

# FAMILY

## Forum

Children's Hospitals and Clinics of Minnesota, Minneapolis/St. Paul

Summer 2008

**A newsletter for families by families who share their experience and wisdom**

### Family strengths

This issue of *Family Forum* focuses on the strengths of family members. In it, you'll find how families who have had a child in the hospital learned to recognize and honor the unique and diverse ways they help their child and each other. You'll also read about what some patients find helpful.

**W**hen our daughter Caitlyn arrived 16 weeks early, with her came an array of emotions that I never expected to have after the birth of my first child. As challenging as the situation was to accept, acceptance was the strength that really stood out for my family. Acceptance, paired with gratitude.

When a hospital staff member cited statistics on the number of marriages that end after a situation like this, I remember feeling a jolt of fear. I didn't want to become one of those statistics. She reminded us that every person has a unique way of expressing themselves. **She encouraged us to accept the way others dealt with our situation – especially each other.** At that moment, I made a conscious decision to accept the way my husband would deal with this crisis and in turn, ask him to accept mine.

The four months that followed were long and exhausting. My husband and I demonstrated very different ways of dealing with the situation. He didn't want to get attached to Caitlyn. I couldn't fathom the thought of losing

her. Although it was hard, we both had the strength to accept each other's way of coping.

Often, the doctors would deliver not so promising news. Rather than dwelling on what could be, we celebrated what was. When she hit two pounds, we had a pound party where everyone brought something that was two pounds. For Halloween, we put her in a golfer costume. At Thanksgiving, we made her tiny handprint into a turkey. We couldn't believe how it had doubled in size in 2 months! We were making progress!

We still may not know future consequences of that fragile time on Caitlyn's life. One thing we do know is that we will accept each challenge as it comes. **Little did we know that the wise insight offered at a critical time and the decision to accept what we couldn't change would shape and strengthen our family in so many ways.** Now, almost seven years later, not a day goes by that gratitude does not flood my heart when I look at her.



This special bear has always been with Caitlyn.



## Double whammy with ice cream: It was a family affair

by Randy

When our two young daughters, ages 4 and 5, were hit with a double-whammy tonsillectomy and adenoidectomy, it unsettled our entire family.

As parents we fretted about absolutely everything. Sedation. Recovery. Whether or not our kids could bring a stuffed animal to the hospital. Our kids just knew they were having an operation to help them breathe more easily, and that recovery inexplicably involved ice cream and popsicles. They were pretty okay with this arrangement.

We jumped at the chance to attend a pre-surgery tour at the hospital in St. Paul. Much to our delight, it was more interactive program than formal tour. Child life staff put on a brief puppet show to explore with kids the idea of having an operation, and the feelings that go with it.

Kids also modeled fashions they'd wear at the hospital, and got acquainted with a few tools they'd likely see nurses and doctors using. All of the children loved picking an aromatic 'flavor' they could use on their sedation mask when it was time for their surgery.

While kids continued to learn and play, staff pulled parents aside in an adjacent room for a group discussion, patiently answering our rapid succession of questions.

The morning of the operations, things at the hospital moved along crisply. Each child was called in for surgery; one accompanied by mom, the other by grandma. Both brought in their favorite stuffed animal.

The surgeries were quick and routine.

The point is that when a child gets sick or hurt, no matter how severe or non-threatening, it becomes an all-consuming family affair. And while nobody is better at caring for and helping kids return to good health, Children's, at every step, is a cut above the rest in caring for and helping families be families.

## Faith and laughter gets you through

by Dan

A wise man once said, "You can either decide to live with fear or faith." I choose faith. Have faith in the doctors, nurses, and staff at Children's. They are the best in the business.

Fear will get you no where, but a laugh, even the smallest one, will at least brighten those dark skies for a moment.



## ¿Qué sigue ahora?

por Myrna

Cierto día en la clínica de hematología/oncología, toda la familia, como comúnmente lo hacíamos, asistimos al chequeo de mi hijo Guillermo, de 7 años de edad. Entonces tenía sus exámenes de sangre cada 3 meses, ya que hace 2 años había terminado su tratamiento contra la leucemia. Pero ese día después de examinarlo, y tras varios estudios, descubrieron que la leucemia había regresado después de haber estado casi 5 años en remisión.

