

Celebrating Holidays With dup15q

by Jane True, Editor



What do the holidays mean to you? Chestnuts roasting on the fire? Snowflakes tickling your nose and eyelashes? Twinkling lights and pretty candles? Or are your holidays filled with sugar highs, meltdowns, ignored gifts, stress and disappointment?

IDEAS can help! In this issue, *The Mirror* tackles the subject of surviving the holidays for families affected by dup 15q. Included is a Guide for Surviving Holiday Parties which you will want to read and share with anyone who may be entertaining you this season. Concerned about finding that perfect gift for your affected child? No worries—study our hit list of gift suggestions contributed by other parents who don't care if the gift is "age appropriate." Read the touching story of a sibling who misses celebrating Halloween with her sister now that both live away from home. Of special interest in this portrait is the story of how the sibling arranged for her sister's housing placement.

A key element for every caregiver, especially at holiday time, is taking care of yourself. Easier said than done? Inside find some helpful advice for meeting this oh-so-important challenge.

Hopefully the information in this issue of *The Mirror* will help keep you and your child smiling all throughout your Happy Holidays!

Jane serves as the editor of the Mirror. She raised Clare idic(15) and her two brothers, Toby and Tyler. She lives with her husband Jim in Kansas City, MO.

jtrue@kc.rr.com

INSIDE THIS ISSUE

- Taking Care of Ourselves During the Holidays...page 2
- Tips for Surviving Holiday Parties with dup 15q kids...page 4
- Gift IDEAS for your child...page 6
- Sibling Family Portrait...page 8
- Italian Dup 15q Conference... page 7
- Join the IDEAS Cause on Facebook... details on page 3
- In Every Issue:
 - Cheers To Our Volunteers...page 10
 - Birthdays...page 11

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.

Taking Care of Ourselves During the Holidays

Written by: Erin McHam, MA, LPCC



Holiday Cards Gifts Shopping Money Bells Lights Presents Food Spirits Family Parties Carols Faith...

As I *free associate* about things related to the holiday season, these are a few words that come to mind. I find myself listing things I enjoy as well as things I would rather avoid. As you scan the list, or create your own, you may be surprised by what you like or dislike about the holidays. There is no right or wrong reaction, but taking a moment to notice what we think and how we feel about any particular holiday can provide us with clues about what has meaning to us.

The holidays are filled with a unique energy. There seems to be a different momentum at this time of year--both an anticipation and an excitement about the nuances of the holiday season. However, this momentum can also be a strong force in pulling us out of our daily routines or in convincing us that we must "do more" in order to fully participate in the season. Whether it's decorating our house, going shopping, attending holiday functions, cooking, wrapping presents or traveling to visit friends and family, the extra features of preparing for and enjoying the holidays can be either a source of pleasure or angst. Taking Care of Ourselves During the Holidays is about slowing down and taking

time to reflect on what the holidays mean to us. Taking care of ourselves involves getting clear about our beliefs and creating holidays in ways that are congruent with our personal values.

I, for one, do not enjoy shopping. Just the anticipation of having to go to a shopping mall makes me feel anxious, let alone the idea of going to a mall during the holidays when parking spaces are scarce and stores are crowded. And yet sometimes I feel bad for not wanting to get out amid the holiday cheer and enjoy the process of finding that perfect gift for someone on my list. After years of experiencing anxiety and wishing I could be different, I have come to terms with the realization that shopping is neither an important nor a meaningful aspect of my holiday experience. I have learned to let go of this expectation and redirect my energies into making gift-giving more simple and reflective of my true nature. Readjusting my priorities helps to free my energy and focus on seasonal experiences I truly love, like taking an all day trip to the tree farm and cooking a special cheese fondue dinner for my husband and son.

For parents of children with special needs, the holidays can present

unique joys and challenges. The holidays can be a wonderful time, bringing family and friends together for fun and meaningful celebrations. However for some children the increased activities, sounds and sights can prove overwhelming. Our hopes and expectations for our children's holiday experience may be different from the way in which our children respond.

So how do we take care of ourselves? First it is helpful to take time and notice what we cherish about the holidays. Once we are clearer about what is important to us, communicating with our family is the next step in designing a holiday that meets the needs of the entire family. Reestablishing expectations and setting boundaries with extended family and friends is a helpful step in creating new traditions. The third step is the fun of implementing traditions that are reflective of our unique essence and family situation. Ultimately taking care of ourselves is about listening to ourselves and doing what is best for our family.

continued on page 3

Killington Race Report by Sarah Rasmussen



Our September race day was sunny and beautiful. *Once again a feeling of warmth spread throughout the day as Killington came together*

for the fourth annual race to help IDEAS and show their support of our family.

