



WINTER ■ 2006

Caring for the Caregiver

JANE TRUE

MIRROR Editor, serves on the IDEAS Board, and lives with her husband Jim in Kansas City, MO

I RECEIVED A HOLIDAY GIFT FROM A FRIEND TODAY— COCKTAIL NAPKINS THAT SAY

“Put on Your Big Girl Panties and Deal With IT”

This is what I, and probably each of you, have been trying to do since we became parents of a child with idic15. Some days I deal with it much better than others. Though I might have preferred the napkins that said *“Drinks Well With Others”* or *“I Dreamed My Whole House Was Clean,”* we don’t always get to choose our gifts in this life. What we can choose is how we respond to what we have been given.

While caring for our child with

idic15 is an act of love, many times the emotional, physical, and financial stresses get in the way of what should often be a joyful experience. In this issue of The Mirror we address for the first time the topic of *“Caring for the Caregiver.”* It can be surprisingly difficult to accept this concept, as feelings of guilt or inadequacy may get in the way. It is hoped that this issue will enlighten us all to the importance of caring for ourselves in order that we may better respond to our challenges, care for our child, and become more comfortable with this role-reversal of caring for ourselves.

Our families have found many ways of caring for themselves, and

Isodicentric 15, abbreviated idic(15), is a genetic disorder in which a child is born with extra genetic material from chromosome 15. In people with idic(15), the extra chromosome is made up of a piece of chromosome 15 which has been duplicated end-to-end like a mirror image. It is the presence of this extra genetic material that accounts for the symptoms seen in some people with idic(15). People born without an extra chromosome but who have a segment of duplicated materials within chromosome 15 (known as an interstitial duplication 15q) can have features similar to those with idic(15).

many obstacles which they have overcome in order do so. In this issue you will get perspectives from parents, a sibling, and a professional. You will learn that many of us have used similar strategies, including a strong network of friends or family, counseling, medication, using respite care, and better educating ourselves about the disability that has so affected our lives. It is our sincere hope that something you read in this Mirror will help you move forward toward taking better care of yourself so that you may experience the joys of caring for a child with idic15.

Managing & Coping With Parental Stress

NICOLE WRIGHT, MS,
Psychology Associate at Elwyn, Inc.,
Elwyn, Pennsylvania

AS THE PARENT OF A CHILD WITH IDIC(15), YOU ARE PROBABLY ALL TOO WELL AWARE OF THE STRESS involved in raising your child. The seemingly simple task of getting your child dressed and fed can be stressful, much less the challenges of teaching independent skills, navigating the educational and mental

INSIDE THIS ISSUE...

- Experience with Counseling
- RESPITE: A Breath of Fresh Air
- Asking for Help & Accepting It
- Maintaining a Social Life
- Parent Match: A Resource
- Caring for the Sibling Caregiver
- Family Portraits: Olivia

And more...



health/mental retardation system, managing behavior problems, and other challenges unique to parents of children with idic(15).

Research confirms that parents of special needs children experience more parenting stress than parents of normally developing children, and higher levels of stress are found in parents of children with lower levels of adaptive functioning.¹ Chronic stress can have a negative impact on your mental and physical health, and can lead to medical illnesses such as heart disease, diabetes, and certain types of cancer.² Chronic stress contributes to depression, anxiety, sleep disturbances, apathy, fatigue, chronic headaches, stomach upset, and muscle tension.

Research also shows that parent-child interactions have an effect on the child's progress in his or her therapeutic or educational programs.³ Increased parental stress levels are associated with a decrease in the quality of interactions between parent and child.⁴

Taken together, the message is clear: you have to take care of yourself to take care of your child. You need coping strategies to reduce, or at the very least manage, your stress. You are not alone in your feelings of stress, depression, or fatigue. It is normal for parents with special needs children to experience either short or prolonged periods of increased stress or depression. Here are some suggestions to help you reduce and/or manage your parenting stress.

Join a Support Group

The good news is that if you are reading this newsletter, then you have already taken a significant step in reducing your stress. Research suggests that having a support network through family, friends, or a support group is an effective coping strategy for parents with a developmentally disabled child.⁵ A support group provides you with information about your child's specific disability and can provide you with answers for many of your questions. Support groups can be helpful in allaying many of your fears, and can provide information about education and therapy programs designed for children with idic(15) as well as help with navigating the "system" to access the appropriate programs. Finally, support groups provide a forum to vent your frustrations, ask questions, and to build a social network of people who understand your situation. Support groups can open up doors that you may not even have known existed.

