't the most comfortable thing in the world as it was made from leather and steel, but it helped support my body.



Carol Meyer at Emigrant Gap, a gap in a ridge on the California Trail as it crosses the Sierra Nevada, to the west of what is now known as Donner Pass.

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

How to contact PHI

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Notify PHI before you move by calling 314-534-0475
or email info@post-polio.org, and tell us your old
and new addresses.

Away temporarily?

Send us your second address and dates you will be there
and we'll do our best to send your newsletter.

QUESTION: *It's easier explaining things to "new" friends as opposed to friends I have had for 30 years. Old friends expect me to be the same as 20 to 30 years ago with the same energy and activity levels I used to have. How can I gracefully handle this?*

Response from Rhoda Olkin, PhD:

New friends accept who you are now because that is how they met you and have come to know you. But longer-term friends met you as a more active person. Remember that you have changed, and as you changed you naturally have been very aware of those changes from year to year, noticing an increase in fatigue, a reduction in mobility, maybe a fall here or there.

But others have not been privy to the nuances of those changes. They might notice major changes but not more subtle ones. I suspect you haven't been giving regular updates each year, so it can seem sudden to others that you now say no to things you used to do. So their expectations seem out of synch with the new version of you. This is not out of lack of caring or callousness, but rather genuine ignorance of your new status.

So you know what you have to do without my saying. You have to talk with them about how things are for you now, the changes you have experienced, the symptoms that are new or increased. You have to explain how you manage your energy, how you choose what to do and what to say no to, how your priorities have shifted and may shift again as you age. Those who understand and accept this version of you are your true

friends. If some drop by the wayside (and truthfully, some may), then you have to let them go, because they aren't good for your self-esteem and mental health.

Of course, not everyone needs the full text and exegesis on the New You. If there are folks you have lunch with twice a year, or go to the movies with when a new Star Wars film comes out, or call/email/text funny cat jokes to, then you can keep some things private.

But your close friends deserve the truth from you and the trust you place in them when you open up. It doesn't have to be a heavy conversation. It could be saying simply, "I wanted to let you know that my physical status has changed as I age with polio. I'm finding I'm more fatigued, that I have to monitor my activity level more. When I say no to doing something together, please know it is not personal, that I love getting together with you. But I have to make hard choices every day about what I do. If you ever feel ignored, let me know, because that is not my intent. And if you have questions, please feel free to ask."

I know I sound easy-breezy, but I recognize that these conversations may be harder than that. Yet I suspect they also will be easier than you think. Pick your safest friend to start with. Good luck, and write back how it goes!



Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

She is a polio survivor and single mother of two grown children.

Response from Stephanie T. Machell, PsyD:

Since most of us don't have the same activity level and energy we had 20 or 30 years ago I'm alternating between being impressed by and jealous of your old friends! What is their secret, and would they consider sharing it with me?

Your new friends only know you as you are now. Old friends who have been around consistently may not see the changes in you and may take for granted that you are the same (as in, "But I don't think of you as a person with a disability."). Old friends who only see you occasionally may be picturing you as that much younger and energetic self (or hoping that you will be, since that would mean they are too!).

But of course you have all changed. And one way of dealing with the issue would be to point out that much as they have changed, so have you, and that your changes have left you less active and energetic than you and they might wish.

This might be enough. But probably it isn't. It might help to talk to your friends about PPS. Depending on your comfort level and your friend's, this talk could be a "sound bite" or a more in-depth discussion that might include your feelings about what has happened to you. Be specific about how PPS affects you and what you can and can't do. Think about things you enjoy doing together and suggest ways you might still do these.

If you've already done this and your friends still seem unwilling or unable to accept or remember your limitations, you can say something like, "Remember how I told you that PPS means I have to pace myself? That means I can go shopping if we stop and take breaks so I can rest. But afterwards, I will be too tired to go to the museum. Could we do that another day?"

With certain people, perhaps casual acquaintances, you might not want to explain your situation. When they plan a day you know will be too much, you could say something like, "I would love to do all of it, but these days I have to pace myself more. Could we just do one of those things?" Or you could plan something that you know they would enjoy that would be less draining for you and suggest that.

Friends want you to be all right. They may hope that if you do the things you used to do that you will feel better. Their own experiences support this, because when they get going they feel better. Helping them understand that PPS works in reverse is difficult – especially so if, like many polio survivors, deep down inside you still believe what you too were taught about exercise and hard work. Remember that helping your friends deal with your changed disability status starts with dealing with it yourself. Your own comfort will make others more comfortable, which after all is what graciousness is all about. ■



Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.

