

Questions and Answers for a Visit to Rotary

Post-Polio health International, St. Louis, Missouri (www.post-polio.org)

Questions to be asked of a polio survivor by a Rotarian. PHI Board of Directors, Staff and volunteers answered these questions.

- 1. Many of us are old enough to remember the polio epidemics of our childhood and know a survivor of polio. Many of us do not. How many polio survivors are there and what is the general age range?**

In 1998, the World Health Organization estimated that 10 million polio survivors were living in the world with some degree of disability caused by polio. (*World Health*, 48th Year, No. 1, January-February 1995, "Rehabilitating children with polio" by Ann Goerdts, p 20.) No new numbers have been released.

According to an analysis of statistics from the National Center for Health Statistics and the United States Public Health Service done by Post-Polio Health International in 2006, approximately 770,000 polio survivors are living in the US today (See FAQs at post-polio.org). That same analysis estimates that more than half were between 55-69 years of age.

- 2. Since polio has not been eradicated and we know there are survivors in the world who are younger than you, what advice would you give them about living with polio? (Here are some concise responses for you to use as a model. Be concise and positive. Do not tell your life story.)**

- Learn as much as you can about post-polio issues. Adopt a lifestyle that accommodates your physical limitations so you won't be harming yourself more—and then get on with your life. Cling tight to your dreams. Don't let anything stop you. Figure out a way. . . . Nancy Baldwin Carter, USA

- Invest your time and energy in achieving good education and learning skills that result in a profession. Financial independence is the panacea for many ills. Physically exacting jobs can be challenging in later years, so have a second profession to fall back on when the going gets tough. Find the balance: don't over stress your muscles, but keep fit and keep your weight under control. Hydrotherapy can be fun. Don't be embarrassed to ask for help, if you need it. Neena Bhandari, Australia

-My advice is to try to do as much physical activity that is possible, so long as it does not induce more than minimal pain or enduring fatigue. I do not think polio survivors should live “half” lives in order to stave off post-polio syndrome. Remember: many polio survivors do not develop post-polio syndrome. Instead, polio survivors should strive to live every athletic, artistic and intellectual dream. I suggest that they develop a relationship with a physical therapist who understands polio and who can offer guidance on how to live a full life with polio. Having a disability is stressful, so take time early on to learn to manage stress. Baldwin Keenan, USA

3. Is there an ongoing health threat to polio survivors after they have “recovered” from polio itself?

Yes. The survivors of polio began reporting new health problems in the late ‘70s and early ‘80s. The most common symptoms, new weakness, pain and fatigue, interfered with the ability of polio survivors to carry out their daily activities. This loss of function they had worked so hard to regain in rehabilitation after the acute phase of poliomyelitis was what drove them to seek medical care. The numbers were substantial, because those seeking attention were part of the major epidemics of the late ‘40s and ‘50s. The word spread quickly because polio survivors who spent time in rehabilitation were connected with each other through a journal for polio survivors created by Gini Laurie, the founder of Post-Polio Health International (www.post-polio.org), including International Ventilator Users Network (www.ventusers.org).

4. How do polio survivors protect themselves from post-polio syndrome?

Post-polio syndrome is defined as a new neurologic condition affecting polio survivors after years of stability and is believed to be caused by the failure of motor units (the nerve cell and muscle combination that causes movement). At this time, there is no medication that can stop the nerve loss. However, polio survivors also can have musculoskeletal problems, such as wear and tear on joints and increased scoliosis due to new muscle weakness. The goal is to protect muscles and joints from overuse while maintaining function and the ability to fully participate in life. The goal can be accomplished with judicious exercise and appropriate assistive devices. It is very important to focus on general good health and the prevention and treatment of other health problems (co-morbidities).

5. Is PPS a greater threat to polio survivors from other countries than for US survivors?

This is a very good question. The assistance that US polio survivors receive can be thought of as re-rehabilitation. They and all survivors who received care and rehabilitation after acute poliomyelitis will continue to need medical rehabilitation advice as they age. Polio survivors who received no rehabilitation or less than optimal care after the acute disease will need all levels of services.

6. What sort of Rotary Projects might be suitable and contributive to aid support for post-polio survivors?

We recognize that Rotarians are involved in a major fundraising effort to finish the job of polio eradication. Nevertheless, yes, local Rotary clubs could provide funding to local post-polio groups. For example:

Provide funding to local post-polio groups to assist members in need with the purchase of assistive devices. Clubs without local support groups can contribute directly to PHI, which has an established fund that assists polio survivors in purchasing shoes and bracing worldwide. Funds could also sponsor a local survivor to attend an important meeting, conference or retreat.

Collaborate with PHI to organize a campaign to find, record and connect all the groups involved in post-polio rehabilitation and support.

Support the work of already established organizations that are providing support to polio survivors in developing countries, e.g., Stand Proud (DRC); Polio Wonders Welders (Tanzania); Polio Challenge Association (Sierra Leone).

Consider co-sponsoring a regional educational conference about PPS in countries such as Argentina, Bolivia, South Viet Nam, Cambodia, etc. Consider funds for sending teams of post-polio experts and survivors to join the teams of PolioPlus workers in endemic countries for the purpose of locating and organizing local polio survivors in order to identify their needs, and begin to provide, educational and advocacy efforts for appropriate/most needed medical and rehabilitative services.

Support PHI's current educational activities, such as its quarterly newsletter, its three comprehensive websites, and the revision/expansion of the *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*.

