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India Needs to Focus on Its Polio Survivors

Neena Bhandari, Foreign Correspondent, *India Voice*, Sydney, Australia

The Indian Government, Non-Governmental Organisations and the larger community must invest in rehabilitating the unknown number of polio survivors facing new physical, social, cultural and economic challenges. India was certified polio-free by the World Health Organisation on March 27, 2014. Polio immunisation has been a great success story of public-private health partnership, but now we need to replicate this to improving the lives of people living with polio.

Unlike the developed world, many polio survivors in India are still very young. They will need treatment and support for many more years to come. Doctors, orthotists and physiotherapists need to be trained to recognise and manage the debilitating effects of post-polio syndrome (PPS).



ABOUT THE AUTHOR:

Neena Bhandari is a Sydney-based foreign correspondent, who contracted polio in India soon after receiving the oral polio vaccine in 1967. Since then, she has lived and worked in India, the United Kingdom and Australia as a journalist and foreign correspondent, reporting on issues ranging

from health and development, environment and education, human rights and gender to crime and law. Many bylines and many callipers on, as PPS poses new challenges each day, she is constantly evolving ways to live life to its fullest as a mother, a wife and above all a professional in the fast-paced, highly competitive media industry.

It is also time to count and document the number of polio survivors and the problems they are facing today.

Despite the odds, stories of endurance and resilience unfold as I meet polio patients in villages, towns and bustling cities.

Abhishek Kumar Kunvar

On a cold January night, I meet 26-year-old Abhishek Kumar Kunvar, a security guard on duty at a friend's house in South Delhi. Abhishek's right leg was affected by polio at the age of five. He hails from Balau village in the eastern state of Bihar, where he went to school with his older siblings. In the afternoons, he would help his parents on their small farm, growing wheat and corn. He would regularly swim in the nearby river, which provided relief to his aching limbs.

He told me how his parents took him to the state capital, Patna, to consult a doctor. He underwent corrective surgery, which made it easier for him to walk. As he grew older, he began experiencing more pain, fatigue and intolerance to cold. He was unable to do hard labour on the farm so he migrated to Delhi in search of work. Through friends and relatives, he found a job with a private security agency and now earns Rs 7,500 (slightly more than \$120 US) per month. In addition, he gets Rs 500 (about \$8 US) from the Government's Disabled Pension Scheme and travel concession on public buses and trains. The daily commute to work from his home in Mahipalpur takes two hours on the bus and one hour of walking, which he is able to manage for now. He does

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ADA is 25

July 26, 1990, was an historic day for people with disabilities.

President George H.W. Bush signed the Americans with Disabilities Act (ADA) as shown in the iconic photo at the left.

In addition to former President Bush, the most recognizable person in the photo is Justin Dart (far right), a polio survivor with Texas roots. Dart, who as Chair of the Congressional Task Force on the Rights and Empowerment of People with Disabilities, traversed the country holding public hearings which were attended by thousands of people with disabilities, friends and families documenting their lives of discrimination.

Seated at left is Evan Kemp, Jr., disabled with Kugel-Welander syndrome, who held a law degree and began his career at the U.S. Securities and Exchange Commission where he received raises until he started using a wheelchair.

He became politically active and ultimately was considered an "insider" because of his friendship with C. Boyden Gray, Bush's legal counsel. Kemp was appointed by Bush to head the Equal Employment Opportunity Commission in March of 1990 and was in the position to argue both publicly and within the administration for a disability rights law.

Behind Kemp is The Reverend Harold Wilkie, born without arms, credited with making organized religion more accessible to people with disabilities. First as a leader within the United Church of Christ, he became a national leader for social action opening the ministry to women and people with disabilities. Reverend Wilkie delivered the invocation at the ceremony and accepted a ceremonial pen from the President with his foot.

The lone woman and the mother of children with a disability is Sandra Swift Parrino. She was chair of the National Council on Disability, which is an independent agency today due to her insistence. The council called for federal civil rights protection for people with disabilities. The document, *Toward Independence*, spearheaded by director Lex Frieden, led attorney Robert L. Burgdorf to draft the first version of the ADA introduced in Congress in April 1988.

