



Stories of Caring



Campers Turned Counselors

The Painted Turtle; where children with serious medical conditions celebrate just being kids! Through innovative, camp-based programs that offer a great big dose of fun and support, children with more than 30 medical conditions visit The Painted Turtle each year, reclaiming the joys of childhood.

As **The Painted Turtle** embarks on the 10th summer, we continue to see the positive, long-term effects of camp. In 2014, ten former Painted Turtle campers are full-time summer staff members; individuals who want to provide campers with the same support, encouragement, and camp magic that they received when they were campers.

One of the remarkable aspects of The Painted Turtle experience for campers is that in so many untold ways it continues to positively impact the way they see themselves, their illnesses, and their futures. When asked to describe their first Painted camp experience they responded with "inspiring," "pure magic," and "unexpectedly amazing."

*"Camp helped me be able to realize that my disease is a part of me, but it doesn't define me."
-Theresa, a former camper turned counselor*

We thank these ten inspiring role models for sharing their experiences and wisdom with the campers this summer. It is so much more than just camp fun.



Click here to view a few camp videos <http://www.thepaintedturtle.org/the-camp/camp-video/>



**National
Multiple Sclerosis
Society**

The Northern California Chapter of the National MS Society serves 40 counties and 84,000 people affected by MS. The Northern California Chapter is a lifeline for people living with MS; by providing reliable knowledge, engaging and innovative programs and services, financial assistance and a sense of community, the Northern California Chapter keeps people moving their lives forward.

Jake Nyden: Fighting for his mom



Jake Nyden has always loved science fiction and realized years ago that he wanted to design airplanes and spacecraft. Now, with the help of a National MS Society Scholarship, the 2012 high school graduate plans to attend Embry Riddle Aeronautical University in Florida, after taking a year off to join the Air Force.

As sure as Jake is about where he's going, he's just as rock-solid on what brought him to this point. His mom lives with multiple sclerosis, and he's been her chief caregiver since he was 13.

"She has secondary-progressive MS with optic neuritis in her right eye, pain in her left leg and occasional numbness in her hands. She sometimes has trouble with her balance and she hasn't had a full night's sleep in five years," Jake says.

In helping his mom with her daily living needs for several years, Jake picked up several life lessons a lot earlier than his peers. He's had to take on the responsibilities of a money-managing, bill-paying adult, a caregiver and a full-time student all at once. Money's always been tight and the scholarship will be a huge help.

Jake and his mom are hopeful that an impending stem-cell treatment will improve her condition enough that she can safely get around the home and care for herself while he's gone.

As he looks back on and thinks about how MS has changed both his mother and himself, Jake says, "I've fought for her for so long. Even though I'll be leaving for the Air Force and college, I'm still fighting for her to get a treatment that works."

Join the National Multiple Sclerosis Society in a World Free of MS
<http://www.nationalmssociety.org/Chapters/CAN>

Juvenile Diabetes Research Foundation



Chris was diagnosed with Type 1 Diabetes when he was just 2 years old. He is 7 years old now and the strongest kid I know. Life has handed this little boy a big plate but he is handling it pretty well. He misses out on some of the fun things in life and everyone is always worried about him. He started to drink a lot and no one thought of it as a big deal just that he was always thirsty. No one in my family has Type 1 Diabetes so I had no idea that anything was wrong. I am a paranoid parent so when he was so sleepy he couldn't wake up I took him to the ER and they told me his sugars were over 600. And ever since then we have had a different life. Now that Chris is getting older he wants to find a way to help him and everyone else find a cure. He has been taking photos that he wants to get framed and sell so that he can give the money to JDRF. This little boy is are families strength, we know that if he can have all these things and still wake up smiling that we can handle what the day throws at us as well.

~ Chris's Mother

To Help create a world without Type 1 Diabetes visit <http://bayarea.jdrf.org>



The only living grandparent that I have had since I was a 6th grader doesn't even know who I am. I am 25 years old now and I still remember the first time she didn't recognize me. I was 19 and home from college for Christmas break. Me and Nanny were sitting right beside each other on the couch. My mom asked her to hand a present to Kelly (me) and she turned to me and asked who Kelly was. She had dementia and early onset Alzheimer's at the time so I was used to her being confused and asking me questions that she already knew the answer to, but to not know who her granddaughter was? Heartbreaking isn't a big enough word. I left the room and cried. I still cry. I am crying as I am writing this. Nanny is living in a home and has been since I was a senior in high school. She cannot walk or form sentences anymore. Just lays there and looks around and mumbles random words. I go in as often as I can. I feed her and talk to her. I know in my heart she can still hear me. She hears all about my life, grad school and running and boys, and I know she is proud of me even though she cannot express it in words anymore. When I hold her hand I can feel her love for me and I know she can feel mine. Dementia and Alzheimer's stole my grandmother from me. It's time to stop Alzheimer's Disease from doing the same to others. I am here to share my voice and my story. I will stand and be strong, not only for myself and my family, but also for my sweet Nanny.

