

THE MIRROR



The Newsletter of
IDEAS

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Exchange, Advocacy & Support

FROM THE EDITOR

By Jean House

Whether your loved one has been newly diagnosed or has been living with dup15q syndrome for many years, attending an IDEAS conference can be a revelation, a crash course, and a comfort. If you can make it to the conference June 23-25 in Philadelphia, you won't be disappointed.

The event is held at a kid-friendly hotel (a pool and a respite room are available) amidst a group of understanding and supportive families, so you can be comfortable taking your child who has dup15q. At the sessions, you will gain knowledge that is not available from any book or website. Experts will share the latest information about neurology, genetics, feeding and gastrointestinal issues, behavior specific to our children, seizures, and new research into dup15q syndrome. Members can share in sessions that focus on moms, dads, siblings, and extended family.

At the conference, we'll learn how to tackle specific challenges, including potty training, handling the IEP process, transitioning to adulthood, and more (a full agenda is available online at www.dup15q.org/Conference.html). And the learning doesn't end with the

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.



CONFERENCE REGISTRATION NOW OPEN

Register and order conference t-shirts online at www.dup15q.org/conference.html

Become a conference sponsor at www.dup15q.org/Sponsorship-Conference.html

If you are unable to register online, please call 877-IDEAS15 to request a registration packet.

Register by May 25, 2011 to avoid late fees.

presentations; meeting other families facing the challenge of living with dup15q and learning from their experiences is invaluable. It is good to find community.

This issue of *The Mirror* is dedicated to the upcoming conference. Inside you'll find previews of speakers' presentations on acceptance, risk and safety management, positive behavior support, developmental optometry, and educational practices. Also, IDEAS members share insights about what to expect at a conference and suggest ways to get involved. As always, our families share their stories and experiences. We look forward to seeing everyone in Philadelphia this summer, where we'll gain new knowledge as well as share the strength and hope we've all gained so far on this special journey.

CONFERENCE REGISTRATION TIME

On behalf of the IDEAS Board and the Conference Planning Committee, I am thrilled to inform you all that the 2011 International Conference materials are now available on the IDEAS website, www.dup15q.org. Registration can be done online, which is new this year.

You will notice that the registration fees have been cut in half from the previous conference. This change is due to the fundraising efforts of our families and friends. Thank you to all who held fundraisers or donated to IDEAS. Your efforts have allowed us to significantly reduce the registration costs to our families!

I look forward to seeing you all in June. It is a conference you will not want to miss. If you have any questions, please let me know.

Kadi Luchsinger, Executive Director

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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.

<http://www.dup15q.org>

Hi Ho, Hi Ho, It's Off to the Conference We Go!

By Jill Baker

Whether you have recently received a diagnosis of dup15q syndrome or have just joined IDEAS, here are a few things to help you prepare for the conference:

WHERE TO STAY

If possible, try to stay at the same hotel as everyone else. It might be less expensive off site, but the contacts, friends, and information you will receive sitting around the pool after the day's meetings are over might be even more valuable than what you gain from the meetings. The friendships that you start to forge will be invaluable for getting you through tough times and answering all of the questions that will come up as your child grows.

WHO SHOULD ATTEND THE CONFERENCE?

If possible, bring some of your family members who will be there with you during your life's journey: a parent, sister, brother, or babysitter who will be a part of your child's care. This is important for many reasons. One reason, the most obvious, is that it is sometimes hard for others to realize what your life entails. At times, it will be hard for you to ask them for help, but what they learn from this conference can be very valuable in explaining what you will need down the road. The second reason: multiple information sessions occur at once, so having more than one adult attending allows you to learn from two or even three sessions at once. Finally, it is nice for other caregivers and family members to attend. It gives them a chance to gain firsthand knowledge about the diagnosis without having to rely on you for the information. It really works to decrease any apprehension they may have and gives them an opportunity to make connections as well.

WHAT YOU MIGHT FEEL

Our dup15q kids have delays and disabilities. You can't deny that. It may be

hard to see some of our kids who have been more affected than others. But you will also get to see the gamut of the problems that affect our kids, realize and see that there is always hope, and understand that—no matter what—we have an incredible bunch of kids! (In fact, you will get to see that our kids are very similar, right down to their looks!)

You will also see that other families have been affected just as much as yours and that we can all survive and triumph over our struggles. You will feel relief at finding all these wonderful people who are going through many of the same things you are. Don't be afraid or hesitant to ask questions: we all love to talk about our children! Make as many friends as possible and especially get to know those in your geographic vicinity. Trade e-mail addresses and phone numbers. It is a time to connect, even if someone's child is several years older than yours.

You may be overwhelmed at your first conference. If your child was diagnosed recently, much is changing in your life right now and all of it is still new. Don't be disheartened or disappointed; just try to take in the meetings that are meaningful now or might have meaning over the next few years. The amount of information can be a lot to take in: take notes, ask questions, and know that you can go back and reread the information later. And while you are there, take a moment to think about what would make the next conference even better.

