

## Post-Polio Health International Doubles Research Fund Grant to \$50,000

**William Stothers, Post-Polio Health International's (PHI) Board Chair announced that PHI will increase the yearly amount given from The Research Fund to \$50,000. PHI's Board of Directors also voted unanimously to include a percentage for facilities and administration.**

Established in 1995 with assets from the estate of Thomas Wallace Rogers, the dedicated fund grew from donations and wise investing. Rogers was a polio survivor who slept in an iron lung and sought the organization's help when his breathing problems worsened. He led an active life and ran his own securities business.

"I recall discussions he had with Gini Laurie about using positive pressure ventilation," said Joan L. Headley, executive director of PHI. "With the help of Oscar B. Schwartz, MD, a St. Louis

pulmonologist, he added the PLV-100 (Philips Respironics) to his breathing aids. I think he would appreciate the fact that additional donors and the market greatly expanded his initial contributions."

Longtime PHI Board member and Chair of PHI's Medical Advisory Committee, Fred Maynard, MD, said, "We are excited to double the amount of our research awards in order to accelerate the rate of investigation into useful solutions to the problems of our aging polio survivors who make up the majority of our membership."

PHI's eighth Request for Proposals has changed from prior years. It is now a one-step process, rather than two, and the award will be given annually, with an option for \$100,000 over a two-year period.

The application deadline for the grant to be awarded in 2014 is February 3, 2014. The recipient, if one is warranted, will receive notice by April 15th. An application is available on [www.post-polio.org](http://www.post-polio.org) to study the cause(s), treatment and management of the late effects of polio and to explore historical, social, psychological and independent living aspects of living with polio.

"In future years we may narrow the focus of the request to particular medical or social problems affecting polio survivors," explains Daniel Wilson, PhD, Chair of PHI's Research Committee. "We invite members of PHI to suggest possible subjects for future research." ■

### Past PHI Research Fund Awardees

2001 – \$20,000

University of Toronto, Toronto Rehabilitation Institute, West Park Healthcare Centre. *Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life.*

2003 – \$25,000

University of Michigan-Ann Arbor. *Women with Polio: Menopause, Late Effects, Life Satisfaction and Emotional Distress.*

2005 – \$25,000

Johns Hopkins University. *Timing of Noninvasive Ventilation for Patients with Amyotrophic Lateral Sclerosis.*

2007 – \$25,000

University of Arkansas for Medical Sciences–Little Rock. *Pilot Study to Identify PPS Biomarker.*

2009 – \$25,000

University of Insubria, Varese, Italy. *Persisting Noninfectious Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral Drugs.*

2011 – \$25,000 each to:

University of Michigan-Ann Arbor. *Oral Glutathione and Health Outcomes among Persons with Post-Polio Syndrome.*

Hadassah Medical Center, Jerusalem, Israel. *Characteristics of Poliomyelitis and Post-Polio Patients among Jews and Arabs in Jerusalem.*

2013 – \$25,000

Texas Woman's University-Houston, and TIRR-Memorial Hermann Rehabilitation & Research. *Effects of Whole Body Vibration on People with Post-Polio Syndrome.*

## St. Louis 2014 – May 31-June 3, Hyatt Regency St. Louis at The Arch

*You are invited to take advantage of an extraordinary opportunity – PHI's 11th International Conference.*

During the three days of programming on June 1-3, you will be able to see the latest in bracing design, respiratory assist devices, multi-mode ventilators and interfaces.

Presentations and interactive discussions will feature the philosophical and personal aspects of spirituality, the philosophical and the practical aspects of end-of-life decisions, exploration of faith and disability and changing relationships through a life span.

There will an opportunity to gather facts and hear about the experiences of other survivors on attendant care, accessible homes and design, aging solo, staying active in mind and body and tips on assessing your abilities.

Included in "Promoting Healthy Ideas" will be topics such as weight management, sleep, managing medications, attention-getting pain, update on research and future needs of polio survivors. You will be able to explore QiQuong, yoga, music therapy, ideas for maintaining posture and dealing with worry.