To date, we raised over \$14,000 for IDEAS. We had 309 competitors with seven IDEAS families on site (Rasmussens, Rivards, Luchsingers, Bopps, Leos, Doucettes and Wises). A pre-race party was held the night before at a pizza restaurant with almost all of the IDEAS families attending. Post-race there was a BBQ back at the Rasmussen house with all of the Rasmussen/Ronan family there, plus out of town guests and most of the IDEAS family. Lots of the money raised by the race came from the other IDEAS families who attended and brought it up for the race.

This is always a special day and makes me truly appreciate the community I am raising our family in. Before I presented the check to Kadi I spoke briefly, "We say it every year, but it is so true--my husband and I feel so fortunate to live in a community like this that provides our family with such support, and helps us raise our children, no matter what their abilities, to be the best they can be."

Taking care of ourselves - continued from page 2

Slowing Down and Getting Clear about . . .

- What do I value or enjoy about the holiday?
- Who do I want to spend it with?
- How do I want to celebrate?

Communicating

- Asking family members what they like about the holidays
- Talking about, "How does our family want to spend this holiday?"; "How does our family want to celebrate?"
- Communicating with extended family and friends about holiday plans.

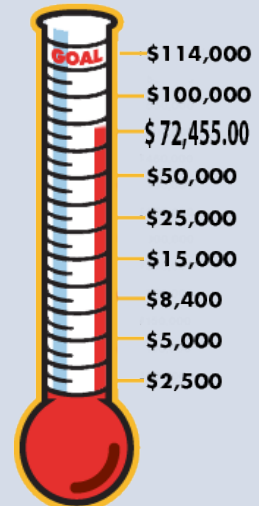
Creating Traditions

- What, if any, holiday traditions or activities do I/we want to carry forward?
What traditions can I/we let go of?
- Creating holiday traditions that are congruent with family beliefs and values.

Erin is a Licensed Professional Clinical Counselor with a Private Practice in Columbus, Ohio. She is also the aunt of Jimmy Trueman, a child with idic15.

2009 FUNDRAISING

You can help IDEAS reach its fundraising goal for 2009. See our website for suggestions.



When shopping online, remember to sign up at www.igive.com to help IDEAS.

BE SURE TO CHOOSE ISODICENTRIC EXCHANGE ADVOCACY AND SUPPORT

AS YOUR GROUP !
(if you choose "IDEAS" it will go to a different group).



Do you use Facebook? Join the IDEAS Cause Page!

IDEAS now has a cause page on Facebook to create awareness of dup15q syndrome as well as raise funds to support our programs. The cause page has over 1000 members! If you use Facebook, please join the IDEAS cause page and share it with your friends. This is a public group so please use caution if posting personal information. To find the cause search "cause IDEAS 15" when logged into Facebook. <http://apps.facebook.com/causes/224306?m=de0957a2>



When attending PARTIES:

↳ BEFORE the party:

Tip #1: Take two vehicles

If your child needs to leave early, not all of the family needs to leave.

Tip #2: Arrange a Check-in Signal

For older kids, arrange a check-in signal so that only you know when your child needs to take a break or leave.

Tip #3: Breaks

Tell your child that you may suggest that he/she take a break or help you in the kitchen before dinner and to not assume that they are being put into "time-out." The break is to prevent something from happening.

Tip #4: Touch and Smells

Ask everyone to let the child initiate touch and interactions. Avoid and ask others to avoid use of heavy smells such as perfumes and candles.

Tip #5: Bring Along an Activity Bag

Put together an activity bag with quiet activities that your child enjoys, like coloring books and crayons, puzzles, books.

Tip #6: Clothes don't make the kid

If your child has sensitivities to certain types of clothes, or just stubbornly insists on wearing something you (or, you suspect, your mother) will find inappropriate, don't pick a battle today. Bring a change of clothes if your child must wear something you want.

Tip #7: Plan an Escape Route

If you are hosting people at your home, help your child know when and how it is OK to peel away and have some down time without offending your guests. When you are visiting friends and family, talk with the hosts and identify a quiet space where your child can "escape" when he or she is feeling overwhelmed or in need of some time alone. Also be sure to ask about any house rules (like no food in the bedrooms and no

chasing the cats) that will make the visit fun for all.

Tip #8: Social Stories

Go over what will happen: it will be loud, crowded, etc. Use of social stories can be extremely helpful and give your child a heads up of what to expect.