Going to a conference can be intense, but we hope that this information has helped to calm your nerves and answer some of your questions. Once you are there, you will feel included, you will feel welcome, and you will feel thankful. It is a wonderful experience. Hope to see you there!

CONFERENCE FAST FACTS

- Childcare is not provided.
- Children are welcome, and many families bring their children. We do ask that if your child becomes disruptive, you step out of the conference room, as not to disrupt the lecture. Some families find it easier to attend sessions without their children, but children are welcome.
- There will be a store on site selling IDEAS-branded merchandise.
- At the dinner, IDEAS has a large raffle and silent auction with many great prizes. This fundraiser helps offset some of the costs of holding the conference.
- If a caregiver or family member is not attending any sessions but plans to eat meals with you, the same registration fee applies. There is a reduced rate for children. People with dup15q syndrome are free.
- A limited number of scholarships are available. Preference is given to families who have never attended a conference before, but all are welcome to apply. If you receive a scholarship, you will be required to volunteer 10 hours for IDEAS within the next year. Scholarship forms are now available online.
- A limited number of conference T-shirts will be available at the conference. It is best to order your T-shirt ahead of time with the order form that is available with the registration materials.
- A break room for children will be provided. This room will have toys, movies, books, etc., but it is not staffed. Children are to be supervised at all times in this room.
- There is a dinner ticket price for people who are attending the dinner only.

IF ACCEPTANCE DOES NOT MEAN GIVING UP, WHAT DOES IT MEAN?

By Robert A. Naseef, Ph.D.



I thought I could never accept my baby's autism. After 29 years, there are times when I still wonder who my son might have been and who I might have been as well. Sometimes it seems like only yesterday when I held Tariq for the first time. My heart pounded with excitement as I held his soft body next to my heart and our eyes met. Instantly he made me a father with visions of playing baseball and building model airplanes together and having a warm, close relationship.

Then everything changed as the "autism bomb" hit and he began endless repetitive activities. He stopped sharing his joy in playing and stopped talking. A few years later he was diagnosed with autism and mental retardation. The impact sent family life veering sharply from the course we were on. That I would lose my perfect baby was beyond anything I could fathom. I can remember believing that I would never smile or laugh again if he never spoke again.

HELP WITH THE CONFERENCE AUCTION AND RAFFLE

By Theresa West

It's time to work really hard to get auction and raffle items for the conference. We need everyone's help to meet our goal of raising \$10,000 and making this year a success. If you are willing to donate a basket from your state, please let me know. Also, if you are willing to help make requests from your local museums, amusement parks, and other attractions, please let me know. (Most of the time they will only consider within a certain radius.) A letter that can be used to solicit donations from businesses is available in the files section on Big Tent (the file name is Donation Letter). You can reach me at theresa.west94@yahoo.com.

How could it be that he would grow to adulthood and not read or write or speak? It is a grief like no other. My dream of a healthy child shattered. As it is for so many people in this situation, my hope for a cure would live on. For a long time I believed that the best medical care and my love and efforts would change him.

Parents need support and good services to come to terms with what is possible and what is not for their child. I could not have ever found peace without support. My wife, Cindy, Tariq's stepmom, weathered the storms of his autism with me and never wavered in her love. She knew autism from working in the field and helped me grasp the diagnosis I was trying desperately to deny. It took me two years before I could utter the word "autism."

Good services and hard work do help tremendously, but autism can be relentless. Frantically and persistently, 25 years ago, I followed various treatment approaches: behavioral, educational, dietary, and developmental. Our culture tells us that with hard work we have the opportunity to achieve anything. Yet, despite intensive treatment, he did not make dramatic progress. I worked so hard to change him, but in the end I would have to say that he has changed me.

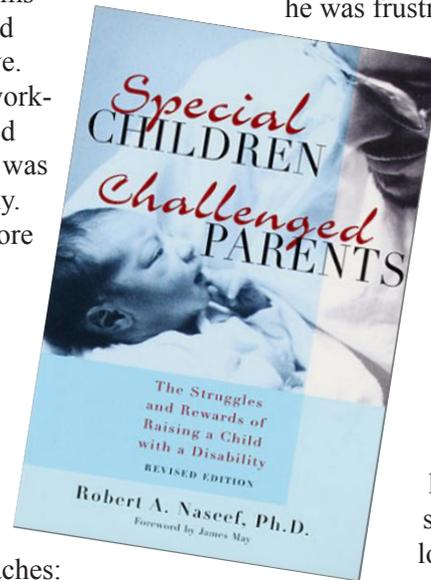
I learned deeply through my experience, what Kahlil Gibran meant in *The Prophet* when he wrote that joy and sorrow are inextricably woven together, for sorrow opens our hearts to the experience of joy in everyday life. Accepting that Tariq's condition would be enduring was

imponderable. Nonetheless, I learned the developmental approach of celebrating what he could do. This made a huge difference for our relationship. He became a happy child, and I learned to enjoy him and accept him as he was. When I played with him in the ways I thought were weird, he laughed and responded and was happy. When I constantly pushed him to look, to feel, and to do the things that seem "typical," he was frustrated and cranky. The

autism that I hated with a vengeance refused to go away.