On Saturday, May 31, PHI will welcome first-time conference attendees at a special session from 3:00 pm–4:15 pm. All will be welcomed at a special dinner Saturday evening at 6:00 pm. (The final session will end at 3:00 pm on Tuesday, June 3.)

The other evenings will be a time for rest and reflection on the day's activities; spending time with old friends and making new ones. At nearby Busch Stadium, the St. Louis Cardinals will play the San Francisco Giants on Saturday and Sunday and the Kansas City Royals on Monday and Tuesday. The hotel is located in downtown St. Louis, and to find other evening activities in the area, see <http://explorestlouis.com>.

A block of rooms has been reserved at the conference headquarters hotel, the Hyatt Regency St. Louis at The Arch, 315 Chestnut Street. Additionally, we have contacted hotels close by and have accessible rooms available in an overflow hotel should the need arise. Individuals registered for the conference may register for a room online ([www.post-polio.org/net/11thConfHotelInfo.pdf](http://www.post-polio.org/net/11thConfHotelInfo.pdf)) or by phone (314-655-1234). As you all know, there are many people in our group who have mobility problems. PHI will make every effort to meet accessibility needs. Please understand these rooms will be assigned based on essential need, not solely on first-come, first-served.

Registration materials and updated program details will be posted on [www.post-polio.org](http://www.post-polio.org) in early November. Individuals who do not have access to the internet may request a print registration packet by calling 314-534-0475 or mailing the request to PHI, 4207 Lindell Blvd., #110, St. Louis, MO 63108. ■



PHI's 11th International Conference

## POST-POLIO HEALTH

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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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*PHI sends PHI Membership Memos via email. Be sure to set your spam filter to receive emails from [info@post-polio.org](mailto:info@post-polio.org).*

### Moving? Change of address?

Notify PHI before you move by calling 314-534-0475 or email [info@post-polio.org](mailto: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.

# A Gentle Death

Nancy Baldwin Carter, BA, MEd Psych, Omaha, Nebraska

**A**t the far end of the end-of-life spectrum lies palliative care, a set of services created to benefit the chronically ill. In fact, it's so far from the end that, at times, it may not appear to classify as end-of-life at all. Patients receiving palliative care may simply be those with grave, life-limiting (but certainly not terminal) illnesses. Their care may consist of providing comfort, relieving symptoms, mitigating stress and pain. This may often exist hand-in-hand with curative treatment for disease.

This could include people such as polio survivors, perhaps struggling with pain, loss of function, chronic weakness, those who are ventilator users or those experiencing continually deteriorating muscle mass. Other people may be affected by serious complications of aging, cancer, heart or renal disease, stroke, Alzheimer's, Parkinson's or diabetes, for example, all longing for symptom relief, serenity, a better quality of life.

On the other hand, some patients may reach a point when their illnesses progress to the terminal stage, where palliative care merges into hospice care, and they are judged to have no more than six months left to live. Yet everyone seeks relief from pain and alleviation of distressing symptoms – the very definition of “palliative.”

## How It Works

The concept is encouraging. Chronically or seriously ill individuals still living in their family homes (not necessarily bedridden), or even those in hospitals or other facilities, are eligible for palliative care, which brings physical, emotional and spiritual support into the picture wherever they are. Easing symptoms. Providing comfort. Patients are treated totally, not merely for their illnesses. Studies show significantly less depression and fewer emergency room visits among such patients.

Ideally, the focus is on the patient through what could be an extensive team approach according to need – this may include doctors, nurses, therapists, pharmacists, counselors, social workers; those addressing spiritual needs, psychological and emotional issues; holistic approach specialists, caregiver support and other members of a multi-disciplinary effort – all considerably enhancing the well-being of patients. In fact, patients themselves and sometimes family members may be an essential part of the team.

The idea is to bring palliative treatment to the patient. This is not about dying, but about living well, even at the end of life. And it fulfills the dream of a large percentage of the population who want to stay in their own homes until the end.

Patients sing the praises of palliative care. They feel safe and supported realizing they are being cared for by a full team who knows them personally and understands their wants and needs. Doctors can be more available, pain-relief honored upon request. They feel the freedom that empathy and hope engender.

