

PATIENT'S PERSPECTIVE

Thalassemia Retreat

by Cheryl Mar

Having missed the last several Thalassemia Retreats (due to work, scheduling, PTO, and hassles), I am glad to say I finally pushed all those annoyances aside and attended this year's retreat in Santa Cruz, Calif. It did not disappoint. Being away made me appreciate the experience and time spent with truly caring friends. To me, that's what the retreats are about. Thalassemia may be one thing we have in common, but we are not just one-dimensional "thal patients." True, we may have additional frustrations and a broader perspective associated with having a chronic condition, but we are subject to the joys and sorrows of everyday life, and this weekend was just as much about life in general as it was about thalassemia, medications, and treatments. Having this weekend of living together and sharing space really allowed us to get to know each other as people—as opposed to just having a day-long event, which is usually focused on medical treatment, research, and maybe an hour to "meet and greet" other patients.

I was excited that there were several first-time attendees as well as many returning attendees. I learned a lot about



Thalassemia Retreat, 2010

many people from both groups, and I learned how important it is to keep in touch and know what's going on in each other's lives, regarding both thalassemia and non-thalassemia issues: it creates a more effective and cohesive support system. As I mentioned previously, we are subject to life's everyday issues, and when one of these issues comes up, we shouldn't turn our backs on each other just because it's not thalassemia-related. We need unconditional support, and retreats such as this one help foster this type of relationship and support system during both free time and the planned Saturday workshops.

Before this year's workshop, Laurice said, "They're going to kill me when they find out what they have to do." I promised I wouldn't, and no one else did afterwards, either. What initially sounded like an arduous and daunting task was actually quite beneficial in helping me think about myself and my life. Sharing such personal reflections also helped me gain an understanding and appreciation for everyone else as well. The second half of the workshop was an open

discussion where we were free to introduce topics and express our opinions, thoughts, and feelings. Despite the fact that we all have anemia (thalassemia or sickle cell), everyone has a different experience to share. Even though I have thalassemia and think I know all about the disease and what it's like to live with it, there are complications and issues I have never faced, so it is intriguing to hear others' stories. At the same time, there are certain thoughts and feelings I've had but never shared with anyone and doubted anyone else could relate, so it's significant and powerful to hear someone else voice the same unspoken ideas.

I had a great time at the retreat and realize I have missed out during the past several years. It's an important event, and I'll be sure to try my best to attend next year. I learned a lot about myself and life. I'm grateful for the experience I had, and especially for all the friends who were there to share it with me.



Abby holds up her soul collage.

THE THALASSEMIA TEAM AT CHILDREN'S HOSPITAL & RESEARCH CENTER OAKLAND
WOULD LIKE TO WISH YOU ALL A HAPPY AND HEALTHY NEW YEAR.

Holiday Party 2010

Approximately 175 patients, families, friends, and staff enjoyed a Winter Wonderland in the Children's Hospital Oakland Outpatient Center atrium on Thursday, December 11. People feasted on food from Panda Express and desserts from Braxton's Boxes. There were winter arts and crafts, gingerbread cookie decorating, and special entertainment from Berkeley Repertory Theatre's *Nutcracker*. The highlight of the evening, as always, was a wonderful visit from Santa Claus and his dear friend Elf Jones.

A great time was had by all.



We would like to thank the following donors and volunteers. Thank you for your generosity, support, and kindness. Because of your dedication, our party was a smashing success! We sincerely appreciate you sharing your time, talent, and treasure:

(Listed in alphabetical order)

Justine Alberto

Bob Bausino

Colombo Club Women's Auxiliary

Frances Chow and friends

Angela Coleman and friends

Mary Compagno, B-Jeweled

Rachel Davis

Marlene Farber

Genworth Financial and Wealth Management, Inc.

Joanne Hoegsberg and members of Metabolex, Inc.

Charlene Kramer

Italian Catholic Federation, Branches 161 and 432

Jim and Janice Jones

Sara Lossett and friends

Zoe Oppenheim

Olivia Jackson and members of the Acalanes High School Leadership Club

Salvador and Mary Lipari

Shani Litwin and Rachel Buckher, Berkeley High School

Mary Sperrazzo

Starlight Children's Foundation

Oakland Chinatown Lions Club

Panda Express/Ling Wu

John and Donna Rossi

Mike and Marcie Rossi

Ruby's Garden Kidwear and Gifts (Mary Prince and Mae Chan Frey)

Gene Simonetti

Jonathan Thong

Our gratitude goes to Sidd and Vijay Talwar for their dedication to providing outreach to the Indian community by attending two summer health fairs. They traveled to a health fair in San Jose, Calif., and another in Phoenix, Ariz. Thank you, Talwars!

