



The Newsletter of
IDEAS

IsoDicentric 15

Exchange, Advocacy & Support

FROM THE EDITOR

By Jean House

Whether working out to stay in shape, competing against ourselves or other athletes, or simply playing for the fun of it, sports and exercise are an integral part of many people's lives. That goes for our friends and family members with dup15q as well: they have participated, persevered, and often excelled in a number of activities—for instance, horseback riding, swimming, and martial arts. Even the tiniest children learning to sit upright, walk, and do somersaults in physical therapy are getting a workout! Many people with dup15q have been dedicated to their favorite activities for years—some from childhood all the way to adulthood.

This issue of *The Mirror* is all about getting moving! In the Family Favorites feature, several parents share their children's favorite activities and why they're beneficial. Also inside, IDEAS members tell stories about a variety of activities: taekwondo, surfing, and Special Olympics. And we'll hear about two outstanding athletic fund-



raisers that took place recently: a new bike race and a half marathon.

In other features, this issue's Family Portrait is by a mother from Texas who tells her family's faith-filled story of growing and changing with their loved one who has dup15q. The Reflections from a Sibling is by a young woman who explains beautifully through prose and poetry why the youngest of her five brothers is such a special part of her life. Finally, be sure to read the very important announcement about the new IDEAS registry. The project is momentous for IDEAS; details about its development and how to get involved are all inside.

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JEAN, A FREELANCE EDITOR, LIVES WITH HER HUSBAND, CHRIS, AND 3-YEAR-OLD SON, JONAH (DUP15Q), IN WILMINGTON, N.C. E-MAILS ARE WELCOME AT JEAN@EDITORHOUSE.COM.

Chromosome 15q duplication syndrome (dup15q) is a clinically identifiable syndrome which results from duplications of chromosome 15q11-13. These duplications most commonly occur in one of two forms. These include an extra isodicentric 15 chromosome, abbreviated idic(15), which results in an individual having 47 or more chromosomes instead of the typical 46. Individuals with an interstitial duplication 15 are born with the typical 46 chromosomes but have a segment of duplicated material within their 15th chromosome.

ANNOUNCING THE NEW dup15Q MEDICAL REGISTRY

By Kadi Luchsinger, Executive Director

For years now, the IDEAS team has been working hard to develop a medical registry for our families. I am pleased to announce that our hard work has finally paid off. It is with great excitement and anticipation that we will introduce the details of the registry at the conference this June.

WHAT IS A MEDICAL REGISTRY?

A medical registry is a medical database that stores information obtained on a group of similarly diagnosed individuals based on questionnaires completed by the group. The information can then be categorized and analyzed with anonymity for the group of respondents as a whole to better understand dup15q syndrome.

To further enhance usability, our medical registry will be available online, in a secure user-friendly database. Families will need to fill out a consent form to join the registry. All of the information in the registry is de-identified, which means no one will know the names or contact information of our children. IDEAS is the owner and creator of the questionnaire, which was developed by collaborating with other rare syndrome groups, our professional advisors, and a group of IDEAS parents.

WHY IS A MEDICAL REGISTRY IMPORTANT?

Having a registry is important because we will gain a better understanding of dup15q syndrome. We can learn

what percentages of children have seizures, have autism, have anxiety, etc. We can learn what treatments worked best for our children. These answers will help us not only define the phenotype (characteristics) of the syndrome, but will enable us to determine which areas need to be further researched. Through this medical registry, we can be the driving force in dup15q research!

SHOULD I PARTICIPATE IN THE REGISTRY?

We will launch the registry in English first and then proceed to add other languages. It will be only as powerful as the information we provide and the number of respondents who participate, so we encourage every family to help make this tool fulfill its potential by participating.

It is our hope that every family will participate in this registry. It will also serve as an excellent communication tool. We can send out reminders to update your information as well as announcements. If a researcher is interested in a particular area—for example, boys with sleep apnea—we have the ability to e-mail all of the families who have a male with sleep apnea and inform them of the study. We will provide you with the researcher's information, and it is the family's decision to participate or not. This development will push research in dup15q to a whole new level. If you are not interested in research, it is still vital that you join the registry. We need to gather as much data as we can

about our children, so we can develop best practices and gain a better understanding of our children.

Once you complete the questionnaire, which consists of approximately 150 questions ranging from developmental milestones to medical systems, you will have the ability to pull up graphs, if you choose to, to compare your child with other children who have dup15q.

HOW DO I GET STARTED?