Example: "It is Christmas morning. Uncle Paul will bring the presents out from under the tree and hand them to all the children. The children will then open the presents. There will likely be lots of loud voices and wrapping paper flying about. If you need to take a break you can go to Aunt Susie's bedroom." Wait a minute, then say again leaving some blanks and have your child fill in the important points so you know that they were listening and actually heard you. There will be lots of _____ voices..."

Tip #9: Discuss good options to deal with bothersome things.

For example: "When the party gets loud, instead of hitting your sister, what is a better thing to do?" Help your child answer, "Go to the quiet room or find you, Mommy."

Tip #10: Do some heavy work activities before you leave home and in the car if the ride is long. Heavy work activities can be found in books such as the *The Out of Sync Child* and the *The Out of Sync Child Has Fun*.

Tip #11: Prepare others for unusual behavior by your child. If any of these things are true, you might tell them that your child:

- *sometimes doesn't get jokes*
- *won't understand a sarcastic tone of voice - will tend to take things very literally*
- *may talk without pause and not notice that someone wants to take a turn to speak*
- *interrupts other people because*

he cannot tell when his conversational partner has finished speaking

- dislikes being hugged, touched, or stroked
- is clumsy and doesn't like being teased about it.

You could tell your guests how you wish they would act in response to these behaviors.

└─ DURING the party:

Tip #1: Be the early bird

Be the first, or one of the first, to arrive so you can arrive when the house is mostly empty and your child can acclimate to the noise and chaos as it grows with each arriving guest.

Tip #2: Safe Space

Show your child the room or space that the child can start out in or retreat to during the party.

Tip #3: Remain calm

Memorize this phrase, and repeat it over and over in your head whenever you feel yourself losing your cool: "I do not have to apologize for being a good parent to my child."

Tip #4: Group photos

Get pictures done during the first half of the party before your child is tired and overwhelmed.

Tip #5: Augment the menu

Whether you're bringing a little something to somebody else's party or planning your own repast, make sure there's something your child will enjoy eating. And then don't comment if that's all he or she will eat. The goal of the day isn't cleaning your plate or trying new foods or pleasing the cook.

Tip #6: Check in

Check in with your child and look for signs of distress. Better to take a break or leave before things go bad.

Tip #7: Be the one who watches the kids

Keeping a close personal eye on your little one has a number of benefits. You can intervene in inter-child squabbles. You can assess your child's level of over-stimulation and act accordingly. You can play with your child if no one else will, or lead the other children in a game your child can participate in.

Tip #8: You're Outta There!

Be the first to leave. Leave when things are still going well, right after the party's peak.

When hosting PARTIES: └─

Tip #1: Less is better

Limit the number of children to the age of your child or less. If your child is four have four children total including your child

Tip #2: Time's Up!

Specify on the invitation the end time of the party and politely lead people toward the door when the party is over.

Tip #3: Outside

Whenever possible, have party outside so smells, noises, crowds can be avoided.

Tip #4: Forget the fanfare!

Sing "Happy Birthday" quietly and without a lot of fanfare if this is usually bothersome to your child.

SURVIVING the holiday season in general: └─

Tip #1: Don't Forget Your Routine

Don't let these routines get away from you completely, as they will be harder to re-establish once the holiday season is done.

Tip #2: Don't overbook.

Hold the festivities down to one event per holiday. Don't hop from house to house, or plan a big outing the night before a family event. Give your child (and yourself) the maximum amount of de-stressing time surrounding the minimum amount of stressful activity. This may be a disappointment to friends and family members who feel you are shelter-

continued on page 11

Gift Hit List:

compiled by Jean House



Playskool Explore 'N Grow Busy Ball Popper

Riley loves the Playskool Explore 'N Grow Busy Ball Popper! She got it when she turned 1, is turning 3 this year, and hasn't even come close to growing out of it. Educationally, it shows cause and effect, in and out, and on and off.

It encourages visual tracking, eye-hand coordination, and anticipation—and it is just plain fun! We tilt it and shoot the balls across the floor. She is starting to walk to retrieve them. She hasn't mastered bringing them all the way back yet. It also encourages her squat to stand when the balls pop out. Several different songs play during the “play” mode, and the plunger is easy enough to push once kids understand cause and effect. When she was younger, we used it to encourage her to sit. It's a great toy!

Jill Baker, mother of Riley, 3

Both my 10-year-old and 4-year-old have dup15q syndrome and a ton of sensory integration issues. We've tried just about every weighted product out there (vests, blankets, lap pads, balls, and ankle and wrist weights) and they've hated them all. Then we finally found two products that they absolutely love and can't get through the day without: the Tote Around Hound and the Tote



Tote Around Hound



Around Turtle. We found these through School Specialty www.integrationscatalog.com, and they cost about \$25 each. They weigh 5 pounds apiece.