Cuando empezó su primer tratamiento a los 2 años y 4 meses de edad, fue muy difícil para nosotros aceptar que él estaba enfermo de algo tan grave, y tuvimos que adaptarnos a la nueva situación que estábamos viviendo. Desde su diagnóstico, hemos estado muchas veces en el hospital y **pienso que la mayor virtud de mi familia es que nos apoyamos y tenemos un compromiso para sacar adelante a Guillermo.** Cada vez que él se tiene que internar en el hospital, tratamos de estar ahí toda la familia para apoyarlo y hacerle su estancia más agradable: le llevamos sus videojuegos favoritos y su ropa más cómoda, también mi hijo mayor lo entretiene contándole algo gracioso o recordando algo de lo cual han sido cómplices. Siempre le hacemos sentir que estamos ahí para ayudarlo a sobrellevar los días difíciles.

Creo sin duda que Guillermo con su fortaleza nos hace dar lo mejor de nosotros mismos porque a pesar de la adversidad, sonrío y pregunta: ¿Qué sigue ahora?



El día de Halloween, Guillermo y su papá piden dulces en el 8° piso del hospital. (On Halloween, Guillermo and dad go trick-or-treating on the 8th floor.)

## What's next?

by Myrna

One particular day in the hematology/oncology clinic, our whole family—as we often did—went along to my 7-year-old son's checkup. At the time, he had his blood checked every three months since he had finished his treatment for leukemia two years earlier. But this particular day, after his examination and several tests, they found out that his leukemia had come back, after having been in remission for nearly five years.

When he started his treatments the first time at 2 years, 4 months of age, it was very hard for us to accept that he had such a serious illness, and we had to adapt to this new situation we found ourselves living in. Since his diagnosis, we have been in the hospital several times and **I think that my family's biggest strength is that we support each other and have made the commitment to help Guillermo pull through.** Every time he has to be hospitalized, we try to all be there as a family to support him and make his stay more pleasant: we bring along his favorite video games, his most comfortable clothes, and my oldest son keeps him entertained by telling him funny things or remembering something they were accomplices in. We always make him feel that we are there to help him and get through the tough days.

I believe without a doubt that Guillermo's strength makes us give the best of ourselves because despite the adversity, he smiles and asks: What's next?

## Elizabeth's story, age 17

I haven't had any major surgeries, but have had outpatient procedures. It was kind of a long time ago, but what I remember the most is staring at the fish in the waiting area and the nurses being really nice and encouraging. I remember they let me choose a flavor of lip balm to put on the mask (mine was strawberry) and then they counted with me 'til I fell asleep. When I woke up, they brought me pop and a popsicle and helped me walk. It was so nice waking up to a friendly face.

I think what makes a great hospital experience is the connection between patient and doctor and patient and nurse. We need to feel comfortable with our caretakers, and having friendly doctors and nurses really makes the overall experience so much better.

## Jacob's story, age 13

One of my nurses liked to play video games, so she came in my room for her two breaks to play with me. She was a good video gamer and we had a lot of fun together.

## YAC page - from the Youth Advisory Council

The Youth Advisory Council is a dedicated group of patients and siblings, ages 10 to 18, who offers practical ideas about how to help Children's focus even more closely on the special needs of children and teens.

Can you find these words in YAC's "Top 10" word search?

S L I P P E R S Q X M A Y A F  
A R O D A T U P M O C S S J A  
A I L I M A F U U T P A B I M  
D E A L B K S G I D L L C B I  
S F Y M G I M V F U A F I O L  
A E O C C X I F C N G U S C Y  
C C I A U D Y I K B I T U Z E  
C O G T A S L E D E J N M J C  
S U M D I E T S J C F A H M R  
D O E P P V E L L W R P T K J  
S S G T U I I C E L I B R O S  
S K F I V T R T Z Y E N I E P  
T Q O O M W E I C S N Q I S Q  
Y G M O Q A V R O A D E X C U  
S A X A B E F S U S S M M W I

ACTIVITIES

ACTIVIDADES

FAMILY

FAMILIA

BLANKET

COBIJA

FRIENDS

AMIGOS

BOOKS

LIBROS

MOVIES

PELICULAS

COMB

PEINE

MUSIC

MUSICA

COMPUTER

COMPUTDORA

SLIPPERS

PANTUFLAS



## Amazing Grace

by Linda



Grace

As I walk down the hall to the NICU, it feels like I'm in a dream. I want to wake up and still have my babies in me. I want to be that big pregnant woman.