(top-bottom, r to l) The Datos; ICF attendees enjoy the party; Santa, Elf Jones, and The Big Kids at Children's Hospital; Watching Santa; Santa and Emma Kaur.

Useful Websites for Thalassemia

The following websites may be of interest to patients and families living with thalassemia. Some are medically informative; others have a more social aspect.

Thalassemia Patients and Friends

www.thalassemiapatientsandfriends.com

Thalassemia/Family Village

www.familyvillage.wisc.edu/Lib_thal.htm

Children's Hospital Oakland Thalassemia Website

www.thalassemia.com

Cooley's Anemia Foundation

www.cooleysanemia.org

Thalassemia International Federation

www.thalassaemia.org.cy

Thalassemia Support Foundation

www.helphthals.org

National Marrow Donor Program

www.marrow.org

Children with Diabetes

www.childrenwithdiabetes.com

The Italian Catholic Federation and Thalassemia

The Italian Catholic Federation (ICF) is an organization started in 1924 with the purpose of bringing fallen-away Italian Catholics back to the Church. Today, with 12,100 members, the purpose remains the same, but people of other nationalities are welcome to join. In fact, many non-Italians on the rolls contribute greatly to the work of the ICF. There are chapters in California, Nevada, Illinois, and now Arizona. The organization has an expansion program and hopes to open more branches in the future.

While members enjoy many social events, the emphasis is always on charitable and apostolic works. The ICF adopted thalassemia as its national charity focus in 1981. The first donation was presented at the ICF National Convention in 1982. At that time, much of the research work for thalassemia was conducted at Cedars-Sinai Medical Center in Los Angeles. Dr. Carol Hymen was the director of the program then. I recall speaking at length with Dr. Hymen about the program and was most impressed with her work. Since those early days, I have become acquainted with Laurice Levine, the Outreach Coordinator for Cooley's at Children's Hospital Oakland. We have shared many great moments together, and, in fact, she has been present at the Valentine's Gala Dinner held at my IFC branch (#52, Healdsburg) for the past two years. This year, this event raised \$5,000 for thalassemia. We are planning this fundraising dinner again for 2011.

Thalassemia, a disease affecting people who live in Mediterranean regions or regions of similar climate, struck a chord with our members. The ICF was quick to take up the cause of those with this disorder and began to donate to a special fund. The money accumulating in this fund is donated for research every year at the ICF National Convention. Over the past 22 years, the ICF has given over \$1 million to the charity. The research and work on thalassemia is now carried out at Children's Hospital Oakland under the direction of Dr. Elliott Vichinsky. ICF members are invited to take tours of the thalassemia facility and observe firsthand the care that patients receive.

To add to the annual donation for thalassemia, individual branches such as ours also have fundraisers and special events. Members do toy drives or attend the annual Christmas party in Oakland to make it possible for patients to have a very special outing every year. It has been wonderful to see so many people give time and money to help patients with thalassemia live longer and better lives. In the past, patients rarely lived past their teenage years, but many are now surviving into their 40s and beyond. The work of the program has helped so many, but the kindness of others has enabled this work to go far. The members of the ICF are to be congratulated for all that they do for those with thalassemia.

The ICF also has a scholarship program for high school seniors entering

college. Each year, money is given to students to help further their education. The ICF also donates money to the Providenza Seminary Fund to help with the education of seminarians. The Gifts of Love Fund aids people with developmental disabilities who need help of a specific nature. All the money for these charities is raised by ICF members at various social events, and every penny collected is donated.

One cannot speak about the Thalassemia Program at Children's Hospital Oakland without again mentioning Outreach Coordinator Laurice Levine. ICF members have taken her into their hearts: She is the spark that encourages us and never ceases to amaze. Her own story is truly remarkable, and she inspires all when she speaks at ICF functions. She is always ready to come to any branch and talk about Cooley's, so why don't you invite her? I guarantee you won't be disappointed.

