

Children's Health Update

Children Create Storybooks To Help Others With Chronic Illness

(NAPSA)—At an age when most kids are reading storybooks, 8-year-old Emma and 3-year-old Charlie were each creating their own books to help them deal with their chronic disease—primary immunodeficiency (PI).

PI is a group of genetic, lifelong disorders of the immune system that make the body unable to protect itself from germs. The condition makes Emma and Charlie, who are not related, vulnerable to serious and potentially life-threatening infections. By the time they were toddlers, both children had logged more time in hospitals than many people do in a lifetime. Now they have turned their experiences into books designed to help other kids and their families as they face the frustrations and fears of ongoing medical conditions.

Healing Expressions

Thanks to advances in medicine, PI can be successfully treated with regular infusions of intravenous immunoglobulin (IVIG) that allow most patients to lead more normal lives because of the reduced risk of infection. Children usually can go to school, play with friends and participate in sports. But sometimes an accurate diagnosis can take years and IVIG treatment requires frequent visits to the hospital for ongoing care. For parents, the experience is life-changing. For kids, it is scary and confusing.

Creative expression became an important tool for Emma and Charlie to understand PI and share their anxieties with their parents and caregivers. Emma, diagnosed at age 3, and Charlie, diagnosed at 2, used pictures to work through their experiences.

With assistance from their parents, Emma and Charlie then created books to capture what they learned and help other kids cope with PI or other types of chronic disease, such as asthma, epilepsy or diabetes. The books tell chil-

dren and their families that the more you know what to expect from a situation, the less scary it is. And the more you express your anxieties and fears, the better able people are to help you.



Emma's Story— "The ABCs of Kids Like Me"

Emma, now 11, was inspired to share her story after she read a book about a boy living with cancer. "I wanted to do one for kids like me," she said.

Her book, "The ABCs of Kids Like Me," uses each letter of the alphabet and colorful illustrations to suggest ways for patients to cope with different aspects of a chronic disease. Packaged with a set of crayons, the book includes blank pages that invite other children to record their own stories.

Emma advises children who are just beginning treatment for a chronic condition to remember, "You get tougher the longer you do it." Emma adds that her family has made life easier by "treating me normal, not like an alien or something!"

Charlie's Story— "This is My IVIG Book"

At age 5, Charlie is the oldest of three kids who have PI. It was Charlie's mother, Dayna, who initially developed his book when he was a toddler to help him understand his condition and accept his monthly IVIG treatments. Using



photos that Charlie took and his own words whenever possible, Dayna crafted a story that reviewed his treatment step by step to reassure him about the process and people involved.

Dayna says that perhaps the fact that all of her kids have PI makes it easier to raise her family. She is acutely aware that her children will one day be adults faced with supporting themselves in a working world. She's made it a priority to help them accept their medical condition and learn to differentiate between acceptable levels of discomfort and real pain that requires help from caregivers.

"Our perspective is different than most people's," Dayna said. "We'd rather teach our kids how to live with this disease than how to die with it. We choose to teach them to overcome."

Charlie's story comes with a book containing blank pages for photos and a collection of stickers for other kids to create their own stories.

Both books, published by Baxter Healthcare Corporation, which processes and distributes IVIG treatment, are complimentary upon request. To order Charlie's or Emma's book, or get additional information about PI, visit www.immunedisease.com.