

## Searching the World for a Match

by Nicole Shen

Two years ago, our son Roman was diagnosed with SDS. Our doctors had also had him HLA typed and ran against the bone marrow registry. In this same conversation, we found out should he need a bone marrow transplant in the future, not one person matched him in the world....yet. I obviously didn't know much about what all that meant but knew it probably wasn't good. I immediately started asking people to join the bone marrow registry mainly through social media. I had a decent response and assumed at least those in my inner circle had swabbed. I was wrong. We had Roman ran against the registry every six months since then. Now two years later, still not one match in the bone marrow or cord blood registries. We can't help but think about what if he did need to go to transplant in this time. A patient's best chance for survival is a perfect match. After watching our friend Rowan pass away last year, partly from not having a match, we pushed our search into overdrive. Likewise, Roman now has a clone that showed up on his last bone marrow biopsy. In February, our family started heading out with Be the Match to host bone marrow drives.

Joining the registry involves simple paperwork and a cheek swab. The entire process takes about 10—15 minutes. Why wouldn't everyone join then? What I soon learned was that most of the people I knew had NOT yet swabbed despite my two years of begging on social media. Less than 2% of the U.S. joins the registry. Approximately 70% will back out once called to donate. We also learned the startling numbers for minorities in the registry. Every minority group represents less than 10% of the registry with mixed race being less than 4%. Roman is Chinese/Italian. 65-95% of patients match up with someone of similar ethnic background. HLA is based upon one's geographic ethnicity going back eight generations. As this is not a 100% predictor, as well as we know patients of all ethnicities needing matches, we decided to SWAB THEM ALL. If someone is within the age ranges and meets the health requirements, we will swab them.

Patients are not normally HLA typed until they are in need of a transplant. We are so thankful to our proactive team of doctors who have given us a two year head start on finding his match. Team Roman swabbed over 600 people in our first month alone. We are now in our third month swabbing the public. Team Roman is in the top 3 in the nation for individuals swabbed and has a very high return rate on

online kits. Every booth and flyer has literature and information about SDS. I try to attend as many events as possible to tell our story. It is our hope that if someone hears our story and learns about SDS they will not back out if called to donate. We pray Roman never needs a transplant but will continue our work to ensure every SDS patient has a committed match should they need one.

For more information, families are encouraged to contact Be the Match or DKMS to see how you can get involved.