Reality soon sets in when I'm told that four days have passed, that I had been in the intensive care unit, and that I almost didn't make it. One baby didn't make it and they were unsure if the other baby would. She was very tiny – one pound and 24 weeks.

We knew that we were in for a long haul. After years of fertility problems, our first biological child was a boy – 27 weeks, 2 lbs. 3 oz. We had no idea how three weeks would make such a difference.

Six long months later, we were ready to go home for the first time. The CPR class that we took saved our daughter. RSV put her back in the hospital for two months.

Although the road has been long, our daughter is doing great. The most important thing is that I would not change a thing. She is happy, as are we. As for our almost seven year old, he is doing good and only requires speech therapy.

It's now been four years since our long hospital stay. I've learned so much. **That the housework can wait until tomorrow, that good friends and family are few and far between, and that my husband is my rock.**

## Accepting help from others

by Marty and Karen

When our daughter Lauren was born, it felt like the world stopped. Just like that -- stopped. On Sept. 25, 2006, we were told the news that our newborn baby had a rare genetic syndrome we had never heard of.

From the beginning, educating ourselves about Lauren's medical issues made us less anxious about being able to care for her. The doctors and nurses encouraged us to ask questions and were so compassionate and generous with their time. As the hospital days melted into weeks and the weeks into months, we often felt mentally and physically drained.

The world really did keep going after Sept. 2006. We're taking life one day at a time with God's help and in many ways know that we're changed forever in positive ways thanks to Lauren. She has brought our family closer and has brought many wonderful people in our path who we wouldn't know otherwise. This includes not only the families we met through the NICU, but also the wonderful staff at Children's.



Lauren



## Did you know?

**Fast-Pass photo ID badges.** All adults, 16 years and older, entering the hospital are required to stop at the Welcome Center for a Fast-Pass photo ID badge. Extended stay badges also are available to families who anticipate being at Children's more than two weeks.

**Where to eat.** Children's hospitals have cafeterias and coffee carts. For information about where to eat in the hospital or nearby restaurants, look for the Dining and Lodging Guide or dial 0.

**Bringing food from home.** In each family lounge, coffee, a refrigerator, and microwave are available for families. Please be sure to write your name and date on all things you place in the refrigerator.

**Breakfast snacks.** In the Family Resource Center, a free continental breakfast is available for families whose children are in the hospital, 7 to 11 a.m. weekdays and 8:30 to 11 a.m. weekends, or upon request.

**Staying overnight with your child.** In some units, it is usually possible for one parent to sleep overnight in your child's room. For information, talk with your child's nurse. Dial 0 for information about area hotels that offer discounted rates for patient families.

**Discount parking coupons available.** Prices are posted at the ramp entrances. For information about discount parking, dial 0.

**Balloon and flower delivery.** When sending balloons, floral arrangements, or plants, please make sure to include the child's full name, and if possible, room number. Only Mylar balloons are allowed at Children's.

**Forget your toothbrush?** A personal care kit containing a toothbrush, toothpaste, comb, and deodorant is available free of charge. Ask your child's nurse or stop by the Family Resource Center or Welcome Center.

**Massage, aromatherapy, and acupuncture available to families, too.** These services and more are available to families as well as patients. For a fee schedule and to make an appointment, call integrative medicine at (612) 813-7888.

**Web site offers parenting resources.** Children's Web site—[www.childrensmn.org](http://www.childrensmn.org)—contains positive parenting tips, medical information, an online medical organizer, and employment and volunteer opportunities. Wireless Internet. Ask your child's nurse or dial 0 to learn about services.

**Sibling Play Area.** Child care services are available for siblings of children in the hospital. Dial 0 for hours and information.

*Family Forum* is a newsletter for families of Children's Hospitals and Clinics of Minnesota, Minneapolis/St. Paul, Minn. Created and inspired by families, *Family Forum* shares the knowledge and wisdom of experienced families with children in the hospital and their families. The next issue of *Family Forum* will focus on collaboration.

To share your stories, or for questions or comments, please call Pat Schaffner, Families as Partners, (612) 813-6059, or e-mail your request to [pat.schaffner@childrensmn.org](mailto:pat.schaffner@childrensmn.org).