

# PERU'S POLIO SURVIVORS

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Now 63, I contracted polio at the age of 6 months. I did not have a long acute polio phase. After I got over it, my mother noticed that I could not move my legs anymore. Although I started walking around one year, I did not need braces, crutches, or any help, walking normally. I had a slight limp going up the stairs.

At the age of 10, I went to Warm Springs, Georgia, USA, because I was falling often. I had surgery on my left leg and spent two months encased in plaster from my feet to my shoulders. Afterwards, I underwent three months of rehabilitation, including pool exercises, to learn to walk again. When I left Warm Springs, I had a brace on my left leg and used crutches until I was twelve years old. I did not use any aids after that, and one could barely notice anything different in my walking.

In 1952, my mother, Victoria Graña, founded the Clinica San Juan de Dios, the country's first polio center for children from low-income homes. The Clinica was named after a Spanish order of priests, who, by coincidence, had arrived in Peru that same year to start a hospital for poor people. My mother formed a committee with all the other mothers who had children with polio (all between 8 and 12 years). They joined the priests for the same purpose: to provide treatment and support to poor children with no cost to their families.

My mother, who was fortunate enough to belong to a well-known family, looked for a

hospital to buy, but only on one condition: the hospital had to be primarily for polio patients. This hospital became the only polio hospital in South America and provided everything from surgery, rehabilitation, braces, and crutches to school and clothing for all the children. For her humanitarianism, the Peruvian government, as well as the order of San Juan de Dios, three times decorated my mother. The hospital (which just celebrated its 50th anniversary) has not closed, but now any kind of illness is treated.

Over the years, I have lived an active life as a travel agent, singer, nurse, administrator, and mother of three. I wore high heels; I climbed the Pyramids and the Great Wall. But several years ago my bones ached, my muscles felt weak, and I had no energy. I blamed it on age, until Patsy, my childhood friend at Warm Springs who also had polio, revealed that she was having the same symptoms. The weakness of my leg was my first post-polio symptom, and then came fatigue, muscular pain, and difficulty with stairs.

When I began feeling the late effects of polio five years ago, no one in Peru knew anything about it. I had doctors tell me I was depressed, needed to eat more meat, needed to be seen by a cardiologist for fatigue, had menopausal problems, etc. I went to Warm Springs (where I had a KAFO made); Houston; Englewood, New Jersey; and Washington, DC, for three consecutive years. I finally settled on National Rehabilitation Hospital in Washington, DC,



Marilú Montero Graña and Dr. Gaston Barnechea

and Lauro Halstead, MD, for treatment. I later asked him to come to Peru to teach our physicians about post-polio.

I now wear the KAFO on my right leg, which used to be my good leg, and returned to using crutches. I have changed my living habits 90%, lost weight, started pool exercises, and rest for small periods during the day. I have stabilized, and even improved, to the point that I now wear the brace only for a few hours per day and use only one crutch or a cane.

There are still Peruvian physicians who do not take post-polio seriously. They say that polio has been wiped out and that it does not appear in the statistics any more. I explain that it is not polio, but a syndrome that affects people who have had polio, decades later. I explain that we need attention from specialists and that we need to find the thousands of Peruvian survivors of the 1950s and 1960s polio epidemics to make them aware of the symptoms.

After the polio vaccine was discovered and the epidemic was over, all polio survivors who were once patients of the Clinica San Juan de Dios were totally forgotten. The social security hospitals in Peru did not provide

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treatment or orthotics for polio sequelae, and survivors live with significant scoliosis, recurvatum, limps, etc.

In August 2001, Dr. Halstead presented five conferences in Lima to physicians. The physicians who had refused to accept the existence of post-polio syndrome were present. Dr. Halstead also presented a workshop on starting and operating a post-polio clinic. Over 600 people attended the polio survivors' conference.

*Sociedad Peruana de Polio*, the Peruvian polio society, of which I have been elected president has 380 members and 23 support groups. Our office is in the same Clinica where my mother started working for

polio survivors 50 years ago. We recently received permission from the Peruvian Social Security Institution to mount a campaign to raise awareness among health professionals for better detection and appropriate treatment of the problems of polio survivors. The Society also wants the Ministry of Health to back treatment centers, because post-polio is considered a pre-existing condition not covered by insurance companies.

One of our allies is Dr. Gaston Barnechea, specialist in orthopedics and traumatology at Guillermo Almenara Hospital, who believes it is important to screen for post-polio symptoms in routine physical examinations. In the past two years,

Dr. Barnechea's hospital has treated about 300 polio survivors, and he is the leading doctor in Peru for treatment. Two groups of 25 selected specialists who belong to the social security hospitals have been trained by him in post-polio management and treatment.

Dr. Barnechea estimates that 60,000 Peruvians contracted polio during the epidemics, that about 40,000 of these would still be alive today, and, of those, about 25,000 may experience the late effects of polio. ■

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Polio survivor Joanna Gaumond and her husband, James, from Salem, Oregon **collect, repair, and distribute used wheelchairs** to people who need them. Please contact Orphaned Wheelchairs at [jgaumond@pop.netzero.net](mailto:jgaumond@pop.netzero.net) or call 503-375-9523. ■