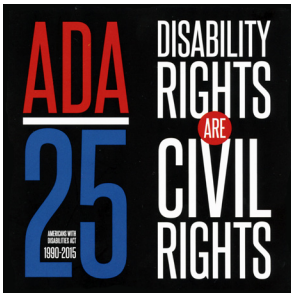
I recall the cramped room in St. Louis in which people publicly and passionately shared their stories as requested by Justin Dart, the signing of several postcards to be sent to Congress and the counting out and packing up of 1,000 postcards sent to post-polio support groups around the country. I worked hard and was hopeful. I was not in Washington on July 26, but I was proud.

The same was true for thousands of people with disabilities living in the United States.

Do you have your own memories of what you did to advance the cause?

Congratulate yourself and celebrate. ■

Joan L. Headley, Executive Director



The History of the Americans with Disabilities Act: A Movement Perspective
by Arlene Mayerson,
1992, is an excellent overview of how the ADA became a reality.
(<http://dredf.org/news/publications/the-history-of-the-ada/>)

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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.

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Away temporarily?

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

PHI Issues Request for Proposals

The Research Fund of Post-Polio Health International is looking for researchers interested in studying post-polio myelitis.

The call for funds to be dispensed in 2016 is broad. The Research Committee is asking for proposals to study the cause(s), treatment and management of the late effects of polio or to explore historical, social, psychological and independent living aspects of living with polio.

The research must have the potential to improve the lives of polio survivors. Preference will be given to innovative or original research that leads to new interventions, products, methods or applications.

The maximum amount of the award for one year is \$50,000. PHI will accept proposals that require two years to complete for a maximum of \$100,000.

The “Request for Proposals Guidelines” can be downloaded from PHI’s homepage, www.post-polio.org, or from the “Research” area at www.post-polio.org/res/rfcall.html. The “Applicant Information,” required when submitting a proposal, is also available for download.

October 1, 2015 is the deadline.

The Research Committee will review the proposals and make its recommendation to the PHI Board of Directors, who will make the final decision in December 2015. The funds will be distributed in 2016 or 2016/17.

Update on 2014/15 grant

Dr. Antonio Toniolo and team continue their study “Poliovirus genome in patients with post-polio syndrome (PPS): Defining virus mutations by novel genome sequencing methods and investigating possible treatments with



Dr. Antonio Toniolo

antiviral antibodies and drugs.” PHI will receive a mid-study report by June 15, 2015. The final report is due April 1, 2016. Summaries will be published in *Post-Polio Health*.

Update on 2013 grant

The final report from Carolyn Da Silva, PT, DSc, NCS, Texas Women’s University, Houston, Texas, about her team’s study, “Effects of Whole Body Vibration on People with Post-Polio Syndrome,” will be published in the August 2015 *Post-Polio Health* (Vol. 31, No. 3). ■

Reminder

For reports and articles about all of The Research Fund recipients, visit PHI’s website at www.post-polio.org/res/.

A Sister Remembers

Mary Navarre, OP, Grand Rapids, Michigan

When Joan Headley, PHI Executive Director, asked me to be on a panel of family members of polio survivors at the conference in St. Louis, I was hesitant to do so as it was, and still is, difficult to talk about my life with my sister who contracted polio at the age of 6 – and even more so to speak about her death four years ago at the age of 64. Yet, I thought it might be helpful to others who are survivors and those who love them. And so I gathered some thoughts on the topic and went to the conference. I soon found myself in a room at the hotel with two other members of the panel, one was the daughter of a survivor and the other was the husband of a survivor.

Who wouldn't be angry? Spouses may not have known the person when he or she contracted polio originally, and they were now puzzled at what was happening. Some survivors appeared to be reacting out of resentment and anger that they were now losing the independence they had fought so hard to achieve, and sometimes they expressed feelings of hostility toward their significant others who didn't seem to GET IT. For example, a husband said, "If I ask her if she needs help she says, 'no,' then, she blames me for not seeing that she does need more help."