Utilize Respite Services

Every parent needs a break from their children—but finding child care for your special needs child may be difficult or unrealistic. Seek out and utilize professional respite services. Research has found that mothers who received at least 6 hours of respite care per week for 6 months reported significantly lower stress levels than mothers who did not receive respite services.⁶ Respite caregivers are trained to take care of the medical and emotional needs of

children with special needs. Pursuing respite care might be a hard step to take, but remember that time away will help you refresh yourself emotionally and physically. Some communities even provide financial assistance with respite care.

Seek Counseling For Yourself

Feelings of depression are a common manifestation of high stress levels. Many parents of special needs children experience clinical depression at some point. Symptoms of depression include sleep disturbance, appetite or weight changes, mood changes, sadness, irritability, feelings of guilt, fatigue, loss of interest in pleasurable activities, and changes in attention and concentration.⁷ Also, if you find that you are engaging in unhealthy behaviors to manage your stress such as excessive smoking, drinking, or taking drugs, these may also be signs of depression. If you or others are noticing these symptoms, you may want to seek counseling. Counseling is a place for you to vent your feelings, fears, concerns, and frustrations without fear or guilt. It is also a forum to learn practical strategies to decrease your feelings of depression and anxiety, and ultimately to decrease your stress. Many counseling services charge for services on a sliding scale, local universities and colleges often provide counseling services for nominal fees, and many employers provide counseling services as part of a company's benefit package.



Ask For Help & Accept Help

If the old saying that it takes a village to raise a child is true, then it takes an army to raise a special needs child, which means you are going to need help from others, including friends, family, and professionals. Asking for and accepting help are very important in reducing your parenting stress. No parent is capable of doing everything, so when others offer to do something to lighten your load—let them! And if your load is too heavy—ask someone to lighten it! Help can range from asking a neighbor to pick up a few things at the grocery store, to requesting respite care for your child from a social services agency.

Exercise

Exercise is a proven method of effectively reducing stress and promoting overall good health. If you don't have the time to do the recommended 30-minutes/3 times a week, at least make an effort to increase your physical activity. For example, take the stairs instead of the elevator or park further away from the entrance to the grocery store. Exercise decreases your risk for many illnesses, depression and anxiety, and it boosts energy.

Eat Healthful Foods

The old adage that “you are what you eat” is being proven by an increasing body of scientific research. Eating a healthy, balanced diet is an effective way of improving your overall health, decreasing depression, and decreasing stress.

Take Time For Yourself

Taking as little as 10 minutes a day of “you” time can reduce stress. Try to incorporate something into your daily schedule just for you – no matter how small. Take five more minutes in the shower, drink a cup of your favorite coffee, or listen to your favorite CD in the car. Also, try to schedule something special when you can so that you have special things to look forward to doing. Anything that you can do just for you counts.

Learn and Practice Relaxation Techniques

Deep breathing, meditation, stretching, and muscle relaxation are very effective in managing acute stress by reducing adrenaline and cortisol levels in your blood stream.

Prioritize Your Goals & Obligations

Identify and prioritize your goals and try to eliminate non-essential activities or situations.

Laugh & Cry

Trying to find something humorous in every stressful situation or

circumstance can be helpful in releasing stress, maintaining perspective, and keeping a positive attitude. Crying is helpful in releasing emotions and stress. Let yourself do both.

Talk About It

Talk with others—friends, family, therapists or anyone else who will listen—about how you feel, your fears, concerns, failures, triumphs, and happy moments. Repressing emotions can increase stress, worry, and tension.

The methods of coping with and managing stress discussed above are designed to help you maximize your physical and emotional health, which in turn benefits everyone around you, including your child. Taking care of yourself is not selfish or self-centered—it is essential to keeping your relationship with your child positive and productive. You never have to be alone in your journey to raise your child, so remember to seek out and utilize all your resources.

