

# THE MIRROR

FALL • 2008

The Newsletter of  
**IDEAS**

IsoDicentric 15

Exchange, Advocacy & Support



FROM OUR EDITOR

As the momentum builds for our International Conference in Indianapolis in June, so does the excitement anticipating the coming-together of our IDEAS Community. This community has grown tremendously recently. So far in 2008 alone, IDEAS has welcomed over 75 new families. Our group truly circles the globe. Just since July we have had families join us from Illinois, Minnesota, Kentucky, Missouri, Washington, Michigan, New Jersey, New York, California, the United Kingdom, South Australia, England, Argentina, Norway, Italy, Mexico and Australia.

As we warmly welcome all of our new members, in this issue of the Mirror we focus on our overall IDEAS Community. This includes a diverse group of children and their parents and siblings, extended

**"SUPPORTING EACH OTHER is one of our main missions"**

this year and read suggestions for possible funding help for attending conference.

Sometimes we have questions for one another that have not yet been officially answered. Listen to a physician/father's thoughts on nutrition in our children. We encourage you to share your own thoughts in various areas of interest to you, and hopefully some of these issues will merit further discussion in a future issue or even at conference. Another key part of our mission is to raise awareness of dup 15q syndrome. To that end, recently some of our board members represented IDEAS at the American Society of Human Genetics

families and friends, professionals who work with our children, and researchers who strive to understand them better. One of our main missions is to support one another. Read about how we do this through celebrating birthdays, remembering those we have lost, helping with the Parent Match program, and celebrating in person at local gatherings. Of

course all of our programs have a cost associated with them, which involves extensive fund-raising. Check our progress for

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.

Conference in Philadelphia. Read what they learned in this issue as well.

One of the Mirror's most popular features is the Family Portrait. After all, that is what the IDEAS Community is really all about—getting to know and love others affected by dup 15q syndrome as we travel this mysterious, challenging, and sometimes rewarding road together.

## INSIDE THIS ISSUE

- Dup 15q Families Gather in the UK...pg. 3
- Representing IDEAS at ASHG...pg. 2
- Nutrition and dup 15q...pg.4 •
- Fundraise your way to the 2009 Conference...pg. 5
- In Every Issue:
  - Family Portrait
  - Cheers To Our Volunteers
  - Birthdays

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 in Kansas City, MO.

[jtrue@kc.rr.com](mailto:jtrue@kc.rr.com)

## IDEAS ATTENDS 2008 AMERICAN SOCIETY FOR HUMAN GENETICS MEETING



*Nicole Cleary (left) and Kadi Luchsinger representing IDEAS at the ASHG Conference in Philadelphia.*

**G**reetings from Philadelphia! This year for the first time IDEAS has a strong presence at the American Society for Human Genetics meeting (ASHG). ASHG is one of the primary organizations for human geneticists. It includes researchers, academicians, clinicians, laboratory practice professionals, genetic counselors, industry scientists, and others with special interests in human genetics. Kadi Luchsinger, Cindy Johnson and Nicole Cleary staffed an exhibit booth, talking with geneticists, genetic counselors, academics, and researchers about dup15q syndrome. Many of the people who stopped at our booth had heard of Prader Willi and Angelman syndromes, but did not know as much about dup15q syndrome. Several were not aware that there is a support group for dup15q syndrome.

Staffing this booth gave us an opportunity to learn things as well. For example, we learned about the increasing use of micro array technology in diagnosing genetic disorders. Micro array is an excellent technology for picking up interstitial duplications of chromosome 15q, so IDEAS can look forward to welcoming many more families raising children with this form of the 15q duplication in years to come.

There were four scientific posters on dup15q syndrome, including a poster that shared the neuropathology examinations from the brains donated to the Autism Tissue Program. It is heartening to see this research moving forward so quickly. Dr. Larry Reiter provided a poster presentation of his preliminary findings from his comprehensive clinical study on children with interstitial duplications of chromosome 15q, the first such study focused on interstitial duplications.

The highlight of the meeting was an invited scientific session entitled The Proximal 15q Syndrome: A Template for Understanding Autism Spectrum Disorders. Several IDEAS scientific advisors and other notable researchers provided a comprehensive presentation on the clinical and molecular aspects of dup15q. These presentations

drew the link between dup15q and autism at the clinical level with reports from Dr. Carolyn Schanen's research study and children seen in Dr. Agatino Battaglia's clinic in Italy. There were several presentations at the molecular level with Dr. Larry Reiter focusing on specific genes involved in dup15q that can be investigated through fly and mouse models. Drs. Amber Hogart and Janine LaSalle reported their findings from the examination of brain tissue from two children with dup15q whose families donated their brain to the Autism Tissue Program. While their presentation on brain GABA-A expression and epigenetic regulation in idic15q patients was extremely technical and difficult for Kadi and me to understand, what is very clear is that the donations of these brains is helping scientists make huge gains in understanding how dup15q syndrome affects the brains of children with this syndrome. It is these understandings that move us closer to targeted treatments. Families who have donated their children's brains to the Autism Tissue Program after a sudden and unexpected death should understand the gratitude from both the scientific community and IDEAS families for their generosity.