On the path to acceptance, I have learned many things that have helped me. My son taught me the meaning of unconditional love: to honor his sacred right to be loved for who he is, not what he has

achieved lately, how he looks, or how much money he will earn. I learned the lesson that hard work isn't everything. That grief comes and goes. That anxiety and sadness come and go. That it takes time to heal a broken heart. That happiness and meaning can abound with acceptance. We don't have to push away our painful thoughts and uncomfortable feelings. I learned that acceptance does not mean giving up but rather learning to live with our mental and physical challenges. I still try to get Tariq to look at me, to sit with me, to communicate with
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WANDERING AND OTHER WORRIES: ARE YOU PREPARED FOR AN AUTISM OR DUP15Q EMERGENCY?

By Dennis Debbaudt



To ensure safety and lower risk for a child or adult with dup15q syndrome, parents and care providers will need to become proactive and prepare an informational handout. This handout should be developed, copied, and carried with you at all times: at home and in your car, purse, or wallet. Also, circulate this handout to family members, trusted neighbors, friends, and coworkers. The handout will also come in handy if you are in an area other than your neighborhood and are approached by the police.

WANDERING

Wandering can occur anywhere at anytime. The first time is often the worst time. A leading cause for concern is children and adults who run away or wander from parents and care providers. For instance, children and adults with autism or dup15q are often attracted to water sources such as pools, ponds, and lakes. Tragically, drowning is a concern.

If wandering is a concern, contact law enforcement, fire, and ambulance agencies. Ask your local 911 call center to “red flag” this information in their database. Dispatchers can alert patrol officers about your concerns before they arrive. When we provide law enforcement with key information before an incident occurs, we can expect better responses. If wandering is an issue for your family member, consider contacting a professional locksmith, security company, or home improvement professional.

ALERT YOUR NEIGHBORS

The behaviors and characteristics of autism and dup15q have the potential to attract attention from neighbors and the general population. Law enforcement professionals suggest that you reach out and get to know your neighbors:

- Decide what information to present to neighbors
- Plan a brief visit to your neighbors
- Introduce your child or adult or bring a photograph
- Provide your neighbor a simple handout with your name, address, and phone number
- Ask them to call you immediately if they see your son or daughter outside the home
- Exchange phone numbers

This approach may be a good way to avoid problems down the road and will let your neighbors:

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Another concern is preparation in the event that you become incapacitated or injured while caring for a person with dup15q at home or in the community.

Knowing your neighbors can lead to better social interactions for your loved one who has dup15q syndrome.

EMERGENCY CONTACT HANDOUT MODEL

- ✓ Name of child or adult
- ✓ Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- ✓ Names, home phone, cell and pager phone numbers, and addresses of parents, other caregivers, and emergency contact persons
- ✓ Sensory, medical, or dietary issues and requirements, if any
- ✓ Inclination for elopement and any atypical behaviors or characteristics that may attract attention
- ✓ Favorite attractions and locations where person may be found
- ✓ Likes and dislikes, approach and de-escalation techniques
- ✓ Method of communication if nonverbal: sign language, picture boards, written word
- ✓ ID wear: jewelry, tags on clothes, printed handout card
- ✓ Map and address guide to nearby properties with water sources and dangerous locations highlighted
- ✓ Blueprint or drawing of home, with bedrooms of individual highlighted

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POSITIVE BEHAVIOR SUPPORT AND PROBLEM BEHAVIORS

By Dan Baker, Ph.D.



If we think of the things a person can do to create barriers to a good life, problem behaviors are surely on top of the list. Problem behaviors may include hitting, biting, breaking things, or screaming, and they are seen among people with dup15q syndrome, especially people with dup15q who also have some of the symptoms of autism, such as communication delays, repetitive behavior, or poor social interaction. The way we respond to a problem behavior is critical, as we may make the problem better or worse. One evidence-based way to respond to problem behaviors and make things better is positive behavior support (PBS).

PBS is a proven strategy for responding to and preventing problem behaviors. It was initially developed as a framework for intervening on dangerous, severe problem behaviors among individuals with significant developmental disabilities, but in recent years it has been used with people who have milder disabilities as well. PBS generally includes the following types of strategies:

MULTI-COMPONENT INTERVENTIONS

Interventions in PBS rarely only have one strategy. People are complex, and, as such, interventions to change problem behavior often must have multiple pieces.

QUALITY OF LIFE

PBS aims to improve a person's whole life. Why? Happier people with things to do don't want to spend their time on problem behavior. Idle hands really are the devil's work tools.