- ¹ Weiss, J. A., Sullivan, A., & Diamond, T. (2003). Parent stress and adaptive functioning of individuals with developmental disabilities [Electronic Version]. *Journal on Developmental Disabilities*, 10, 129-136.
- ² Kiecolt-Glaser, J., Preacher, K. J., MacCallum, R. C., Atkinson, C., Malarkey, W. B., & Glaser, R. (2003, July 2). Interleukin-6 levels increased with chronic stress, Retrieved November 16, 2005, from <http://www.stress.about.com/cs/medicalconditions>
- ³ Lessenberry, B. M. & Rehfeldt, R. A. (2004). Evaluating stress levels of parents of children with disabilities [Electronic Version]. *Exceptional Children*, 70, 231-244.
- ⁴ Mahoney, et al., 1998
- ⁵ Devenny, D. A. (1993). Stress and parenting [Electronic Version]. *Down Syndrome Today*, 2, 22-23.
- ⁶ Rimmerman, A. (1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. *Mental Retardation*, 27, 99-103.
- ⁷ American Psychiatric Association. (1994). (4th ed.). *Diagnostic and statistical manual of mental disorders; DSM-IV*. Washington, D.C.: American Psychiatric Association.

JULIE SAENZ,

mother to Emily (idic15) and five other children, she and her family lives in Belvidere, IL



Counseling has had a significant impact on my life. There was a point where my life was one crisis after another. Some of the things I had difficulties with included a divorce from a man I had been with for twenty-one years. We have six children together. One of my daughters had been badly injured and her story was covered by all the major news networks. We were dealing with an upcoming trial and our youngest child Emily had just been diagnosed with isodentric 15.

These were some of my issues that I could no longer deal with. I became a non-functioning person. I waited until things became too overwhelming to handle. I had to find a way to take better care of myself. My Early Intervention coordinator recommended counseling. Counseling has been very rewarding and has had such a positive affect in my life. My life has completely turned around. I know and now understand the importance of counseling. At first, I thought counseling was a sign of weakness. I have found the opposite to be true. I have been able to deal with each crisis in my life without falling apart.

Counseling is like going on a diet. When you begin, you do not see instant results. It is over time that you begin to feel and see the results. Counseling is an on-going process. My counselor is my support system. Finding someone to simply understand the day-to-day struggles

of raising a child with idic 15 makes it a lot easier to get through the hard days. It helps to be able to share my struggles, grief, and triumphs. In counseling I do not have to sugarcoat anything. I have the freedom of not being judged and I get unbiased opinions. I have learned to focus on the positives. I became aware of my strengths and capabilities that for a long time I did not know I had.

Counseling is any relationship in which one person is helping another person better understand and solve problems. Sometimes, it is just someone to talk with. Counselors have a broad range of experience in developing helping relationships and working with many different situations. Counseling is a change in growth and healing. You can expect your counselor to listen to your concerns and to help you develop a better understanding of them so that you may deal with them more easily and effectively. Your counselor will maintain strict confidentiality. My counselor is my hero and mentor. I am so thankful for my Early Intervention Coordinator who recommended counseling. The first and most difficult step for me was making the decision to seek counseling.

I'm so glad I did.

RESPIRE: A Breath of Fresh Air

ALISON KALNICKI

and her husband Darrell, with their children Logan (idic15) and Jesse live in the Yukon Territory, Canada

THIS MORNING I AM ALONE IN MY HOUSE—gloriously alone.

I love my husband, Darrell, and our two sons: Jesse, an energetic two-year-old, and Logan, an enthusiastic four-year-old with isodentric 15 and autism. We fill our little house to the brim with a home office, and therapy room. *But why I am alone today?* Friday mornings I have respite.

Respite is a temporary and recuperative break. Today, for me, it means writing this article, washing the kitchen floor, and going for a hike behind our house. I might fit in some errands. Last week I went out for lunch with Darrell and volunteered for a local sports group. Some days I curl up with a good book and have a long nap. Some people question floor washing and errands on respite time, but one of the benefits of respite is that I alone decide what will be rewarding to do.

To receive respite, ask around in your area about what programs are available, the program's criteria, and who to contact. People to ask

Respite: A Breath of Fresh Air

might be a special needs teacher, therapist, or a parent of a special needs person. Many different respite systems exist. My government sends me a cheque in exchange for timesheets I submit after hiring and paying a Friday respite provider. On Sundays, I also receive respite. A teenager spends three hours with my children. I pay for this respite privately. I also know two single parents who take turns looking after the other's special needs child. Other systems provide government employees trained to care for special needs individuals. The respite might be outside or within your home. It might be overnight, daily, or monthly. Sometimes there are camps or homes provided for longer periods of respite. It might include typical children.