Attending conferences like ASHG is both expensive and exhausting. Thank you to all of you who support IDEAS fundraising efforts to make this possible, and thanks to Cindy and Kadi for attending this conference with me.

*Nicole Cleary (pictured on left) is the Chair of the IDEAS Board. She lives in Portland, OR, with her husband Tim and daughters Corrina (idic15), Sierra & Jasmine.*

 **HOW CAN I HELP SUPPORT IDEAS?** IDEAS news flash  
 There are many ways you can help support IDEAS. Learn more — go to:  
[http://idic15.org/ideas\\_supportingideas.php](http://idic15.org/ideas_supportingideas.php)

## "A Dup 15q Party in the Park"



by Pamela Taylor, Mummy to Olivia (aged 13) IDIC15

“Stanley Park was a wonderful place, gardens full of colour and smells. A perfect setting for what turned out to be a fantastic day!”

I just love the buzz and excitement that starts as soon as the suggestion of a family gathering is mentioned. What started as just a casual conversation on 'facebook' with another 'Dup 15 syndrome' family... talking about just the two of us meeting up one Sunday, turned into the biggest gathering of families to date. The weeks leading up to the 7th Sept had been the wettest. There had been floods in various areas, and I was dreading what we would be up against on the day. To make sure we had a plan B this time...I had arranged with Blackpool Leisure Centre for us to take shelter there. The manager Martin couldn't have been more helpful. He made sure there was a room big enough for the 60+ people and he let us use it free of charge!

This gathering was the biggest yet. There were thirteen families and the children ranged from 14 months to 26 years. For five of the families it was their first ever gathering and for two of the families it was their first ever contact with other '15 ers'.

It was great to see some of the families I had met before. It was also wonderful to see some of the changes



Will, Olivia, Pamela and Bob Taylor

in the children too. I was blown over when Callum said "Hiya" to me. To see Charlotte walking towards me also made me smile with delight. Our children are a beautiful bunch and there were many looks from complete strangers.

The families mixed and mingled with each other, exchanging stories and ideas. Some learned new things while others were being reassured that what they were doing was right.



"Olivia helping Stephanie"

“Older and younger brothers and sisters were a joy to meet, and a credit to their families. I think we some times forget about siblings and the need for them to meet others who understand the life they share with Idic 15 families. And the support they can give one another. Looking forward to next meeting.”

*The Holland Clark Family*

“We weren't sure how easy it would be to talk to each other, but once we got there, we realized that all the families were in the same boat and talking freely was not an issue for us all because we had idic15 in common. It was amazing to hear other families talk about their children having no sense of danger, a high pain threshold, obsession with water, inability to concentrate etc, the exact same things that we had noticed with Rajan early on and at last it felt like we weren't on our own and that someone else understood what it was like raising a child with idic 15.”

*Sabby and Ravi –parents to Rajan*

I know that families with younger children were encouraged by what the older ones can do. Like many of them, we were told when we received the diagnosis that Olivia would not walk, talk, and would be severely disabled...Oh I wish they could see her now!

*Pamela lives with her husband Bob and their three children, Rebekah aged 20, Will aged 19 and Olivia (IDIC15) aged 14. They live in the beautiful Yorkshire Dales in the north of England. Pamela organises many of the Chromo15 gatherings in the UK, trying to get together with the other families three to four times a year. This has given many of the families the opportunity to talk to each other face to face and to feel like they are sharing their journey with others. As much as Pamela would love to come to the USA and meet many of the families there too, finance and the thought of Olivia having to endure an eight hour flight fills her with dread!*

# Food for Thought...

By Dr. Jim True

## A Parent Poses a Question on Nutrition in the Individual with dup 15q



Nutrition is important for all of us, but especially so if certain foods or chemicals can cause or worsen problematic sensory and behavioral issues or seizures.

Could it be possible that the molecule glutamate affects dup15q persons in such ways? Glutamate recycles with gamma amino butyric acid, or GABA, in several complex chemical steps. GABA receptors are inhibitory, meaning they are calming, generally, or the opposite of excitatory. Glutamate receptors and aspartate receptors are excitatory, and over stimulation of these can cause seizures. Given that persons with dup 15q have fewer or abnormally-functioning GABA receptors, might any increase in glutamate or aspartate, or any decrease in GABA, either in amount or relative balance, cause some of the problems seen in dup 15q?