We have conducted an extremely thorough due diligence of registry options and are very pleased with the one we have chosen for you. It is something that our children deserve and will help us know how to better help them. While you wait for the official launch, you can start gathering and organizing your child's medical records, most importantly a genetic report confirming your child's diagnosis. You will have the ability to upload medical records, including EEG's, sleep studies, and other test results anonymously. We have a coordinator who will be available to help you with this task, as needed. More information will be provided on our website (www.dup15q.org) and through Big Tent.

This is an exciting time for IDEAS, and we encourage you all to look for upcoming announcements on the registry and to participate. If you have questions about the medical registry, please email me at info@dup15q.org or call 877-IDEAS-15.

THE PATH TO A TAEKWONDO BLACK BELT

By Len Poore

Lisa was born in 1990 with dup15q syndrome. When she was born, fewer than 50 people in the world were known to have this diagnosis, but today we belong to IDEAS and we know of more than 550 in the world. Because she was born with dup15q she has low muscle tone (hypotonia), fine motor and gross motor delays, cognitive and speech delays, seizures, and attention deficit disorder (ADD). Her seizures began just after her eighteenth birthday, but they are controlled now by medication.

Since she was little, Lisa always liked and wanted to learn karate. She started taking Taekwondo in Tewksbury, Mass., in August 2004, which is when she was beginning the seventh grade. She was so excited to start, but we were not sure if she would have the balance or be able to learn and remember all the Taekwondo movements. We all met with Master Jayne, who showed Lisa how to do a few movements and thought she would be able to do Taekwondo. Lisa was excited and started taking Taekwondo classes three days a week; she loves it. All of the teachers and our family are amazed that she has continued Taekwondo for so long, passed so many color belt tests, and learned so

many words in Korean. In October 2010, Lisa obtained her Black Belt. Our family is always amazed when she breaks a board with her hand or foot. Lisa loves Taekwondo, and it all started because Master Jayne believed in her and encouraged her to practice and try to do her best. And "just try to do your best" is what we always tell Lisa about everything she does.

Master Jayne and other students at Taekwondo are supportive and always helpful in showing Lisa how to do her moves correctly. Because of her disability, she has to practice her moves over and over again until she can do them right. Every time she has taken a belt test, the staff, students, and other parents tell her how well she has done, which encourages her to work even harder to learn her moves. After each belt test, Lisa waited for a letter in the mail to find out whether she passed or not. She is always so happy when she gets that letter that she jumps and shouts for joy.

Since Lisa started taking Taekwondo, she has better balance, strength, and flexibility, and she can focus better in school and home. Also, she is better at remembering her manners. Lisa is



From left: Master Kwon, Master Greg, Lisa, and Master Jayne

now more confident and focused when practicing Taekwondo movements and has better self-control. Although respecting her family, friends, and teachers has always been important to her, the Taekwondo teachers always remind her how important it is.

Our family is thankful for Taekwondo. We are happy that we encouraged Lisa to attend class and practice, and Lisa is very happy that so many people are so proud of her, including her brother Michael. He is studying for his master's degree, which is a milestone that Lisa will be proud of him for achieving. As far as we know, Lisa will be the first person with dup15q to receive a black belt in Taekwondo.

LEN, IDEAS BOARD CHAIR, LIVES IN TEWKSBURY, MASS., WITH JOANNE, HIS WIFE OF 33 YEARS, AND THEIR TWO CHILDREN.

SPECIAL OLYMPICS UNIFIED SPORTS: WINNING IS SECOND TO ACCEPTANCE

By Marc Edenzon, President of Special Olympics New Jersey

Traditional sports is about winning: winning the Super Bowl, winning a high-school state football championship, or even taking first place in a recreation basketball league. There is one overall winner in the New York Marathon, and everyone else is second place and beyond. Every team in the NCAA Basketball Tournament ends the season with a loss, with only one team being crowned the national champion, but in Special Olympics it's different!

Special Olympics athletes are some of the most dedicated athletes in sports, committed to developing not only their skills, but also gaining a comprehensive understanding of the rules and strategies behind successful participation. And while the prize for coming in first is a medal, even more important is the acknowledgement and recognition of achievement, which results in the real prize: acceptance. *Continued on page 7...*



Alexis (dup15q), Amanda and Shelbie, daughters of IDEAS members Cindy and Andy Johnson.