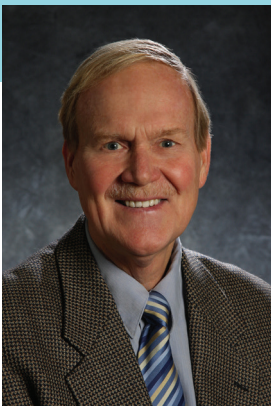
Palliative care programs are a relatively new concept, still in various stages of development across the country. Doctors can be board certified in Hospice and Palliative Medicine, working with well-established programs, which themselves can be accredited by the Joint Commission on Accreditation of Healthcare Organizations.

## Meeting Home-based Goals

Not all home-based programs have met their full potential. Some teams may consist of no more than a doctor and a nurse practitioner, far from satisfying all aspects of their palliative goals. There may be no counselor, no chaplain. These teams may still struggle to provide pain management through holistic methods

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*This is the last of a three-part series by Nancy Baldwin Carter about end-of-life issues. While difficult to think about, avoiding the subject can result in last-minute decisions based on incomplete facts and misconceptions.*



Frederick M. Maynard, MD

## Ask Dr. Maynard

Send your questions for Dr. Maynard to [info@post-polio.org](mailto:info@post-polio.org).

See other questions at [www.post-polio.org/edu/askdrmay.html](http://www.post-polio.org/edu/askdrmay.html).

**Question:** I am a 1949 paralytic polio survivor (at 10 months old). I have rheumatoid arthritis and most of the typical drugs to control pain and progression have frightening side effects. I do well on a modest dose of prednisone and have read in *Arthritis Today* about a time-released prednisone called Lodotra®. One of Lodotra's precautions, however, refers to patients who have had polio. Can you tell me why a polio survivor would be at risk for taking Lodotra? It sounds like a perfect solution for me otherwise.

**Answer:** I reviewed some of the internet information about Lodotra. I believe the precaution mentioned about poliomyelitis refers to an acute infection with the poliomyelitis virus, or after receiving the live polio vaccine. It is my opinion that your risk of side-effects from Lodotra would not be different from anyone else's, since your history of paralytic polio as a child was 50-plus years ago. Consider the pros and cons of Lodotra as an alternative to your current use of prednisone for control of your RA in consultation with your doctor, independent of your polio history.

**Question:** Do you have any advice about sciatica nerve pain? I have been in physical therapy three times a week for three weeks, with home exercises. It helps, but the pain is not gone yet, and my physical therapist gave me some bad news. My hyper-extended right leg has gone from -11 degrees to -13 degrees. I noticed I was not walking as well as I had been. I took off my Velcro knee brace several months ago because I was doing so well, but then noticed I was not walking as well as I used to, so now I am wearing my Velcro knee brace again. My other question is, how far back can a leg go before you can't walk on it? This is very discouraging.

**Answer:** First of all, one of the most downloaded files from PHI's website at [www.post-polio.org/edu/pphnews/pph22-3p1-3.pdf](http://www.post-polio.org/edu/pphnews/pph22-3p1-3.pdf) is about sciatica problems. It sounds like wearing your Velcro brace is a good idea, at least as a strategy to prevent worsening. Don't worry too much about the exact angle, because one CAN still walk when it is hyperextended to 30-40 degrees or more, BUT it isn't good then and can cause lots of other problems, including knee pain. If you can keep at 15 degrees or less, you should be OK. Stick with the therapy if it is helping and don't be discouraged if pain is not all gone after three weeks. It make take a few months of home exercises after completing therapy before all sciatica is gone – hopefully enough that you can function.

**Question:** Are gabapentin or pregabalin effective medications for post-polio neurological damage, the type of damage that leads to leg and hand muscle cramps?