Each has a vinyl cover that can be wiped clean, and they are filled with poly beads. They're perfect for preschool and elementary kiddos who have sensory issues and need the calming influence of a weighted item.

Desiree Byrne, mother of Preston, 10, and Tori, 4

The Playskool Made for Me MP3 Player is one of Ben's favorite toys. We purchased it because he loves his music, and we thought it would help him sleep and transition. This simple MP3 player allows you to add your own songs in three categories: playtime, sleep time, and favorites. The buttons are very simple, and there is a sleep timer. It also has lights to help at sleep time. Besides his love of music, Ben likes this toy because of the handle (he loves to carry things with handles). Although Ben was out of his crib when we got this toy, it can be covered with a fun animal cover, which is included, and attached to the crib.



Madison just got the Razor Rip Rider 360 Caster Trike for her ninth birthday and absolutely can't get enough of it. What makes this tricycle spectacular is that it enables her to spin around 360 degrees because it has small caster wheels on the back. It can accommodate kiddos up to 160 pounds and is suggested for kids 5 years old and older. Because it is low to the ground, she doesn't have to balance as she would on a traditional bike. We have found that this product is sturdy and well built and can take a beating, and it gives her the sensory input (360-degree spins) and gross motor input that she craves. This has been by far the best product we have ever found for her, and we love hearing her laugh and giggle when she's riding it! We laugh just as hard as she does because watching her spin around and “spin out” is hysterical. This gift was a winner!

Sandi Winger, mother of Madison, 9

Rachel Doucette, mother of Benjamin, 3



Razor Rip Rider 360 Caster Trike

My son Jacob is incredibly oral and is in a constant drive for oral, auditory, and tactile stimulation. One of Jacob's favorite toys is the Rapper Snapper, an accordion-style, plastic, colorful, hollow tube that makes noise when it is pulled and squeezed. Jacob absolutely loves pulling the tubing with both hands to hear the noise, and he enjoys running his semi-closed hand around the accordion-style texture of ridges and valleys when it's pulled apart. He also rubs the pulled-apart Rapper Snapper across his lips like he's playing a harmonica. He even sticks out his tongue for extra stimulation.

I love Rapper Snappers because they are washable, inexpensive, soft, bendable, and safe to carry and mouth (because Jacob tends to fall a lot) or hold and mouth while jumping on a trampoline. The downsides are that new ones don't stay new very long, and they don't always respond to being pushed back together into their original accordion-style shape. But even in their used state, he will continue to play with them. We cut the old, stretched ones into shorter lengths for him to play with. We tuck one end of a used, stretched out Rapper Snapper into its opposite end and make a ring with it. I order Rapper Snappers from www.therapro.com. I've seen them in various stores in the toy section, but they're not called Rapper Snappers in the stores. They cost about \$12 for one dozen.

Susan Gazewood, mother of Jacob, 10

continued on page 11



A Dup15q Holiday in Naples, Italy

by Lorenzo Cerutti

THE FIRST WEEKEND OF OCTOBER, Italian families met together for the first Italian Dup15q Conference. We were eight families with our children and we spent two lovely days in a holiday house managed by a few nuns in front of Naples's gulf.

We all arrived on Friday and we spent the evening and dinner time for the first meeting because most of us had never met before. On Saturday, after a nice breakfast, we started the conference. The first half of the day was chaired by Dr. Agatino Battaglia, who updated us about latest idic15 research news. We had the opportunity to exchange with each other and with Dr. Battaglia our experiences, our doubts and our questions.

In the meantime, thanks to some fantastic volunteers, our children and siblings played together: some drawing or watching DVDs, others playing in the garden under a warm autumnal sun.

In the afternoon we had a moving meeting with a girl who has Downs syndrome and her unique brother, who taught us how a sibling can love and take care of his unlucky sister. As parents I think we could only hope to grow up our babies this way.

We decided to spend the last part of the afternoon talking and playing together and, why not, having an afternoon snack with many homemade sweets: Italian cooking is always the best one!

On Sunday, we tried to plan steps for our Italian Association, and we outlined milestones and owners. Unfortunately after lunch we had to leave, because many of us had to catch our flight home.

We were a little bit sad to leave, but aware that this was just the first meeting together of many in the future.