SURFERS HEALING: A DAY FOR KIDS AND FAMILIES

By Jean House



Jonah House, at age 2, surfs with Josh Tracy. (Photo credit: John Belch)

Christmas doesn't tend to be a whole lot of fun at our house. Neither does Halloween—even birthdays are hard. For many families, these are celebratory days, preceded by happy anticipation and culminating in parties, laughter, and joy. For us, it's different: At their best, they mean an opportunity for the three of us to spend a little quiet time together. At their worst these days mean frustrating work with little reward and possible meltdowns. But it's OK if holidays don't work out for us. We have Surfers Healing. This one day a year feels like the best Christmas, Halloween, and birthday imaginable—all at once. And it's not just our little family enjoying one another's company. The entire local autism community gathers together to have a great time at the best party venue there is: the beach.

Surfers Healing was founded by husband and wife Izzy and Danielle Paskowitz. Izzy, a former competitive surfer, discovered the calming effect the ocean had on his son, who had been diagnosed with autism at age 3. Riding the waves with his dad offered respite for the boy, who, like many children with autism, often suffered from sensory overload. The Paskowitzes began to offer camps for other families with children on the spectrum, and over the years the organi-

zation has spread from the West Coast and Hawaii to the East Coast, offering a dozen camps during the summer. This year, Surfers Healing added camps in Rhode Island, Maryland, and Maui. Also, they are holding their first private camp limited to children with autism from military families in Florida.

While growing up as a surfer, North Carolinian John Pike was a fan of Izzy's and followed his career. After his own son was diagnosed and he learned about Paskowitzes' program, it was natural to make contact and begin the Wrightsville Beach, N.C., camp. Pike explains that kids with autism are often cut out for board sports such as skateboarding, snowboarding, and surfing because they're independent activities and have a strong sensory component. "It's a perfect marriage," he says. "It's something they can do on their own and have for the rest of their lives."

Surfing in particular is very powerful because of the relationship between the surfer and the ocean. Pike says Izzy Paskowitz coined a fitting nickname for the sea: "the extreme special-ed playground." "You're actually one with Mother Nature," Pike explains. "You're moving with earth and water—there's nothing else like that." The sensation can be at once very calming yet fun for children on the autism spectrum.

Here's how the camp works: Several months before the



event, local organizers announce the day and time registration opens. News travels fast by word of mouth, posters, Facebook, and local message boards and e-mail lists. At the designated time on sign-up day, excited parents wait in front of their computers with nervous anticipation for the online registration to open. Spots fill quickly and registration closes within hours. Families are notified about a month after sign-up whether their children will be assigned a spot in the day camp and, if so, what time they will surf.

On camp day, we take a copy of our confirmation to the beach and mingle with friends while we wait for our son's surf time. Surfers Healing isn't just a sporting event; it is a party and a reunion. We catch up with current and former therapists, as well as teachers, advocates, caseworkers, and other friends and helpers in the local special needs community, and of course other families and their children. Restaurants and grocery stores donate food and drinks; professional photographers volunteer their services; and businesses provide gift bags. (Environmental advocacy organizations are involved; sponsors, donors, and camp organizers are careful to minimize the event's impact on the beach.) Hanging

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Jonah House (dup15q), at age 3, surfs with Che Pilago. (Photo credit: Julian Kehaya, www.Kehayaphoto.com)



SUMMER IS JUST AROUND THE CORNER, AND IT'S TIME TO GET OUTSIDE AND GET MOVING. WHAT IS YOUR CHILD'S FAVORITE SPORT OR PHYSICAL ACTIVITY? HOW HAS IT BEEN BENEFICIAL?

Our favorite exercise is swimming. Our 8-year-old just started private swim lessons so he can enjoy the water from the top instead of only being able to swim under water. Any pool, lake, or ocean keeps both of our boys happy all summer long. Also, Jack loves to throw rocks, so he does prefer a rocky shoreline to anything else. Hiking is also a good family sport. We all go at Jack's pace and have a treat halfway along the hike. These usually last no more than an hour. The basketball hoop in the yard has proven to be fun, too. If you lower

the basket, the kids love being able to get the ball into it.

Sarah Rasmussen, mother of Jack, 8 (dup15q), and Kyle, 11

My 8-year-old son, Roland, enjoys playing on the playground equipment—albeit walking up the slide.