**Answer:** Gabapentin and pregabalin are only approved for control of seizures and fibromyalgia (in the case of pregabalin). There are no studies supporting their effectiveness for leg cramps in post-polio survivors or others. Gabapentin is the most widely prescribed and used off-label drug for chronic pain syndromes of all sorts. If these drugs are used for leg cramps, they should be evaluated carefully on an individual basis relative to their effectiveness and the optimal minimally effective dose. For post-polio survivors with leg cramps, a thorough history and exam should be done regarding the most likely cause(s) of the cramps. Tight muscles that can be treated by stretching exercises are the most common contributing factor, followed by overuse/misuse of the leg muscles. Metabolic imbalances of calcium and magnesium are also common. None of these common causes are likely to respond to treatment with gabapentin or pregabalin. ■

## The Role of Oral Glutathione in Improvement of Health Outcomes among Persons with Late Effects of Poliomyelitis

Claire Z. Kalpakjian, PhD, MS, University of Michigan,  
Department of Physical Medicine and Rehabilitation, Ann Arbor, Michigan

Glutathione is a powerful antioxidant and plays an important role in a number of cellular processes and the maintenance of cellular homeostasis associated with health and longevity. The goal of this pilot study was to examine the effectiveness of oral glutathione for improving health outcomes in persons with the late effects of poliomyelitis.

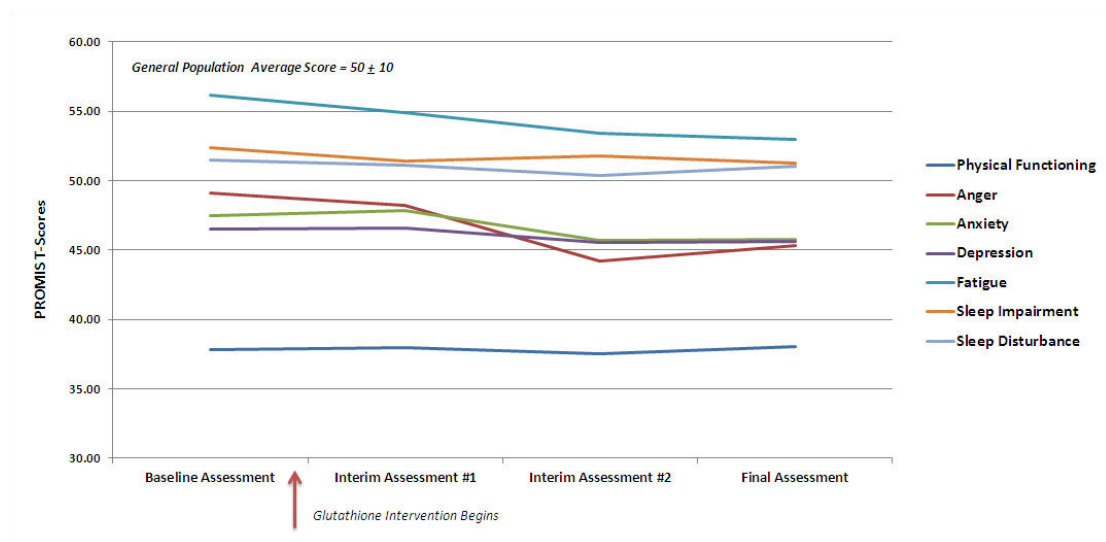
A total of 20 individuals who were between the ages of 50 and 65 with clinically identified post-poliomyelitis late effects and who were able to ambulate at least 100 feet, with or without assistive devices, enrolled in this study. The intervention was a three-month trial of twice-daily, oral, 1,000-mg glutathione supplements. This study involved four assessment periods across the three-month study period (two clinic visits, two home-based assessments).

Outcomes were self-reported physical functioning, fatigue, sleep problems and mood. Scores on these questionnaires were compared to the U.S. population to see if this sample was different than their peers. A device worn on the upper arm was used to measure physical activity, and how well people slept at night was measured using weekly sleep diaries.

Contrary to expectations, the results of this pilot study did not provide support for the hypothesis that a 12-week trial of oral glutathione supplementation would improve health outcomes. While outcomes of anxiety and sleep improved from baseline to the final assessment, there were no other changes in outcomes across the study period. There also was not a significant change in total glutathione levels in the blood. People in this study were a lot like their peers without polio on self-reported health outcomes like mood and fatigue, but they were much lower in terms of physical functioning.

