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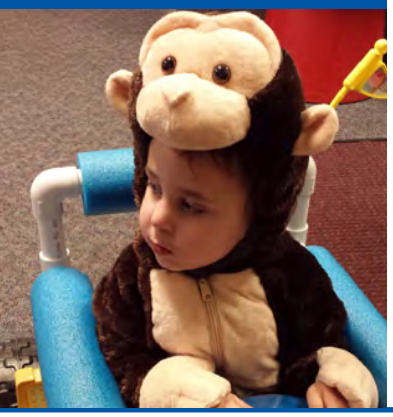
Spokane Guilds' School & Neuromuscular Center
And The Spokane Guilds' School Foundation



Gavin monkeying around on Halloween.

Working together to make a difference

Vision Quarterly

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John, Chelsea and Ansel ready for trick-or-treating

Making Progress Everyday!

We would like you to meet one of the inspirational children who recently received services at the SGS&NMC. Her name is Eily, and this is her story as told by her mom, Shannon

I was thrilled to find out I was pregnant with our third child. We have two boys who were one and two years old at the time and I really wanted a baby girl.

I had an ultrasound during my 13-week checkup and some abnormalities were discovered. My doctor warned me that the baby probably wouldn't survive another week until we could meet with a specialist.

A genetic counselor told us that the complications could be related to Down syndrome, Turner's syndrome and other conditions that involve an extra chromosome. The doctors monitored my pregnancy closely and the baby appeared to be normal.

We were ecstatic to learn we were having a baby girl! By the end of the pregnancy, she looked great and we weren't expecting any problems.

Eily was born two and a half weeks early. The labor went smoothly. She was born with a full head of hair and a hearty cry. However, as the nurses were cleaning and weighing her, our baby stopped breathing.

When the medical staff talked about admitting her to the Neonatal Intensive Care Unit (NICU), my heart sank. My husband followed the baby to the NICU. Eily was doing great until they tried to feed her. She struggled with the coordination it takes to suck, swallow and breathe. Eily was admitted to the NICU after four hours and two unsuccessful attempts to feed her.

During the first week in the NICU, we worked tirelessly on feeding Eily. She didn't have the energy to eat and appeared to have painful reflux. I also learned that the doctors had other concerns. Eily had low muscle tone, an unusual cry, a recessed chin, a high pallet and she made abnormal breathing sounds. She was checked out by a neurologist, geneticist, cardiologist and an ear, nose and throat specialist. No one could figure out what was wrong.

Eily Dayton

After four weeks, we decided to have a feeding tube inserted and a surgical procedure done to prevent reflux. Watching my tiny baby go through surgery was scary. Little did I know things would get worse.

After 42 days in the hospital, we finally went home and our family was together. Eily was sick all winter long and was hospitalized every week. During a six-month follow-up appointment, we learned that our baby needed open heart surgery to fix several worsening problems.

It felt like a nightmare we couldn't wake up from. Her surgery went well, but she continued to have problems with feeding and infections. The heart surgery brought her to life though, and quickly her life turned around.

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Executive Director's Message

Since I wrote to you last, we have replaced some great staff members with some new staff members. Dr. Matt Thompson is our new Medical Director. Before Dr. Piston's retirement, he handpicked Matt from all of the great pediatricians in Spokane. Christina Fox is our new Nurse Coordinator after working in the newborn section at Sacred Heart for nine years. Donna Riggers is our new Administrative Assistant. Melodie Little is our new Community Relations Manager, joining us after a long service at Second Harvest Food Bank. Korin Michielli has been promoted to Development Director and Tammy Sweeney has been promoted to Events Manager. Jodi Varecha, one of our alumni mothers, has joined us as a Team Room Assistant. Jennifer Morgan, MSW, is a new Family Resource Coordinator from Spokane Regional Health District outstationed at SGS. Taylor Western has also joined SGS as a Speech/Language Pathologist. Karin Cook has replaced Heather Notske as the Development Assistant and Heather is now the agency's bookkeeper. I hope you will welcome these new people to our family and recognize the promotions we have made.

As our readers know there is little turnover in our staff, so this is a big deal for all of us. I am going to miss all of the people who retired or moved on, but I am very excited about the enthusiasm these new people bring to the organization.

Marilyn Henderson, our Program Coordinator, and I have been at the SGS for 38 years now, Marilyn longer than me. Marilyn and I are energized by these changes and we are still having fun in our jobs. The Guilds' School is so contagious. We are constantly meeting new children, parents, families and volunteers. I know the balance of the staff feel the same as Marilyn and me. There is something special about the school that makes us all feel blessed to come to work each day and to strive to do a better job. I am so proud of our staff and the exceptional job they do for the children and their families. I love to observe the staff in their day-to-day activities. They are so gifted and clever about how to work with the children. The kids love the staff and they succeed because they want to please.

If you haven't had the opportunity to visit the school, I would encourage you to do so. Just call 509-326-1651 and we will set you up for a tour. As they say, "Seeing is Believing." Miracles are happening every day and it makes one a true believer in the spirit of the human being to develop in a positive way.

Dick Boysen

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Since the school has to raise 40 percent of its budget privately each year, our donors are all-stars. Without their support we would not be able to help the children and families at the level we do. Even with this tremendous effort, 70 percent of the eligible children in the county cannot get into the school. With your help we can reduce this percentage and increase the number of children we do serve.

The school has come a long way since its founding in 1960. There is a passion and sense of caring that is so apparent. I know with your continued support and help we can KEEP THE DREAM ALIVE!

Eily

(continued from front page)

After months of appointments, doctors discovered that Eily has a rare deletion of part of her fifth chromosome that is linked to congenital heart defects, and has a defect that impacts her left ventricle. The ventricle can't be repaired and Eily will be monitored throughout her life. We are grateful for the good days and are hopeful that she will become healthy and strong enough to live a "normal" life.

I first heard about the Spokane Guilds' School while Eily was in the NICU. A Guilds' School staff member called me the first week that we were home from the hospital. They came to our house to meet Eily and gave us hope.

It's hard to have a baby with special needs without a background in medicine and no prior experience. The Guilds' School offers more support and understanding than I can explain. Eily receives speech, physical and occupational therapy.

The team of therapists have helped Eily reach goals that I wasn't sure were even possible. Eily, who is now 1-year-old, can eat food orally and crawl. She is also starting to say a few words. She's making progress every day – progress that she wouldn't make if we were doing this alone.

Eily loves her brothers, Enzo and Leo. Because they love Ninja Turtles…so does she! She is always happy. She loves babies and giving kisses. She says hi to everyone she sees and has a smile that reminds me how beautiful life is. Her smile proves that even through the hardest times there is always joy. She is a fighter.

I refer to her therapists as my therapists, too. Her therapists listen closely, care deeply, and know us better than any of her doctors. They helped me follow my motherly instincts when things weren't going well.

I hope that Eily continues to bring hope and perspective to others. My daughter amazes and inspires me every day. Her future is still unknown, but because of early intervention and the Guilds' School we have hope!