If this is so, then our children with dup 15q may have relatively too much glutamate/aspartate compared to GABA, and so could be over-stimulated. It then would seem reasonable to try to decrease or eliminate the amount of glutamate and aspartate taken in the diet or in medication.

The question is how best to do this. Gluten is so named because of the high amount of glutamate it contains. There is much in the media about the advantages of being gluten free. Nutritional advice is readily available, and foods known to contain gluten can be eliminated. It is harder to avoid disguised gluten products. Prepared foods such as canned soups, sauces, crackers, fillings, etc, usually contain gluten and/

or MSG (monosodium glutamate). If a label says “hydrolyzed vegetable protein”, “vegetable protein content”, or has similar wording, it is still likely to contain high amounts of gluten. With the current media exposure, it is easier to avoid gluten now than previously. One theory about the ketogenic diet is that it lowers the glutamate pool in the brain, thereby decreasing the chance of seizures. Some of our children with behavior or seizure challenges have shown improvement on the ketogenic diet.

An additional difficulty is aspartame. This is the sweetener in diet sodas, yogurts, some toothpastes, and many other products including some medications. It breaks down into phenylalanine and aspartate, the amino acid closely related to glutamate. Phenylalanine is the active ingredient in chocolate and also a neurostimulant in its own way (remember Valentine’s Day before kids?). While in many people aspartame may cause little harm, in vulnerable people, such as those with dup 15q, it could be dangerous. There are several anecdotal reports of children in our group having seizure episodes after ingesting aspartame.

As a member of the IDEAS community, I would like to see research which will elucidate the nature of GABA receptors, glutamate and other stimulant issues, and the effect of diet and medication on our children. We need to know which seizure meds work best, and are they best because of their mechanism of action? Do they block glutamate receptors or enhance GABA receptors? Can we find a diet as free as possible from biochemical stimulants? Will this help us improve quality of life for our children

with dup 15q?

Being gluten free and aspartame free will not harm, and can only help our vulnerable children. What do we have to lose?

Editor’s note: Nutrition Issues in the individual with dup 15q will be addressed in a keynote session on Friday of our upcoming conference in Indianapolis.

*Dr. True is a practicing psychiatrist and was the father of a 26-year-old young woman with dup 15q.*

## 3RD ANNUAL IDIC15 RUN/WALK KILLINGTON, VERMONT

BY LEN POORE

At 6:45 a.m. on Sunday, September 14th, a group of volunteers, including family and friends of Sarah and Eric Rasmussen and IDEAS families, arrived at the Killington Recreation Fields in Killington Vermont. In a very steady rain they set up the registration, finish line, presentation and snack areas for the 3rd Annual IDIC15 Run/Walk. The race director was Sarah Rasmussen, mom to Jack (idic15). With her group of local women, known to the locals as the “Friday Night Knitting Group”, she organized this entire event. In addition to Sarah, the “Group” includes Nancy Blessing, Kim Robertson, Trina Hotchkiss, Joyce Stevens and Mary Haff. The commonality in this group is that they all have children (their own or nieces) in the local elementary school and most met when their children started preschool. These women are the backbone of the race and donate numerous hours of their time in advance as well as on the day of the race. Though the group started out with a knitting focus, it has evolved more into a social event for these ladies. But I’ll leave that for a future article!

When registration time arrived the rain continued, but by race time it stopped and remained dry during the race with the exception of a few brief showers. As the final groups crossed the finish line and we moved to the awards portion of this event, the weather improved. Awards were presented to various male and female age categories. Even with the rain this was a great event to witness.

*continued on page 6*

## CONFERENCE – Funding Ideas for Families

As the enthusiasm builds for our conference in June in Indianapolis, we are all faced with the challenge of how to afford attending. Especially in the uncertain economic times we now face, this may be difficult for some families. IDEAS has budgeted limited funds to help a few families with some of their lodging expenses. Often times this is the only way it is possible for a newly-diagnosed family to attend. It is IDEAS' policy that conference scholarships will only be considered after the applicant has exhausted all local and other possibilities for financial assistance. In addition, those accepting funds will be asked to volunteer about 10 hours of their time to help with an IDEAS project during the coming year. Following are some suggestions for agencies and organizations that have helped families with conference expenses in the past:

**State Agencies** – Developmental Disabilities Council – usually found through the Dept. of Public Health

**Early Intervention Program** – for families with kids 0-3 years (some states go 0-5 years). Each state will have a different name for this service. They sometimes provide funding for parent education and attending conferences related to your child.

**Local School District** – ask your special needs coordinator or the person who oversees your child's IEP about helping pay for parent education. If too late for this conference, get it written in the IEP for the 2011 conference.