~Kelly Harkey

To learn more about Alzheimer's, locate a support group, or join a local Walk to End Alzheimer's visit <http://www.alz.org/norcal>

Leukemia & Lymphoma Society

Seeks cures for leukemia, lymphoma, Hodgkin's disease, and myeloma, while improving the quality of life for patients and families through research, patient-aid, education and advocacy.

<http://www.lls.org>



Linnea's Story:

Affectionately known as Diva, Linnea was usually a friendly outgoing little girl. But when her sparkle began to diminish, we were very concerned. Either sleeping on the couch or watching TV, little Diva began to lose all interest in playing outside with her siblings. Acting so out of character, nothing was able to get Linnea up.

She then developed a fever and could no longer walk.

After rushing her to the ER and about five hours of testing, her doctors broke the news that she had acute lymphoblastic leukemia. That was December 9, 2010. After blood transfusions, a bone marrow aspiration and a spinal tap, chemotherapy was started.

After two months Linnea was in remission, and still is a year later. Linnea will continue with chemotherapy until 2014. "She is back to being the affectionate and loving child she always was and continues to be an inspiration to everyone she meets. We have our little Diva back," say David and LaShaye, Linnea's Mom and Dad.

Be The Match Foundation

We support the National Marrow Donor Program. Together, we help patients who require a marrow transplant find a donor and receive the treatment they need.

<http://www.bethematchfoundation.org>



Clara, a happy and thriving 2-year-old after receiving a bone marrow transplant from her perfect match, John.

Clara and John's Story

"You Made a Choice that Many People Don't Make." A Parent's Personal Thank You to Donor:

Hi, John. Her name is Clara. She is very much alive and is a thriving 2 year old.

I imagine that's the answer to your biggest question. And I have no idea how to thank you or how to really begin the conversation with you. I've been waiting a long time to be allowed to contact you. But I also haven't known what I wanted to say to you or what you'd want to know or say to us. It's kind of impossible to truly express our gratitude, and I also do not know what you have thought about how this moment would go.

At Clara's 1 year anniversary of what we call her "Butterfly Re-birthday," I began preparing myself for making contact with you. You beat us to the punch – and I was thrilled to hear that you had shared your contact info with the NMDP. That was 4 months ago. It took me about a month to get our signed consent to the hospital where Clara was treated and 3 months for us to finally get your info from the NMDP. We got your name and contact details today. I immediately Googled your name.

Here is what I think you might like to know: •Clara was born on April 14, 2010. •You registered with the NMDP on May 1st when Clara was 17 days old. •She was 4 months old when she was diagnosed with Acute Myeloid Leukemia. •The specific form of her leukemia was high risk and, because of the infection that the NMDP apparently told you about, her chances for survival were so slim, you couldn't calculate it.

•You were a PERFECT match for her. A 10 out of 10 and a match for ALL of the other less important indicators including down to blood type. •Your donation was 3.5-4.5 times more than required, and they used it all on January 12, 2011. •Your stem cells engrafted so quickly that they didn't tell us initially for fear of getting our hopes up, and we were discharged from the hospital a month after transplant day. It is usually 100+ days and her hospital has never discharged someone that early.

There is a lot more that I could tell you. But I will begin to close this letter like this: Your blood is clearly running through my daughter's veins. She LOVES football. When I told one of Clara's nurses that we got your contact info today, she asked me to thank you on behalf of all the nurses who cared for her. Clara was a favorite on the unit – and there aren't many good outcomes in the cancer unit.

You made a choice that many people don't make. And your choice and your self-sacrifice and your prayers saved our daughter's life.

I am grateful that your roommate and coach were able to publicly express the inspiration that you were to them. I am grateful to your 50 classmates who wrote you letters of thanks. I wish I could have been there for your speech at the Cortland youth football banquet. I look forward to hearing your story. I hope that you can feel comfortable telling us your story – if that is something you'd like to do.

With much love and respect for you, Brooke, Clara's mom; Alan, Clara's dad; and Rosalyn, Clara's little sister.