IDENTIFY BASIC CAUSES

PBS teaches us to address the root causes of problem behaviors. Is a person bored? Is a person frustrated? Does a person have trouble letting people know their needs? Crucially, is the person rewarded for the right things or the wrong things?

How do you figure out the root causes? That is where a functional assessment fits in. A functional assessment is a process in which the various causes of problem behaviors are identified. It may involve interview and observation, along with collection of information about the problem behaviors.

A quick Internet search will point you toward many free online resources that will give you more information. As a family, you might do some reading and try it on your own, and you might ask for assistance from your child's teachers or other care providers. Local family organizations can direct you to local professionals who may have skill in this area as well. Basically, the message is to figure out what's going on and try some different things to change it, being as positive as you can be throughout the whole process, even when things may get frustrating.

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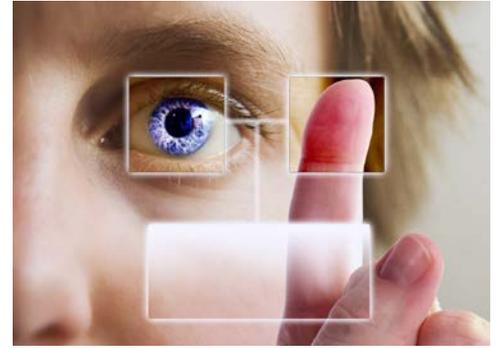
Vision Testing and Optometric Visual Training

By Steve Gallop, O.D.

When most people think of vision, especially vision testing, they probably think of a chart of letters on a wall. Vision is a very different thing for me, however. I am a developmental optometrist. I help people of all ages to be more comfortable and more effective with anything they do while using their eyes—which brings up another issue. We do not see with our eyes; we see with our brains. Obviously, light enters our eyes to start this process, but most of what I call the visual process

takes place in the brain. In fact, the visual process is a full-body process. The optic nerve, which carries the signals created by light entering the eyes, sends this information to many parts of the brain and body, including a pathway that reaches the balls of the feet and pathways to brain centers related to emotions, motor planning, and life planning.

The primary purpose of the visual process is to guide our actions. The visual



process is pervasive in human behavior and develops throughout our lives. It can also enhance or hinder our overall development. Eye movements begin in the
Continued on page 7...

EDUCATIONAL BEST PRACTICES: WHAT SHOULD YOU LOOK FOR IN A PROGRAM FOR YOUR CHILD WITH DUP15Q SYNDROME?

By Barbara Haas-Givler, MED, BCBA

INFORMATION OVERLOAD

Parents and educators alike often have a difficult time sorting through various educational models and approaches. Not only do they get information from school personnel but also through other parents, advocates, and the Internet. Parents often feel overwhelmed by the Individual Educational Program (IEP) process, unfamiliar terminology, special education laws, and the range and types of classroom placements and services proposed by their school district.

EVIDENCE-BASED AND BEST PRACTICES

Educational practices and intervention techniques come and go much like a pendulum swings. Keep in mind that some programs are new packages for old techniques. Some are new but others are refinements or improved treatment models or strategies. Parents and professionals are cautioned to seek, whenever possible, evidence-based programs or programs that have demonstrated effectiveness. Parents should be wary of popular programs that may be fads and have limited authentication of educational benefit.

TOOLS AND TOOLBOXES

It is often useful to think of the intervention model as a toolbox with accompanying tools. Information will be presented to help parents better understand many of the tools and toolboxes frequently used to address the needs of children with dup15q. Some of them are: Applied Behavior Analysis (ABA), Floortime (DIR), Picture Exchange Communication System (PECS), Verbal Behavior/ABA (VB/ABA), Assistive Technology (AT), Augmentative and Alternative Communication (AAC), and Treatment and Education of Autistic and other Communication related handicapped Children (TEACCH).

Parents who are “in the know” are better prepared to make decisions and work with their children’s school team and therapists to design an appropriate, effective program for their child with dup15q.

BE INFORMED AND TRUST YOURSELF

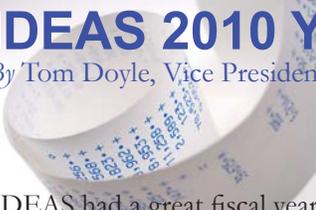
Is there an exact right program for the child with dup15q syndrome? The answer is no. What is most important is finding out what works and is right for your child and your family.



BARBARA HAAS-GIVLER, MED, BCBA, IS AN EDUCATIONAL CONSULTANT AND BOARD CERTIFIED BEHAVIOR ANALYST WITH 35 YEARS OF EXPERIENCE IN SPECIAL EDUCATION, SERVING IN MANY DIFFERENT CAPACITIES OVER THE COURSE OF HER CAREER. SHE HAS PARTICIPATED IN RESEARCH FOR CHILDREN WITH DUP15Q AND PRESENTED AT IDEAS CONFERENCES. GENETIC SERVICES AT ELWYN OFFERS CONSULTATIVE SERVICES FOR INDIVIDUAL STUDENTS, AS WELL AS STAFF TRAINING TO HELP SCHOOLS ADDRESS THE COMPLEX NEEDS OF CHILDREN AND ADOLESCENTS WITH DUP15Q SYNDROME.