Carmen Kilcullen
ICF Past Grand President



PATIENT'S PERSPECTIVE

The Painted Turtle Camp

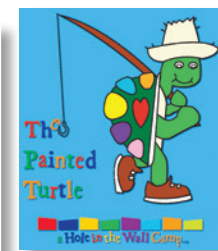
by Rammeet Kaur

Hi, I am Rammeet Kaur, and I went to the Painted Turtle Camp in the summer of 2010. My experience in camp was amazing and very enjoyable. The Painted Turtle Camp is its own special world. I enjoyed many fun activities, such as flying through the air on a zip-line, singing songs near the campfire, dancing under rainbows, eating spaghetti with no hands, fishing, boating, riding horses, practicing archery, swimming, and much more. We had Stage Night to show off our talents, and we even had Silly Olympics, where counselors and campers splatter each other with oatmeal, chocolate syrup, and other soft or liquid foods that made us all dirty.

I made many friends at camp who are still in touch with me. I will always remember sharing good times with them. We ate three meals

a day at the grand dining hall. The food was healthy as well as tasty. It is very safe there, because doctors and experienced counselors are there to help us and comfort us 24 hours a day. Each cabin of 10 campers had its own nurse and four counselors.

This camp was founded by people such as Paul Newman, an Oscar-winning actor who wanted to help children with chronic illness. Thanks to generous donors, the Painted Turtle is full of life. This camp gives kids with chronic illness a chance to escape from the hospital and have fun just being a normal kid for a whole week. Going to this camp was an life-changing experience that will be cherished in my memory, because I learned a lot from group involvement with my fellow campers in all the activities I did.



(top-bottom, clockwise)
Rammeet practices her
archery and fishing; relaxing
in her room.

TOP 10 TIPS FOR TAKING A CHILD TO THE EMERGENCY ROOM

As winter days grow colder, children are exposed to more viruses and bugs. Having a chronic condition such as thalassemia can sometimes complicate matters even more. As you consider medical issues for children, the nation's emergency physicians remind you to be prepared in case you have to take a child to the Emergency Room.

Here are 10 tips from Emergency Room physicians for when you take a child to the ER:

1. Plan ahead. Where is the closest ER? How would you get there in an emergency?
2. If it's a life-or-death situation, call 911. If it is safe to drive, remain calm, which will help your child remain calm.
3. Communicate clearly to the emergency staff. Good communication on all fronts makes the process run more smoothly.
4. Bring a list of the child's allergies and medications.
5. Bring contact information for your child's physicians, as well as the child's immunization records.
6. Provide consent-to-treat forms for those who take care of your child (e.g., guardian, babysitter, daycare provider, school nurse).
7. Explain to the child what is happening. Be sensitive to the situation and the child's age, but be honest and continue communicating. Explain anything that may be confusing, and reassure the child that the emergency staff is there to help. Also, let the child know it's okay to be examined by the physician.
8. Don't let your child eat or drink anything if you are going to the ER. If the child has a condition that requires evaluation or specific treatment, the child may require certain medications or sedatives. Let the physician recommend when it's okay for the child to eat or drink.
9. Bring a sleepover bag in case the child is admitted to the hospital. This bag should include a change of clothes, pajamas, and some of the child's favorite objects—a small toy, a favorite blanket, a book, or a stuffed animal.
10. Stay calm. Remember that kids feed off cues given by adults. If you are impatient and panicked, the child most likely will be, as well. Don't add stress to an already stressful situation.

Lisa Bloch, Director of Communications, Blood Centers of the Pacific

It's hard to believe it was nine years ago that I met someone with thalassemia for the first time. I had been working for Blood Centers of the Pacific (BCP) for a little over a year and was tasked with finding "patient stories"—stories from people who had received blood and who would be willing to share their stories to motivate others to donate blood.

I was put in touch with a very enthusiastic, bright young woman named Laurice Compagno. Now known as Laurice Levine, and serving as Children's Hospital Oakland Thalassemia Outreach Coordinator (along with Eve Alley), she educated me about thalassemia and talked about how blood donations are vital to her survival. I had often thought of people needing blood in response to injuries, surgeries, or sudden illness, but I hadn't thought much about those who need blood donations on an ongoing basis just to live.

Laurice spoke eloquently about the effect of receiving blood transfusions and how she says a silent blessing for the donor who gave selflessly every time she receives a transfusion (about twice a month). It made me grateful to be part of an organization that helps provide this life-sustaining substance to people like Laurice. So when I learned a few months ago that BCP was selected to be Children's Hospital's new blood provider, I was thrilled.