**ARC (of your State)** – this is an agency that supports people with developmental delays.

**Private Agencies** – Parent Information Center – usually the name of this agency begins with your state name i.e. Vermont Parent Information Center. This is a non-profit group that educates parents on their rights related to people with disabilities.

**Parent to Parent** – a non-profit in most states that supports families with children that have special needs. GREAT resource for many things and most will give you some \$ for conference attendance.

**Local Women's Club** – they raise money to help support community needs. Ask them for funding for the conference.

**Local Church** – ask your church's community groups to help support your attendance at the conference.

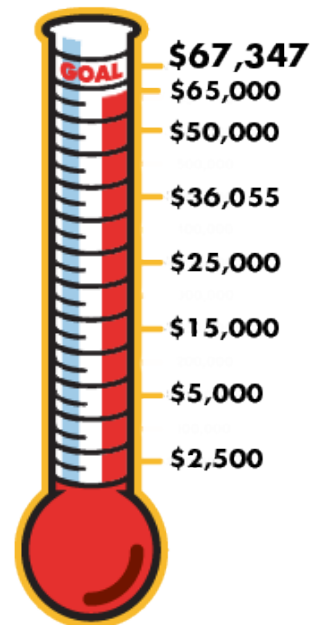
**Local Agencies and Groups** –  
 Rotary Club  
 Knights of Columbus  
 March of Dimes  
 Easter Seals

**Other Groups** –  
 Genesis Fund

Those who have been successful in getting funding in the past advise that it is important to apply very early in the year before allocated funds are exhausted. Also you will need the registration form to apply. This should be available before the end of the year on our website : [www.idic15.org](http://www.idic15.org) . We ask if you are successful in receiving funding from these or other sources that might help other of our families that you share your experience via the list serve.

### 2008 FUNDRAISING

As IDEAS climbs toward its fundraising goal for 2008, there is still time for you to help. See our website for suggestions. Let's head into our conference year financially strong!



## Reflections from a Sibling

### Being a Sister to Chromosome 15

by Sierra Cleary

"Everyone is different  
in the world.  
We can't all be the  
same."



inside when that happens. Sometimes I feel mad.

Being Corrina's sister gives me a way to be special in this world. Because I am helping somebody. And not just anybody. I'm helping Corrina Cleary who is my autistic sister.

*pictured left from left to right: Corrina, Sierra and Jasmine enjoying a family outing to a corn maze.*

*"My name is Sierra Cleary and I have two sisters, Corrina and Jasmine." Jasmine is the smallest. She is only 6. I am 10. My sister Corrina is 12 and she has a problem called chromosome 15 duplication. She can't talk and she can't think as fast as normal kids. She can only focus on one thing at a time. She needs help with a lot of things like going to the bathroom and getting dressed. That means she's autistic.*

The chromosome 15 problem has its ups and it has its downs. The ups are that it is fun to sing to her. She will laugh and laugh and sign "more" "more". She types the word "music" on her letterboard. It makes me feel like I've done something good when I make her laugh. Another upside is when Corrina points to my head and I know she wants me to say "Sierra". Then she points to my chest and sometimes even touches my heart. I know she wants me to say "loves". Then she points to her head and I'm supposed to say "Corrina". When you put it all together, it says "Sierra loves Corrina". That makes me feel joyful and I know that she does have feelings and that she does love me.

Corrina has a disability so we get to park in disability spots whenever she is with us. That means we get to go in first and we get to park close. That's good because we live in Oregon so it rains a lot here. We also get to go to this awesome camp called Camp Prime Time because of Corrina. It's a camp where families who have a kid with chromosome 15 problems can spend time. It's great. You can go fishing and boating and ride horses. I've met a lot of families who have kids like Corrina. I really like getting to be with Katie and Megan Lowell. Their little sister has a chromosome 15 problem like Corrina.

The downside is that sometimes I see people gaping at me and I bet they are wondering, "Why is her sister holding a music toy and looks like she's dumb?" That happens a lot at my school. So, that makes me feel really sad because she's not dumb. Everyone is different in the world. We can't all be the same. Sometimes I think that dumb doesn't mean dumb...it means different. Like my sister Corrina can find music toys even when we hide them up in the cereal cabinet. Corrina pulls up a chair, opens the cabinet and takes the toy out. That's amazing for a kid that people think is dumb.