IDEAS 2010 Year-End Financial Report

By Tom Doyle, Vice President of Finance



IDEAS had a great fiscal year in 2010 thanks to the outstanding support of its families and the direction of the board. When looking at the IDEAS budget, one has to keep in mind that one year's budget includes a conference and the next year doesn't. We have just completed a non-conference budget year in great shape.

In 2010, we budgeted for \$64,000 income and \$61,000 expenses. At the end of the year, actual figures were \$88,000 income and \$43,000 expenses. The income was more than expected, primarily as a result of the awesome Chicago area Golf Tournament (which raised \$27,000) and the amazing Vermont Fun Run (which raised \$22,000), as well as other family fundraisers such as the basketball pool, the Christmas Card sale, the dress for work days, escrip, the tea, and others. Expenses were significantly smaller than projected, too.

As we budget for the 2011 fiscal year, we are going into some uncharted areas, including a conference in Philadelphia. We have some history from former conferences but little documentation to guide us, so the board is continuing the process of making sure we are fiscally responsible and base our budgets on concrete data, not hopes.

For the fiscal year 2011, we have budgeted \$166,000 for income and expenses. Our hope is that our budgeting process again will produce more income and fewer expenses than projected as we try to tighten up the budget so it provides us with a realistic set of assumptions.

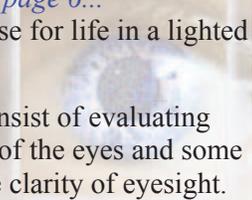
The board has also taken the first step in making IDEAS a very viable charitable organization, as we decided to begin paying a small stipend to our executive director and communication vice president. In order to have the opportunity to apply for grants and for other programs, we need to make sure that IDEAS's

interests are represented properly. An investment today will produce many benefits over time. The board decided now was the time to make this move.

All in all, IDEAS is a very healthy organization. As a result of the generosity of our families and the great volunteer work of several of our members, IDEAS was able to drastically reduce the registration fee for this year's conference in the hopes that many more families will be able to attend. We take our responsibility for IDEAS funds very seriously and hope to be able to continue to provide great support and services to our families. We have moved to new software to help us with fundraising and hope to have an IDEAS registry up and running in the very near future.

Thank you for your support and encouragement as we make IDEAS an even greater organization that allows us to continue to provide great support for our families.

Vision Testing from page 6...



womb as we rehearse for life in a lighted environment.

Most eye exams consist of evaluating the physical health of the eyes and some measurement of the clarity of eyesight. While these are important issues, there are much more important issues if one wishes to understand how a person uses his or her visual process to gather information from the environment and to use that information to carry out actions from crawling to walking to driving, from writing to reading to catching a ball. A thorough visual evaluation should include a dynamic investigation of eye movements, eye teaming, and focusing.

The most basic aspect of the visual process is the ability to aim the eyes at whatever we choose to look at. This may sound simple, but many people are less than precise at aiming their eyes where

they intend. While some inaccuracy may be normal, the more precise we are at aiming our eyes, the better everything else works and the more effective and efficient we will be at whatever we do. Eye teaming is about aiming both eyes at the same thing at the same time. This is how we see 3-D. Poor eye teaming may result in double vision, poor coordination, and/or difficulty learning. Our focusing must be able to shift from one distance to another accurately and instantaneously countless times during an average day.

We should be able to do all of these things with minimal effort. And we should be able to sustain each one of these abilities for sufficient periods of time as well. That is, we need to keep our eyes aimed at certain things for stretches of time to accomplish specific tasks; in fact we must be able to keep both eyes on target

as long as is necessary and we must be able to sustain the appropriate level of focusing so that whatever it is we are looking at remains clear.

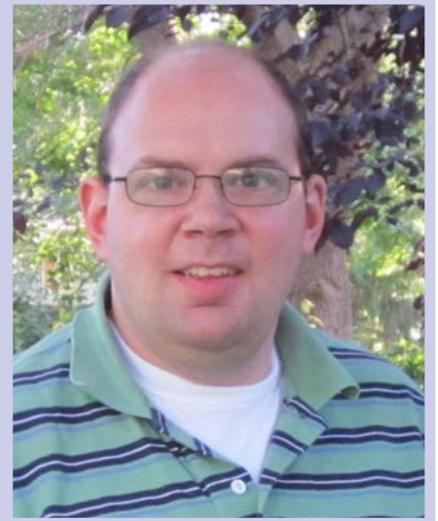
Almost everyone with a developmental or learning difficulty has some type of visual disturbance that can be remediated with optometric visual training, which often includes therapeutic lenses of some kind. Proper lenses can help the brain and visual system develop more appropriately. Optometric visual training can help with all the visual abilities mentioned above as well as improving eye-hand coordination, general coordination, balance, and eye contact, as well as reading and writing. For more detailed information, find a behavioral/developmental optometrist in your area.

