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# Family to Family

A Newsletter to families from families

## Meet Jimmy's Family - Mountainside Long Term Care By Josanne Pearsall

Jimmy and his family have called Children's Specialized Hospital in Mountain-side his home since the Fall of 2008. Jimmy is 13 years old and loves school, music and just being around his friends and family. You can easily pick out Jimmy amongst his friends because he's wearing a cap that his grandmother lovingly chose for him and sporting that big welcoming smile.

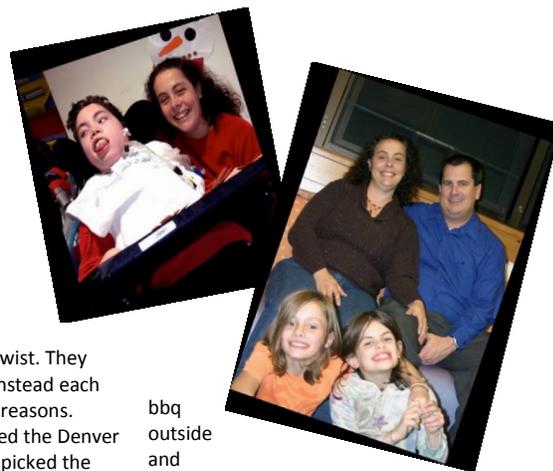
Jimmy has two sisters, Danielle, 11, loves art and soccer and Stacy, 8 is involved in Girl Scout and gymnastics. His sisters and family have been coming to our Family Events for the past several years, but last summer Danielle and Stacy helped plan, design and assist in running our new Dad's event. They had so much fun thinking of games and puzzles that everyone could enjoy, like the Olympic competition that challenged the 5 senses. Their involvement helped make this event a real success for everyone who attended.

Jimmy's mom, Kim, enjoys time with Jimmy at his on-site school as well as the Open Recreation sessions where they create artwork, play musical instruments and just socialize with everyone. His dad,

Jim, is a regular at our Family events and Family and Staff meetings. One of Kim and Jim's favorite things about Mountainside is that Jimmy is treated like a 13-year old boy should be treated. He has lots of fun during all his activities, watches TV and listens to music.

Jimmy's family is big football fans, BUT with an innovative twist. They aren't just fans of one team, instead each has picked a team for specific reasons. Stacy loves horses so she picked the Denver Broncos, Kim likes cats so she picked the Cincinnati Bengals, Danielle loves the colors orange and brown so she picked the Cleveland Browns and Jim grew up in Kansas City so he picked the Kansas City Chiefs. Of course, Jimmy roots for all his family's teams, never wanting to hurt anyone's feelings.

Every summer Jimmy's cousins and sisters go to Camp Grandma's for a two-week stay. When they get back, Jimmy gets to hear about all the fun they had with grandma and the cousins. They go on special trips to the swimming pool and Chuck E Cheese, they



bbq outside and stay up late with their cousins watching movies. When the girls get back they have fun telling Jimmy about their adventures and as he attentively listens, he just smiles that beautiful smile we've all come to love.

## Hand in Hand by Pat O'Hanlon

To me "hand in hand" means partnership. Sharing and listening to each others ideas, with the expectation of achieving positive outcomes. One of the most effective ways to partner with senior leadership at Children's Specialized Hospital is to complete the Press Ganey Patient Satisfaction Survey. When the survey would come in the mail I would automatically include it with all other junk mail. It never made it to the "important" pile. My son began coming to Children's Specialized Hospital as a baby, yet the first time I completed a satisfaction survey my son was 15 years old. It was at that time



that I became a Family Faculty. In that role, I soon found out that our hospital values the information received from Families on the Press Ganey and reviews each and every score and comment. I also discovered that the hospital receives a very low percentage of surveys back; under 20% overall. Having a say in my child's health care is extremely important to me. I realized that by discarding my survey I "threw away" my opportunity to have a say. Since I discovered the importance of the Press Ganey, I have completed every survey I have received. I always take the

## Share your Feedback

opportunity to share ideas, suggestions and my family's experiences at the hospital in the comment section on the survey. Now I am a true partner with senior leadership at Children's Specialized Hospital. I complete the survey, share ideas, and value the partnership we have. I hope you will fill out your Press Ganey Patient Satisfaction Survey and become a valued partner as well.