I can relate to this reality as my own sister was fiercely independent, yet as she became more dependent on assistive devices, oxygen and ventilator, her rage was sometimes vented toward those with whom she felt most safe – her family. Understanding this helps relieve some of the sting, but is not the whole answer.

Outside Help May Alleviate Stress

My sister and I learned through trial and error that we needed outside help to enable us to negotiate the treacherous waters of the post-polio world; she needed to hire a lot more done for her along the lines of physical help, domestic duties, transportation and home health aides so that we could be sister to each other, and I would not be in the role of nurse, cleaning lady or chauffeur whenever we were together. Cost was an issue, of course, but eventually there was no other choice and with some assistance (albeit minimal financial help from government programs like Independent Living), the stresses were alleviated – somewhat.

From the very beginning, our relationship was one of big sister (me) and little sister (her) as I was 9 years old and she just 6 when in 1952, polio dropped into our family's life like a bolt out of the blue. We have three brothers who were part of the picture – each of them coped with the



As the polio survivors, their spouses, siblings and adult children began to fill the room, I became aware of enormous amounts of fatigue, pain and confusion in the air. And this was not among those using wheelchairs. This was among the significant others of those who had survived polio. After the three of us spoke, questions were asked that revealed puzzlement, mixed messages, anger and hurt. Some of the survivors had overcome many of the physical limitations they had experienced at the onset of the disease and were now experiencing what seemed like a recurrence.

family dynamics in his own way; but that is a story for them to tell.

My parents were heartbroken as they watched their darling, red-haired, lively 6-year-old struggle to breathe and move and live. And we, the siblings, were baffled completely. In that day and time and place, children were not told much of anything and we were left to figure it out for ourselves.

My own response was to try to make it up to my sister that she could not and would never walk again. I felt guilty for walking and doing things she could not do. I always looked out for her and tried to flatten the bumps and smooth the way. Although we each came to lead our own very productive and fairly happy lives, I still to this day survey new terrain for accessibility. Nice restaurant! Hmm. Steps at the front entrance. No ramp. How does a person in a wheelchair get in?

Eventually, I learned that I could not make it up to her, but I could be her sister. I could walk beside her even if I could not be the fixer-upper and the problem-solver – although I must say I can leverage a wheelchair just about anywhere and coax a reluctant battery to kick in when the wind chill is well below zero.

Counseling and Support Groups Are Useful

I think in some cases, a family systems counselor could have helped all of us negotiate this terrain, and support groups for both relatives and survivors could be useful in airing the emotional baggage and strategizing on how to make life better for all concerned.

Polio doesn't happen to one person; it truly does happen to an entire family. In fact, in the 1940s and 1950s, it happened to our entire nation, and that has had its effects too. Those who **survived** the polio epidemic tended to be lionized as heroes (millions had died over the decades), and of course President Franklin D. Roosevelt was the epitome

of the polio hero who pulled the nation through the great depression and never appeared the least bit stressed. Hugh G. Gallagher's story, *FDR's Splendid Deception*¹, is a well named book as it depicts the intense efforts he, his family and staff took to conceal his disability from the public.

But lionizing a survivor can be an added burden. Polio survivors are not lions, nor victims, nor heroes, nor saviors – neither are their significant others any of these things. We are people, interdependent, sometimes loving, sometimes really pains in the back sides of one another.

My sister had a favorite poem which I would like to quote here as it is just two sentences in length, but captures much of our lives together then and even now in this new day and way of being family. ■

*We sat talking
in the summer sun,
lazing on the swing
and as it swung,
we moved from light to shadow,
weaving strands
of memories and plans.*

*And so we added length
and strength and color
from the varied fiber
of our lives,
knowing that the parts
may fray and ravel,
but the fabric
of our family survives.²*

1. Hugh Gregory Gallagher. *FDR's Splendid Deception: The Moving Story of Roosevelt's Massive Disability and the Intense Efforts to Conceal it from the Public*. Vandamere Press, 1999.