Deciding on the frequency and duration of respite care is a balancing act with your needs, your child's/children's needs, and what options are available. I find at least one respite time per week keeps me sane and capable. I schedule two times per week so when a respite time is cancelled I still have another to look forward to. One mother I know says she needs three 5-hour time slots per week. One to look after herself, another to keep on top

of administering her autistic son's programs, and a third to spend time with her husband.

There are challenges. First, if you go through a government respite program it adds more assessments, professionals, and paperwork to your life. When I applied, I was horrified when the intake social worker asked if I was hitting my children. I complained to her supervisor. I completed 2 eleven page application forms. Since then the process has been successful.

Another difficulty is admitting that I need help. Even after three years of regularly scheduled respite providers, I occasionally feel guilty for wanting and needing time away.

Finding the time to have a break has been a problem for me. No matter what I do, there never are enough hours in a day. I look for the best times of the day and week for my family to have me absent and schedule a respite provider for one of those times.

It is easy to let my respite time erode away with "important things", but when that happens I pay with exhaustion and emotional upset. In the same way that I have become an advocate for Logan, I have had to become an advocate for my own needs. I guard my respite times judiciously.

Sometimes I am sad or moody after having a break. I believe that

my respite times allow feelings to surface that I do not face on a regular basis. I think this is good and hope to schedule in another respite time where I can do more to explore my grief, anger and confusion.

I know, and Darrell will agree, that our lives are much better when I am receiving respite regularly. All week long I adapt to the many challenges that swing our way. It is easier for me to prioritize what I need to accomplish. I find the energy to jump onto my exercise bike, dance with Logan, and provide horse rides for Jesse. My family moments are more relaxed. I can focus on them, not what I have to do. My children enjoy their time playing with the respite providers. For Logan this means someone to have fun with – no assessments or goals. The best part of respite is the tranquility of knowing that special "me" time exists.

Well, my floor is shining but my elbow is sticking to the kitchen table. The jam will have to wait. It is my time to go for a walk in the snowy forest. With each step I will fortify my strength, patience, and love for another week. In the meantime, I encourage you to take some steps towards respite for yourself, your patients or clients, or your loved ones. Remember, caregivers need care too.

I Need Help —and this time I really mean it!

ELLEN DOXTATOR,

and her husband Peter are parents to Cheyenne (idic15, age 13) and Samuel (11), living in Ontario, Canada

ASKING FOR HELP ISN'T ALWAYS EASY, especially for parents of special needs children. We get so used to caring for our children that sometimes it's hard to let go. We question if our child's behaviours will be understood, will he/she get the same level of care and then there is the guilt—"How can I leave the care of my child to someone else?" This is compounded when a child has complex medical/behavioural needs. Having a special needs child is a lifelong responsibility. To be effective as parents, we not only need to reach out for help but accept it willingly and gracefully and without guilt.

Here are ten top tips for asking and accepting help.

1. Know Your Limits

Recognize when your plate is full, your temper is getting shorter and your stress level is higher. This is a good time to ask for help, before the situation escalates.

GOT NEWS?

The MIRROR welcomes the stories, insights, and ideas of all parents and professionals interested in idic(15). We'd also like to hear your suggestions for future articles.

Send correspondence to Jane True, MIRROR Editor at:

JTRUE@kc.rr.com

or to IDEAS
6699 SE Scott Drive
Portland, OR 97215

Jane True, Editor

Lin Neighbors, Design & Layout

Printing costs for this newsletter provided by Elwyn, Inc.

2. Learn to Say It

- Can you help me?
- Could you spare some time?
- I need a break.

Asking for help isn't easy.

Practice saying it. Ask someone you feel comfortable with first. Even if that person can't help you immediately, they still may be able to help you later.

3. Acknowledge Other People's Strengths

Realize that others have wonderful gifts to share with your child during difficult times. For example: a teen may have more stamina to let your child use up boundless energy or a behaviour therapist may be better equipped to develop a comprehensive behaviour program after spending 1:1 time with your child.

4. Giving Yourself a Break Can Increase Other People's Awareness of Isodicentric 15

By accepting offers of help, your family member or friends will have a greater understanding of what caring for a child with idic(15) entails and more empathy for the level of skill and energy that is required.

5. Recognize that Renewing Your Spirit Enhances Your Parenting Skills

Sometimes we do so much for others we lose our own sense of self. Continually putting other people's needs ahead of your own can lead to stress and burnout. By doing something for you (watching



a movie, taking a walk, spending time with a friend), you are able to keep up with the demands of raising your children.

