

# Family Ties

By Abby Torkelson

Being a thal (thalassemia) patient is one of the loneliest and greatest experiences in the world. “What do you like most about having thalassemia?” This was the stimulating question that was asked of us at the thalassemia retreat this past November. As one of two thalassemia major patients living in Alaska, thousands of miles away from any other thalassemia patients--a state that the U.S. postal service treats as a different country, in which people are surprised to discover that we do not live in igloos or have to dog mush to a first-aid station to be transfused bear's blood--I feel rather alone. Staying alive is a challenge and dying is to become a statistic. At least, it felt that way for most of my life.

One day, I met Children's Oakland's very own Thalassemia Outreach Coordinator, Laurice Levine, and my life has never been the same. Sunlight broke through the clouds and warmed me to the core; it shed its light on the narrow path I walked alone. Suddenly, I have found myself belonging to a family with invisible ties that I had only to meet.

The thalassemia retreat, organized by Laurice, was truly a retreat, a haven, and a place of safety from frustrations and fears. Although I met many people for the first time at this retreat, the weekend mirrored a family reunion. Conversations could instantly drop to a deeper level; bonds were made and strengthened as though each side had been waiting to adhere to just the right piece.

From carpooling, playing games, and talking, to making meals and doing chores together, the experience was amazing. The thought of waking up that first morning and wandering around to see what others were doing still brings a smile to my face. There was a cluster of people in the kitchen making breakfast and a table with food and more people. Another group of people was checking their blood sugar while others were eating. I belonged to the group that couldn't dig in until the little white tablets of the oral chelator Exjade had dissolved all the way in the gritty, milky white water and the water was drunk--the only thing allowed in my stomach for 30 minutes before I could put anything else down there to keep it company. But almost all the little groups had to swallow pills to begin the day.

Besides the wonderful opportunities to ask individuals questions such as, “How often do you get blood?” and “Does Exjade make you constipated?” we also had a group session where Huythong Nguyen and Laurice lead us in therapeutic discussions as only they could do. Only those who have stabbed themselves thousands of times with needles, swallowed enough horse pills to kill a horse, and watched their life trickle away in medical waiting rooms have the authority of speech and credentials to say, “I know it is hard but you really need to be compliant.” However, the most interesting question posed was, “What do you like most about having thalassemia?”

What do I like most about thalassemia? It is all the amazing people I have met and the fact that I am invisibly linked to them like family. I am not implying that this “family” is perfect, but it seems very much like a family to me. Many families have inside jokes and a family lingo--such as “getting poked,” “Exjade,” “L1,” “squid,” and “HMOs”. I think this is why even though I have only known Laurice since this summer, when she did outreach activities with my sister and me while we participated in the EDICT study, it feels as though I have known her my whole life. What do I like about thal? I like that the uncertainties in life have made so many of us stronger. It pushes us to live life to the fullest. It pulls us together as family. It gives us the opportunity to encourage others.