2. Genevieve Smith Whitford. "Reunion" from *Queen Anne's Lace and Other Poems*. Harp Press, Madison, Wisconsin, 1982.

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night shift from 8 p.m. to 8 a.m., which gives him time to study for Class XII and also take computer lessons.

His family has found a girl for him to marry. With a shy smile, he says, “If you have a job, you can get married, regardless of your disability.” Marriage is a strong and sacred institution in India.

Anjula Sharma

I then meet 39-year-old Anjula Sharma in Jaipur, capital of the western state of Rajasthan. She was afflicted with polio in her left leg at the age of three. Her first memories are of the leg being put in a wooden splint every night. She was provided a KAFO (knee-ankle-foot-orthosis) with a hip band. She remembers being teased by other children and being discouraged from participating in school functions.

“I loved to dance like other girls, but was not allowed to participate. My teachers would say that I can’t do the steps properly or I will fall and hurt myself. It was depressing and disheartening,” says Anjula, who enjoyed playing hopscotch jump and skipping rope with her sisters and brother at home. Her parents ensured that she went on to complete her Master of Science in Entomology and

then a PhD in Geology.

Once she reached early 20s, her parents faced immense pressure from the community to find a polio-affected boy to marry her.

Anjula says, “My parents didn’t bow to social pressures. I am married to a loving man with a good job. We have two children – a girl, 12, and a boy, 8.” With a family to look after, Anjula has to wear the calliper for most part of the day. She finds the KAFO made of polypropylene



Anjula Sharma



Abhishek Kumar Kunvar

and leather very uncomfortable during the hot and humid summer and monsoon seasons. She is up at 6 a.m., getting the children ready for school, then sweeping and mopping the house, cooking and doing the dishes. (Most household chores are still performed manually. The middle class can employ household help and most have washing machines.)

“If you have a job, you can get married, regardless of your disability.”

She is finding it difficult to stand for long, walk long distances and climb stairs, which has greatly restricted her activities. She now goes to the market only when it is absolutely necessary. She used to teach, but quit her job when standing for long periods became exhausting.

“Geology entails fieldwork and it is physically demanding with limited job opportunities. I am planning to study fashion design and upgrade my computer skills so I can work from home. I am beginning to get lower back pain, joint and muscle pain and headaches. I am trying to space the chores and take a brief nap, which helps,” Anjula adds with a charming smile.

Laxman Garasia

From city to a remote tribal village in Rajasthan, I meet 25-year-old Laxman Garasia, who had polio in his left leg at the age of three. He lives in a thatched hut in the hills with his parents and seven siblings.

He quit studying after Year VI because he couldn't walk 5km to school daily. He wore a KAFO, but discarded it after five months because the rigid steel calliper made it impossible to use Indian-style toilets and he found the leather very uncomfortable during the long summer season. His mother would carry him to most places till he was 10 years old. He then learned to use his hand to support the thigh and walk. Sometimes he uses a crutch for support, but the hilly terrain makes it difficult. Recently, he has got a job in a café in the nearby Muchala Mahavir Jain Temple complex, where he makes chappatis (unleavened flatbread) during lunchtime and earns Rs 100 (slightly more than \$1.60 US) and gets free food and accommodation.

With a sheepish smile he tells me that he has two wives. He had met his first wife at a village fair and the second one nearby. His wives work in the fields and contribute their income to the family. Laxman says, "I have worked in a sweet shop and steel factory in big cities. The income was good, but I couldn't cope with the physical demands of the job. I have begun to experience more pain, fatigue and intolerance to cold."

Polio Still Stigmatized in India

Polio is one of the leading causes of physical disability in India. Disability still has a stigma attached to it. It is seen by many as a curse or bad karma or destiny. But I found the stares and glares from the people around were less than it used to be during my growing up years with polio.

It was heartening to see survivors so well adapted to the challenges of everyday living. But as they grow older and the debilitating effects are compounded by



Laxman Garasia

the weakness, pain and fatigue of the post-polio syndrome, they will need all the help they can get to continue to have a productive life. Accessibility at home and in public spaces is a big issue. Some NGOs are providing motorised wheelchairs, three-wheeled scooters and modified automatic cars to survivors to enable them to pursue their education and employment.