BCP, which has been providing blood to Children's for the past several months, will supply approximately 10,000 pints of blood and blood components a year to the hospital—including blood for rare blood types for its sickle cell and thalassemia programs. In addition to providing blood donations, BCP will also run regular blood drives at Children's so that staff and patients' families can give blood conveniently. This new partnership continues a tradition of collaboration



**Blood Centers
of the Pacific**



between BCP and the hospital, as several former Children's physicians have gone through BCP's Blood Banking Fellowship program and are currently doing research on pediatric transfusion medicine via BCP's research arm, the Blood Systems Research Institute.

BCP, formerly known as the Irwin Memorial Blood Bank, is a nonprofit organization that supplies volunteer blood donations to more than 40 hospitals throughout Northern California. It is the nation's oldest community-sponsored blood organization, with centers and blood drives throughout the region, from the base of Silicon Valley to the Oregon border. BCP is an affiliate of Blood Systems, the nation's second-largest blood collection organization.

"We're honored to be able to support the mission of Children's Hospital Oakland," said BCP president Nora Hirschler, MD. "Both our organizations have a long history of service to our community, and we look forward to combining forces to ensure lifesaving blood is always there for the kids and adults who need it."

That's where blood donors come in.

BCP relies on volunteers who selflessly roll up their sleeves to donate blood for patients battling illness, like Laurice. There is no substitute for it. But of all the people eligible to give blood, less than 4 percent do. The numbers are, unfortunately, even lower for people of color.

Donating blood is safe and simple. Donors even get to learn their cholesterol levels with each blood donation. Soon they will also start earning points that can be redeemed online for gifts like movie tickets, T-shirts, or ice cream.

To learn more about BCP or to donate blood, visit www.bloodcenters.org.

If you'd like to share a story about yourself or a loved one needing blood, please contact Angela Woon at 415-749-6698 or awoon@bloodcenters.org.

Mary's Little Blanket Makers

Every couple of months, Children's Hospital Oakland's Thalassemia Program makes a trip to our dear friend Terry Rosser's house. Terry (right) is from ICF Branch



161, and she is an angel right here on earth. Throughout the year she worked tirelessly collecting knitted blankets, hats and other kids' clothing, fleece blankets, and stuffed animals. These items of love are given to patients and families when they come to the day hospital for blood or when they are admitted into the hospital. Many of the quilts are given to patients in the NICU as well. We would like to thank the knitters whose gifts of time and talent are priceless.

Anna Biggio
Lonnie Fugate
Barbara Fugate
Diane Hollister
Rita Pinzon
Giovanna Pomilia
Imma Sottile
Phyllis Rbyensky
Julie Corroo
and the latest addition to the knitting circle, Jeannie

We would also like to extend our gratitude to the donors who make this effort possible by purchasing supplies:

Charlie Abela
Leroy Cheda
Marlene Farber
Lorraine Iavarone
Ellen McKeon

And special thanks to Terry Rosser, who makes this all happen.

In 2009 and 2010, we received the following from Mary's Little Blanket Makers:

22 shawls
24 lap robes
23 quilts
217 blankets
122 caps
28 bibs
13 toys and books
6 sweaters

Welcome Khai

by Heather Ayris

In May 2009, we eagerly awaited the arrival of our summer visitor from Afghanistan. Our family had decided to work with a nonprofit organization (Solace for the Children) and host a child with minor medical needs for six weeks. Our objective: expose him to a fun-filled summer in America, away from the war-torn country where he had grown up, and take him to doctor appointments to receive basic care such as teeth cleaning, cavity filling, treatment for his anemia, and eye examinations. While we were excited about the fun we would have and the exposure our two biological children would gain from the experience, we were nervous about the language barrier, as we knew the arriving child would speak no English at all.

We were greeted in June with a beautiful boy of nine, whose soulful eyes soon captured our hearts. I am quite certain that at that moment in the airport, as I hugged a tearful and overwhelmed Khai, he became a part of our family—no words needed. Little did we know that he would forever change us and how we would band together to help him in his quest for health.

Just a few short days after Khai's arrival, I took him to his initial doctor appointment. When we were told he had beta thalassemia major, I calmly asked, "What is that?"

The doctor said, "It's a severe form of anemia."

Okay. No big deal, I thought. We had been told that he was anemic before his arrival. "So what do we need to do? Give him iron supplements?" Looking back on that reaction now makes me laugh at how naïve I was!

