

Rotarians in action



By Annemarie Mannion
The Rotarian

Ray Taylor, 83, was stricken with polio as an infant. “I didn’t walk until I was two,” says Taylor, a member of the Rotary Club of Pinehurst, N.C., USA, and past governor of District 7690. “But I was lucky. My legs turned out to be the same length. So I’d tilt a little, and with my back muscles I’d be able to walk.”

Yet decades of using his upper body to propel himself forward – he even became a scratch golfer – took their toll. In the late 1990s, Taylor felt his overused back muscles weakening and his mobility decreasing. He also had worn down the ankle bones in his right leg, making it painful to walk.

“I noticed that it was getting difficult to walk uphill. I was starting to fall. By 2001, I was becoming a nuisance on the golf course,” Taylor says.

Medical tests determined that he had postpolio syndrome, characterized by extreme fatigue, muscle weakness, pain, and difficulty sleeping. Today, he relies on a wheelchair to get around.

In 2003, Taylor founded Polio Survivors and Associates: A Rotarian Action Group. Its goals include providing a voice for polio survivors everywhere, addressing health issues such as postpolio syndrome, and working through Rotary’s PolioPlus program to eradicate the disease.

The group also aims to support those for whom the vaccine came too late. Members would like to establish community-based rehabilitation centers in polio-endemic places that would provide vocational training, physical therapy, fittings with therapeutic devices, and corrective surgeries, such as the one Taylor underwent earlier in life to lengthen a tendon.

“We want to start clinics that could help new polio [survivors] with rehabbing so they can be returned to society,” he says.

Staying vigilant

Since Rotary launched its PolioPlus program in 1985, more than two billion children have received the oral polio vaccine through the Global Polio Eradication Initiative, and cases of the disease have dropped by 99 percent. Today, polio is endemic in just four countries.

Robert S. Scott, chair of the International PolioPlus Committee, stresses the importance of continued vigilance: “Every talk I give in North America or in Europe or wherever I am, I say you must, must keep your children and your grandchildren vaccinated against polio.”

“The search for a polio vaccine truly set a precedent in the medical research field,” says Ann Lee Hussey, chair of the polio survivors action group. “When it is eradicated, it will be only the second disease, after smallpox, ever eradicated.”

Facing fears

Hussey doesn't lift cats and dogs from cages anymore or carry them up and down the stairs at the veterinary clinic where she works in Maine, USA.

At age 53, she can no longer negotiate stairs with ease and recently noticed that she's starting to lose her balance. The member of the Rotary Club of South Berwick, who leads a busy life as a veterinary assistant, is falling down more often.

She admits to putting off the next step: a medical checkup to determine whether these changes add up to a diagnosis of postpolio syndrome. Hussey, who contracted polio when she was 17 months old, is afraid she'll discover that the symptoms she's encountering are linked to a disease she believed she had conquered.

She's hardly alone in her fears. Of the approximately one million polio survivors in the United States, many face the prospect of or have already begun to feel the delayed effects of the viral attack they thought they overcame decades ago as infants, children, or young adults.

"For some people, it feels like they are having polio all over again," says Hussey, past PolioPlus subcommittee chair for District 7780 (Maine, Massachusetts, New Hampshire).

As a baby boomer, Hussey is part of the last generation in the United States to have been widely affected by the disease, which she contracted in 1955. Like a number of other polio survivors – many of whom have described themselves as overachieving or driven – she's been working through Rotary to eradicate the disease worldwide.

She also hopes to spotlight polio's long-term effects. Though the virus was eradicated in the United States in the 1970s, the country is still feeling the impact of the disease, Hussey says. She predicts that developing countries now battling polio will have to deal with its aftermath too.

"As long as there are polio survivors, there will be a drain on societies, both economically and socially, for years to come," she says.

Anna Rubin, education and outreach coordinator for the International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital in Framingham, Mass., agrees. She estimates that her clinic receives about five calls a day from people from across the United States wondering whether the new weakness, fatigue, or pain they feel is a sign of postpolio syndrome.

"It's a real thing. It's a real problem for polio survivors. There aren't many doctors who know about postpolio," she says. "These are people who are really struggling with what to do with their health. They're desperate."

Daring to dream

Polio survivors undergo three days of extensive testing to be diagnosed. The facility provides physical and occupational therapy, a bracing clinic, analysis of sleep disorders, and nutritional and

psychiatric services.

“It’s a diagnosis of exclusion, but it’s important to do that because you want to rule out any other health issues,” says Joan Headley, executive director of Post-Polio Health International, a nonprofit organization in St. Louis that works to enhance the lives and independence of polio survivors.

Accepting the diagnosis of postpolio syndrome is often difficult. Not only is there no cure, but many survivors, who overcame great odds once before in their lives simply to learn to walk again, thought they had put the disease far behind them.

“Many polio survivors don’t want to revisit this. They don’t even want to have this conversation. For them, just being able to walk is the good life,” says Headley.

Neither Taylor nor Hussey has let polio define their lives, but it has clearly played an important role. Hussey’s e-mails, for instance, always contain this quotation from Jonas Salk: “Hope lies in dreams, in imagination, and in the courage of those who dare to make dreams into reality.”

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