STEVE GALLOP, O.D., HAS BEEN WORKING WITH CHILDREN ON THE AUTISM SPECTRUM FOR MORE THAN 20 YEARS. WWW.GALLOPINTOVISION.COM.

Our Lives Changed

By Deb and Bruce Lindgren

Our lives changed 35 years ago. We planned it. We were 22 years old and expecting our first child. We had an uncomplicated pregnancy and delivery. Chad weighed in at a robust 9 pounds, 5½ ounces. Immediately after birth, his right side didn't move, but moments later we were assured that all was well. Feeding was a problem from the first day, as Chad did not know how to suck, but we enlarged the holes in the bottle nipples so the formula would drip automatically. He gained weight and seemed to be developing normally. Little things happened along the way; for instance, at four months, we were told to double diaper him because his hips were too tight, and at six months a substitute pediatrician commented on what a "special little one" he was—a comment we mistook as positive.



In retrospect, Chad started showing signs of autism at a very early age; we just weren't looking for them. By four months old, he had an intense obsession for our car keys. As he got a little older, he would shred anything he could get his hands on, usually holding it up to a light and ripping it in front of his eyes. Anything in a circle fascinated him, and he would classify things as "circle" or "not a circle." He got "stuck" on drains in public restrooms, and we would have to drag a screaming Chad away. He also had (what we considered) positive obsessions. He was fascinated with puzzles, tools, and books. He could unlock, unscrew, or undo childproof caps, and he could push chairs to climb up on. Yes, he could get into anything he set his mind on.

When Chad was four, we witnessed our first seizure. Both of us stood and watched our son freeze in place, not responding to his name, then unfreezing and collapsing into tears. This prompted his first EEG. Chad started talking at about five years old. Five was a very eventful year, as he also got basically potty trained (although to this day, we have accidents). We were told he would not learn to do a lot of things, such as ride a bike. We wish you could have been there with us as we cried while watching Chad ride his bike in the school parking lot, squashing yet another obstacle that was in his way. Now he also skates, skis, swims, and bowls.

We have been through many cycles with Chad in both health and behavior. As a child, he was rarely sick. We saw that he had difficulties but always saw him as a happy, content child. As he grew older, we have had some bumps in the road. His behavior cycles more and he has developed some medical issues. For instance, he struggles with sleep issues and manic cycles, as well as Crohn's disease. He needs one-to-one supervision, as he still would run into the street without looking and has very impulsive behavior. Although he knows that he needs to pay for items, \$100 is the same as \$1—you just go to the cash machine and money comes out.

We have also learned that there is a difference between talking and being able to communicate. Chad talks a lot, sometimes in a very manic way. Yet communication is a very serious issue for us. He is not able

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Our Lives Changed from page 8...

to express how he is feeling or indicate pain or emotion. We have learned that he does feel pain, but when it is happening, he seems to go inward and is unable to explain, yet afterward he will talk about how it “used to really hurt” and ask why we didn’t make it stop.

Chad still “loves” certain things, including Barry Manilow, KISS, and James Bond movies. He loves other movies, too. He can tell you all kinds of details of movies, such as production companies, directors, and Academy Award winners. He loves biographies of historical figures and can give you much information about Martin Luther King Jr. or the Wright Brothers, but he particularly loves U.S. presidents—assassinations, their wives’ names, and whether they had children. He also loves state capitols. He has visited 48 of the 50 states and recognizes every one. He really has a fascinating memory.

Chad currently lives with us, and we are participating in a one-to-one pilot day program that combines in-center participation in art, sensory, and discussion groups, as well as community opportunities such as museums and recreation.

Our lives changed 35 years ago. Everyone knows that it is possible to have a child with special needs, but we think no one really believes it will be them. We guess that is a good thing because no one would choose this life for his or her child. Yet, our personal world has been greatly expanded by living life differently than most. We have met so many families and gained so many friends who have priorities similar to ours. We are grateful for your support.

BRUCE AND DEB ARE PARENTS TO CHAD, 35 (DUP15Q), AND ROBB, 33; IN-LAWS TO ROBB’S WIFE, SAMMY; AND GRANDPARENTS OF TWO, ZOE AND BECKETT. THEY FOUND DONNA BENNETT IN THE EARLY ’90S AND WERE THE FIFTH FAMILY TO JOIN IDEAS. THEY RESIDE IN MINNESOTA.



As IDEAS members are planning to travel to the conference in Philadelphia, we asked:

WHAT ARE MUST-HAVES FOR TRAVELING?