As the weeks progressed, we were exposed to dozens of tests and numerous doctors, and we learned more about a genetic disease I had never even heard of before. We were informed that Khai's chronic iron overload was the main concern and the result of nine years of blood transfusions without chelation. With a ferritin count in excess of 13,000, there was no telling how high the iron concentration was in his organs, yet we knew they were at risk for failure. We also learned, through his family in Afghanistan, that three of his siblings had already been



Cade (8 years old), A.J. (9 years old), Khai (10 years old)

lost; most recently, a beloved sister died of heart failure at 13 due to the iron overload. Suddenly, the situation became all too real, and we were determined to do anything we could do to help save this child's life!

So much happened in such a short period of time. As the six-week visit was coming to an end, we were desperately trying to find a way to keep Khai with us in the United States so he could receive treatment. Just three days before his scheduled departure, his family in Afghanistan—demonstrating the true meaning of unconditional love—agreed that Khai should remain here, and Solace for the Children worked with the U.S. Embassy to get an extension for his visa. One day later, we received a call from the Novartis Patient Assistance Program. Khai had been approved to receive Desferal and start subcutaneous infusion treatments. Presbyterian Blume Pediatric Hematology & Oncology Clinic in Charlotte graciously agreed to help with his monthly blood transfusions. As the pieces fell into place, we were convinced that God had this planned out for us.

Throughout the next months, countless phone calls were made and e-mails sent, trying to understand more about beta thalassemia major and the concerns with chronic iron overload. Through these actions, I met some wonderful people. Most of the e-mails I sent went unanswered, but one very important e-mail received a reply, and I'm thankful every day for the response from Eileen at Cooley's Anemia Foundation.

Eileen has been a wonderful supporter of ours. Every time I called with a tearful question on how to make the infusions less painful for Khai or to celebrate the lowering of his iron counts, she was there!

As winter approached, it was time to think about more advanced forms of treatment, so I began to investigate clinical studies. What a wonderful day it was when we heard back from Nancy Sweeters at Children's Hospital Oakland and learned that Khai (along with another child here from Afghanistan) were being accepted into the combination chelation trial! We have seen amazing results! Khai's ferritin levels are now less than half of what they were. His T2 test has improved by 100 percent in six months, and we are confident that we will continue to see this type of progress.

We still have a long way to go, and Khai's situation continues to be critical. The doctors estimate that it will take another four to five years to remove all of the excess iron in his little body, and at that point, we'll need to keep it down to prevent finding ourselves in the same situation again. However, to see a child who had no hope a little over a year ago now progress into a healthier boy with hope for the future is nothing short of a miracle. We remain optimistic that there will be a cure in Khai's lifetime and look forward to the day when we can celebrate that with him!

A Letter to My Class

by Aaron Cheng

Throughout the course of this year you all have learned little snippets about my interests: my passions for science, for music, and for learning in general; however, you do not yet know my whole story. You do not yet understand what has led to my extreme love of learning, my dedication to the sciences, and my goals for the future. And through this speech, I intend to tell you about my greatest passion of all.

My life began—well, when I was born, as lives tend to do. And for a while I lived normally, a chubby little tyke who rolled around on the floor, spending my days observing the world from eleven inches off the ground, philosophizing, getting acquainted with the floor on which I crawled; however, when I was only a few months old, a five-syllable word crudely entered my life and took control of it.

“Thalassemia.”

This seemingly Martian term isn't as alien as it may appear. In fact, this term describes a blood disease that is carried by over sixty million people in the world. But thalassemia alone isn't what made me genetically unique. No, doctors discovered soon after my birth that I had the worst form of thalassemia, the form that affects only a thousand people in the United States, the form that renders the victim helpless and completely dependent on blood from other people: beta-thalassemia major. My innocent, happy life came tumbling down around me with this medical discovery.

And my bright, hopeful days as an infant became the darkest days of my life. You see, thalassemia, in simple terms, is a genetic mutation that affects the blood cell and causes it to be unable to carry oxygen. While a red blood cell should be plump and red, my blood is shriveled and useless. The single change in the nucleotide sequence



Aaron Cheng

in my DNA that caused this monstrous disease leads to a multitude of problems. Ever since I was born, I've had to go to the Miller Children's Hospital in Long Beach to receive a four- to eight-hour blood transfusion every month. And every day at home I took shots to counteract the iron deposits that have resulted from these transfusions.

Thalassemia is a daunting disease.

