



Family

By Dona Darr

IF YOU LOOK in the dictionary, you will find that the definition of family is referred to most as a group that is related by blood or marriage. You will also find a definition that states a family is a group of things related by common characteristics. In the world of chronic illness, the word “family” can take on many definitions, leaving me to ask the question: How do we determine who becomes a part of our family? Through our journey with primary immunodeficiency disease (PI), I have found that my daughter and I have several families, some of which might not fall under the traditional definitions.

Family of Non-Believers

Although we have been on this journey for nine years, we still have those people, friends and relatives alike, who do not believe this disease is real. I try to look at things from their perspective, and I do realize why they have come to believe the way they do. PI is a rare group of immune system disorders with very common symptoms. The commonality of those symptoms is what makes it difficult for the mainstream public to understand. I get this! In the beginning, it was difficult for me to understand as well. My daughter kept getting sick with common illnesses such as ear infections, strep, pneumonia, etc. She was in daycare and, thus, exposure to the many germs that young children can come in contact with was large. It was easy to dismiss the frequent bouts of sickness. After all, a child in daycare is going to get sick. When we were finally referred to an ENT, we were made aware of a possibility, which blood work later confirmed, that this could be

more than just “a child in daycare is going to get sick” thing. People will believe only what they know and understand. It took many hours of research for me to understand and come to terms with what this disease meant and that this disease could become a lifelong battle for my daughter. I don’t expect everyone we know to conduct this same research just to understand what my daughter’s diagnosis means. If PI garnered as much research and publicity in the mainstream media as other diseases such as the many different types of cancer, Alzheimer’s, Parkinson’s and many others, I believe the thought that such a disease as PI is not a real diagnosis would go away, and the family of non-believers would begin to get smaller. While I do not mean to imply that the diseases I have listed above are not worthy of publicity, the fact is that the research and publicity they have received have made them recognizable terms within the general public and, therefore, people understand how they affect the patient and the caregiver. Ask some stranger walking down the street what PI is, and the answer will be: “Huh? Never heard of it.” This is what needs to change; it also is what makes this group of family members important because they keep me motivated to teach and preach the world of PI.



Family of Medical Professionals

The immune system affects several of the body’s organs, thus making it necessary to build a trusted family of medical professionals. This disease makes a patient more susceptible to common infections, as well as other diseases such as leukemia, lymphoma and autoimmune diseases like lupus, rheumatoid arthritis and many others. I mention these specifically only because these are the diseases my daughter has already been tested for and is on the “watch list” for. The list of doctors she sees is ever growing. This list, so far, consists of a pediatrician, ENT, gastroenterologist, orthopedist, rheumatologist, psychologist and immunologist. Some PI patients have more specialists, while others have fewer. The fact remains, however, that these people become a big and important part of our family. Without this family of “ologists,” my daughter would not be healthy. I don’t even want to think of where she would be without these wonderful family members.

Family of Social Networking

When a diagnosis is made of a rare unknown disease, a patient or caregiver is left devastated by the news and the search for information begins. With the Internet, there are many articles to be found with information on just about everything. But, just how reliable is all



that information? The information gained from trusted sources such as the National Institutes of Health, the National Organization of Rare Diseases and the Immune Deficiency Foundation, to name just a few, is priceless. But, who is a more trusted resource of information than a fellow patient or caregiver struggling with the same disease? Social networking has allowed these otherwise strangers to get “connected” and become a part of our family. I have gained as much knowledge from our social networking family as I have from our medical professional family. This family can help guide me when something arises that I am unsure about. I can post a question and instantly get advice as to how they have dealt with similar issues. I can read other posts to learn what may lie ahead for my daughter, thus allowing me time to prepare for the “what ifs.” This family has taught me how to maneuver through the medical world and stay on top of this disease, and it has helped me to gain the knowledge and strength to help my daughter get through each illness that comes her way. This family, like the medical professionals, is an important part of our lives.

Family of Compassionate Friends

Everyone has friends. There are friends, and then there are friends who truly understand our circumstances. This

group of family members consists of those people who are not related by blood or marriage, but have a place in our hearts as if they were. It is made up of people who have taken the time to read, research and understand the disease they are now connected to through friendship. This family is made up of people who have taken the time to lend a helping hand, or have offered a shoulder to cry on or just the time to allow a patient or caregiver to talk, yell or scream and have a moment of breakdown without judgment. These members of our family find ways to uplift and keep us strong. This family gets involved and helps keep the focus on fighting this disease and providing an emotional outlet when needed. I could go on and on about what this family means to the patient or caregiver, but there are not enough words to describe their importance.

True Family

This family is the one that is closest to us: our husbands, wives, parents, grandparents, brothers, sisters, aunts and uncles. This family includes our step parents, step brothers, step sisters, our partners and our significant others. These are the closest members of our overall family. This group of people, like the family of compassionate friends, sees us at our worst and at our best and everything in between; they are right there beside us every step of the way. They celebrate the victories with us and they

console us in our defeats. They are the first ones we reach for when times are good and when times are bad. This group is our first line of defense against this disease. Without this core group of people, life with a rare chronic disease would be a much more difficult road to travel. Their love and support is unconditional, which makes them the most important of all the families.

A Connected Family

As you can see, family can mean different things to different people. This is our family, and I love and treasure each and every one of them. From the non-believers who keep me motivated to educate and promote awareness, to the medical professionals who use their skills to care for my daughter, to the compassionate friends who provide the focus and emotional outlet, to the true family that keeps me grounded and my spirit alive, our lives would not be complete without any of them. ■



DONA DARR is the mother of Emily who was diagnosed with IgG subclass deficiency and complement deficiency. Dona and Emily have been dealing together with this disease since 2004, when Emily was initially diagnosed. Dona and her support system of family and friends will continue to care for and encourage Emily for the rest her life.

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Patients who rely on IG therapy have unique life experiences. If you have a story you'd like to share about your adventures, experiences, relationships, reminiscences, self-portrayals, etc., for publication in this column, submit it to editor@igliving.com. All submissions must be 600 words or fewer and can be accompanied by high-resolution photos.