Some comments from families who attended the conference:

Lorenzo (father of Matteo and Simone (idic15)):

We were very enthusiastic to fly into Naples all together and meet our new friends. We knew it wouldn't be easy for us, as it wasn't in Indianapolis in June. Having a one-year-old affected boy who doesn't seem too different from other babies and being aware of how he could become in the following years is still very difficult to accept. But we met some fantastic parents

continued on page 10



Last Halloween was the first that I did not take my sister Anna, 21, trick-or-treating. Instead I arrived in New York City, my new home, in time to see costumed children traverse the sidewalks in search of candy. I stumbled out of my car, exhausted from the drive from Chicago, and tried to suppress the inevitable twinge of guilt that I felt. I was in Manhattan, pursuing my dreams of writing, while my sister was at her group home, spending a quiet evening with staff and roommates. I wished desperately to be at my parents' house, dressing Anna in her pointy witch hat and shuffling her out the door, careful not to leave her favorite plastic pumpkin behind.

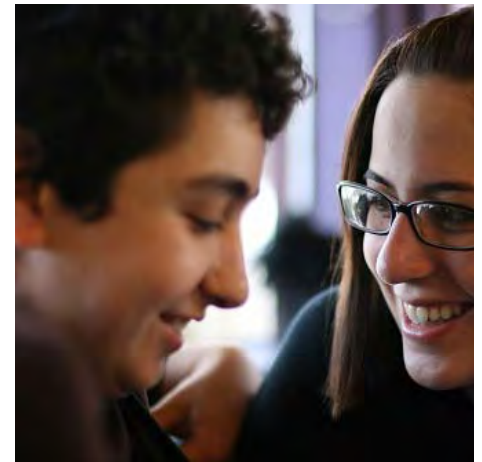
My younger sister, Anna, was born in Minsk, Belarus, in the USSR a year before my family immigrated to the U.S. While other new immigrants were acclimating themselves to the language and culture, my parents were desperately trying to figure out why my sister was experiencing significant developmental delays. My mother traveled from hospital to hospital in search of answers while my father worked to support our family. I stayed at home by myself for hours at a time in our tiny one-bedroom apartment. I ate Spaghettios and watched daytime television. I was five years old.

Genetic testing uncovered an inverted 15th chromosome. My parents and I gradually adjusted to life in the U.S. and to Anna's diagnosis. I couldn't understand what it truly meant because I couldn't see it. My sister looked absolutely normal. In fact, she was adorable with a mop of black hair and deep brown eyes. And she had very specific interests and a strong will. She loved to sing, dance and listen to music. She was obsessed with her VHS tapes of Barney and Friends, Kidsongs and especially Xuxa, an obscure Brazilian pop star. Anna had entire movies, namely Kindergarten Cop and Problem Child, memorized. I thought it was so adorable when she shook boxes of Cheez-its at the supermarket and lugged stacks of my Seventeen and Teen People magazines and full bottles of Tide around the house. She hugged every member of my family daily.

We pursued the American Dream by moving to a house in the suburbs, but Anna's behaviors moved with us. She became less cute and more unbearable as she got older and stronger. People at the grocery store stared disapprovingly as she shook boxes of Cheez-its she grabbed out of their cart.

My magazines were held hostage in her room before I had a chance to read them. We stepped in puddles of detergent on the stairs. It was then that her seizures started as well. I dealt with it by escaping to books and writing my own reality in stories that I feverishly worked on. I also tried to change her. Every time I would see a shooting star (even if I secretly knew it was an airplane), blew out birthday candles or lost an eyelash, I would wish for the same thing—for Anna to get “better.” Sometimes I would turn to her and beg her to stop faking. I would constantly have vivid dreams in which she was “normal.” In those dreams I cried with happiness and told her how relieved I was that we could finally have long, meaningful conversations about life. I would wake up in a daze.

During high school and college, I helped my mom care for Anna and my brother Michael (born in 1997) every day after school and on weekends. This involved practical



“ For some families, having a child with disabilities at home is an option and something that they are equipped to handle, both financially and emotionally. I knew that was simply not possible for my family to continue and I couldn't leave my parents to do it on their own. ”

— Elina Miller

matters such as preparing her seizure medication (liquid Valproic acid) that had to be painstakingly measured, mixed with water and re-measured and administered with her beverage of choice (a steaming cup of decaf black tea with three spoons of sugar), changing her diaper, and giving her a bath. I also provided her with entertainment by endlessly singing the first verses of many children's songs until she got tired and moved on to the next. Futile attempts (including several broken locks and homemade contraptions) at keeping her away from the refrigerator so that she couldn't eat anymore "brown" (sour cream) or "more" (spinach dip) or "tato" (potatoes) peppered our time together. In return, I received affectionate head rubs and hugs. All the while, Michael

would run in between my feet seeking his own much-needed attention. My mom would be out at the supermarket or the bank. Neither of us could go on the simplest errand without the other being home to watch the kids.