Although not the primary focus of this study, the use of a device to monitor physical activity indicated that people in this study had an extremely high level of sedentariness with an average of nearly eight hours lying down per day (in addition to night-time sleep). Efforts may be best spent to design and test interventions to reduce sedentariness in this population. This is likely to have a greater and more direct impact than a supplement like glutathione for improving mood, strength, flexibility and to reduce risks associated with reduced physical activity. ■

### Self-Reported Health Outcomes



**QUESTION:** *My brother, now 68, had polio in 1961. It affected his legs, and he has used a wheelchair since then. He lives alone, is very independent and has always been able to find a way to take care of himself. He just told me that he has lost the use of his (already weak) right arm and does not want to go on living. I told him I would take care of him, but he doesn't want to be a burden. I am devastated – what can I do? Is there any way to help him?*

**Response from Rhoda Olkin, PhD:**

First, let me acknowledge how scared you must feel that your brother is talking about wanting to die. This can arouse all kinds of emotions in you, including powerlessness, anxiety, anger and everything in between. I will let my colleague address what you can do to help. Here, I will address what might be going on with your brother.

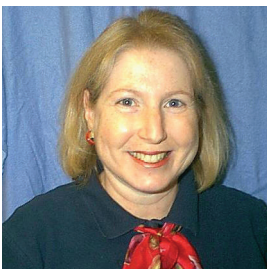
A few studies suggest that people with polio have lower rates of depression than the general population. Perhaps the need to deal with adversity, usually early in life, provides some coping and resilience. But with your brother the opposite seems to be occurring. Thus, you need to consider the possibility that your brother is depressed.

He had polio when he was about 16 years old. That experience may have left emotional traces that reverberate now. He went from a healthy body to probably being hospitalized, probably being helpless, probably feeling isolated

in his experience. Now, as he ages and has decreased physical functioning, these feelings, dormant for many years, are reawakened. The idea of old emotions being re-triggered is not just theory. One example comes from studies of monkeys who got depressed after their mothers were removed. They recovered when reunited with the mother, but years later they were more prone to depression again. The brain chemistry seems to be ignited again when a current situation reminds us of an older experience.

It is important to keep in mind that people don't want to die because they have polio per se. They might feel like dying because of polio's effects on daily functioning. This might include not being able to visit friends whose houses are not accessible, or being less social due to fatigue, or finding that simple daily tasks are too taxing, or needing help with activities of daily living when one is used to independence. I wonder what your brother used to be able to do, that limited use of his right arm now might prevent him from doing. As an example, I used to do woodworking every weekend, but then as my arms got weaker, I found power tools too dangerous. This forced me to find a different (and more sedentary) hobby, which I did, but I still miss woodworking. What is different or missing in your brother's life now?

I am guessing your brother does not have a partner. This means he has to find social support outside the house, which requires energy and mobility. Social support is one of the predictors of well-being (and even longevity) in older adults. Just today I pondered cancelling a social event for Friday night because this has been a hard week. It is easy to do this and not notice that weeks can go by without any socialization. If daily life requires too much of our energy, we start



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.

cutting out things that sustain and feed our emotional being. It is better to hire someone to vacuum the house to reserve energy for having coffee with a friend. Your brother is blessed to have a caring sibling such as yourself.

**Response from Stephanie T. Machell, PsyD:**

Without speaking with your brother, it's hard for me to know if he is clinically depressed. It is clear that he is grieving a major loss – his arm, certainly, but more significantly, his previous lifestyle and independence. Saying he no longer wants to live may be more an expression of grief than a wish to commit suicide, or even to die at all. He needs the chance to experience and process this grief as well as find solutions to the problem of how he will move on with his life.

It can be easier to do this with someone who your brother doesn't fear hurting by expressing these feelings, which is why seeing a therapist would be helpful whether or not he is clinically depressed. A therapist can help your brother deal with his grief and with thinking about and planning the future. A therapist can also assess whether or not your brother is clinically depressed and/or at risk of committing suicide.