Another downside is that sometimes my mom has to spend a lot of time with Corrina and sometimes we don't get to do what we want because of Corrina. Like sometimes I'm not on time for school because Corrina's bus is late. But sometimes Corrina has to wait for us too, like at swimming lessons so I guess it all goes round and round. Corrina sometimes pinches and hits us if she's mad or frustrated. She doesn't have any words so what else can she do? I feel icky

### 3rd Annual IDIC15 Run/Walk *continued from page 4*

This year's race had better representation from IDEAS families and their extended family members (aunts, uncles, grandparents, nieces and nephews). Attending the race were the Rivards from NH, the Luchsingers from NY, and the Bopps and Poores from MA. Members of each of these groups did participate in the race, but I want to specifically mention that our IDEAS Executive Director, Kadi Luchsinger, ran her first 5K race and in doing so obtained race sponsors and raised \$1300. The Bopps also obtained sponsors and raise \$1,740 and the Rivards had sponsors and raised \$550. Congratulations to these three families and thanks for the money they raised during this event. IDEAS merchandise was brought to the race by the Poores and we had sales totaling \$460. I know Sarah truly appreciated the efforts these families made to attend the race and it showed race participants the commitment there is to IDEAS. Sarah and Eric were proud to present IDEAS a check for \$15,370.

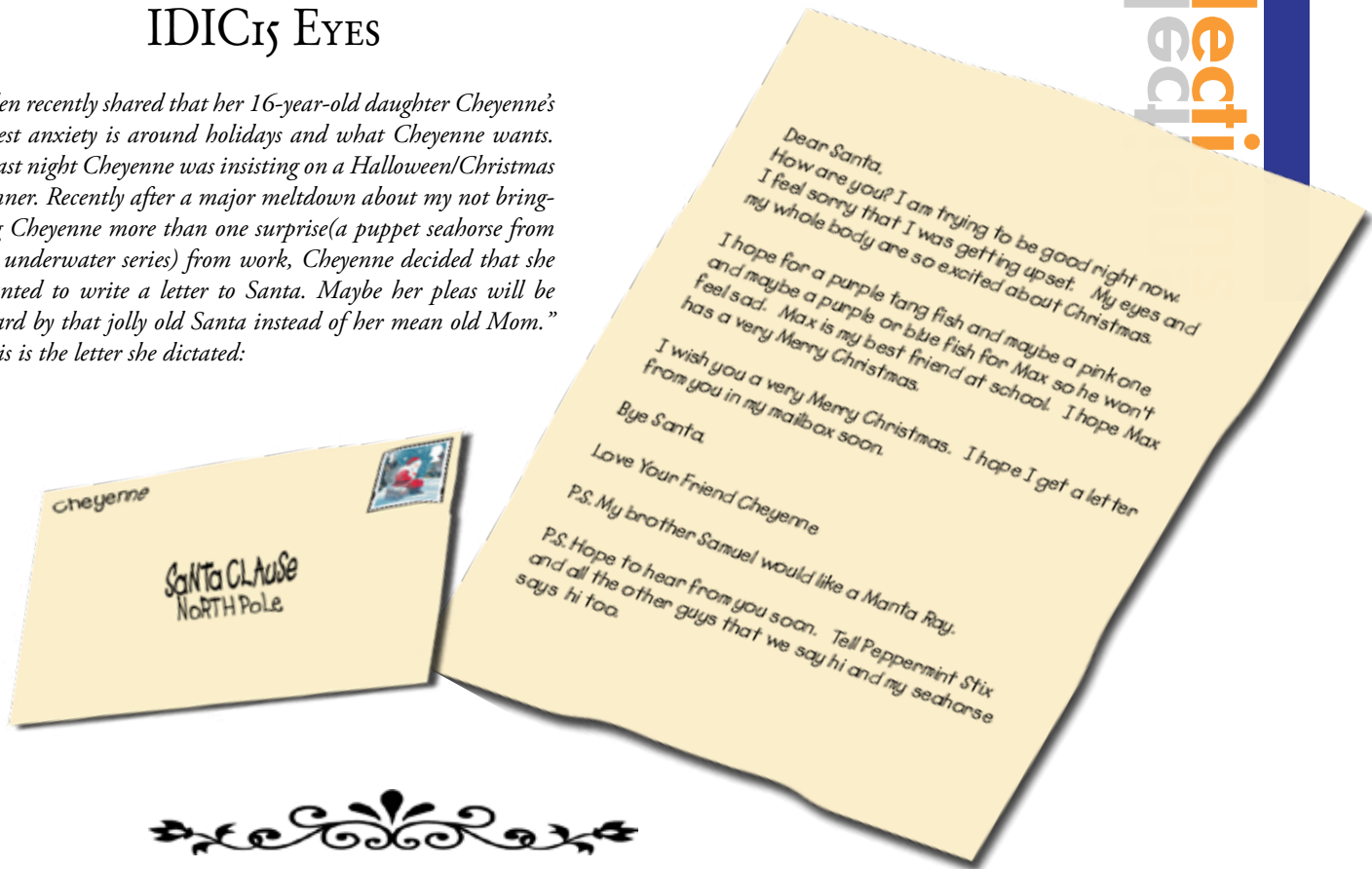
This was my second year attending this event and I was just as much in awe this year as last year, and I am already looking forward to next year's race. Sarah and Eric do all of this on behalf of their son Jack, who is one of the very special group of children that bonds us all together in the IDEAS organization.