Anna's erratic behavior including hitting, headlocks, pushing, tripping and rough play was also negatively impacting Michael. He was imitating her aggression and was easily lured into altercations with her over the toys she took, the fact that she refused to wait her turn, and often over nothing at all. Sometimes my mom and I would have to break up as many as twenty incidents in one day. Anna simply thought he was playing with her and was happy with the daily entertainment. She would take his favorite toy and purposely show him that she had it in order to elicit a response from him. It killed me to see this behavioral pattern seeping into Michael's interactions with other children his age at preschool. I quickly realized that I could never hope to have a life outside of my family as long as my sister lived at home. I dreamed of traveling to exotic places (anywhere but Chicago), of writing important works of fiction, of meeting interesting, creative people. I lamented the reality of my life and acted out, often resulting in unpleasant exchanges with my parents. We were all thoroughly exhausted.

I was so relieved to get my drivers license on my 16th birthday. It meant that I could begin the process of placing my sister in a group home

or CILA, as it is known in Illinois. I could finally drive to the various group homes in the state and I started volunteering to see what each facility was like. I also reasoned that the state could not hang up on me if I was standing before them. I became entrenched in this process, navigating the often impossible and counterintuitive regulations the state put into place largely on my own. My parents were unable to help me because of the language barrier and general exhaustion. My dad worked twelve hour days six days a week at his auto shop and my mom worked there part time and cared for my sister. It was often a painful road and I traveled it alone. The state agencies and government bodies I frequented practically laughed at me. I was advised to give up on placing my sister. Yet the nagging feeling of wanting to have Anna safe and happy and my brother to avoid long-lasting consequences of fighting on a daily basis while I pursued my own goals persisted, and so I turned that into fuel for the fight.

When Anna turned 18 and qualified for adult placement and funding I applied on my own and was denied twice. I began to understand how families already intensely strained by caring for a child with disabilities and feeling guilt for wanting their child to live away from home can halt the process. It is much easier to simply give up; I thought about it many times. As a last hope I turned to my state representative, Karen May of Highland Park. I provided Karen with

all of the documents, applications and even a vacant spot waiting for my sister—which was as far as I could have taken the process. Karen did the rest and was able to attain CILA funding for my sister. She continues to be a hero and role model for me. Anna moved into a residential facility on March 1, 2007.

I thought that I would feel relief but instead I was wracked with intense and painful guilt, paralyzed by it. It was as if I was trying to rid myself of Anna, much like the family in Franz Kafka's "Metamorphosis" tried to get rid of their son after he turned into a bug. Making peace with my family's new reality is still an ongoing process. For some families, having a child with disabilities at home is an option and something that they are equipped to handle, both financially and emotionally. I knew that was simply not possible for my family to continue and I couldn't leave my parents to do it on their own.

Today my sister has lived at the CILA for a little over two years. She has lost weight and we have faced challenges with stabilizing her seizure medicine. Overall she is adjusting wonderfully and her behavior has improved a great deal. She spends the night at home once a week and everyone looks forward to it. My brother has matured and understands her disability. He reminds me that we have to love her because we are her family and she has no one else who can protect her. He is also steadily improving his ability to socialize with peers. My parents are attempting to adjust to their newfound freedom. The realization that they can go to a movie, run an errand or go away for a weekend is still new to them. I moved to New York and now work as a television producer.

I have had time to reflect on my journey with Anna and although it hasn't always been ideal, I would not rewrite a different path for myself.

continued on page 11

Cheers to our Volunteers



Volunteers of the Quarter

IDEAS honors **Tina and Corey Mueller**, parents of 3 1/2-year-old Grace, as our Volunteers of the Quarter this Fall. Tina and Corey ran in the Crim Festival of Races for IDEAS. The Crim is a national event held every year in Flint, Michigan. The Muellers are new to running and decided to raise money for IDEAS by collecting pledges for their run. They didn't organize the race, they just chose one to run in for IDEAS. Their entry fee for running went to the Crim charities, which include youth fitness programs to fight childhood obesity. But all pledges raised by the Muellers and their friends and family went to IDEAS. They composed a pledge sheet and an informational letter about IDEAS to send to friends and family, and invited them to either join the Muellers in the run or collect pledges for them. They had t-shirts made for the event to make it more "official". Congratulations Tina and Corey—IDEAS is proud of you and thanks you for supporting our families!

