



# Connecting Chronically Ill Children with Others

By Jessica Leigh Johnson

**PARENTS OF CHRONICALLY** ill children know the reassurance that comes from connecting with other adults who have kids with chronic illness. Until I found my X-linked agammaglobulinemia (XLA) Facebook group, I felt helpless and alone whenever one of my boys got sick or developed a new and unusual symptom. Now that I'm part of a group of individuals facing similar situations, I don't know what I ever did without them. Whenever life seems out of control, this group is my only connection to sanity. How could my friends with healthy children possibly understand my panic when I hear that the Zika virus may be a bigger threat than we first thought (and when I consider selling my house in mosquito-infested Minnesota and moving to Sweden)? But I know that my fellow XLA moms online will be quick to respond to my fears with an "I hear you" or "I totally get it."

If this camaraderie helps parents like me survive the trials and face the unknowns of daily life with chronically ill kids, it just makes sense that the children themselves need that same kind of encouragement from someone who understands — someone who has "been there." All children need to feel like they belong. But, the need to belong can be exaggerated when children suffer from chronic illness. Connecting chronically ill children to one another is a great way to help them feel "normal," especially when their diagnosis and symptoms might tell them otherwise.

The question is: How do we, as parents, connect our chronically ill children with others who know what they're going through? This can be especially difficult when children have a rare disease.



**Internet.** Thankfully, our world is connected by the Internet, which gives this generation of children an advantage that others before didn't have. With just a few mouse clicks, parents can join online communities such as Facebook groups, or follow blogs dedicated to their children's specific condition. A simple shout-out such as "Hey, does anyone live in my area?" can connect parents to others in their community who are seeking the same thing — someone who understands. Once a friendship is established, parents can arrange play dates for younger children or family outings where their kids can meet others in their city or state who have the same condition. As always, take caution when using the Internet to meet people, and be sure to monitor any of your children's online activities.

**Specialists.** Additionally, parents may not need to look further than their children's hospital or specialist's clinic to find a connection. Most major hospitals and clinics can provide information on

local support groups for parents, families and children affected by the same illness.

**Summer camps.** A great way for children to connect with other kids like them is by attending a summer camp geared toward a specific illness or condition. At a camp where daily activities are centered around being active and enjoying the outdoors, these kids may find that they not only share the same condition, but also enjoy similar activities and have common interests. The Federation for Children with Special Needs has a summer camp listing at [fcsn.org/camps](http://fcsn.org/camps) for children with a variety of conditions, including asthma, cancer, diabetes, metabolic conditions, epilepsy and chronic illness. In addition, the American Camp Association's website also lists camps for children with physical and/or mental challenges at [www.acacamps.org](http://www.acacamps.org).<sup>1</sup>

**Immune Deficiency Foundation (IDF).** An invaluable resource for both children with primary immunodeficiency (PI) and their parents, IDF has numerous events scheduled throughout the year where



parents and children can connect and network with other families facing similar situations.

For teens living with PI, IDF has created a social networking group called IDF Common Ground, an online community that gives them the opportunity to share their feelings and experiences about their diagnosis through group forum posts and chat room conversations, as well as videos and pictures.<sup>2</sup> In this safe online environment, teens can discuss a variety of topics centered around their daily life and the challenges of living with PI such as positive and negative experiences with immune therapy and issues they might face at school.<sup>2</sup>

The IDF Peer Support program can also assist parents in connecting their children with someone who may share the same diagnosis or live nearby. The program gives patients, parents and caregivers the opportunity to interact with an IDF volunteer who shares a similar relationship to PI. Parents requesting support for their children or teens are networked with volunteers who are parents and have children in similar age groups. They then determine the best way for their children to communicate. All volunteers undergo training and background checks.

Another unique opportunity for older children with PI to meet others is by attending one of the two IDF Teen Escape weekends. Designed as a getaway exclusively for teens ages 12 years through 18 years who have been diagnosed with PI, these weekends promote and nurture friendships and provide attendees with entertaining and educational activities, while parents attend sessions that focus on their own issues and concerns.<sup>3</sup> According to IDF, the weekends can be life-changing, empowering experiences for teens

with PI where they can make lifelong connections.

Parents and their children can also attend IDF Family Conference Days and IDF Retreats held throughout the country that offer programs for youth ages 6 months to 18 years. These events help patients and their families learn more about living with PI while connecting with others and having fun.

themselves, chronically ill children may feel isolated, different and even burdensome. But they don't have to feel like they're the only ones living with their specific illness. As the saying goes, there is strength in numbers. Together, chronically ill kids can share their experiences in order to feel understood, supported and accepted. No one knows what your children are going through like other

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IDF's National Conference is held every other year to bring together individuals from all sectors of the PI community. It is the world's largest gathering of families affected by PI. At this conference, families meet each other and get the latest information from medical experts while enjoying social events. Youth programs geared toward children ages 6 months to 18 years are offered to provide fun, educational activities for those diagnosed with PI. They help children understand their primary immunodeficiency disease and connect often-isolated youth with peers who are facing similar circumstances.<sup>4</sup>

Childhood is a time of growth and self-discovery, and a time for friendships to take root and blossom. Unfortunately, by

children with the same condition. When connected with others who are facing the same disease, they can receive social and moral support that might make life just a little bit easier. ■



**JESSICA LEIGH JOHNSON**

is a stay-at-home mom and mother of four kids, three of whom have X-linked agammaglobulinemia.

She is a member of American Christian Fiction Writers and has written one book about the loss of her son to a primary immunodeficiency.

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