6. Let Go of the Guilt

When a friend offered to help me recently, I said "Are you sure?" My friend pointedly said, "I wouldn't offer if I didn't mean it." Next time my friend offered to help, without hesitation I said "great."

7. Accept Help From Your Child's Siblings When It Is Offered

My son Samuel taught me this lesson. My son is sometimes able to deal more effectively with his sister than we are. In fact, he was the one who suggested this tip:

A few years ago I brought home a movie for us to watch as a family. My daughter (not liking change) kept saying, "I don't want to watch Chitty Chitty Bang Bang. I don't like Chitty Chitty Bang Bang," (even though she had never seen it.) The more we as parents tried to encourage her to watch it, the more adamant she became that she would not watch it. Finally our son Samuel said, "Either you watch Chitty Chitty Bang Bang or you're going to bed." She looked at him and quickly said, "I think I'll watch Chitty Chitty Bang Bang."

8. Getting Feedback From Your Help Can Assist You in Defining Better Goals for Your Child

When you ask for help, you may get other people's perspective on your child. Your helpers may give

I Need Help—and *this time I really mean it!*

you insight that can help you to define goals and behaviours which can be included in programs that can assist your child.

9. Take the Help Now— You May Need it Later...

Resources can get harder to access as your child gets older. Behaviours can get increasingly difficult as the child grows (take this from a Mom dealing with a terrible teen with idic15). Access the supports when your child is young. Don't wait until the situation

becomes unmanageable and the supports aren't readily available.

10. Directing Your Child's Care— Know Your Needs and Know Your Child's Needs

You have a right to direct your child's care! To do this effectively you have to know your needs and your child's needs. You need to define and explain to the worker exactly what your child requires and how the support can best assist you and your family. By directing your child's care, you can make

maximum use of the help that is being received. Also, realize that the helpers are not mind readers – they might need direction as to how you want things done. Also keep your help happy – acknowledge and appreciate them for a job well done.

And as Samuel says, "Remember, asking for help isn't always easy but when you get it, you will be really thankful for it."

Take pleasure from helping hands, accepting help renews the spirit and the heart...

Maintaining a Social Life (3 stories)

KATHY WISE,

with her husband John and daughter Julia (idic15) live in Pelham, New Hampshire

Counselors I have seen over the 6 years since Julia's diagnosis have always stressed to me the importance of maintaining a social life. It is important not only for the caregiver, but also for the child. Parents who have time to them-selves inevitably will have more energy for their child! Let's face it, our role as parents of children with idic 15 is not easy. I look at my time away from Julia as a "breather"—a time to regroup.

We are fortunate because John and I have always been able to count on my mother to watch Julia when we go out. But my mother is aging, and John and I felt that we needed to find others to help with Julia. Our sisters and sister-in-law have recently joined the ranks of people we call on. We've also been able to ask Julia's past one-on-one school aides.

John and I try to get out alone as a couple at least once every month for

dinner or dinner and a movie. We have a membership to a local theater and attend plays there. After the play, we meet with friends and we go to dinner. It's a great night out. Sometimes Julia has a sleepover with my mother.

Every year for the last twelve years, we have gone on a summer camping trip with another couple to Vermont. My mother has always cared for Julia when we go on this trip. Up until two years ago, our trip lasted three days and then we decided to extend the trip to four days. We get creative with childcare because we don't want my mother to watch Julia for the entire time. People have stepped up to the plate to take Julia for one of the days that we're gone so my mother can get a break. We look forward to this extended break every year!

At least once a month, I go out with a friend or two in the evening for dinner. Often, it's with Moms of children with special needs, but we try not to talk about our kids too much!

When Julia was younger, it was more difficult for me to leave her. Now I know how important these breaks are. One thing we do to ease our minds when we are out is to provide the caregiver with a list of things that Julia likes. We make sure that all of her favorite toys/activities are on hand. Of course, we also call the caregiver while we are out to make sure that things are going well.

My advice to parents of younger children with idic 15 is to enlist the help of as many friends/relatives as you can. Let these people get to know your child so that when you leave your child you will feel comfortable. Maintain an active social life! It will be beneficial to you and your child!

NICOLE MARMO,

and her husband Tony are parents of Madison (idic15) and two typical children. The family lives in Upper Saddle River, New Jersey.

For the past three years, our social life was very minimal or almost non-existent. Most of our time was spent researching, comforting our daughter Madison from sickness and

pain, and trying to deal with sleep deprivation. It looked like we would never have the time or energy to maintain a social life again. My husband and I had always enjoyed wonderful friendships, great food and a good time. Was that to be in our life again?