MIRROR CONTRIBUTORS

Editor: Jane True
Kansas City, MO

Assistant Editor: Jean House

Design and Layout: Durban Graphic Design
Southaven, MS

Printing: Service Printing and Graphics
Kansas City, MO

Dup 15q Hliday - continued from page 7

and we really found a lot of love in these families. At home again I really miss them and we're looking forward to the next conference.

I'd like to thank all the volunteers who allowed me and my wife to forget for some hours our two babies and be able to relax during these days .

Christine (mother of Daniele and Fabio (idic15))

With the help of our volunteers and some parents I have been working for this little "conference" for months. Seven of us started from our small village: my husband, Fabio and me, and four volunteers of our association. We travelled with the old bus from the "Misericordia" which we had for free, and all my fear about travelling with Fabio had no reason, all took care of him and we had such fun together.

The program for the meeting had three parts: the medical part with Dr. Battaglia, the emotional part with a psychologist and the participation of the organization "siblings", and at least the Sunday morning talking about our future as an association. It all went fine, with the support of a volunteer group at Naples who took care of our kids during the meeting. The place was wonderful, the Naples family took care of taking families from and to airport and station and provided fantastic snacks for the breaks.

But the most important thing was staying together and getting to know each other. The feeling that you are so familiar also with persons you never saw before. And when I asked at the end, when will we meet again, in two years? The answer was, no, next year, we should meet every year since now.

A better result I could not have wished.

Christine

Meri (volunteer):

I was in Naples with Fabio's (idic 15) parents. The conference has been useful for better understanding the idic 15 syndrome, but the experience most enriching is about meeting the children affected by idic 15 (they're lovely angels) and their families. Their determination to overcome difficult situations, the capacity to relate to others, the courage, the sensibility demonstrated to take care of each other...they aren't normal people. They have unusual qualities and uncommon energy; they are a model for everybody.

I wish to express my gratitude for having made their acquaintance. ☐

Remembering Kacey

Kacey Lynn Tenhoff passed away on August 20, 2009, ten days before her 'Sweet 16' Birthday. Kacey had lived in a therapeutic home in Spokane, Wa., since 2004.




Kacey loved life. The minute her feet touched the ground in the morning she was off and going. She had a way of accepting each day for what it was. She loved car rides, fast foods, going for walks, snuggling into a pillow, playing in the water, and Blue's Clues.

This little girl touched many people's lives in her short time with us. As Spokane said in Kacey's obituary, "We are honored to have been able to love this child." As Kacey's mother, I was blessed with a child with idic15 who taught me so much.

AWW- BE- DAH (Kacey's word for "I'm happy")

Stocking stuffers that Marlena has enjoyed are the rubber band ball from OfficeMax and Uno cards. Both of these items can be used functionally, but she uses them to calm herself. Flipping the cards and watching the colors is calming, and she can sit quietly in a car while she takes the rubber band ball apart. She then likes to put the rubber bands around her wrist.


Ruth Kross, mother of Marlena, 10 

ing your child too much or rewarding difficult behavior, but you know best. Better one successful foray into the outside world than three or four really miserable ones.




Bad behavior usually means that your child is overwhelmed, anxious, or fearful.

PREVENTING ISSUES IS ALWAYS EASIER THAN DEALING WITH BEHAVIORS.



I am happy that I grew up with her because she was able to give me unconditional love. The smile that overtakes her face when I walk into a room fills me with intense joy. I know that I can take on anything because I successfully navigated the nearly impossible process of placing her in a residential facility. I still occasionally dream of “normal” Anna when I am snug under the covers in my tiny Manhattan apartment. Now, instead of telling her how glad I am that we can carry on a conversation, I hug her warmly. I whisper that I am so lucky to have her the way she is and promise her that I will always be there to love her, fight for her and protect her as I drift out of sleep into my waking life. 



