



## Transition Story

Submitted by Anna Cyr – November 2012

Looking back over the last 27 years, I see now that our family began planning for my daughters' transition to adult health care very early on! My wonderful daughters, Mallory and Maisy, were both born with a rare genetic condition called Microvillus Inclusion Disease, which causes them to be

unable to absorb nutrients and dependent on Total Parenteral Nutrition (TPN), intravenous nutrition.

I was so worried about the effect of this disease on their lives. How would the physical pain affect them? How would they deal with having to be “hooked up” 12 hours a day at different ages? How would we help them cope with being “different”? How could we make sure that they could still have the same opportunities as “biotypical” kids?

My husband, Mike, and I began by giving them choices whenever possible. We asked them if they wanted to perform various aspects of their care as soon as we thought they were developmentally ready. They started flushing their own central lines, first with help, then with supervision, and then independently. As soon as they began to develop language, we asked them if they had questions about their care and encouraged them to talk to their doctors and other providers. (Most providers loved this but some needed a little encouragement.) Mike and I researched how to do “normal” activities safely. When the girls wanted to go swimming with friends on their own, we taught them how to apply a special protective central line dressing. We figured out together how to manage slumber parties and summer camp. This was often very stressful for all involved! However, we communicated constantly with one another and with the folks we needed on our team, in order to be successful. Things got easier over time.

Some families we knew that had kids with significant special health needs had no plan to transition to adult providers. Some were just informed by providers, when their kids turned 18, that they needed to move on. Others stayed with their pediatricians and pediatric specialists. My kids are a generation apart in age, so we learned things with our eldest that made things easier with our younger daughter. Our oldest, Mallory, had so many challenges transitioning to college, that we thought it best to keep all the same providers until after college and that worked well for her. When she graduated from college, we looked for a new primary care doctor and then began to transition to adult specialists. When Maisy was 17, the pediatrics office let us know that she was expected to transition to adult care and discussed a plan with us.

Change is never easy. We find that the adult health care culture is not as “family-centered or patient-centered” as the pediatric culture, and some providers really seem surprised when the girls express the desire to keep their lives as “normal as possible”. Some providers just assume that their convenience is

most important, as opposed to understanding how challenging it is for the girls to balance their medical need with other responsibilities. We have learned to cherish providers who “get it”! We have learned not to give up, although, at times, it is tempting.

Now that both girls are adults, we find that they still need help navigating the system from time to time; insurance, communicating with providers, and other aspects of their medical life, just as they need guidance with other aspects of adult living.

Having to depend on a complicated, expensive, fragmented health care system continues to be a challenge. We find that it is up to us, as a family, to keep up with changes, find creative ways to make it all work and support one another through the frustration. The good news is that, because of these efforts, Mallory and Maisy are able to reduce the number of life-threatening medical complications, avoid hospitalization, and are able to live life! Mallory is in graduate school and Maisy is a sophomore in college looking forward to being a part of the Study Abroad Program. Transition is ongoing!