On a personal note, I want to thank both Sarah and Eric for opening their home by extending an invitation to all the IDEAS families to a barbeque after the race. It was nice to have time to sit and talk with the other families, as well as watch the children play.

This column is designed to share perspectives from recent Listerve discussions.

## HOLIDAYS THROUGH IDICIS EYES

*Ellen recently shared that her 16-year-old daughter Cheyenne's latest anxiety is around holidays and what Cheyenne wants. "Last night Cheyenne was insisting on a Halloween/Christmas dinner. Recently after a major meltdown about my not bringing Cheyenne more than one surprise(a puppet seahorse from an underwater series) from work, Cheyenne decided that she wanted to write a letter to Santa. Maybe her pleas will be heard by that jolly old Santa instead of her mean old Mom." This is the letter she dictated:*



## In Loving Memory of our Dear Will



When Will was born on Nov 11, 1998, the genetic doctor who gave us the diagnosis didn't know much about Inverted dup 15, so Pat went on the net searching. He found IDEAS and at the time I told him I didn't want to have anything to do with it because my little baby was fine. Will was already receiving PT & OT at the house twice a week. My goal was to make sure Will walked. I could live with him not speaking but I always thought if he could walk his life wouldn't be so restricted. If there was a therapy that we thought would help Will, we tried it, from swimming and therapeutic riding to oxygen therapy at 6:30 in the morning before school.

When Will was 9 months old he started having seizures and then began the medicine game. We tried so many meds with him and he wasn't getting any better. Some days it seemed like he was getting worse, so we started him on the Keto diet. He stayed on the diet until this past September. We took him off because it had been 3 years and Will didn't gain any weight on the diet.

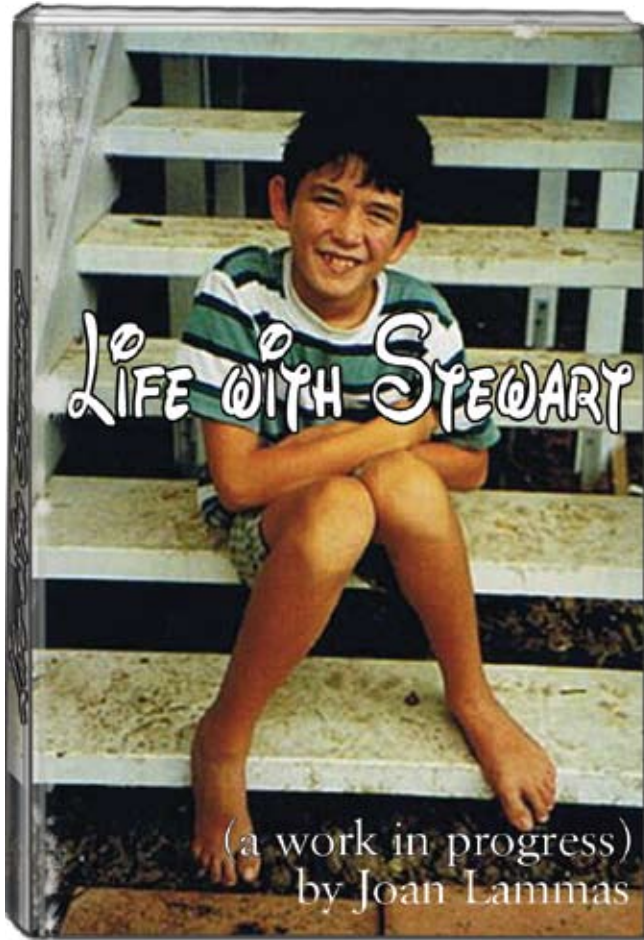
Will taught me things that I never knew I needed to learn. If I had to describe myself before Will, I would have said I was a kind, caring person but Will taught me how to really care for someone unconditionally. He taught me that being different was OK, he taught me that it was ok to lean on someone for support during hard times because I always thought I was so strong and not much would affect me, but I was so wrong. Will taught me that having a lot of material things just wasn't important as long as you had someone who loved you just for you. Will taught me to fight for something instead of giving up and moving on to something else. Before Pat and I got married over 16 years ago, I was

told marriage was hard, you had to work at it, but when you put a completely disabled person in the mix working at it was an understatement. We have so many happy times and we as a family never left Will behind. If going somewhere couldn't accommodate Will then we didn't go. Will taught Pat and me what true love was all about and to truly love someone without even giving it a second thought. I was told that Alex is the kind person he is today because of Will. Unfortunately Jacob and Samantha didn't get that much time with him but they will know him. I am so happy to know that Will brought much love and joy to a lot of other people and not only his family.