Accessibility at home and in public spaces is a big issue.

More investment is required in the research and design of low-cost prostheses, orthoses and developmental aids appropriate for Indian seasons and cultural setting. "Callipers are now made of polypropylene and aluminium rods and joints. Patients prefer open sandals to shoes because of extreme heat and humidity. There are government subsidies in public hospitals for patients from lower income families," says J.K. Bhinda, orthotist, who retired as the Head of Orthotics at the Rehabilitation and Research Centre, Sawai Man Singh hospital, Jaipur.

Resources for Parents

Parents of young polio survivors must ensure that their child has a comfortable calliper at all times. Children outgrow their callipers very quickly and if it is uncomfortable, they will discard them. So it is essential to consult the orthotist on a regular basis. Deformities can be prevented in most children with polio

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with simple things such as wearing the calliper and daily exercises. A good resource is the World Health Organization's 60-page document entitled "Guidelines for the Prevention of Deformities in Polio" (<http://apps.who.int/bookorders/anglais/detart1.jsp?sesslan=1&codlan=1&codcol=93&codcch=79>).

Parents must treat their child normally. Encourage him/her to participate in play and other social and cultural activities. Over-sympathising or doing all the errands for your child will prevent him/her from growing into a confident and independent young person. Modify your home to increase mobility. For example, do away with stairs where possible, provide proper rails in bathrooms, get a mobility chair.

If parents can form support groups and meet regularly to exchange news on latest research, orthotists, physiotherapists, hydrotherapists in their local area, it will go a long way in benefitting the young polio survivors. I would be keen to help facilitate such support groups and organise a conference on Living with PPS with the help of PHI.

India Should Consider Salk Vaccine

The other problem in India has been the number of Vaccine Developed Polio Virus (VDPV) cases. It makes no difference

whether the child contracted polio through a wild poliovirus or through VDPV. The oral polio vaccine can cause paralysis in very rare cases (about one in 2.7 million children). Maybe it is time for India to move to the injectable Salk vaccine like some of the developed countries.

"India needs to evolve a holistic model for the large number of polio survivors living in India."

Deepak Gupta, a doctoral fellow and a senior United Nations advisor on strategic health communication in Asia, says, "India needs to evolve a holistic model for the large number of polio survivors living in India. It is a dire human need for the government and the programme sector in India to actually have specialised units dedicated to rehabilitation and treatment of polio survivors, providing socio-psycho counselling, education (including skills-development) and livelihood."

Neena and PPS

On a personal note, my good leg is losing power. I can no longer walk or stand for long, get on and off escalators on my own, and climbing stairs is painful. Osteopenia, fractures, bursitis, headaches, fatigue, muscle atrophy and constant pain are posing new challenges. Regular hydrotherapy and massage helps, and I am learning to conserve energy by spacing activities and household chores, and using technology for work and entertainment. Above all, I am learning to be kind to myself. ■

Suggested Readings:

After Eradication, India's Post-Polio Problem
(<http://www.bmj.com/content/348/bmj.g2275>)

A Life Battle With Polio
(http://www.india-voice.com/joomla/index.php?option=com_content&task=view&id=451&Itemid=52)



J.K. Bhinda, a retired orthotist, working at the Rehabilitation and Research Center in Jaipur.

PHI Columnists Weigh In on Future Life with a Polio Survivor

The following question has come to Post-Polio Health International a number of times via phone, email and letter. We asked our regular Post-Polio Health columnists Frederick M. Maynard, MD; Rhoda Olkin, PhD; and Stephanie Machell, PsyD, to comment on it for our readers.

QUESTION: I am dating a woman who had polio, but if you didn't know it, you could not tell it. We are both in our late 20s and I am very interested in her. I have heard about post-polio syndrome and am wondering what I may expect in our future years if I marry her.

Dr. Maynard's response: People with a history of polio in childhood who “pass” as normal and able-bodied in their 20s are at risk of developing new health problems during their middle-age and later life. These problems are known as the late effects of polio and include post-polio syndrome (PPS), which is a slow weakening of affected muscles many years after the polio infection and recovery.