Nancy Barnett, mother of Roland, 8 (dup15q), Nelson, 11, and Maya, 3

My son, Richard, is 24 years old. Although his seizures have slowed him down in the past few years and he appears highly allergic to horses, here is a list of activities he has done: ice skating (great for balance), rollerblading, Alpine skiing, bowling (proprioceptive input), walking (calming effect, muscle toning), swimming (aerobic, calming effect, muscle toning), adapted bike-riding (aerobic), horseback riding (muscle toning), basketball (hand-eye coordination), and water bottle delivery to other classes (proprioceptive input). Richard also participates in the Special Olympics track and field, which consists of running and some basic gymnastics.

JoAnne Mosel, mother of Richard, 24 (dup15q), and four other children



Roland Barnett walks up the slide.

Chloe loves the sprinkler! She will stand there and let it hit all over her face. She also loves going to the pool. She swims well with a life jacket. She can put her face in and then lift it out. She will swim circles all around us. As a family, we like to go bike riding. The girls no longer fit together in one bike trailer, so each parent has one. We usually bike to the park or duck pond. Chloe also likes to chase the ducks. She loves it, but the ducks don't seem to have much fun, so we don't go too often!

Sarah Johnson, mother of Chloe, 5 (dup15q), and Sadie, 2

Klara is a Free Spirit Rider (therapeutic horseback rider). This is her eleventh year. She also loves to fill her stroller with about ten babies (dolls) and cruise down the road with me. She should be a speed walker!

Michelle Hokenson, mother of Klara, 19 (dup15q), Hannah, 20, and Holly Ann, 15

Carly has had a Plasma Car since she was 7 years old. She is now 11 and still rides it. Younger children can ride it as well. She has to make it move by using her legs to get it rolling and then moving her arms and body left to right to keep it moving. She loves it because it is close to the ground. It has taught her to steer and go around objects. It is at the top of my favorite list of outdoor activities. Recently she got a Flying Turtle, which is similar to the Plasma Car.

Robyn Corpus, mother of Carly, 11 (dup15q), and Bridgette, 8

Half Marathon for IDEAS Nets \$17,000+

By Mike Porath

My wife, Sarah, and I set out to raise \$5,000 for IDEAS by running a half marathon and asking friends and family to support us with donations. We launched the fundraiser a week before the race and were overwhelmed by the response we got and the amount we raised: more than \$17,000. The online fundraiser was very easy to set up. Here are the steps we took and some insight on why we think it worked so well. We'd love to help others set up similar events.

WHAT WE DID: Set up a fundraising page on www.firstgiving.com, where people could donate using a credit card. The page included a photo and video of our daughter Annabel and a few paragraphs explaining why we were raising money. This took less than an hour to set up.

HOW WE DID IT: We e-mailed the fundraising page to about 500 friends, family, colleagues, and other groups we are associated with. We even reached out to people we haven't seen in more than 10 years. More than 100 people made donations after the first e-mail we sent. We sent a second e-mail the day before the event and got another 50 contributions. Contributions ranged from \$15 to more than \$1,000, averaging over \$100 each, which really surprised us. We ran the half marathon, a local event that we had registered for, and sent thank-you notes with pictures of our family at the event to all contributors.

WHY IT WORKED: We were very specific about what the money was going toward, a genetic registry that IDEAS will soon be launching. We explained why this registry could really help individuals with dup15q, like our daughter, and the families, doctors, and researchers who are working so hard to help them. This really resonated



The Porath family after the race. From left: Annabel, Sarah, Mike and Isaac

with people, based on their e-mails back to us. They saw that they could make a real impact.

WHAT'S NEXT: We want to help raise \$100,000 for IDEAS by getting 20 families to do an event like this, be it a run, a walk, or a bike race—any kind of local event you want to do. Write me at mikeporath@yahoo.com, and I will help you make it happen.

MIKE PORATH IS AN IDEAS BOARD MEMBER. HE AND HIS WIFE, SARAH, HAVE A DAUGHTER, ANNABEL, 4 (DUP15Q), AND A SON, ISAAC, 2. THEY LIVE IN THE LOS ANGELES AREA.

New York Bike Race Benefits IDEAS

By Tom Allen



Credit: Jim Danvers <http://jdanvers.com>

We had a strong showing of teams from Rochester, Syracuse, and surrounding areas in New York, 60 registrants in all. It was a chilly 35 degrees at the start of the Category 5 (CAT 5) race at 9 a.m. The roads had icy patches and the dirt sections were frozen. By the second lap, the roads had thawed and the dirt sections were

slick mud. Racers were working to keep their bikes upright in the mud as much as they were competing against each other. Covered in all that mud, it was hard to tell who was who; nice, pristine bikes became raggedy looking blobs of mud and dirt. Some riders, after the first lap, opted to take a "did not finish" (DNF) due to the deteriorating dirt sections. But the other hard-as-nails riders kept on lap after lap, feeling the repeated burn in their legs from the quarter-mile-long "wall": a fast uphill climb. At the bottom, it was a leg-cranking 18 percent grade; closer to the top it became as steep as 22

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Cheers to Our Volunteers!