About a year ago, my husband Tony and I fortunately met this wonderful woman who has helped us with our children. We have specified Thursday nights as “Our” night. We go to dinner and have quality time not only amongst ourselves but with friends as well. I have asked two aides in Madison’s school to baby-sit as well. I’m comfortable with them and they know and love Madison. I know this can be financially draining, but we feel it is important for us and well worth the cost.

I’ve always been worried that it would be difficult to have and maintain friendships with people who only have typical children. We’ve found through our experience with Madison that the “cream rises to the top.” The people in our community who have accepted our situation and Madison are wonderful loving people and our dearest friends.

It continues to be a struggle at parties when the crowds are too much for Madison and we end up bouncing her in our laps for hours on end. When she walks, we must be right behind her at all times so she does not fall or start chewing on a chair. It is difficult for us to have any conversation, as we are busy keeping her happy in any way we can. I am hoping in the future things will improve for her in these types of situations.

Life has been very good lately. Tony and I have respected each other’s needs to maintain a well-

balanced social life. He has been on golf trips and outings with friends, and I have started taking classes such as jewelry making and photography for myself. I enjoy “girls night out” with different circles of friends including my wonderful support group from Maddie’s school (amazing mothers!!!). I just got back from a short trip to Chicago to see the Oprah show with my girlfriend. I have never enjoyed life more because I am living, laughing, and experiencing again. I have never more appreciated the time I spend with friends, family and my husband. Today, we are happier and seem to have a better home life than most of our friends with typical children.

I will forever be grateful for the people who have helped us maintain a “life” again. Our dearest family, our friends, and the wonderful people who care, respect, and truly love people with disabilities. There are many...find them and let them let you have a life again!

MARGARET KELLIHER-GIBSON,
and her husband Bob are parents of Suzy (idic15) and Matt. The family lives in Ashland, Massachusetts

Both my husband and I come from families with six children so when our daughter Suzy was born, there were grandparents, aunts, uncles, and cousins galore awaiting her. In the beginning, Suzy was a “good baby” who slept a lot. Family and friends invited us to the usual gatherings and get togethers.

The only trouble was Suzy couldn’t stand them. Anything new bothered her—new places, people and toys. At first, everyone insisted she come because they thought she would get used to it or she was just having a

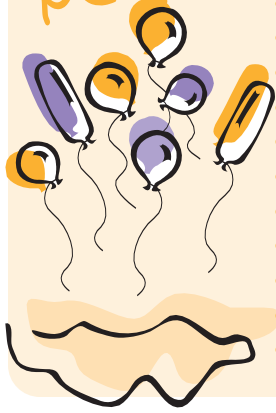
bad day. We tried, but it was just too much for Suzy and for us as well. At a year old, Suzy was diagnosed with idic15. Even though the doctors didn’t know what it would mean for the future, for my husband and I it meant that whatever was wrong was probably a lifetime condition, so we had to start dealing with it head on.

It was not easy, but we developed routines with our families that helped us integrate Suzy. My family usually gathered at my parent’s house to celebrate birthdays. In the beginning, when more than three people were in a room, Suzy would panic and try to escape, so we would have a designated room for her escape. Dinners consisted of between eight to thirty people at the table. Suzy started eating in another room in her high chair while watching her favorite videos. Over the years, she slowly improved to the point where she can eat with us at the regular table with everyone.

Thanksgiving with my family is a big deal. We always attend, but we tell whoever is hosting what we need as a family to survive...a TV, VCR, microwave (Suzy is on the gfcd diet) and separate room where Suzy can retreat. In the beginning, this felt very bossy to me and probably others but it has allowed us to do some really fun things together. We visit my husband’s family in N.J. after Christmas every year for several days. In the beginning, they always had everyone do everything together but after one very distressful trip they’ve gotten used to us picking and choosing what we think Suzy can stand and what kind of help we need. My in-laws also baby-sat one night so my husband and I could go to a party with friends he grew up with.