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I went on to the University of Missouri—Columbia and became a high school English and speech teacher, but I kept being plagued by bronchitis and pneumonia. I had a spinal fusion in 1978 and wore a halo body cast for nine months, and when I emerged from my cocoon, I got to throw away that heavy old body brace for good!

I returned to my teaching job and met the man of my dreams at a ballroom

dance class in Edina, Minnesota! We got married in June 1981, and soon I was pregnant. Little did I realize what a nightmare that pregnancy would be. At six months, I started to have lots of problems with my breathing, and my efforts to breathe spiraled downward because I was unable to blow off the CO₂. Finally I had an emergency C-section. My baby girl was fine, but I was not.

I fought valiantly to live, but I still couldn't breathe well and sleeping was out of the question. Since I was in a hospital in Minneapolis, Minnesota, my

pulmonary specialist decided to get an iron lung out of storage to save my life ... and it did! I was finally discharged from the hospital, but for a year afterwards I had to go into the hospital every once in a while to sleep in the lung for a few days.

When our daughter was in first grade, I caught a cold, which turned into pneumonia. I ended up in the hospital on New Year's Day, 1989. I finally consented to being intubated, but I was faced with another life and death situation a few weeks later: to have a tracheotomy or not. I chose to live and consented to the tracheotomy. Immediately I started to

get better, I could talk and eat real food, I could go down to physical therapy, and I could sleep hooked up to a vent. I had a great nurse who taught me how to clean my stoma, suction myself and hook up to my portable vent. Later after being home for a while, my husband learned how to change my trach tube, something that has to be done every two or three months.

“They have not been ‘polio doctors,’ but they have been extremely insightful and careful in their medicine, yet aggressive when needed in emergencies.”

I have been lucky to have several wonderful pulmonary specialists throughout the years. They have not been “polio doctors,” but they have been extremely insightful and careful in their medicine, yet aggressive when needed in emergencies. I refuse to work with any doctor who has an ego problem and doesn't treat me like an intelligent human being who is very much in touch with her body.

Whenever we've moved to a new area, I have interviewed my doctors to make sure that they are willing to work with



Carol and Chuck Meyer in Napa Valley, California.



Carol shopping in St. Helena, California.



Carol in St. Helena, California.

me as a team in my health care. I learned early on how necessary it is to be my own advocate. All of my pulmonary specialists have cared so much about my health that they've generously given me their home/cell phone numbers (unsolicited) and have encouraged me to call if I am ever in trouble. I never abuse that privilege.

“Having the trach was one of the best decisions I’ve ever made for myself.”

Since I've been trached, I have not been hospitalized, and I haven't had either bronchitis or pneumonia because I can suction myself. Having the trach was one of the best decisions I've ever made for myself. I've been trached now for over 25 years and have never had an infection in my stoma. I continue to live a full life, I've gotten to watch our daughter grow up and begin her career, and my husband and I have been able to travel from coast to coast almost every year. We drive to California every summer to visit my husband's siblings and mother, and later in the summer, we drive to

Massachusetts to visit our daughter. In between these major road trips, we often do several smaller ones.

I no longer fly because I have to carry along a small medical clinic wherever I go, but we do road trips. To do a road trip safely means lots of planning in advance. At least a month before we leave, I get our route all mapped out and make our hotel reservations. We travel with our cell phones, GPS and laptops. I carefully pack all of the trach and vent supplies that I will need on the trip.

I have learned the hard way to make sure that I have spares of everything with me whenever we travel, e.g., extra vent hoses, trach care kits, external batteries and charger, viral filters for my vent hose, humidifiers that fit onto my vent hose, swivel elbows that connect my vent hose to my trach tube. I also always take along an extra trach tube (Portex Blue Line Cuffed, 6mm) with all of the materials needed to do an emergency trach change, clean ribbons that hold my trach tube in place, lots of Q-tips and saline solution for trach care, approximately 10 suction kits for each day that I will be gone, my two DeVilbiss suction machines, my pillow wedge and extra pillows for sleeping. (We sleep in an adjustable bed at home.)