Congratulations to our volunteers of the quarter! **Tom Allen** was instrumental in organizing an exciting new fundraiser for IDEAS: the Hornby Hills Kermis bike race. We hope this inaugural race was the first of many to benefit the organization. **Sarah** and **Mike Porath** ran a half marathon on behalf of IDEAS and in less than a week solicited donations exceeding \$17,000. Thank you Tom, Sarah, and Mike for raising awareness about dup15q syndrome and raising funds for IDEAS!

IDEAS 2011 First Quarter Financial Report

By Tom Doyle, Vice President of Finance

As we enter the 2011 Philadelphia Conference year, your IDEAS Board requested an audit of our books along with our 2010 tax return. The audit demonstrated that the record keeping for your organization is sound and efficient. The auditor made some small recommendations that we will implement in the coming months. As of the end of the first quarter, the IDEAS balance sheet indicates that we had nearly \$19,000 in our checking account with just over \$313,000 in our money market accounts for a total of \$332,106.76 current assets.

Those funds will be put to good use in a conference year, as many of the conference expenses are subsidized by our budget. With the reduction of registration fees to \$80 per attendee this year, we hope to make it possible for more of our families to attend this important event during some rough financial times.

In addition, we plan to go to the next level for our organization as we complete the audit, prepare our annual report, secure our future by establishing a strong leadership model for IDEAS, begin a registry, further research, and apply for grants. All these steps take precious resources, but they are necessary for growth and to better serve our families.

We continue to be grateful to the many volunteers who make IDEAS work and to our families who so generously support our efforts. Thanks for all that you do.

New York Bike Race continued from page 6...

percent. This is the type of climb the pros do in the Tour de France. Nonetheless, riders pushed and mashed their pedals, fighting for position and for the bragging rights of placing in the inaugural Hornby Hills Kermis to raise money and awareness of dup15q and IDEAS. Hornby Hills Kermis race promoter Brian Klotz and members of the Corning/No-Tubes Race Team were instrumental in making the event happen. This year's race raised \$250; we are looking forward to the second annual race to raise funds for IDEAS.

TOM ALLEN IS THE FATHER OF JAKE, 5 (DUP15Q).



Credit: Jim Danvers <http://jdanvers.com>

Special Olympics continued from page 3...

Traditionally, we watch sports to see who wins, but when we look closely at why we appreciate sports, we realize that we are fascinated by exceptional performances, superior effort, and teamwork. We find that when our athletes are afforded the opportunity to train and compete in sports, they excel, which levels the playing field when they look to participate in school or the community.

Special Olympics emphasizes the importance of learning an entire sport—skills to competition strategies—and with that growth comes a natural understanding of place finish and the appreciation of competition. With a successful competitive experience comes an acknowledgement of being recognized as an accomplished athlete, a confidence that says our athletes belong in sport—in Special Olympics or anywhere else. But anywhere else only happens when the school or community allows a winner to be accepted on their field or court. Special Olympics athletes deserve the opportunity to be accepted on school and intramural teams and township recreational teams, as well as in private sports clubs. And the question that needs to be asked is “Why Not?”

Unified Sports, an inclusive sports program offered by Special Olympics, places typical and atypical athletes of similar ages and abilities on teams to compete together. Unified Sports provides an inclusive opportunity, and research conducted by Special Olympics Incorporated shows that 98 percent of Special Olympics athletes who are included in Unified Sports show increased sport skill levels, with 96 percent stating that they feel better about themselves.

In turn, research shows a remarkable impact on teammate perceptions, with typical team members dramatically increasing their understanding of people with intellectual disabilities. Sports seem to serve as the great equalizer for understanding and acceptance. But how can Special Olympics get the word out? Attending a Special Olympics competition as a volunteer or spectator is a great opportunity to gain an understanding of our athletes. Witnessing the passion these athletes have to succeed defines the character of a person anyone would want to call “teammate.”

Everyone has the potential to understand people with intellectual disabilities and offer them the greatest prize: inclusion as athletes and teammates. Whether through Unified Sports or by including Special Olympics athletes as teammates on your school or community teams, you will only contribute to creating even a greater opportunity to compete. And when these athletes are included, it will be clear that winning takes second place to acceptance.