Our precious Will died on Oct 9th as I was getting him ready for school. He had a bad seizure and his little heart couldn't take it anymore and stopped. Will, I hope you are ok now, like we have been told. We love you and you will forever be part of our daily life.

LOVE,  
Mommy, Daddy, Alex, Jacob & Samantha

# Family Portrait



Fast forward six years to when Stew began to discover that he had an opinion. This was new! Stew wanting something! The quiet time was over and life with Stew began to get interesting – and hectic – and we learned about autism. We learned about obsessions and fears, tantrums and frustration, behavior management, and communication techniques. Oh, yes and we also learned that being embarrassed in public is a waste of time.

As the years rolled on Stew grew bigger and stronger. We struggled with his difficult behavior. We cried when others were thoughtless. We rejoiced in his every small achievement and we kept on believing that Stew could always learn a little bit more. Along the way we met some wonderful people who gave us help and encouragement and we found out who our real friends were.



Along

Life with Stew began quietly enough. There he was - a beautiful, soft little bundle who never cried and who slept all night and most of the day. A dark-haired boy who lay in his rocker, looking at the sky and sometimes smiling to himself but never looking at me. Then came the doctor's visits and the therapies and the play groups while we worried and wondered what the future held. Slowly but surely he began to respond and then one day when he was 15 months old a most exciting event occurred – for one brief moment he caught my eye and I was jubilant! Then onwards, ever onwards with physio, OT, speech therapy and special ed classes so that it seemed our whole life was absorbed in moving our placid, passive little boy to the next milestone.

*"we cried when others were thoughtless. We rejoiced in his every small achievement and we kept on believing that Stew could always learn a little bit more."*



So now here we are after 19 years of life with Stew. In Terry Pratchett's words, "we've gone through crazy and come out on the other side". Please join us for a few moments.

Life with Stew is waking up at the crack of dawn to hear an eager voice, "One, two, three up!" It's cooking sausages (yet again) because Stew can be relied on to eat sausages. Life with Stew is singing Wiggles songs as we walk through the supermarket and watching looks of surprise turn to quiet smiles.

Life with Stew is adjudicating between two brothers, each with





their own obsessions. Stew's obsession demands that all the lights be turned on and his brother's obsession requires the planet to be saved and the lights to be turned off. Turned on, turned off, turned on.....we have some interesting evenings. It's buying yet another CD player because Stew has managed to break it (again).

Life with Stew is discovering a sticky trail of chocolate and realizing that Stew has found the latest hiding place. Then hiding the chocolate in a new place and forgetting where you hid it!



*"We learned about obsessions and fears, tantrums and frustration, behavior management, and communication techniques. Oh, yes and we also learned that being embarrassed in public is a waste of time."*

Life with Stew is having one foot in the world which requires that we earn a living, pay our taxes and listen to politicians while the other foot is in a happy little bubble where birds sing, fridges hum, chip machines tinkle and no-one has ever heard of the war in Iraq.



Life with Stew is getting really excited because at the ripe old age of 19, he has looked at himself in a mirror for the first time. Life with Stew is celebrating 20 years of cleaning up bums and wondering when the job will ever end. It's being so, so tired, breathing a great sigh of relief when he falls asleep and kissing his sweet, angelic face good night.



*Stewart lives in Brisbane, Australia with his mother (Joan), father (Ted) and long-suffering brother Chris. Grandma Mac, who lives not far away, is his constant friend and teacher. Our family enjoys bushwalking, kayaking and singing. Stewart attends a day activity centre where he joins in walking, swimming sailing and ball games.*

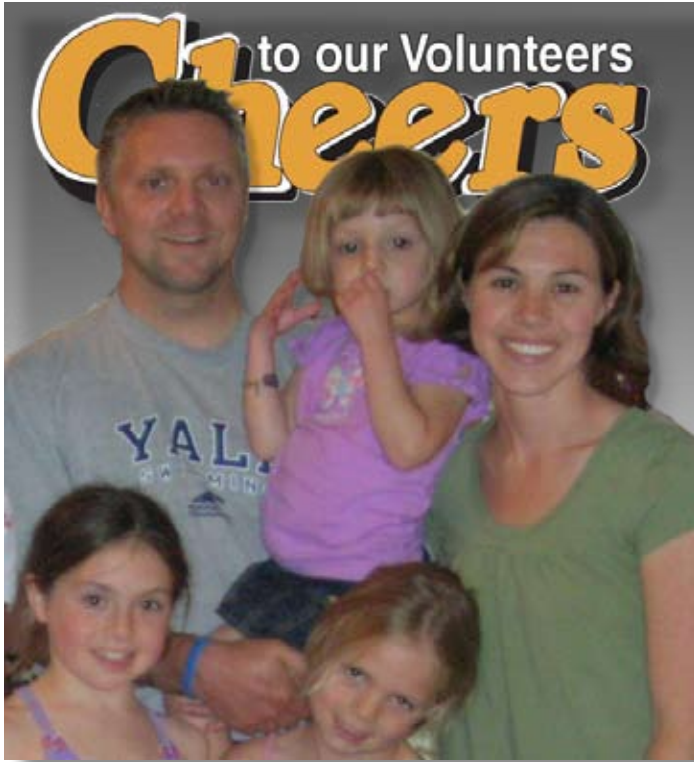
IDEAS is in need of items for the raffle at conference. In particular, we would like to have baskets from different states. We will also be looking for people who can obtain sponsors for the conference on the business level \$500-\$5000 and also for individual session sponsors in the \$100-\$200 range. Also remember company matching programs and to check out the IDEAS store on our website

