‘Just Let Him Be a Seven-Year-Old Kid’

Heather and Paul learned early on that they needed to treat their youngest son as they would any seven-year-old, but “within reason,” adds Heather.

Jack suffers from a rare bone disease called McCune-Albright Syndrome. As a result, his bones are fibrous, weak, and easily broken. Some activities, such as tackle football, are taboo. “Jack knows his limits,” she said.

Her husband agrees. “Overall, we don’t treat Jack any differently. If we treat him as if he has a disability, he’ll think of himself that way.” Jack enjoys riding his bike, passing the football with his older brother, Evan, and “is really into the Wii” (home video game), Paul said.

No Treatment or Cure

Jack’s birth was normal, but within a month, his parents noted the appearance of a large birthmark. They took him from specialist to specialist, but doctors were stumped.

Finally, at age four, a geneticist gave the diagnosis of McCune-Albright. There is no treatment or cure for the disease, which is caused by a gene mutation. “It’s a freak of nature,” Paul said.

“The good news is that if Jack someday marries and has children, his disease won’t be passed on.”

Support Group Is Saving Grace

The alienation that parents feel when their child is afflicted with a rare medical condition was eased for Paul and Heather when they connected with the Magic Foundation. The nonprofit charity offers support and resources for parents of children with growth disorders. “It’s been a saving grace,” Heather said. “Our biggest base of support is other families with McCune-Albright, especially boys who have it.”

Through the Magic Foundation, Heather and Paul learned of two acclaimed endocrinologists at the National Institutes of Health, Dr. Michael Collins and Dr. Penelope Feuillan (Dr. Feuillan very recently passed away).

NIH Study Recommended

Dissatisfied with Jack’s doctors in their hometown of Raleigh, North Carolina, they were eager to enroll him in a natural history study at NIH recommended by Dr. Collins. The study would follow him throughout his life to document all systems related to his disease.

To help with travel, the couple contacted Angel Flight, having learned about the nonprofit (Continued on page 2)
‘Just Let Him Be’ (Cont. from page 1)

organization through a neighbor of Paul’s parents who is himself an NIH patient.

During his most recent, four-day visit in February, Jack “went through it all, all day long,” his mom said.

Despite the barrage of X-rays, scans, and needle pricks, Jack “looks forward to coming here. He likes the game room, and he can order what he wants from the menu.”

She went on to note that her family has had a good year since last February.” She said that Jack had once broken his femur and was unable to walk for an extended period. “It helps you keep in perspective what’s important in life.”

Looking Up to Save Lives

The economy may be down, but we are looking up. NIH patients and families can be assured of our continued service in providing charitable, medical air transportation for those traveling to Bethesda for an evaluation, a diagnosis, or participation in a clinical trial.

One way individuals can help us keep helping is to donate frequent flyer miles, as explained below. My wife had about 83,000 US Airways miles built up over time with her credit card. By donating the miles to Mercy Medical Airlift, she made it possible for three patients in one month to receive the gift of flight.

We are very grateful to US Airways and the American Cancer Society for being our compassionate partners in a common cause. Remember—there are miles to go before you sleep, so please give!

Edward R. Boyer is the CEO and president of Mercy Medical Airlift, which this year is celebrating its 25th anniversary.

Providing Wings for Patients

The small, private airplanes flown by Angel Flight pilots are one source of air transportation for NIH patients with a financial need, but other resources are available, too.

These are managed by Mercy Medical Airlift (www.MercyMedical.org) which operates the Angel Flight program and others as well. MMA has partnered with US Airways for 12 consecutive years to provide charitable airline tickets to patients. MMA is a partner with the American Cancer Society and helps cancer patients by obtaining donated airline tickets through United and Delta airlines. Call Marita Eddy, transportation coordinator, at the number listed below to donate your frequent flyer miles.