I travel with two LTV® 950 vents, each the size of a laptop computer. Finally, I use 1½ liters of liquid oxygen per minute; it is fed to me from a small portable canister into my vent. On road trips, we carry a four-foot tank of liquid oxygen with us in the car; it holds 45 liters of liquid O₂ when it's full. My husband Chuck keeps it well-anchored in our Toyota Sienna, and he fills my little portable canister from that about three times per day. I would not be able to travel in high elevations without my vent and O₂. I get my liquid O₂, trach and vent supplies from Apria Healthcare, which is



Chuck filling Carol's portable oxygen canister.

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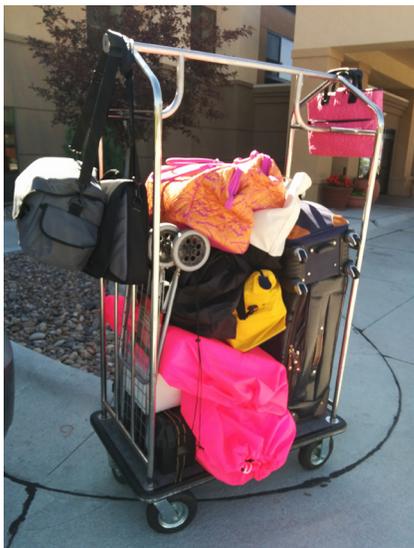
a nationwide company. Before we travel, I always make an appointment to stop at an Apria location to have my liquid O₂ tank filled if I need to.

Even though I am trached and vented, I am able to walk. At home I have a miniature grocery cart that I push; it carries my external battery, vent and liquid O₂ canister. I am able to cook, do our laundry, entertain guests, etc., with this system. When I go out to eat or to the grocery store or anywhere out of our apartment, I pull my external battery,

vent and canister in a black bag on wheels (made by Reisenethel). It is made out of a heavy mesh material so that my vent can breathe. (A vent puts out a lot of heat and requires good air flow.) My husband lifts this bag in and out of the car when we go places.

Unfortunately there are so few vent users who are mobile like I am that we had to figure out all of these travel and living methods ourselves. I purchased both the push cart and the pull bag at The Container Store.

Since Chuck and I are old hands at traveling like this, it was with great confidence that we made



Carol's equipment ready for hotel check-in.



The Meyer van ready for a road trip.

plans to attend the wonderful conference in St. Louis. I got along just fine at the conference. If you attended, you might have noticed me walking around with a hose connecting me to my vent in my black pull bag.

“The key for a great travel experience is to plan ahead ...”

The key for a great travel experience is to plan ahead and make sure that my small medical clinic is intact! Then we can enjoy all of the splendor that our beautiful country has to offer. ■

Thank You

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Patience (Penny) Chrisler James Troesh
Charlotte Schwebke

In Honor of

Lawrence Becker, PhD Carlos Vallbona, MD
Mary Ellen McCabe

Contributions to the Research Fund ...

In Memory of

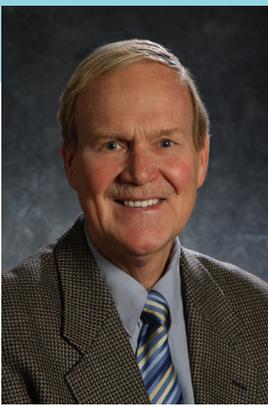
Dorothy Churchill Kathryn Kniep

In Honor of

Ann Doucette

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

In memory of Larry Rosen



Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: *I have just been diagnosed with venous insufficiency in addition to atrial fibrillation, mitral valve problems and partially closed carotid arteries. I also just had a test to check my arterial blood gases. I use a BiPAP ASV every night and have serious pain some days from coccyx down both legs to my feet. I cannot walk at all, and now I cannot stand for less than a minute without holding on. I have fibromyalgia, and I have a painful left rotator cuff. For two months, I have been wearing compression hose. How does the venous insufficiency fit into this picture?*

A: Your history is certainly distressing. I presume that the “venous insufficiency (VI)” diagnosis was used to explain swelling/edema of your feet and legs. While you may have some VI that contributes to this problem, your heart problems (especially the mitral valve problems) are more likely to be the major cause for ankle/feet swelling. Your description of symptoms and diagnoses suggests right-sided heart failure, which would also explain your major new weakening and loss of functional capacity and is a common late problem of people with chronic respiratory failure. Please work closely with your internist – both cardiac and pulmonary medicine expertise is needed – to find out what your options might be for treatment/management. Any VI is not that important and could be minimized by use of lower limb support stockings or wraps.