The right therapist for your brother would be someone who understands disability issues. A therapist who doesn't might simply assume your brother is depressed and miss the issues related to the disability. If you and he can't find a therapist with a background in disability, someone who works in health psychology and deals with issues related to chronic illness could be a good option.

Your brother may be reluctant to see a “shrink” because he assumes it represents a failure on his part or an assumption by others that he is weak or

mentally ill. Reassure him that the right therapist for him is one who recognizes his considerable strengths and is there to empower him to use these to move through the current crisis.

It might also be helpful for your brother to know that getting help and being independent aren't mutually exclusive. A personal care attendant (PCA) is an option you can pay for either through insurance or out of pocket. Your brother would be responsible for hiring and training this person. He would have control over what the PCA does for him and how and when it is done. When this model works well it provides independence and the freedom to live in the community. Receiving such help would allow your brother to use his energy for activities he values rather than simply maintaining. Being able to do things he enjoys will serve to improve his mood and help him to feel less helpless.

Being the family member of someone struggling with these issues is difficult. It's hard and painful to hear someone you love say he doesn't want to live. And it's hard to have your help rejected. You need a place to deal with your own feelings about what your brother is going through in order to be able to be helpful to him. Apart from confiding in family and friends you might benefit from speaking with a therapist familiar with these issues. Caregiver support groups are available in many different places. ■



**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.

Stephanie T. Machell, PsyD

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such as massage therapy or acupuncture, or relaxation techniques such as yoga or even a pleasant drive through the countryside, for example. Home-based possibilities, the ideal for a large percent of end-of-life patients, may not yet exist.

Today our elderly population is growing rapidly. Estimates say that in the United States the number of people over the age of 65 will increase to 88.5 million by the year 2050. Many of these individuals will have serious illnesses. Chronically-ill patients are living longer. Home-based

palliative care is designed to answer the unique needs of such patients, providing an important measure of the highly-treasured independence most patients long for as a basic quality in their lives.

### Funding

Finding financial solutions can be a challenge. Palliative care specialists are trained to discuss treatment preferences with their patients. Results show that patients are happier and even survive longer when their wishes are carefully followed. Being assured they will get exactly what

they want brings them peace. Patients who choose to cut short aggressive treatments that don't improve their conditions, avoiding the agony of the drawn-out inevitable, may also discover that a result of this decision is lower costs.

Additionally, because palliative care patients are not considered terminal, Medicare does not view that program in the same light as it does hospice care. The term "palliative" isn't used by Medicare. Although Standard Medicare Part B benefits may cover a small number of key elements of palliative care, such as certain physician, nurse practitioner or social worker visits in the home, this does not necessarily include paying the expenses that would bring in the rest of the team members, the very soul of any palliative care program.

Whoever offers the palliative care (a community-based organization, a hospital, or some other provider) can

bill Medicare, but the patient may be required to pay fees or other charges Medicare won't cover. Medicaid operates on the same standards in most states. Certain private health insurance plans cover palliative or chronic care costs, and other means of funding for the home-based option may be available.

One doctor asks, "Why should Medicare fund only patients needing our help in the last six months of their lives? Patients who don't qualify for hospice because they are not yet at the final stage of life might still benefit greatly from palliative care."

### Hospital-based Palliative Care

At the same time, hospital-based palliative care is on the rise. Surveys show that 63% of U.S. hospitals had palliative care teams in 2009, compared with only 24.5% in the year 2000. Clearly, hospitals are realizing the benefits palliative care brings to seriously ill patients at any point in their illness.

Doctors see this as a win-win situation. Not only do they get to supply significantly better quality and efficient personal care to their patients, but their patients recognize and appreciate receiving the extraordinary amount of empathy palliative care provides. Palliative teams bring an extra layer of expertise and efficiency to the hospital setting, easing the burden of care placed on physicians.

The presence of these teams lowers hospital costs through shortened stays, thus increasing capacity by working on care plans with those patients who hope to reduce unnecessary tests and treatments. Through it all, teams provide that special personal, compassionate, palliative care touch. Satisfied patients are good news to the hospital, which values being capable of delivering such excellent patient-centered care so cost-effectively.