Questions to be asked of a Rotarian by a polio survivor. Carol Pandak, Manager, Division of PolioPlus, Evanston, Illinois, answered these questions.

1. Rotary committed to eradicating polio in 1988. Since that time, Rotary has raised an impressive amount for this cause. What is the total so far?

To date, Rotary has contributed more than US\$900 million to global polio eradication efforts. By the time the world is certified polio free, that figure will increase to more than US\$1.2 billion. **Follow up question: I know this has been a very special project for your club. How much were you able to contribute?** Each club will have a different answer.

2. How many individuals contracted polio per year in 1988, the year Rotary took up the cause; how many people contracted polio last year?

When Rotary launched its PolioPlus program in 1985, there were more than 350,000 cases of polio annually in more than 125 polio endemic countries--that's the equivalent of 1,000 per day! Last year, there were only 1604 cases of polio in 4 endemic countries.

The Global Polio Eradication Initiative is a project of the World Health Organization, Centers for Disease Control and Prevention, Rotary International and UNICEF. Their website <http://www.polioeradication.org/> features the most current information.

3. We have all heard about the Gates Foundation assistance in eradicating acute poliomyelitis. Tell us more about the Gates challenge to Rotary and the impressive success to date.

As of 25 May 2010, Rotarians have [raised about \\$127.4 million](#) for Rotary's US\$200 Million Challenge. These contributions will help Rotary raise \$200 million to match \$355 million in challenge grants received from the Bill & Melinda Gates Foundation. The resulting \$555 million will directly support immunization campaigns in developing countries, where polio continues to infect and paralyze children, robbing them of their futures and compounding the hardships faced by their families.

4. What specifically is the money used for, and through what channels did the funds get to where they are needed to immunize the world's children?

Rotary provides funds for operational support, surveillance activities, social mobilization, and technical assistance. Operational support can be defined as everything it takes to get the vaccine into a child's mouth including vehicles, fuel, chalk to mark houses where vaccinators have visited, paper and pens to maintain records, computers to analyze data, cold storage boxes to transport the vaccine, generators to keep the vaccine cool in refrigerators, and aprons to identify vaccinators. Surveillance are those activities carried out to identify children with cases of polio, and then test the samples that are collected from them. Social mobilization activities are those which raise awareness in the community about immunization and inform parents about the benefits of vaccination. And finally, technical assistance describes the training and manpower required to carry out polio immunization activities. Rotary primarily makes grants to the World Health Organization and UNICEF for these purposes.

5. The New York Times recently reported remarkable progress in halting the spread of the polio virus globally and quoted certain scientists who believe total eradication is possible soon. When do you anticipate this could happen? What more is needed to finish the job?

The new Strategic Plan for the Global Polio eradication Initiative has as a target stopping all incidence of polio by end 2012, with certification occurring three years after no cases of polio. However, reaching this target relies on successfully securing the necessary funds to completely implement the plan, political support from both

donor and polio affected countries, and the ability to carry out polio immunization activities in conflict affected and security compromised areas. Funding is critical at this time.

6. The final result will be the eradication of polio worldwide, but there are other long-lasting effects of the effort. Will you explain a few of them?

The Global Polio Eradication Initiative has delivered many additional benefits to the overall health systems of the world. For example, the Global Polio Eradication Initiative has developed a global laboratory network of 145 laboratories for disease surveillance for polio that is used to track other diseases such as measles, neonatal tetanus, avian flu, and SARS. There are now hundreds of thousands trained community health care workers who have learned about polio and other health matters, etc.

7. Has Rotary considered extending their polio agenda to include assistance to the 770,000 polio survivors in the United States and the approximately 10-12 million worldwide?

There is a group of dedicated Rotarians and non-Rotarians who are members of the Rotarian Action Group, "Polio Survivors and Associates" who actively promote awareness of post polio syndrome. In addition, many polio rehabilitative surgeries have been carried out utilizing the Matching Grants program of The Rotary Foundation. Rotary International's immediate goal, approved by its Legislative Body, is the certification of the eradication of polio.

Resources:

Centers for Disease Control and Prevention [Immunization Schedules](#)

[Global Polio Eradication Initiative](#)

[International Ventilator Users Network](#)

[Post-Polio Health International](#)

Post-Polio Directory

Resources for support groups

[Polio Survivors and Associates](#)

[Rotary International](#)

Reminders:

First, connect with your local Rotary and ask them if you may present a program about polio and post-polio. Make arrangements *now*, because many Clubs book their speakers months ahead. Use the "Club Locator" on the website of Rotary International

<http://www.rotary.org/en/AboutUs/SiteTools/ClubLocator/Pages/ridefault.aspx>

Second, ask them for the name of their member(s) who have been the most involved in polio eradication. Contact this person and invite him/her to help you present facts about polio eradication and the late effects of polio.

Third, in collaboration with the Rotarian decide which of the questions from “A Rotarian’s Primer on Polio Eradication and Polio Survivor Support” and “Questions and Answers for a Visit to Rotary” you want to ask about polio eradication that he will answer; decide which questions you want him/her to ask you about the late effects of polio. Pick the ones that are the most appropriate for your town and country and practice your part of the Q & A presentation. Most programs are ½ hour or less. Check with the organizer.

Fourth, on the day of the meeting, thank the Rotarians for what they have accomplished and encourage them to finish the job, and, with the Rotarian, present your Questions and Answers. Remember to take along some materials for the Rotarians to let them know WE’RE STILL HERE! Contact PHI for copies of material specially made for this occasion.