

# 2019 Oley Corporate Partnership Program

I learned the necessity of study groups in college. Everyone brings a different perspective, allowing you to see the material in a way you didn't before, and to know that you are not alone.

Imagine showing up to a classroom full of empty chairs. Being dependent on parenteral or enteral nutrition (PN/EN) can feel like this. It is a class we did not sign up for, but like it or not, we've been enrolled. We are sent home with an overwhelming amount of supplies, and a heavy backpack to carry. Doctors, family, and friends help us navigate, but many of us still feel alone in this new way of life.

Diagnosed as an infant with chronic intestinal pseudo obstruction, a world of digestive disease, surgeries, and PN is the only life I have ever known. In junior high I came to understand that as normal as I attempted to be, having a chronic illness gave me a different class schedule, one that included nausea, leaky tubes, and frequent trips to the restroom—where I would hope and pray to be the only one in there.

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I eventually grew a strong desire to find others who had taken this same class. In 2014 I connected with a group of women who shouted, "I understand!" when I shared the story of my life. Finally, my very own study group to talk about diet, and finding clothes that don't sit too tight on a bloated belly.

I also attended an Oley conference. Here I found a classroom full of supportive, understanding friends who create a feeling of unity and belonging. We range in age, live in different time zones (even continents), and have varying diagnoses and therapies. As grateful as I am for the many ways technology allows us to connect, there is something gained from being face to face that cannot be duplicated in an online group. Where else can you experience a young girl jumping for joy when she saw six of us lift our shirts to reveal scarred bellies, ostomies, and feeding tubes—just like hers!?

The Oley Foundation works to connect those of us who have lived with this for a lifetime, and those who are just being handed their enrollment slip. Through the newsletter, conferences, online support, and a host of other resources, Oley helps to equip those of us on PN and EN with everything we need to make the grade.

Seeing that we are not in this alone compels us to seek other consumers and give them the community that we have been given. This domino effect of generosity will not stop until everyone who feels alone in this knows that the classroom was never empty. Please help us by supporting these programs and building the community that so greatly contributes to our well-being.

—Jana D.



*Jana (right), with some of her "study group" friends on an outing in Arizona.*