**To be a hero and join the bone marrow registry click here:
<http://bethematch.org/Support-the-Cause/Donate-bone-marrow/Join-the-marrow-registry/>**



Imagine life without breast cancer. Make it a reality for all nations by racing for the cures and funding life-saving research and community health programs.

<http://www.komen.org>

Meet Jennifer Holmes



Treatment: Mastectomy, Chemotherapy

I was never one to do a self exam since I have such fatty breast tissue. But I did one in September 2008 on a whim and to my surprise there was a lump. I waited a week or so to go to the doctor since I had my period, I prayed it was just the normal changes that happen during that time. I was wrong. I went to primary that immediately sent me for an ultrasound, followed by a mammogram and a BSGI, all done in one day. I knew right away that I had cancer.

When two doctors come into a room to discuss your mammogram and request you have one more test you just know. After these tests were done (October 15, 2009) I had to have an MRI done followed by a biopsy. My doctor during this time was very upfront and honest. I asked point blank "Do you think I have cancer" she said unofficially yes. On October 31, 2009, I received the phone call no woman wants to get, your biopsy came back positive. Now to make like of the situation, I called my mom to ask if this meant I have cancer, since the doctor didn't say "cancer."

I'm a blonde, so I had a blonde moment. My tumor was 4.5cm, so I had to have adjuvant chemo along with Herceptin before any surgery. I began Chemo on December 22, 2009. I lost my hair within two weeks of chemo. My three sons were so strong and thought I was cool with my newly bald head.

My sons were 11, 7 and 5 at the time. I did scare my niece and nephew, as well as a few of the neighborhood kids. But they all got used to it.

I finished up Chemo on April 16, 2009 and had a radical double mastectomy on May 7, 2009. I still had to have my Herceptin treatments once every 3 weeks until December. I also had to have two months of radiation. In January 2010, I had my first reconstruction surgery. I opted to have the TRAM Flap surgery along with an implant. The tram was done to recreate the left breast and the implant will be put in the right breast (this to be done on 4/14). I will have lipo and my nipples done by the end of the summer. This was a shocking and unexpected diagnosis for me. No family history and I am fairly healthy.

At 34, my first concern was my boys. How do explain to them what is going on and what will happen. But my husband and family were there to support me. The one thing you don't think about

is how I am going to pay for this. I have insurance, but it doesn't cover my doctor visits or my plastic surgeon, so I am left to pay those bills.

The bills mount and you do what you can but it will never be enough. Breast cancer affected my whole family and my outlook on life. I realized what is important and who is not. You see people in a new light. I see my husband in a new way as well as my sons.

Staying positive and having a good outlook as well as a support system really make all the difference!



Committed to finding a cure for diabetes, improving care and providing information and support to help Stop Diabetes® through research, community programs and advocacy.

<http://www.diabetes.org>

Meet Romelle Slaughter



Hi! My name is Romelle Slaughter. I'm 34, live in Des Moines, Iowa, and I am a young professional with diabetes. I was diagnosed in 1998 several days before I left home to attend college. For the next decade, I have struggled like many young diabetics in managing my diabetes, feeling like no one in my age group understood the challenges of being a young professional and a having a life-long chronic diseases.

I am a member of a young professional lunch group in Des Moines. One of our lunch members was an assistant director of our local ADA chapter. She knew I had an interest in getting involved, but I was hesitant because I didn't think I could devote enough time to volunteering. In the fall of 2006, I was let go from my job and I didn't know what to do. I made a phone call to her about ADA.

Since that phone call 4 years ago, I have been positively affected by the work of the American Diabetes Association, not as a citizen, but as a volunteer and a board member. How has ADA positively affected my life? I learned how the ADA not only raise money for research in finding a cure to **STOP DIABETES**.

The ADA provide education and classes for certified diabetes educators (CDEs) for continuing education on diabetes, sponsor support groups for people affected by diabetes, and bringing awareness about a growing epidemic that continues to get worse.

I have learned that I'm not alone. There are over 19,000 diabetics between the ages of 19-44 that live here in Iowa, and there is a sense of shame in being talking about it in public. I choose not to

hide it. The more young professionals understand about diabetes and not the "myths" and misinformation, the hope is that they start to take diabetes seriously as they do with all forms of cancer and AIDS. Death due to complication of diabetes claims more lives than breast cancer and AIDS combined.

Ben Ahnen, who is a son of a fellow board member and a past youth ADA ambassador, said it the best when he was asked by a classmate "*which diabetes is the worst? Type 1 or Type 2?*" His response was "***the worst type of diabetes is the one that you don't take care of.***"