Question: *In 1988, I was your patient at the University of Michigan when you diagnosed my post-polio syndrome. I am preparing for a complete knee replacement on my right leg, which is the one affected by polio. My question is: Should my physical therapy after surgery be specialized to my condition or will normal therapy be OK? My surgeon has not had any dealings with polio patients. Any information you can supply will be greatly appreciated.*

A: The important thing about knee replacement in a polio leg is the strength of the quadriceps and hamstring muscles. If they are 4-/5 or less, the artificial knee joint should be protected with bracing in the post-operative period, and sometimes even long term for walking long distances in order to prevent loosening of the artificial knee joint. PT is best done by a therapist who has evaluated you **pre-operatively** and can then help you post-operatively with both re-mobilization and with exercises. Exercises need to be planned out on an individualized basis based on your pre-operative muscle strength in that leg. Strengthening may need to proceed slowly to avoid overuse damage, but that is usually not an issue in the early period. It is more important later when strengthening is a major goal and is relevant if and when a protective brace can be safely discontinued. You may want to share these thoughts with your surgeon.

Question: *My 83-year-old wife had bulbar polio when she was 17. She is now wheelchair-bound and is suffering severe pain from shingles. My question is: Since polio and shingles are both nerve diseases is there any special precaution, medicine or treatment she should have?*

A: Although polio and shingles are both a result of virus infections, they are not related viruses. People with post-polio syndrome are not more vulnerable to shingles and need take no special precautions. Please read a recent *Post-Polio Health* article about shingles vaccination among polio survivors. www.post-polio.org/edu/pphnews/pph29-4f.html.

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not be typed. Based on clinical history, 22/107 poliomyelitis cases were associated with polio vaccination (18%). In vitro, leukocytes of poliovirus-positive PPS patients did produce enhanced levels of inflammatory mediators as compared to leukocytes of healthy donors. This is in line with a pathogenic hypothesis indicating that chronic inflammation is a hallmark of PPS.

Serum immunoglobulin levels were measured in PPS patients, their family member and controls. As compared to healthy blood donors, levels of IgG1, IgG2, IgG4 and IgA were significantly reduced both in PPS patients and their family members. IgM levels were not significantly different. This suggests that modest immunoglobulin deficiencies may be present in individuals who developed clinical manifestations after being hit by poliovirus as well as in their family members.

The group also measured titers of neutralizing antibodies to the three poliovirus types in sera of PPS patients, their family members, and healthy controls. No significant differences were found.

Conclusions to date

The results lend support to the idea that residual poliovirus activity does persist in PPS patients and that virus persistence could be of pathogenic significance.

Their data also show that poliovirus cannot be found in family members of PPS patients, i.e., that virus is not transmissible within families. This finding tells that PPS people are “not infectious” and has reassuring implications. (This point has been made epidemiologically but not definitely in virology.)

The Next Steps (2014-2016)

The document submitted to PHI explained in detail the questions the study proposes to answer and the methods it will use. Building on the research previously described in this article, the group aims to verify the persistence of poliovirus components in post-polio syndrome patients decades after the acute attack and to determine whether the persisting viruses are still pathologically active.

To date, a problem has been the low levels of virus found in PPS individuals. Consequently, the prior tests used were unable to determine the genetic mutations of the poliovirus strains found.

Toniolo has enlisted the assistance of Dr. Konstantin Chumakov, U.S. Food and Drug Administration, to help solve this problem. Chumakov and his collaborators are well-known worldwide for having set up novel sequencing methods specifically designed for characterizing poliovirus genomes of different strains isolated from human cases and the environment. The U.S.-based group will analyze the poliovirus isolates from the Italian participants from the 2009 study with the goal of defining the mutations and deletions in the genomes of the poliovirus in those individuals over the decades. The test will also be able to determine vaccine strains from wild-type strains based on genetic markers.

Chumakov and collaborators have also produced and characterized human monoclonal antibodies capable of neutralizing the three poliovirus types. Another aim of the study is to check whether these antibodies are able to neutralize the biologic activity associated with the poliovirus strains obtained from PPS patients. If so, a new possibility of immunotherapy could emerge stopping the development or progression in survivors deemed chronic poliovirus carriers.

The study also plans to test in vitro the most promising antiviral drugs that may be capable of blocking PPS progression.