## Parent Tips

- Now that it is Spring, pack up a small box of outside toys like balls, chalk, bubbles, etc. and put it in the back of your car, so you are prepared for an impromptu trip to the park. There will be lots of activities to keep the kids busy. And always leave a beach chair in your trunk just in case you get a minute to sit!
- Don't forget to check expiration dates on sunscreen and bug spray. Make sure you leave some in your car.
- Springtime is usually such a busy time, with sports and spring break holidays. Take some time to go over your calendar with your family so you can keep everything and everyone organized.
- As we "spring ahead", remember to replace all the batteries in your smoke detectors.



Children's Specialized Hospital

## Healthy and Happy

By Luciana Mendes-McGuire

I cannot stress enough the importance of a good nights sleep. All children do best with healthy sleep habits. A consistent routine is particularly important if your child has special needs.

### Here are a few reasons why sleep is so important:

Sleep is restorative for the brain.

School performance improves in kids with good sleep habits.

When kids sleep well, parents' sleep improves, too, doing wonders for their ability to function during the day (and maintain their sanity in the evening).

### Here are some Tips for a Good Night's Sleep

- Avoid late afternoon or evening caffeine and sugar consumption. (Sodas are usually a huge source of both sugar and caffeine.)
- Limit overstimulation. Limit television and video-game playing as well as reading an especially exciting book before bed. Play beautiful, soothing music of

## Did You Know?

By Lori Velasco

Need help navigating your child's IEP? Not sure what steps to take to get the services that your child is entitled to? Want to be ready for your next IEP meeting? There is a fantastic resource available on line which has the laws in language that is easy understand even has sample letters! The Right to Special Education in New Jersey - A Guide for

## Family Fun

By Nancy Panarese

Spring is coming I can smell it in the air. Winter always seems so long. I have been thinking of activities that I used to do with my children and now I do them with my grandson Christian who I am raising. One thing we used to do is go out when the weather starts to get warmer

your choice to help calm and relax your household.

- Give your child a ten minute warning before it's time to get ready for bed to help him make the transition and finish up what he is doing.

- Have a consistent bedtime and bedtime routine. A warm bath is particularly soothing for most children because it relaxes the muscles and gets their bodies ready for rest.

As a mother of two children (one being special needs) and a wife, it is very easy to get drawn in to the evening routines that can focus you on all of the things that need to be done; dinner, dishes, laundry, etc. There were times when my family would not get to bed until 10:00 pm. As you can imagine getting my children up for school the next morning was a challenge, not to mention getting them to focus in school. It



### Good Night and Good Health

was obvious that we were not getting enough rest. After some research and talking to our children's pediatrician, we decided that it was time to take action and change our focus. Our special needs daughter had a hard time sleeping but we worked with her neurologist and came up with a plan. After

a few days of putting the kids to bed at 8:00 pm every night, we saw a tremendous change in their moods and focus. It was like magic. The kids that required me to drag them out of bed were now waking up on their own with a smile on their face. We even noticed a change in their school work and attitude overall. I know they say, "An apple a day, keeps the doctor away" but I believe a good night's sleep is a great start to keeping you and your family happy and healthy!

## "Need help navigating your child's IEP? "

Advocates is sponsored by the NJ State Bar Foundation and was written by the Education Law Center. Check it out on the website: [www.edlawcenter.org](http://www.edlawcenter.org).

I have personally used it a number of times and have passed it along to friends. It has been a life saver for my family and has helped us be the best advocates that we can for our child!



and look for all the trees and flowers that are starting to poke their heads through the soil and on the trees. We list them and try to follow their growth every time we go out.

My children also used to like to keep track of the groundhog. We used to then do a countdown to day light savings time, when it starts to get lighter. Egg crates became little homes for plants, we used to start with the seeds in the egg crate and watch them grow and then plant them outside



when the time was right. I also used to encourage them to go out and take pleasure in the fresh air. ENJOY SPRING it goes by quickly.