Without Valleys, There Would Be No Peaks

By Buffie Guetersloh



Livi at a Special Olympics event

Our journey has peaks and valleys. If God allows us to fully experience the valleys, He surely will allow us to fully experience the peaks. There is no other way to describe the joy of having Livia, 8 (dup15q), in our lives. When Livi was born, the only thing obvious was that she was absolutely beautiful. As time passed, my husband, Chad, a pediatrician, noticed small things that were not typical of a newborn. By the age of six months, it was apparent that Livi had delays. She began traditional physical and speech therapy to treat her low muscle tone and feeding issues. At 10 months, she was diagnosed with infantile spasms.

As a result of her seizure disorder, her neurologist ran a chromosome test and she received a diagnosis of dup15q syndrome. After her diagnosis, we considered alternative therapies that could promote progress while continuing traditional therapies—physical, occupational, and speech. Fortunately, Livi's traditional therapists think outside of the box. The most beneficial treatment that each therapist incorporates is sensory integration therapy. In addition, they are willing to use Livi's service dog in her therapy sessions.

The Make-a-Wish Foundation worked with Assistance Dogs of the West (Santa Fe, N.M.) to provide Livi with a seizure alert and therapy dog. Therapists use her seizure alert dog as a therapy tool. Since getting Berkeley, Livi's awareness of her surroundings has broadened. The alternative therapies that we have explored have also benefited Livi. At 11 months old, the only therapy that she emotionally responded to was music therapy. She developed a keen sense of anything musical, so we began to teach her through songs. For instance, she still loves for us to sing the "Livia" song we made up when teaching her name.

Livi began horseback riding at 2. For about six months, she had rocked back and forth on all fours attempting to crawl. After just two sessions of riding a horse, she began crawling. At 3, she started conductive education. This is the therapy in which she took her first steps. By 4, she was a walker. As a walker, Livi tends to toe walk. Any opportunity to build up her strength is important. Suit therapy is a type of physical therapy that really developed her strength and appropriate gait. Swimming is another therapy that improved her strength. Both of these therapies also fed the sensory input that she needs.

When Livi was 6, she received Applied Behavior Analysis (ABA) therapy. Although she began to say words, she did not necessarily communicate. After nine months, we decided to focus more on her augmentative device in order to develop her cognitive skills and encourage her to communicate her needs to us. We do not know if she will ever be verbal, but we never thought she would walk. Of course, Livi is never shy and communicates in her own special way with a joyful song in her heart.

Recently, prism glasses were prescribed for Livi. Her progress is unbelievable! Her toe walking has improved, as well as her focus and receptive processing. All of her teachers and therapists are amazed that these glasses make such a difference. The relationships she has with those in her circle are solid. Since she began wearing the glasses, though, she is initiating contact with others outside of that circle. She recognizes the world around her and wants to communicate with everyone in it. Our social butterfly!

Livi is always happy and appreciates the simple things. Things like being outside; feeling the wind blowing in her face; running and jumping; having books read to her; swinging her long, dark hair; looking at herself in the mirror; and enjoying the color pink. Above all, she loves music and interacting with others.

She always responds to music and loves to make it. When Livi plays the piano, it sounds like a waterfall. Sometimes she will start dancing, and then we realize that she hears music playing somewhere. She also loves to sing along with others. Social interaction is something she craves, especially with her family. The unconditional love that she expresses impacts our family—we are unique. My husband, Chad, and I

realize how different we would be without Livi. Our faith in God is stronger, and we know that He entrusted us to take care of her, while she in turn keeps us grounded. God makes no mistakes—she is perfect in every way.

It is amazing to witness the connection she has with her brother, Connor, 14, and her sister, Adisyn, 11. Livi has a special relationship with each of them, and even though she is fully dependent and nonverbal, they are responsive to her needs. Their love for her is truly vivid.

Livi is a light that makes our family shine. We pray that God will take away her seizures—the only thing we would ever want to change. Fortunately, we are blessed with support through Livi's organization, IDEAS, as well as her teachers, therapists, and the parents of other children with special needs. Peaks and valleys continue to abound, but our journey with Livi allows us to experience true joy. I thank God every day for our wonderful, "not typical" family.

