

November 2009

Dear Friend of Oley:

RE: Changing lives!

We are hoping to capture your interest and nudge you towards contributing to the Oley Foundation. The Oley Foundation's efforts enhance the lives of those who require home IV or tube-fed nutrition, like our son Rafael. Please take a minute to read how Oley has changed our lives.

Our son Rafael was born very sick and with an intestinal birth defect called gastroschisis. His birth was a disaster. What was supposed to be a natural delivery, with a normal baby, turned into an ordeal. Rafael was whisked



Rafi (right) and a friend bond at the 2007 Oley conference.

away for corrective surgery within an hour of his birth, and over the next month, instead of getting better he got even sicker. Most of his intestines gangrened and required removal due to NEC — necrotizing enterocolitis. He remained in the NICU for two more months, slowly healing, and was discharged to home at age three months. He had undergone three major abdominal surgeries. Hospital staff told us they rarely saw babies survive what he did... and that those who went home rarely stayed home. They described complications that included frequent hospitalizations and a very high mortality rate within the year. "Go home," the hospital staff said, "Leave him in the rehabilitation center and have more children. Why do you want to sit at home with a dying baby?" Against everyone's advice, we brought him home onto unknown turf.

Rafael now had a lifelong condition known as short bowel syndrome. Without enough intestines to absorb his nutrition, Rafael would be on IV nutrition and tube feedings for life. Our house was filled with more medical supplies than baby items, and looked like an ICU. Rafael received IV nutrition twenty hours/day and continuous

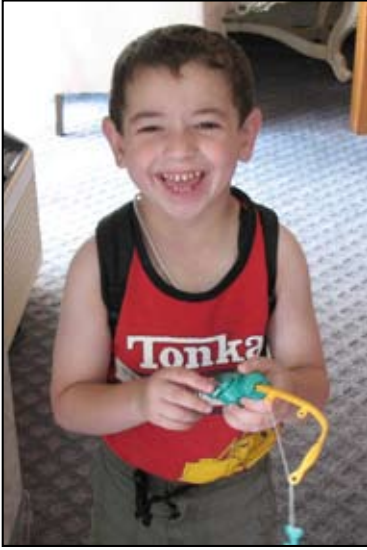
G-tube feeds. He also required hourly diaper changes, and strict restrictions on his activity and oral eating. Bathing was complicated by the need to keep his central line protected.

We searched for information to help us learn about caring for him, and to keep him safe and understand what to expect for his growth and development. All we found were memorial sites! We were in despair. What could we do to help our son? We feared "normal" activities like attending Mommy and Me classes, trips to the library, or just strolling in the park. We feared that they would cause life-threatening infections. Bathing, eating, and tummy play were out of the question.

When Rafael was seven months old we received the Oley Foundation newsletter, the *LifelineLetter*, from our homecare company. Our lives were transformed! The newsletter was filled with photos of smiling people who were living full lives on HPN (home IV, or parenteral, nutrition). One visit to www.oley.org and I was further surprised to learn that many Oley members had been on HPN for years... and were thriving! They bathed, swam, and enjoyed public events without complications! The annual Oley conference was being held in San Francisco that year, and we began making plans to attend. This meant crossing the country from New York City. We packed up our seven-month old Rafael, countless bags of medical supplies, five outfits, and ten diapers.

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This was the best decision we have ever made. At the conference, the hope and positive feeling in the air was comforting beyond words. Just watching other patients and caregivers walking around was overwhelming. Conversing with experienced clinicians and networking with other parents was enlightening. We learned great tips on how to minimize Rafael's central line infection risks and about new medications and products that could improve our quality of life. Everyone was smiling and "living" their lives.



It's hard to catch Rafi wearing anything but a smile at the Oley conference!

We returned home and our doctor implemented a lot of the recommendations we received at the Oley conference. Within a few weeks, our son was much healthier, we were able to get around easier, and above all, we had hope for the future. Our family has returned to the Oley conference time and again to receive our "infusion" of hope and confidence.

Rafael is now an active five year old who attends preschool, goes swimming (and down the water-slide, too!), enjoys the beach, and plays on the playground like every other child. He sees his team of doctors every month. They all marvel at his growth, beauty, wisdom, and glowing positive attitude. He does not feel any different than any other child, and loves going to school with his friends. We owe much gratitude to the Oley Foundation, which has taught us not only how to get on with our lives, but to live fearlessly and joyfully. They have improved our quality of life, and extended Rafael's life immeasurably.

Please consider a generous gift to support Oley, to help other thousands of families like ours learn to advocate for and receive better care. Oley provides an invaluable amount of support and love for our families, and gives us updates on the newest treatments and technology available to better help patients like Rafael, who are technologically dependent. The Oley Foundation helps bring together patients and clinicians to keep patients on IV and tube-feeding therapies healthier and living better lives. Thank you very much!

Sincerely,

Jacquelyn and Joel Katon

Parents of Rafael, age 5, and Aron, age 3