We have a 3½-year-old daughter with dup15q, and what we take for her are: snacks, CDs with children’s songs, toys, her favorite blanket, juice in a sippy cup, and (last but not least) the portable DVD

player with plenty of Elmo, Backyardigans, and Yo Gabba Gabba movies (this is an absolute must!) Also, we might have to stop every two hours to let her stretch her legs, sometimes every hour.

Franny Mackling, mother of Kasaria, 13, Kaylor, 3½ (dup15q), and Kole, 18 months

Adam has always been a great traveler. He loves looking out the window at everything rushing by. We have always had to stock lots of snacks, drinks, and books. I throw in a stuffed animal or two and a pillow if it’s a long trip. Now that he has an iPad, we can’t go anywhere without it. He loves that thing. We’re fortunate he’s a good traveler, but he’s a lot happier with all of his things along for the ride.

Patti Rubel, mother of Adam, 19 (dup15q)

Number one is her stroller. Chloe hates to be held still in a lap but is content to go in her stroller. We also always have her “hair baby” with us. Chloe has always had a thing about pulling and playing with hair. When she gets tired she will pull her own. A friend of a friend told me about a woman who made these little stuffed dolls with a lock of your own hair sewn into the top. You just mail her a small ponytail. Imagine a gingerbread man with about three inches of hair sticking out! They are a little funny looking, but both of my girls love theirs. Chloe also loves her See ‘n Say. She also listens to the same lullaby CD every night, so we have it on the iPod. Then, of course more snacks and drinks than we could ever need because if she gets hungry or thirsty, the world ends! Patience is not her strong suit!

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

Riley has a see-through block that has some monkeys in it. They go up and down, depending on how you turn it. She likes to put things in it since she can see them through it. She is so funny with it: She puts her “man” (a dollhouse man) in it and then she looks at him through the sides. She sleeps with it every night; it keeps her occupied for hours. Riley also needs a Barney DVD case (she likes to hold the cases) and her musical CD that we play in the car, and that is about it. As long as she has something to hold, she will sit in her carseat without fussing.

Jill Baker, mother of Riley, 4 (dup15q)

Cheers

to our Volunteers

By Kadi Luchsinger

Cindy Johnson is our IDEAS volunteer of the quarter. She lives in New Jersey with her husband and three girls. Cindy is our conference chair and has been working very hard to bring this fantastic conference to you all. While securing speakers, sending out contracts, planning our meals, holding committee conference calls, and much more, Cindy has been attending school full time to become a special education teacher. She recently graduated. Also, her husband has been deployed overseas. Talk about a full plate!

Make sure to thank Cindy for all of her efforts in putting on this conference. Mark your calendars; you won't want to miss it. Thank you, Cindy, for all you do for IDEAS.



In Memoriam

Anna Miller 5/9/88 to 2/1/11

Sometimes when people are gone, we have regrets. We didn't tell them that we loved them enough. We didn't see them enough. We didn't care or try for them enough. In this case, I don't need regrets. My parents and I told her "I love you" each time we saw her. We tried our best to take care of her, to make sure that she had everything she wanted and needed. I imagined myself growing old and fat and saggy while she stayed a big kid with a giant smile overtaking her little face. I hope she knows how much we will miss her. So, my advice to everyone: love your family, cherish them. Hug them. That's what I'm about to do right now and for the rest of my life.

From the eulogy by
Elina Miller,
Anna's sister
February 4, 2011



My Friend Ethan...

ETHAN AND HIS FRIENDS ANDREW, KIERA, AND CASSANDRA ARE IN THE SAME FOURTH GRADE CLASS. THEY LIVE IN UPSTATE NEW YORK.

Ethan is a good friend of mine. I have known Ethan for five years and have been in his class for five years as well. I like seeing him every day, and he says "Hi Andrew" every morning.

Ethan is fun to be with, and he is silly. He likes to bow a lot at gym, and it's funny to see him do it. He is good at sports and has a good arm at football. One time he threw the football and hit me in the stomach, and I fell down laughing so hard.

Every day, I look forward to seeing and sitting next to Ethan. Some people, like me, call him "E." He has a good imagination. And I like E as my friend.

By Andrew



I loved being in Ethan's class. He's so sweet. He's always really excited to see me when I see him. Ethan loves one of the books I read him. It's called "Helping Hippo." Whenever I see him he says, "Baby crying." It's so cute! Ethan is awesome!

By Cassandra

"E" has been in my class for three years. I like sitting in art class with him and having him watch me draw. He likes to get really close to my paper to see what it is. We have a frog puppet in our classroom that Ethan loves to play with. He has a great imagination.

It makes me laugh when he repeats what other people say. It is especially funny in music class. One of my favorite parts of the day is when I get to read to him. He loves the "Froggy" series! Life in class would be pretty boring without having Ethan in it. I hope he is in my class next year!

By Kiera

Acceptance from page 3...

me. And simultaneously, I offer to do the activities I know he will enjoy and offer the food he loves and the freedom for him to be himself.