It has been challenging over the

Happy Birthday to these special people:



• Joseph B	01/02/84	• Nathan H	02/08/85	• Kameron R	03/02/00
• Khalid E	01/03/95	• Graham R	02/09/00	• Jacob C	03/03/03
• Naomi G	01/05/71	• Matthias W	02/09/00	• Lis R	03/06/98
• Shane R	01/07/00	• Emma D	02/09/99	• Jackson R	03/08/94
• Frederique D	01/08/92	• Abby E	02/09/90	• Samuel C	03/08/83
• Ethan L	01/08/01	• Joshua B	02/09/76	• Shawn K	03/09/93
• Christopher O	01/09/92	• Robin R	02/13/85	• Benjamin R	03/13/98
• Mason B	01/12/96	• Thomas Q	02/15/00	• Kathryn B	03/14/00
• Pavel G	01/17/91	• Noah H	02/16/99	• Patience V	03/15/99
• Genevieve M	01/17/91	• Tristan W	02/17/98	• Jacob L	03/16/00
• Nathan L	01/18/00	• Johanna C	02/17/82	• Michael H	03/17/80
• Sarah B	01/24/94	• Ben I	02/20/85	• Kathryn M	03/18/95
• Nicholas L	01/25/89	• Connor L	02/22/94	• Jacob G	03/19/99
• Alexa V	01/25/87	• Kathryn G	02/28/93	• Christina M	03/20/85
• Kiam S	01/26/94	• Payton F	02/29/00	• Joshua R	03/21/96
• Matthew B	01/26/89	• Allison G	03/01/97	• Joseph G	03/21/88
• Katie B	01/27/98	• Dylan M	03/01/94	• Jason K	03/23/90
• Ryan M	01/27/86	• Fabio C	03/01/93	• Katherine C	03/29/97
• Ryan T	02/07/02			• Cody K	03/31/99

Maintaining a Social Life

years, but both our families have been able to get to know and love Suzy. We've been able to stay close to our families by taking turns watching Suzy during the day and by doing things like playing games together after she has gone to bed. My son Matt has been able to be a part of everything. We have found that routine works best for us, though we can do new things as long as our "demands" are met. We are flexible about whether we take Suzy on a particular outing or whether one of us stays behind with her. Suzy is 16 now and when her grandfather died this summer she joined the family after the graveyard service and stayed for the rest of the gathering at the house. Many people remarked at how well she did staying in the room with people, sitting on the couch quietly, and even playing the piano with my brother in law. In that moment I just realized how far she has come in being comfortable in the "regular world."

IDEAS

CORPORATE OFFICERS & BOARD MEMBERS

NICOLE CLEARY, MSS	Executive Director
Portland, OR	
LORI GEORGE	Finance Officer
Canton, MA	
KADI LUCHSINGER	Corporate Secretary
Fayetteville, NY	
DONNA BENNETT	Co-founder & Board Member
Thomasville, PA	
HEATHER BRUCE	Board Member
Indianapolis, IN	
JULIE ORTON	Board Member
Quincy, IL	
PATTI RUBEL	Board Member
Fairfax, VA	
JANE TRUE	Board Member
Kansas City, MO	
DANIELLE WAGNER	Board Member
Schaumburg, IL	

PROFESSIONAL ADVISORS

EDWIN COOK Jr, MD
Department of Psychiatry, University of Chicago
BRENDA FINUCANE, MS, CGC
Elwyn Training and Research Institute
BARBARA HAAS GIVLER, MED
Educational Consultant
N. CAROLYN SCHANEN, MD, PhD
Nemours Biomedical Research
CHANTELL WOLPERT, MBA, PA-C, CGC
Duke University Center for Human Genetics

Parent Match Helps Parents Care for Themselves

KADI LUCHSINGER,

coordinator for the IDEAS Parent Match program, serves on the IDEAS Board, lives with her family in Fayetteville, NY

One of the hardest things about raising a child with a chromosome 15 duplication is the feelings of grief that come at different times as our children grow up. Often, this grief stems from feelings of isolation and stress as our children's needs become more complex and challenging. Parents may have few friends or family members who understand what life with their affected child is like on a daily basis. One of the best ways that parents can care for themselves during these difficult times is by reaching out for support.

The purpose of the IDEAS Parent Match Program is to support families during hard times. Parent Match is available for any difficult situation that may require emotional support. This may be when a child receives a diagnosis of autism, starts a new school, develops challenging behaviors or seizures, enters puberty, or faces decisions about life after aging out of school services. We hope to decrease parent's stress and feelings of isolation during these times by matching families needing support with mentor families who can listen and offer information, encouragement and support.

Parents who would like the support of an IDEAS parent mentor can contact me for a parent match at kadi@twcny.rr.com or 315.637.4191. All requests and information are kept confidential.