WHAT'S NEW

CHECK OUT



IDEAS store



*Volunteer of the Quarter:  
 Colleen Lowell and IDEAS Parent Match Program*

**What a Match!** This issue the IDEAS Volunteer Spotlight shines on Colleen Lowell. Colleen has been helping with IDEAS' Parent Match Program for about two years. She never did a formal training session as the timing for the training conference calls really didn't work for her, living on the West Coast. However she did receive and read the packet about being an effective mentor. Parent Match was interesting to her because when her daughter Grace was diagnosed, it was so helpful to talk to people who understood and could relate to the issues her family was having. She wanted to give back in that same way.

She has spoken with probably a dozen families. In the beginning, she was matched up with families similar to her own, but that has changed. She has found that it doesn't make much difference to her. She has always done this by phone, and then sent a follow up email. In several cases, she has continued to speak with the family after the initial call, leading to a real friendship. It takes her less than an hour a month to do this job. She definitely thinks this is something that relatively new families could help with; in many cases, the families being called have infants/ toddlers and those who recently went through those stages often remember better and have

more current info to share than experienced families. She would definitely encourage others to get involved with Parent Match as it is really pretty easy, doesn't take up much time, and introduces you to others in our amazing group. She has gotten a lot out of being a mentor in that she loves talking and connecting with other families dealing with chromosome 15q duplication syndrome. Colleen thinks the more that we are able to share with one another, the better off we all will be. Congratulations to Colleen Lowell, our Volunteer of the Quarter.

*Editor's Note: With IDEAS' recent rapid growth there is more demand than ever for support. There is a huge need for more Parent Match mentors. IDEAS will train you! To help with the Parent Match Program contact Kadi Luchsinger at 888-64-IDEAS or email [info@idic15.org](mailto:info@idic15.org).*

## FUNDRAISING IDEAS

### THE SIMPLEST FUNDRAISER

For those of you living in the Northeast who shop at either Shaws or Star Market, you can help IDEAS without much effort at all. Just save your receipts and send them to Lori George at PO Box 568; Canton, Ma. 02021. Mark them with IDEAS number, 5297102, and IDEAS will get a percentage of every purchase. Ask your friends and family to save theirs too and help support IDEAS' many programs and conferences that are created to support you. What could be simpler?

### YANKEE SWAP

*(from the family of Emma Davis)*  
 Emma Davis' family usually does a Yankee swap on Christmas Eve. This year they are all donating to IDEAS instead of buying swap gifts. Then they will have a little game they have come up with that will take the place of the Yankee swap that doesn't include additional gift giving. Thank you for remembering IDEAS!



# HAPPY BIRTHDAY TO YOU!

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



## My Daughter's Smile

by Louise Gerber

*Your smile*

*emiting rays of warmth*

*saturating the abyss between us*

*showering its light in halo*

*tickling my soul*

*mirroring my love.*



*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.*

## ***"It's Full Steam Ahead"***

for the next IDEAS International Conference  
 in Indianapolis, Indiana,  
 June 25 – 27, 2009.  
 Don't forget to mark your calendars



# IDEAS

## CORPORATE OFFICERS & BOARD MEMBERS

- NICOLE CLEARY Board Chair  
Portland, OR
- KADI LUCHSINGER Executive Director  
Fayetteville, NY
- LORI GEORGE Corporate Finance Officer  
Canton, MA
- PAULA DAVIS Corporate Secretary  
Westford, MA
- DONNA BENNETT Co-Founder & Board Member  
Thomasville, PA
- HEATHER BRUCE Board Member  
Indianapolis, IN
- FRANK KOBUSZEWSKI Board Member  
Camillus, NY
- LEN POORE Board Member  
Tewksbury, MA
- JANE TRUE Board Member  
Kansas City, MO

## SCIENTIFIC & PROFESSIONAL ADVISORS

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