Finding “stable” post-polio participants

During the review of the grant internally by PHI, concern was expressed that the study did not include samples from polio survivors who were not described as having post-polio syndrome. The research as planned tested PPS patients, family members and individuals with other neurological disorders. The researchers agreed to check whether poliovirus is detectable in a cohort of polio survivors who, in spite of age, failed to develop PPS.



PHI will assist the team in finding non-symptomatic polio survivors in Italy. An earlier study done in Arkansas, in 2007/08, had problems recruiting stable polio survivors. The reason was not analyzed fully, but it could have been due to lack of interest of “healthy” polio survivors in participating, inadequate recruiting or the dilemma of the expansion of the definition of post-polio syndrome to the point that anyone who had polio is assumed to have PPS particularly as they get older.

It takes a team

Dr. Toniolo is the face of this research but does not work alone and acknowledges the contribution of neurologists Giorgio Bono, Salvatore Monaco, Laura Bertolasi, Franco Molteni, Luisa Arrondini who provided samples of their PPS patients and the essential contribution of virologists Martina Colombo, Giuseppe Macca-ri, Merja Roivainen who dedicated their time and efforts to this noble task.

Lastly, he acknowledges Post-Polio Health International and Regione Lombardia, Milan, Italy, and expresses gratitude to Joan L. Headley, St. Louis, and Dr. Frans Nollet, Amsterdam, for their continuous encouragement and support.

More about the Fund

The Research Fund was started in 1995 with a bequest from the estate of Thomas Rogers, a quadriplegic polio survivor who spent about a year and a half in three hospitals. He had been successfully weaned from the iron lung to a rocking bed and with a “great proficiency in frog breathing.” In later years, he used the portable Bantam Positive Pressure Respirator and the PLV-100. Rogers died in 1994 leaving a lasting legacy of supporting research for the ventilator user and post-polio communities. ■

Contributions to the fund may be made online at <http://shop.post-polio.org> or by check to 4207 Lindell Boulevard, #110, St. Louis, Missouri, 63108.

Ask Dr. Maynard continued from page 9

In regard to treatment for your wife’s pain, if it is a result of post-herpetic neuralgia that results from the shingles infection in one localized area of skin, Zostrix cream applied on the skin twice daily for several days is the best and safest way to gain relief. If her pain is very severe and more widespread, she would have to be fully evaluated by a specialist physician in management of post-herpetic neuralgia pain for other options. Encourage your wife to maintain a positive outlook because in the vast majority of cases, post-shingles pain does eventually improve and resolve. ■

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You can join online at <http://shop.post-polio.org> or send (or fax, 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

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POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110
Saint Louis, MO 63108-2930 USA

Scenes from the 11th International Conference



The DisAbility Project of
That Uppity Theatre Company
and Common Threads
Dance Company.



Sessions and more sessions ...



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Another Successful PHI International Conference!

Polio survivors, their families and friends and health professionals with expertise in promoting healthy ideas met at PHI's 11th International Conference in St. Louis, May 31–June 3. Arriving from seven countries, 35 states and the District of Columbia, 212 individuals participated in a wide variety of sessions learning new ideas and skills, participating in discussions and meeting new people strengthening their networks.



The conference began with a dinner on Saturday evening, supported by The Rehabilitation Foundation for Disabled Persons, Inc. Before dinner, PHI Research Committee Chair, Daniel J. Wilson, PhD, introduced Antonio Toniolo, MD, FAMH, University of Insubria, Varese, Italy, the leader of a team that was granted PHI's latest research award (see page 1).

Dinner guests were entertained by a group of young adults with disabilities who danced with members of the Common Threads Dance Company and who told their personal stories of having a disability, exposing the challenges that still exist today for people with disabilities. The audience of polio survivors identified with them – actors and creators of the material as members of The DisAbility Project, part of the St. Louis-based That Uppity Theatre Company.

Some sessions were lectures, some were participatory and some were designed to initiate dialog. PHI compiled the materials (abstracts, handouts, PowerPoints) made available by the presenters to the attendees on a flash drive, which was distributed at the meeting. This flash drive is available to those who could not attend along with a DVD of your choice of sessions filmed at the conference.