Fanny M.	10/01/98	Zachary T.	10/21/97	Taylor Michelle P.	11/12/02	Parker J.	12/09/98
Logan K.	10/01/01	Renate D.	10/22/92	William C.	11/14/94	Freya A.	12/09/0
Lucy B.	10/01/02	Makenna J.	10/22/01	Elizabeth P.	11/14/03	Ellie Smith A.	12/12/96
Daniel W.	10/02/75	Taliyah L.	10/23/06	Lindsay K.	11/15/90	Ashley B.	12/12/04
Adam R.	10/02/91	William S.	10/24/02	Stephen L.	11/15/93	Matthew K.	12/12/96
Joshua C.	10/02/94	Krisanto Z.	10/28/00	Isabella A.	11/17/04	Daniel T.	12/12/81
Sarah D.	10/02/96	Emily A.	10/29/02	Benjamin K.	11/17/04	Andrew T.	12/12/02
RyAnne F.	10/03/74	Lucas W.	10/29/06	Twan V.	11/19/02	Chase W.	12/13/00
Janique W.	10/04/96	Jarod W.	10/30/89	Michael S.	11/21/00	Caitlyn N	12/14/06
Riley R.	10/04/03	Lucas W.	10/30/06	Carly G.	11/21/02	Finn P.	12/14/04
Lachlan M.	10/08/06	Khye B.	11/02/98	Melanie P.	11/22/86	Corey & Cody C.	12/14/95
Joshua K.	10/10/01	Sam R.	11/02/99	Kaelyn C.	11/24/01	Declan B.	12/15/98
Alexendra M.	10/10/06	Anna B.	11/03/99	Kristina L.	11/25/81	Sofia O.	12/15/06
Cameron M.	10/11/96	Richard M.	11/04/86	Andrew S.	11/25/01	Olivia T.	12/16/94
Tyler K.	10/12/00	Corrina C.	1/05/96	Chad L.	11/27/75	Sven D.	12/16/98
Colby M.	10/15/01	Carrie J.	11/07/83	Dejuan S.	11/27/98	Ingvild S.	12/16/86
Nick V.	10/15/05	Zoe L.	11/07/05	Bryan W.	11/28/95	Nicholas B.	12/18/87 
Oliva P.	10/16/98	Jordan R.	11/07/99	Ellie K.	11/28/07	Emma T.	12/19/02
Matthew P.	10/17/04	Gavin T.	11/07/03	Gabrielle H.	11/29/00	Aston C.	12/21/02
Nathan L.	10/18/01	Hayley P.	11/08/99	Lillianna S.	11/29/06	Riley B.	12/22/06
Giulio V.	10/18/04	Rohan N.	11/08/02	Carson K.	11/30/00	Austin B.	12/22/95
Jake L.	10/20/03	Will G.	11/11/98 	Lisa P.	11/30/90	Megan R.	12/22/95
				Charlotte C.	12/01/0	Caroline W.	12/22/00
				Max S..	12/01/04	Ethan F.	12/23/03
				Ruth O.	12/02/89	Chelsi C	12/23/93
				Emma and Hannah H.	12/02/05	Seth H.	12/23/01
				Kelley A.	12/03/98	Justin O.	12/23/97
				Gilzon John D.	12/03/95	Stephanie J.	12/26/96
				Hunter M.	12/04/00	Chandler P.	12/27/96
				Jared L.	12/04/02	Ada E.	12/29/99
				Naomi H.	12/07/90	Teddy S.	12/29/90
				Jade P.	12/08/04	Ryan L.	12/29/00
				Jimmy T.	12/08/04	Kevin C.	12/30/95 
				Abigail S.	12/09/97	Joseph T.	12/30/96

IDEAS is a non profit organization that provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome. IDEAS offers help and hope for chromosome 15q duplications.

“Did you know?”

“The chromosome 15q 11-13 maternal duplication is the most common chromosomal abnormality identified in patients with autism spectrum disorders.”

(Clinical Psychiatry, March 2009)

Check out IDEAS magnet ribbons and other holiday gifts from the IDEAS store (at idic15.org) for teachers, family and therapists.



IDEAS

CORPORATE OFFICERS & BOARD MEMBERS

- NICOLE CLEARY
Portland, OR Board Chair
- KADI LUCHSINGER
Fayetteville, NY Executive Director
- PAULA DAVIS
Westford, MA Corporate Secretary
- LORI GEORGE
Canton, MA Corporate Finance Officer
- DONNA BENNETT
Thomasville, PA Co-Founder & Board Member
- RACHEL DOUCETTE
Georgetown, MA Board Member
- TOM DOYLE
Bellevue, WA Board Member
- MICHELE HUGHES
Cincinnati, OH Board Member
- CINDY JOHNSON
Wrightstown, NJ Board Member
- FRANK KOBUSZEWSKI
Camillus, NY Board Member
- LEN POORE
Tewksbury, MA Board Member
- Karen Sales
Ankeny, IA Board Member

PROFESSIONAL ADVISORS

- AGANTINO BATTAGLIA, MD, DPed, DNeurol
Calambrone (Pisa), Italy
- EDWIN COOK, Jr, MD
University of Illinois at Chicago
- BRENDA FINUCANE, MS, CGC
Elwyn Training and Research Institute
- JANNE LASALLE, PhD
UC Davis
- LAWRENCE T. REITER, PhD
University of Tennessee College of Medicine
- N. CAROLYN SCHANEN, MD, PhD
Nemours Biomedical Research