### Caregivers

In the meantime, caregivers reach out to provide help at home for longer periods of time. Family members and friends step in, devoting endless hours to the comfort and needs of loved ones. Over

**Live for today ...**



**But plan for tomorrow.**





▷ 43.5 million individuals care mainly for parents and spouses in this country every day. The effectiveness of the palliative program depends upon everyone's working together.

Much of the success of palliative care is generated at the communication level between team members and the family. Certain physicians have been reluctant to participate in end-of-life discussions. Team members, however, are specifically trained to help patients determine their treatment preferences, to explain recommendations, and to answer their questions.

Patients and families should be prepared to ask any questions they have about palliative care, such as:

- ◆ What is palliative care? How is this different from hospice? How serious is my problem?
- ◆ Can I get the care I need at home? How will this care be continued if I am moved from my home to a hospital or another location?
- ◆ How will you treat my pain?
- ◆ Will I have contact with my regular doctors?
- ◆ Who will be on my palliative care team?
- ◆ Will palliative care volunteers work with me? How are they trained? Does this include family members?
- ◆ What should I know about services involved?
- ◆ What fees and expenses will I be responsible for paying? Who will help me finance my care if Medicare won't?

## In the End

Preparing for the end can be a long and involved process. It includes not only research, trying to find the path that suits us best, but also talking with loved ones about issues we hoped never to have to face. Following through, however, is what offers us that gentle death. Comfort rather than pain and suffering. Serenity rather than anxiety.

And so we search and discuss, examine possibilities like Death with Dignity and hospice and palliative care and others.

We reveal our choices to our families and friends and those in the medical community who have us in their care. We make sure everyone understands this is how it must be for us. Our wishes must be carried out.

And then we turn to those we leave behind. We want our death to be as gentle for them as it can possibly be, as well. Some of us will say our goodbyes at special end-of-life get-togethers, others wait to express words of love and farewell until our final moments.

Some may plan the end with their loved ones over a long period of time: Mark, a practical and loving man, and Pat, his practical and loving wife, devoted eight years to fighting his cancer. They both wanted the best for him, worked together on every aspect of recovery. Yet they realized what the chances were and spent long hours talking about what she'd do when he passed on.

"He helped me make initial adjustments as a widow during that time – made lists of things for me to remember – property upkeep, taxes," Pat says. "He coached me on how to inflate the car tires with air, how to fill the sump pump battery with distilled water. He made a handy tool box for my personal use, saying 'Here's everything you should need for most small repairs.'"

He made death gentle – the final gift of a practical, loving man to his practical, loving wife. ■

## Resources:

Palliative Care Services of Nebraska ([www.palliativecarenebraska.com](http://www.palliativecarenebraska.com)) is an excellent source for information on the topic. Created by Lisa I. Mansur, MD, FCCP, FACP, who is board certified in internal, pulmonary, critical care, sleep and palliative care medicine, the site is designed to educate people about what palliative care is and what it offers, as well as related issues such as advance directives and other practical matters. The site provides links to a wide array of articles, podcasts, videos, a glossary of terms and other resources for patients, families, caregivers and medical professionals. Dr. Mansur received the CHEST Foundation's 2012 Roger C. Bone Advances in End-of-Life Care Award for her work and that of her team in creating this site.

## Shingles Vaccine Experience among the Survivors of Polio

Frederick M. Maynard, Chair, PHI Medical Advisory Committee, Marquette, Michigan

Members of PHI concerned that polio survivors might have abnormalities of the immune system questioned whether taking the shingles vaccine would either increase the risk of complications or make it less effective. In early 2013 PHI distributed a six-question survey through its PHI Membership Memo, website ([www.post-polio.org](http://www.post-polio.org)) and Facebook. The *PHI Association Member Communiqué* asked support groups to recruit survey takers who had had polio from their memberships.

By late April, 293 people completed the survey. Some 64% of respondents (186) had taken the shingles vaccine (Zostavax®). Only six of these respondents (3%) reported any problems as a result of taking the vaccine.