BUFFIE LIVES IN PROSPER, TEXAS, WITH HER FAMILY: CHAD, LIVI, CONNOR, AND ADISYN. SHE IS EXECUTIVE DIRECTOR OF PROSPERITY PLACE, WHICH ASSISTS PARENTS OF SPECIAL NEEDS CHILDREN IN NORTH TEXAS BY EDUCATING THEM TO BE ADVOCATES FOR THEIR CHILD, ACTING AS A RESOURCE CENTER FOR FAMILIES, AND PROVIDING FINANCIAL ASSISTANCE TO CHILDREN WITH SPECIAL NEEDS, SPECIFICALLY FOR THERAPY (WWW.PROSPERITYPLACETX.ORG).



From left: Connor, Livi, and Adisyn Guetersloh

Family Portrait

Surfers Healing continued from page 4...
out with our community, we cheer the campers as they ride to shore.

"It's our day, a day for everyone to enjoy fellowship and introduce the wonderful sport of surfing to our kids," Pike says. At the camp, there's a nonjudgmental sense of acceptance that reflects the inclusive spirits of both the special needs community and surfing culture.

"[Board sports have] always been a counter-cultural activity, where you're part of the group no matter what music you listen to, no matter how you look," Pike says, which makes the culture a good fit for people who have autism. "It's an accepting, eclectic, diverse group. It doesn't matter if you're different—if you ride, you're part of it."

The main event is surfing, of course. When our son's surf time is announced, a volunteer fits him with a personal flotation device. Another volunteer whisks him into the ocean, where he is handed to a surfer. He is placed on the board, the surfer turns the nose toward the waves, and the magic begins.

The professional surfers who accompany and support the campers on giant tandem surfboards are incredibly strong, agile men who are specially trained to assist the kids in the water—whether the campers lie on their bellies, stand up on their own, or even in the surfers' arms. The first year my son, Jonah (dup15q), surfed, he was a tiny 2-year-old who was barely ambulatory; his surfer, Josh Tracy, grasped my little boy under his arms and carried Jonah in front of him as if he were a gift for Poseidon. Last summer, when Jonah was 3, he stood on the board in front of his surfer, Che Pilago, who helped him remain upright.

Between rides, while waiting beyond the break for his next wave, Jonah would splash around the surfboard



Jonah with Josh Tracy, 2009.

or sit calmly on top with his new friend, feeling the undulation of the ocean. His surfer kept a protective hold on my son's lifejacket the whole time. When Jonah rode his last wave to shore, the crowd cheered and we rushed to greet him.

How to describe Jonah's demeanor after 20 minutes of surfing and playing in the ocean? Relaxed exhilaration—that state his occupational therapists call "regulated" or "organized"—not a hint of overstimulation or agitation. Many children react positively to the experience, but because different kids have different sensory triggers and anxieties, it isn't for everybody. One common effect Pike does see, though, is its profound healing impact on families. An important shift often occurs for parents once they hand their children over to a surfer.

"First-timers physically and emotionally let go of their children," Pike says. "It's powerful for those with newly diagnosed and younger kids on the spectrum." That brief respite offered by one day and one sport, has a lasting impact. Gathering together and surfing makes children, families, and communities stronger, healthier, and happier. As Pike says, "The ocean is magic; it does heal."

FOR MORE INFORMATION ON SURFERS HEALING, VISIT WWW.SURFERSHEALING.ORG OR CONTACT JOHN@SURFERSHEALING.ORG.

Reflections from a Sibling

By Samantha Nardi

Living with Moe

When I was 11 years old, my brother, Massimo, was diagnosed with dup15q syndrome. At first, I wasn't sure how much it would affect my life. When I did start to realize the impact it would make on my life, I wasn't sure how I would handle it. But now that I've been lucky enough to get to know Moe, I know that it isn't a punishment, but a blessing. Even though having a little brother like Moe makes life ten times crazier, it is worth it.

With Moe, one day can be completely quiet and he won't say a word, and then the next day he is having full-on conversations with me. Even though his words may not be completely developed yet, they still mean everything to me. And even though he cannot yet fully express what he wants to, I know the deep love and protectiveness Moe feels for me every time I hold him. If something happens that upsets me, Moe is there with his arms wide open trying to smother me with one of his

giant bear hugs. There is no possible way for me not to feel happy when he is giving me a hug. Every once in a while, I will be holding Moe and turn to face him and he will be there with his lips puckered waiting to give me a kiss. Sometimes I just have to look at his innocent face and think of how lucky I am to have such a wonderful addition to my many siblings.

