

Our Journey to India

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Over the past several decades, South Asian countries including India, Pakistan, Afghanistan, Bangladesh, Sri Lanka and several countries in Africa have been under the “double burden” of diseases – both communicable as well as non-communicable. This is a reflection of poverty, poor sanitation and decreased access to healthcare. The global effort to eradicate poliomyelitis is the largest public health initiative in history, and efforts are concentrated in these countries.

While most of the resources and time continue to be focused on eradicating polio in these countries, very little attention has been paid towards polio survivors. In a country where the polio virus has not been eradicated, it is commonplace to see individuals with obvious gait deviations walking with no canes, braces or any assistive devices. Rarely are individuals seen in manual or power chairs/scooters in public. If this sounds like the mid-20th century in the United States, guess again! Come with the authors on their journey to India in December 2009.

The Dream

Dr. Sunita “Soni” Dodani contracted polio in Pakistan at the age of two. Raised in an enriched environment, her parents were able to provide her with the best in rehabilitation care, and, despite some physical limitations, she ultimately received her education in medical science and became a cardiologist practicing in the United States. After working and living in the United States for many years, Dr. Dodani became acutely aware of the disparity in health care services for polio survivors in South Asia.

She saw the need for a state-of-the-art rehabilitation center in India that could serve both children and adults from India and Pakistan. In 2008,

overcoming many initial hurdles and disappointments, a diverse group of humanitarians, researchers, information technologists and healthcare professionals who had worked with polio survivors, met to help establish the Center for Post-Polio Rehabilitation in India (CPPRI). The group came from three continents and included post-polio organizations, orthopedic surgeons, physical therapists, orthotists and cardiologists.

Following this meeting, Dr. Dodani submitted a grant to the Bill and Melinda Gates Foundation to help build CPPRI to serve patients with physical disabilities and polio in particular. If funded, CPPRI would provide evidence-based surgeries and rehabilitation treatment options to achieve optimum outcomes in India and Pakistan. In addition, the creation of a central surveillance database of all individuals with polio in India and Pakistan was proposed. Although the initial grant proposal was not funded, feedback from Gates Foundation encouraged Dr. Dodani to collect pilot data to document the need and benefit for such a center and resubmit the proposal.

Finding a Partner

To help with the collection of pilot data, Dr. Dodani needed to secure a

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Chaitanya Hospital and rehabilitation center in Pune, India, welcomes Dr. Holly Wise and Dr. Sunita Dodani.



Children at a school wait to be examined by the CPPRI team for polio treatment.

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Dr. Anant Bagul (right) and his staff at the Chaitanya Hospital.

partner in India – a non-governmental organization (NGO) and/or an individual dedicated to helping individuals with polio and willing to assist in this endeavor. Many long distance telephone calls, emails and letters later, Dr. Dodani invited Dr. Anant Bagul, an orthopedic surgeon in Pune, India, to join the CPPRI team.

Dr. Bagul donates 30 percent of his time to work with children and adults with disabilities resulting from polio and other diseases. Ten years ago, Dr. Bagul created a charitable NGO to assist in the funding of his work and established Chaitanya Hospital and rehabilitation center. An interdisciplinary team of nurses, physical therapists and orthotists provide rehabilitation following the corrective surgeries that he performs.

The Journey

In December 2009, Dr. Dodani and CPPRI team member Holly H. Wise, PT, PhD, met in Pune, India, and spent a week collaborating with Dr. Bagul and collecting pilot information.

Dr. Wise is a physical therapist with more than 25 years experience working with polio survivors. During the week in India, they traveled to a special school for children with disabilities to identify children and young adults who would benefit from corrective surgery. Fifteen corrective surgeries were completed followed by rehabilitation.

Following the surgeries, physical ther-

apy was implemented to return the individual to the highest level of physical function whether walking with or without a cane, crutches brace or other assistive device. The most common corrective surgeries involved soft tissue releases of the hip, knee and/or ankle where contractures developed due to imbalances in muscle strength caused by polio. A femoral osteotomy or surgical breaking of the thigh bone to realign the knee joint was the second most common surgical correction for polio survivors. This surgery is generally followed by six weeks in a long leg walking cast that allows the individual to walk without braces even when the quadriceps muscle is severely weakened or absent.

Functioning and Disability in India: A Time Machine?

In India, Dr. Dodani and Dr. Wise reported feeling as if they had taken a journey in a time machine back to an era in America when polio survivors were rarely seen out in public places and President Franklin D. Roosevelt refused to be photographed in a wheelchair.

“We saw first-hand how the interaction of environmental factors – social influences, physical accessibility, transportation, assistive equipment – and personal factors such as health, age, gender, money, education and attitude determine participation in life activities,” said Dr. Dodani.



Drs. Wise, Dodani and Bagul evaluate a child for polio surgery.

“When informally interviewing patients and family members, we were told that there is a stigma associated with using braces, canes or any type of assistive device unless you are old,” she said. “Individuals would rather walk with a noticeable limp and inefficient gait than use a cane, brace or crutch. Corrective surgery to realign or fuse the lower extremity is viewed as a better choice over the long-term use of an assistive device.” She noted that while patients temporarily use these devices post-surgery, they are rarely adjusted to the correct height.

“Even though many polio survivors in India have been identified in need of medical care and support by health-care providers, support groups are non-existent, said Dr. Wise. “Given the stigma of physical disability, it is easy to understand why there has been an absence of these groups.”

“There does not seem to be an equivalent to the Americans with Disabilities Act in India,” said Dr. Wise. “When driving around Pune and the surrounding countryside, people using wheelchairs or scooters out in the community were never seen. Safety may be one concern as the streets are overcrowded and very congested with traffic (as well as goats and free roaming bulls). Motorcycles and scooters often crowd the sidewalk, and curb cuts have not been routinely implemented.”

Dr. Dodani said that the ability to use bathroom facilities is very difficult for someone with a physical limitation. “Many public bathrooms in India are holes in the ground consistent with the traditional method of squatting

when toileting. Elevated toilets have side extensions for foot placement to allow squatting on an elevated seat, but there are no grab bars in public bathrooms.”

The two said they observed vast differences in the reality of circumstances for an individual in India as compared to the United States. Poverty, poor sanitation and low educational levels are examples of the personal factors contributing to the decreased ability of polio survivors in India to participate fully in life activities. Awareness of strategies to reduce the late effects of polio is minimal. Personal motivation and confidence in individual ability to manage limitations associated with polio may be diminished by the reality of environmental factors.

Hope for Polio Survivors in India and Pakistan

Dr. Dodani’s goal for the establishment of CPPRI is to improve services to individuals in India and Pakistan diagnosed with polio. She sees CPPRI becoming a demonstration center for accessible, evidence-based healthcare, innovative rehabilitation technology and appropriate assistive devices and equipment.

Once established, CPPRI would provide the optimum environment for fostering polio support groups in India. Through educational initiatives, the stigma of disability would be reduced. Informed healthcare professionals and support groups would begin to advocate for changes in social policy that will ultimately enable individuals with polio to participate in life activities and improve their quality of life. ▲



Dr. Holly Wise and Dr. Sunita Dodani.

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WEBSITES:

Center for Post-Polio Rehabilitation in India:
www.cfppr.org

Chaitanya Hospital:
www.edisability.org