Among the four respondents who described their problems, two reactions were mild with transient aching at the vaccine injection site. One, who took the vaccine after having had a case of shingles, described persistent itching at the injection site. One individual reported fainting while exercising about two weeks after taking the vaccine, which most likely was coincidental. These side effects are similar to those reported in non-polio survivors<sup>1</sup>.

Regarding the vaccine's effectiveness, eight of 186 respondents (4.3%) reported developing a case of shingles after having received the vaccine. All of the cases were described as mild and no one reported postherpetic neuralgia (nerve pain), the severe persistent pain problem that is the most feared complication of having shingles. The worst case was described as "not severe but pretty painful and a downright nuisance."

Since the respondents received their vaccine a mean of 2.9 years before answering the survey, they represent

about 531 person years at risk for developing shingles. These numbers suggest an estimated incidence of clinical shingles among post-polio individuals who have taken the vaccine as 15 cases per 1000 patient years. This compares to a rate of 11.1 cases per 1000 patient years among placebo vaccine recipients and 5.4 cases per 1000 patient years among immune-competent, 60-plus-year-old vaccine recipients in the largest and best designed study of the vaccine's effectiveness<sup>2</sup>.

Because PHI's survey was open to all its contacts and was voluntary, it undoubtedly had a responder's bias among its sample for people who had received the vaccine and still developed a clinical case of shingles (not laboratory confirmed).

In summary, our survey's estimated rate of developing shingles in spite of receiving the vaccine suggests that the shingles vaccine is most likely as effective among polio survivors as in people who never had polio, especially in preventing severe cases with disabling pain.

The low number of responders with side effects after receiving the vaccine is also reassuring in that its use is similarly safe for polio survivors. Given the high rate of shingles among older Americans, survivors of polio with a competent immune system are encouraged to receive the shingles vaccine. ■

1) Simberkoff MS, RD Arbeit, et al. Safety of Herpes Zoster Vaccine in the Shingles Prevention Study. *Ann Int Med* 2010; 152:545-554.

2) Oxman MN, MJ Levin, et al. A Vaccine to Prevent Herpes Zoster and Postherpetic Neuralgia in Older Adults. *NEJM* 2005; 352: 2271-2284.

## Study Says Shingles Vaccine Not Reaching Enough U.S. Adults

Too few American adults have been vaccinated for shingles, according to research that calls for efforts to increase the U.S.-recommended inoculation.

Fewer than 2 of 10 Americans ages 60 and older have been vaccinated, while the rate is less than half that for those in their 50s, according to a study presented in September at the Interscience Conference on Antimicrobial Agents and Chemotherapy.

Almost one-third of Americans will get shingles in their lifetime, with about 1 million cases in the United States each year, the Centers for Disease Control and Prevention said. The vaccine Zostavax® was cleared for sale in 2006 for people 60 and older and for use by those in their 50s in 2011. Still, too few people take advantage of it, doctors said.

Shingles is caused by the same virus as chicken pox; it can remain in the body after a chicken pox infection and become active again years later. It's characterized by a painful rash that generally clears within a month and can be accompanied by fever, stomach ache and chills. A more problematic lasting side effect is postherpetic neuralgia, a burning nerve pain that can be severe enough to disrupt sleep and affect appetite, according to the Mayo Clinic.

Shingles becomes more prevalent with age; about half of infections occur in those 60 and older, according to the CDC. Yet just 16 percent of Americans in that age group had been vaccinated in 2011, the study of almost 30,000 people found. That compares with 4.3 percent of U.S. adults in their 50s.

The vaccine is generally covered by insurers for people 60 and older, researchers said.

Source: *Bloomberg News*

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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.

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### Post-Polio Health Article Translated into Japanese

Although *Post-Polio Health* is distributed around the world, we sometimes received requests to translate and reprint specific articles. Such was the case with “Conquering Mysterious Foot Pain” that appeared in Vol. 28, No. 4 in December 2012, which was translated into Japanese and reprinted in the July 2013 issue of the Japanese Network of Polio Survivors newsletter.

“This article gives many suggestions to polio survivors,” said translator Masakuni Mukoyama.

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