The victim must receive blood from donors, but in doing so he receives an excess of iron through the transfusion. The very process that is saving his life is killing him. Though there are drugs that help patients excrete iron, the sad fact is that not all the iron exits the body. As a result, iron deposits form in the pituitary gland, the liver, the pancreas, and eventually, the heart. So while the victim of thalassemia usually does not die from lack of functioning blood cells, he eventually dies from heart complications caused by the iron.

My infancy was the most difficult part of my life. Doctors were unable to find suitable veins in my tiny arms, so they stabbed my feet with the needles. Needles often fell out during the course of the transfusion, so one trip to the hospital could mean up to five shots. At home I continued to take shots every day to counteract the deadly iron deposits. By the age of five I had taken more shots than most adults had taken in their lifetime.

I still remember my elementary school days. I was often ostracized because of the frequency of my doctor appointments, and I missed up to three days of school per week. And when I realized that the blood was being pumped into my body was from other living people, I felt like a

vampire. Not as shiny as Edward Cullen, but a vampire nonetheless. It was during my elementary school days that I resolved to repay all of my blood donors for their generosity, to pay back all of my doctors for all the work they had put into me.

Through middle school I immersed myself in the world of academia, motivated to help the medical community all I could. Whenever I felt exhausted of studying, it only took one more visit to the hospital, one more transfusion, to make me work at full speed once again. I was determined to make an impact on the medical community, to ensure that everybody with diseases as devastating as thalassemia would be able to fulfill happy, productive lives.

Upon entering high school I joined every club associated with academics that I could, such as the Academic Decathlon, science club, and math club, with the hopes of being as prepared for my future as possible. And my internal drive to learn and to contribute to society continues even as I speak.

As I write this, I realize that within thalassemia is a hidden jewel: the treasure of dedication and passion. Thalassemia is no longer a monster to me; rather, it is a part of me, and it breathes the fire of passion and inspiration throughout my body. What was once a weakness, a flaw, is now my prized gem. The darker my circumstances, the brighter its light will shine. It is because of thalassemia that the motivation to succeed runs through my veins. It is because of thalassemia that I have learned to endure pain. And it is because of thalassemia that I am able to lead a productive, albeit shortened, life today.

There is something I want you all to take away today from my experience, since I'm not just up here to tell my life story. Always embrace obstacles, for obstacles are actually valuable lessons cleverly disguised. Without confronting obstacles you will never grow. Obstacles will never crush you as long as you have the resolve to overcome them.



P E R S P E C T I V E S

Northern California Thalassemia Center
Children's Hospital & Research Center Oakland
747 52nd Street, Oakland, CA 94609

Address change requested

UPCOMING EVENTS

February 12, 2011: ICF Branch 52 Valentines Day Fundraiser, Healdsburg, CA. For more information or for tickets, please contact Mary and John Delmonte at icf52@aol.com.

May 11-14, 2011: 12th International Conference on Thalassemia/14th TIF International Conference for Patients and Parents, Antalya, Turkey; www.tif2011.org; www.thalassaemia.org.cy

August 4-9, 2011: Painted Turtle Camp, Lake Hughes, CA

COOLEY'S ANEMIA FOUNDATION AND TAG EVENTS:

May 1, 2011 - National Care Walk fundraiser needs your help. We are asking that everyone walk or sponsor a walker to raise money for thalassemia. To register for the walk, go to www.cooleysanemia.org.

June 24, 2011 - Cooleys Anemia Foundation (CAF) and Thalassemia Action Group (TAG) Annual Patient and Family Conference, Disneyland, Anaheim, CA

For more details about any of these events, or to get involved, please contact Laurice Levine, Thalassemia Outreach Coordinator, at 510-428-3885, ext. 5427 or go to www.cooleysanemia.org.

Thalassemia Action Group (TAG) is looking for new board members for the 2011-2012 term. If you are interested, please contact Laurice Levine, TAG President, at lauricetag@aol.com or 360-860-2023.

Founded in 1985, TAG's mission is:

- To promote a positive attitude toward life.
- To stress the importance of compliance and chelation therapy.
- To provide patients with a channel of communication and information.

TAG is a patient-run support group that helps individuals meet the challenges associated with thalassemia. TAG enables people with thalassemia to have contact with others who share similar experiences and who can offer advice and support. TAG also works to spread information on the latest advances in care for thalassemia and to ensure that each person with thalassemia has the information necessary to obtain the best treatments available.