Other common problems are excessive fatigue and musculoskeletal pain problems. The likelihood of developing symptoms and their severity are both related to the extent and severity of initial paralytic polio and to one's personal lifestyle and health behaviors.

In general the late effects of polio do not significantly shorten a person's expected life span, nor should they cause one to avoid a long-term commitment to someone they love because of fear of excessive disablement in the future. There has been a lot written about the late effects of polio, and by learning about them one can often postpone, prevent or minimize their occurrence and can make timely lifestyle adaptations to them in order to prevent their significant interference with having a high quality of life.

Please read about the late effects of polio and discuss them with your friend. By having an honest and supportive attitude about her history of polio, you will gain a special intimacy and will be in a great position to assist her in maintaining optimal health and function into your older years.

Dr. Olkin's response: Good for you for being honest about your concerns! No one can tell you what the future will be for her, whether she will develop any post-polio symptoms (pain, fatigue, new weakness) or not. Of course, marrying anyone brings the possibility that the person will develop future infirmities, which is why there is the whole “for better or worse, in sickness or in health” part of vows.

What is possible for the woman you are dating is that she had a mild case with few aftereffects. There may be some weakness that is not very apparent, which could be more apparent with age, as nerve axons naturally die off. But given that she is starting from a place of relative strength, it might not be that noticeable. She might get a bit more fatigued than peers without polio, but again it won't be too intrusive on activities of daily living.

But predicting what will happen is not the right question, since the future with any partner brings unknown risks. So, you have to ask yourself: “If in twenty to thirty years ... would I still want to marry her?” What goes in the missing spot could be:

- ◆ She develops sufficient leg weakness that she uses a cane, or crutches, or a scooter or a wheelchair.
- ◆ Her fatigue means she naps every day.
- ◆ She is unable to work and take care of children due to fatigue, so you make hard choices about income levels, or number of children to have, or using income to hire help.

Suggested readings:

Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (www.post-polio.org/edu/handbk/)

Post-Polio Health Care Considerations for Families and Friends (www.post-polio.org/edu/healthcare/)

Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome by Lauro S. Halstead, MD

Traveling without a Spare: A Survivor's Guide to Navigating the Post-Polio Journey by Wenzel A. Leff, MD

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- ◆ She loses balance and falls more easily, and breaks bones, and you have to take care of her intensively for a couple of months.
- ◆ You have to modify your house for thousands of dollars to put in ramps and grab bars and wider doors and lower counters.
- ◆ She develops a circle of friends with disabilities, and you find that disability topics become a major topic in your household.
- ◆ She becomes an activist in disability rights.
- ◆ She needs to, but refuses to, use assistive technology such as a scooter, and thus you no longer go to museums or large stores or shopping malls or walks together.

Are any of these likely? No one knows. But if you are not able to think about a future in which you could handle any of these scenarios, then don't sign up. You would be doing both of you a favor by being honest with yourself.

Dr. Machell's response: All you can know with certainty is that having had polio she is eligible to develop post-polio syndrome. I've known polio survivors whose polio was all but invisible in their late 20s who went on to develop severe PPS. I've known others who were always more visibly disabled but whose PPS was relatively mild.

Some polio survivors I've known developed PPS relatively early. Some developed it later. Some never developed it at all. And some developed another disabling or chronic condition in addition to or instead of PPS.

And some polio survivors' spouses become chronically ill or disabled. Or die young.

At any moment of any day of our lives all of us, including yourself or any woman you might marry, are eligible to develop a disability or a chronic illness. Whether or not we become disabled, all of us will

age. As we do, our appearance will most certainly change, along with some or all of our physical and cognitive abilities.

Some of us will age well. Some of us won't. Some of us won't live long enough to find out.

Marriage is a leap of faith into a great unknown. However happy, well-matched, and/or in love you may be, all marriages face challenges. A spouse's disability is a major challenge for any marriage. Some marriages, often but not always the ones that are already troubled, end as a result. Some, often but not always the ones that are already strong, come through the crisis stronger. And some, often but not always the ones that are neither great nor dreadful, continue as they always have.