Sometimes the best way to help yourself is to help others. Through my own struggles I tried reaching out to help others, and it worked, not just for them but also for me—and I haven't stopped for the past 20 years. I try to help others to grasp the diagnosis, knowing how hard that is and how much they do not want to. I have learned that this is necessary for the lives of parents and children. I try to help them to learn the lessons of acceptance.

Several themes emerge as parents travel the road to acceptance. Initially, parents struggle with the symptom clusters of autism: problems with speech and language, difficulties relating to others, and repetitive activities. Time stops as parents initially become very upset with their child's difficulties and struggle to accept their child's eventual diagnosis. They begin the protracted journey to put together the appropriate interventions. Through the heartache, in the passage to acceptance, they love their children passionately, they learn everything they can about their children, about autism, and they learn about themselves in the process. Some go on to create programs and services for others.

When parents get more comfortable talking about how life really is with their child, they often reveal signs and symptoms of clinical depression, anxiety, traumatic stress, anger management issues, sexual dysfunction, etc. All the while, love makes giving up unthinkable. The goal in acceptance is helping people to regain balance, take care of everybody's needs, and rejoin the current of their lives. This involves

endurance, courage, and accepting whatever remains unchangeable.

In my work with parents, I first try to help them really look at their grief. It doesn't help to pretend to be positive when underneath you may be lonely, afraid, or sad. I learned we don't have to lie to ourselves. You can grieve. You can complain. You can mourn. This helps you to go on, make the best of the situation, and enjoy life. Our life force is resilient, but the longing for the healthy child or a typical existence may endure. You have to learn to live with that yearning, but you don't have to lie to yourself about how hard this can be. As the eminent child psychiatrist D.W. Winnicott said, "Mothers are helped by being able to voice their agonies at the time they are experiencing them. Bottled up resentment spoils the loving which is at the back of it all." Feeling our experience is the first step in handling it wisely.

Second, I try to help people accept themselves just as they are. This is key in accepting our children with an open, kind, and loving heart. A perfectly lovely child or adult on the spectrum can be very hard to be with because of his or her behavioral, social, or communication issues. But when you love someone, you expect yourself to love to be with them. When you don't feel that and think you should, the guilt can be unbearable and your heart aches. This is an inner conflict that any parent can relate to, but when a child has autism, this can happen much more frequently.

You cannot accept yourself or any experience without seeing it clearly and with compassion in a tender sympathetic way. What Tariq has taught me besides accepting him is to accept myself. The challenges in our children radiate inwardly to our own imperfections. I had to begin accepting my own flaws, warts, and blemishes—things I could work on

and change and things I could not. As Carl Rogers taught, when we accept ourselves, only then can we change.

Finally, accepting our pain and ourselves leads to accepting and enjoying our child and our family life. That awareness is the gateway to love and wholeness. Children and adults on the autism spectrum bear witness to the diversity of the human condition and the resilience of our souls. We are all so perfectly imperfect. Awareness keeps the heart open and the mind as clear as possible. Yearning for what we don't have blocks knowing and loving the child we do have, seeing our child for who she is and giving what she needs from us to whatever extent that is possible. This is the path of acceptance for families. We don't have control over the autism, but we do have a lot to offer in our relationship with our child or loved one who is living with this condition.

I have come to know that Tariq's life does make a difference in the world. He is still my little boy. He still puts his head on my shoulder, and I have never stopped wanting to hear the sound of his voice. Yet I love him no less because of that and perhaps more in ways I could have never imagined. He has brought many kind people into my life and helped me to understand myself and others. He made me a better father and a better man. His greatest gift to me is a glimpse into the human heart where it is not who you know or what you know or what you have, but who you are. My son has only ever spoken aloud to me once in a while—in my dreams—but this is how his autism has spoken to me every

ROBERT A. NASEEF, PH.D., IS THE AUTHOR OF SPECIAL CHILDREN, CHALLENGED PARENTS AND THE CO-EDITOR WITH CINDY N. ARIEL, PH.D., OF VOICES FROM THE SPECTRUM. TOGETHER THEY FOUNDED ALTERNATIVE CHOICES, AN INDEPENDENT PSYCHOLOGY PRACTICE, IN PHILADELPHIA. WWW.ALTERNATIVECHOICES.COM.

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 duplication.

Save the Date:



June 23rd, 24th, 25th 2011

Crowne Plaza Hotel
 Philadelphia Downtown
 Philadelphia, PA 19103

www.crowneplaza.com/philadelphia-centercity

Reserve your rooms by Saturday, May 21, 2011

Reserve under IDEAS for special rate. Room rates are locked in at \$159 per night plus tax. Overnight parking is currently \$33 per night but might increase slightly.

Hotel is located in the center of Philadelphia. For questions, contact Cindy Johnson at cynthiaj100@verizon.net.

<http://www.dup15q.org>

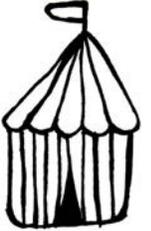
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