Having a little brother with dup15q has its ups and downs. Of all the ups and downs, there are many more ups than downs. One of the ups is that Moe never acts like a game is too foolish for him to play, or he will always be willing to laugh and sing along to the radio, no matter how off-tune I am. But along with all the ups comes the downs. One of the more frustrating things we have to deal with, as a family, is that Moe does not have a lot of patience. We cannot, on the spur of the moment, go out to the store and have a shopping spree. But sometimes this is a good thing. We can stay home and play and visit with family more often.

Of the many things that my little brother Moe does for me, always being there is something that I love the most in him. I can always trust Moe to be there and comfort me when I am feeling down. Although Moe's ideas of fun playtime (watching Spongebob) are different than mine, I still enjoy the little



Just Because I'm Special

By Samantha Nardi

Don't stare at me,
Don't point and whisper,
Don't ignore me . . .
Just because I'm special.

Don't talk about me when I'm
not listening,
Don't make fun of me,
Don't tease me . . .
Just because I'm special.

Invite me over to play,
Sit with me at lunch,
Talk to me in school . . .
Just because I'm special.

Please try to be my friend.



moments I can sit on the couch and laugh at Spongebob and Patrick with him. Moe is the one who is constantly reminding us of God's plan and that we are all perfect in His eyes.

Every day, I look forward to seeing the improvements he has made while I have been gone. Recently, Moe has learned to put trash into the trash-can. Although we can never be too sure what is getting thrown away, it makes me proud when I see him throwing away my crumpled paper. When one of our landline phones went missing, we all instinctively *Continued on page 11...*

Reflections from a Sibling continued from page 10...

thought of Moe. A few days later we were outside and the phone was ringing . . . from the trashcan. I guess Moe thought it was time for us to get a new phone.

My name is Samantha Nardi. I am 14 years old and Moe is just one of my five brothers. He has made a huge impact on my life recently, and I believe that it is for the best. He has taught me about the importance of being a family and staying true to who I really am. With Moe, I can be silly and play with little baby toys and not feel the need to explain myself. Moe is a full-time job, and even though I may not be the one to always be taking care of him, I know that I will be important in his life, as he is important in mine.

SAMANTHA, 14, LIVES WITH HER FAMILY IN ST. PETERS, MO. IN HER SPARE TIME, SHE LOVES TO READ AND TAKES A BOOK ALONG WITH HER ALMOST EVERYWHERE. IN THE FALL, SHE WILL START HIGH SCHOOL AND HOPES TO BE ON THE VOLLEYBALL TEAM. SHE HAS FOUR BROTHERS IN ADDITION TO MOE: TINO, 18, DOMINIC, 16, LEO, 10, AND GUS, 6.



Clockwise from top left: Cathy, Tony, Dominic, Massimo (dup15q), Leo, Augustino, Samantha, Santino



CARE TO Go PAPERLESS?

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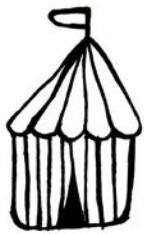


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PLEASE JOIN BIG TENT TODAY! BIG TENT IS OUR ONLINE FORUM WHERE FAMILIES CAN CONNECT, ASK QUESTIONS, LEARN FROM EACH OTHER, AND—LAST

BUT NOT LEAST—SUPPORT EACH OTHER. GO THE WEB SITE AT WWW.DUP15Q.ORG FOR THE LINK TO BIG TENT. IDEAS HAS A RESTRICTED GROUP, SO THE GENERAL PUBLIC CANNOT JOIN; YOU MUST BE A REGISTERED FAMILY WITHIN IDEAS TO READ AND POST TO THE FORUM. THIS RESTRICTION IS IMPORTANT TO MAKE THE FORUM A SAFE AND SECURE SITE FOR OUR FAMILIES. IT IS IMPERATIVE FOR YOU TO SIGN UP, AS BIG TENT IS OUR MEANS OF TRANSMITTING IMPORTANT INFORMATION QUICKLY TO OUR MEMBERS. PLEASE DON'T DELAY; SIGN UP TODAY!



<http://www.dup15q.org>

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There are different ways to reply or comment on a forum topic. It depends on your notification settings for the forum postings.

1. Always an option: Log into the IDEAS Big Tent online community and choose the forum message, scroll to the "Add a Comment" section, type your comment, and click the "Post Comment" button.
2. Daily Digest: Use the "e-mail a Comment" link under the original posting message. This will automatically give you the reply e-mail address in a new e-mail message.
3. E-mail every message or e-mail every message and comment: Reply to the message that was sent to your e-mail account.

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