No matter how much you know about the possibilities, the future is uncertain. And no matter who you choose to marry, you may regret your choice. To make the best decision possible it helps to be aware of your own feelings, values and beliefs.

Does knowing that this particular woman might someday develop PPS overshadow your current feelings about her and the life you could have together? For just a moment, imagine your future if she does develop PPS. Imagine living with a wife who has less energy and more pain, one that needs to use a brace, or crutches, or a wheelchair or scooter. Imagine that she can do less in the home, that she can no longer work, that she is less able to engage in active leisure activities. That she can no longer pass as temporarily able-bodied.

Still interested in her? If not, better you know now, when you both have the opportunity to make different choices. If so, you may have realized that no matter what your futures hold, you can't imagine yours without her in it – which is the best reason to marry anyone.

Whatever you decide, I wish you, and her, all the best. ■

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

Toni Williams Holland
Arlene M. Leventman
Walter S. Lindsay
Charles "Butch" Millner
James C. Sailor
Alon P. Winnie, MD

Contributions to The Research Fund ...

In Memory of

Toni Williams Holland
Walter S. Lindsay
Charles "Butch" Millner
William G. Ohme, Jr.
James C. Sailor
Alon P. Winnie, MD

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

In Honor of

Rabbi Elizabeth Hersh

PHI Welcomes Two New Board Members

Two new members have been named to the Post-Polio Health International board of directors.

Carol B. Vandenaeker-Albanese, MD, is a Health Sciences Clinical Professor, Residency Program Director and the Director in the Department of Physical Medicine and Rehabilitation; and the Director of the Post-Polio Clinic at the University of California, Davis Medical Center. She established a post-polio clinic at the University of Miami in 1993. With her move to Sacramento in 2001, she continued her post-polio practice by establishing a post-polio clinic at the UC Davis Medical Center. She is board-certified in Physical Medicine and Rehabilitation. Her clinical practice encompasses diagnosis and non-operative treatment of spine conditions and post-polio related problems. Her research and publications have focused on exercise, post-polio syndrome and aging with a disability. She serves as the medical advisor for the San Francisco Bay Area and Sacramento polio support groups and serves on the medical advisory board for PHI. She lectures locally and nationally on issues regarding polio survivors.

Padma Hirandani Reichwald, MS-SBB, is a polio survivor and has been a Member of PHI since 1988. She is Chairperson of Heart and Hands for the Handicapped (www.hhhonline.org), a not-for-profit 501(c)3 organization founded in 1971 and run by volunteers. HHH raises funds to support organizations in India and the United States that empower children with physical or mental challenges. The \$30,000 per year raised for polio patients in India funds surgery and therapy at an average of \$250 per patient. Prior to retiring, she helped run transfusion services at a New York City hospital. ■

Not yet a Member?

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55 Years Later: Friends Reconnect Via PHI

“Joyce Tepley ... Joyce Tepley ... I kept repeating to myself,” thought Beverly Schmittgen, as she read an article in *Post-Polio Health*.

Schmittgen recalled “a petite little girl with dark brown hair and a friendly personality” who occupied the bed next to hers in the polio ward at Cleveland’s City Hospital in August 1952.

“I wondered what had become of her. I just HAD to contact her!” said Schmittgen. “Her response was delightful. She told me many details about her schooling, her move to Dallas, her career as a social worker, her 20-year marriage and her symptoms of post-polio syndrome.” And so began a barrage of emails, phone calls and reunions.

Tepley said, “I couldn’t believe it! An (email) voice from the past. And not just the past, but the very time when my life changed completely ... It all came slamming back. The minute I read the email, I was transported back

to that bed in that ward filled with little kids like me who were scared and sick ... I was so excited to finally see a long-lost friend who I shared such a significant time with.”

Would you like to read more? Go to www.polioplace.org and type Friends in the Search box. Beverly Schmittgen and Joyce Tepley both write about how they renewed a friendship after more than 55 years.

Visit www.polioplace.org. You may find an old friend there. ■

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