



Lindsay Ruiz, 22, with Zvi Grunwald, MD. Ruiz, who lives in a small town in New York, was diagnosed with fibrodysplasia ossificans progressiva a decade ago and came to Jefferson in June when physicians at her community hospital feared she needed surgery they did not have the expertise to perform. A multidisciplinary Jefferson team including general surgeons, neurological surgeons, gynecologists and radiologists managed her medically, averted surgery and discharged her the next morning.

"It was a relief to know someone as wonderful as Dr. Grunwald was there to check up on me while I was in the hospital," Ruiz says.

Specialized Anesthesia Services Help Patients with Rare Disorder

Patients will often travel far and wide to obtain care from renowned experts in specialties across the board: oncology, cardiology, neurology, surgery. Rarely, however, does a hospital become a destination because of its distinct *anesthesia* services.

Jefferson is one exception to that rule.

Thanks to the leadership of an anesthesiologist and multidisciplinary support team with expertise in the management of patients with fibrodysplasia ossificans progressiva (FOP), a rare genetic disease of the connective tissue, Jefferson draws patients from around the world.

FOP, which occurs in approximately one of every 2 million people, causes soft tissues to transform into bone that grows abnormally in muscles, tendons and ligaments, forming bridges across joints and restricting movement — if not rendering it impossible. As the condition frequently affects the jaw, administering general anesthesia to these patients proves difficult.

"It is common during anesthesia to insert a breathing tube through the mouth to safely provide oxygen and control breathing. How do you accomplish this with patients who cannot open their mouths?" says Zvi Grunwald, MD, the James D. Wentzler, MD, Professor and Chair of the Department of Anesthesiology and the world's foremost expert in caring for FOP patients who require anesthesia.

Previously a faculty member at the Children's Hospital of Philadelphia, Grunwald cared for children with various congenital anomalies and disorders. When he encountered patients with FOP, he became fascinated by the debilitating condition and began exploring and developing best practices for managing their anesthesia care, which usually involves nasal fiber-optic intubation since the oral cavity may not be accessible.

FOP creates hurdles in many treatment areas, not just anesthesia. The condition affects patients' lives on many levels, so "managing them as a whole is a challenge. Ambulation, personal care and positioning are a few of the issues that must be addressed during the perioperative period. There is a need to take very special care at every step," Grunwald says. "At Jefferson, we have assembled a team of experts who join together to provide a continuum of care for these unique patients from admission through discharge."

Patients with FOP have come to Jefferson from as far as South America, Europe and Asia. Grunwald also leads a team that has traveled outside the United States to treat patients on four continents. In 2008, they cared for an individual at Hadassah Medical Center in Jerusalem, Israel, where Grunwald received his medical degree 33 years ago. "We successfully treated the patient and also taught the local team our methods in case other patients would need it," he says.

— Karen L. Brooks