Funding to assist with filming of the sessions was received from Clark Callahan, Edouard Foundation, Grifols, and the Roosevelt Warm Springs Foundation (RWSF). At the conference, twelve health professionals and polio survivors were individually filmed presenting lectures on a wide-range of topics for PHI's website Polio Place. This project is funded by the Roosevelt Warm Springs Foundation. Watch *Post-Polio Health* and *PHI's Membership Memo* for a notification of posting.

Promoting Healthy Ideas: PHI's 11th International Conference Order Form

Flash drive of conference materials

____ Quantity at \$15 each = \$ _____

Promoting Healthy Ideas conference bag (12"x18" with a 12" long strap and 5" gusset made of polyester)

____ Quantity at \$12 each = \$ _____

Printed copy of "Handouts" (42-pages) made available by some presenters (included on flash drive)

____ Quantity at \$8 each = \$ _____

DVD of all of the sessions (19) video recorded at the conference

____ Quantity at \$35 each = \$ _____

About the DVDs: The filming was "point and shoot" and to help you select which to purchase, go to (www.polioplace.org/sites/default/files/files/AbstractsDVDSessions.pdf) to review abstracts for the sessions listed on the next page. If you have questions about the content of the material, please contact the presenter, who is responsible for it, or contact PHI for clarification.



(continued, reverse side)

DVD of the following sessions (\$3 each session):

_____ Review: Late Effects of Polio & Your Health (Frederick M. Maynard, MD)

Conditions of Aging

_____ Managing More Meds (Marny K. Eulberg, MD; Alicia B. Forinash, PharmD)

_____ Cardiovascular Aging (Michael W. Rich, MD; Martin B. Wice, MD)

_____ A Good Night's Sleep (Ann Crocker; William M. DeMayo, MD)

_____ Maintaining Posture (Holly Wise, PT, PhD; Carol Vandenakker-Albanese, MD)

Medical Matters

_____ Pain: It Gets Our Attention (Ann Crocker; William M. DeMayo, MD; Frederick M. Maynard, MD)

_____ Let's Talk about the Spine (Cynthia Henley, PT; Carol Vandenakker-Albanese, MD; Kathryn Wollam, PT)

_____ Update on Anesthesia (Selma Calmes, MD)

_____ Roundtable on Post-Polio Bracing (William M. DeMayo, MD; Marny Eulberg, MD; Marmaduke Loke, CPO, Dynamic Bracing Solution; Dennis Richards, CO, Townsend Design)

_____ Roundtable on RADs, Vents & Interfaces (Betsy Thomason, RRT; Ronda Bradley, MS, RRT, FAARC, CareFusion – Alternate Care; Tony Mengwasser, RRT, Philips Respironics; Michael Madison, RRT; Bob Richardson, RRT, ResMed)

Post-Polio Research

_____ Lessons from The Rehabilitation Research & Training Center on Aging with a Physical Disability (Alexandra Terrill, PhD; Aimee Verrall, MPH)

_____ Summary from Brazil & South America (Sheila Jean McNeill Ingham, MD, PhD) & Genetic Predisposition to Polio: New Research from Canada (Mark Loeb, MD, MSc, FRCPC) & Endurance Training: How to target intensity? (Eric Voorn, MSc)

_____ Update on PHI-funded Research (Antonio Toniolo, MD; Carolyn Kelley Da Silva, PT, DSc, NCS; Claire Kalpakjian, PhD)

Managing Our Relationships

_____ Relatives of Survivors: Three Perspectives (Stephanie T. Machell, PsyD; Mary Navarre, OP, EdD; Willard [Bill] Smith, PhD)

_____ Communicating for Understanding (Stephanie T. Machell, PsyD; Rhoda Olkin, PhD)

Life Decisions of Aging

_____ Advice on Solo Aging (Jann Hartman; Alison [Sunny] Roller, MA; Susy Stark, PhD, OTR/L, FAOTA)

Recreating Ourselves

_____ Assessment: Our Home (Gina Hilberry, AIA; Cyndi Jones)

Wellness Practices

_____ Why Worry? Stop Coping and Start Living (Kathryn Tristan)

UN Convention on the Rights of Persons with Disabilities

_____ Disabilities Treaty (Judith E. Heumann, MPH, Special Advisor for International Disability Rights at the U.S. Department of State)

_____ sessions at \$3 each= \$_____

Total of all choices = \$_____

Enclosed is my check to Post-Polio Health International

Or charge \$_____ to my MasterCard VISA Discover

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Name on card _____

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