Caring for the Sibling Care Giver

WENDY HARRIS

and her sons James and Warren (mosaic ring chromosome 15) live in British Columbia, Canada

The assignment seemed simple, caring for the sibling care giver, yet James couldn't wrap his head around the concept as he stood there, watching me make supper. "But what does it mean?" he asked, puzzled. Explaining not once, but twice, the blank look on his face convinced me he truly wasn't getting it. Aha! He needed some kind of an example he'd understand. Here's the gist of our conversation.

"You know. Like when Warren is bugging you, and you've answered the same question a zillion times, don't you ever wish you were playing basketball with Nolan and Will?"

"Huh? I play basketball with them."

"No, I mean like...well...you know Warren is the way he..."

"Huh?"

"...he doesn't do everything that you do."

"Like what?"

"Uhhh."

As I scrambled for succinct words to help James understand the concept of taking care of a sibling care giver, Warren came into the kitchen.

"James."

"Yeah."

"James."

"Yes, Warren."

"James."

"Yes, Warren, I'm listening."

"James. Do you want to marry Ella?"

The chase was on, and James thumped up the stairs after Warren. I stirred the gravy, mulling over a way to explain this better, as the words "you butt," and "James, are you a monkey?" drifted faintly through the floorboards.

Mashing the potatoes, I knew what I did to recharge my batteries. What I did when the enormity of having a child with a chromosome disorder, along with the seemingly endless rounds of specialists, geneticists, IEP's and every other kind of meeting under the sun, threatened to suck me into the abyss of despair. Yes, I knew what I did, but what *did* James do for himself?

The answer came a few days later when a worried looking James brought a sealed envelope home from his teacher. He thought he must be in trouble, but here's what the note read:

Dear Wendy,

Every now and then I read a journal that brings tears to my eyes. It would have been unthinkable not to share this with you. (I hope James won't mind). What wonderful boys you are raising!

Sincerely,

Mrs. Haussmann

P.S. The topic as it always is, was "What I's On Your Mind"—nothing more than that.

Apart from correcting the spelling, I haven't tidied up the journal entry, because as is, in all its naïve glory, it shows me why James didn't understand the concept of what he did to care for his own self. It made me think of my relationship with my own siblings when we were young. We fought amongst ourselves, yet were fiercely proud and looked after our differences in a way that our parents didn't quite get either.

As much as I've begrudgingly learned to cope and accept limitations and constraints, engage in the odd self-pity trip, and mourn for the days when I didn't know what it was like to have a child with autism, I've come to the realization that James' perception of reality isn't so fogged by memories of when life was, well...so uncomplicated.



November 2005
James H. • Journal

My little brother

has a Chromosome 15 disorder, which means that he has one extra chromosome in half of his cells. In the whole world, doctors have never found the type of Chromosome 15 that Warren has. Warren was first diagnosed with Chromosome 15 at six-years old. Once my mom knew this, she started looking things up on chromosome disorders and found out that most babies with chromosome 15 are most likely to die before birth, or just after, or would have lethal mental or physical abnormalities. Warren is now eight-years old and has been through many things. He was born with two fingers webbed together so he had to go to the hospital to get them separated, he had a triggered thumb so they had to cut the tendon in his thumb, he has had to punch holes in his tear ducts to unblock them, and has had tubes put down his ears to help hearing. Yet Warren is physically and mentally well. He has a good sense of humour, is very, very smart, absolutely hilarious, very kind and friendly guy, and most of all, he is the BEST little brother ever.

Olivia

PAMELA TAYLOR

is mum to Olivia, 11 (idic15). The Taylor family lives in North Yorkshire, England. The names of medications in this article may be unfamiliar since medication names are different outside the U.S.



I CANNOT BELIEVE THAT OLIVIA IS 11 YEARS OLD!

It has been some time since I wrote to **IDEAS** about our daughter. There have been many changes in how Olivia's chromosome disorder presents itself. As Olivia grows she is getting stronger, which seems unbelievable for a girl who can not stand for more than 5-10 minutes before she starts to sway and she gets her 'Zebedee legs'. She literally looks like her legs are on springs bending and wobbling from side to side. Her endurance levels are low – so she goes from being a huge ball of energy to a little girl with low muscle tone and very lethargic.

Since having the diagnosis of PDA (Pathological Demand Avoidance—www.pdacontact.org.uk) we have learned to understand her behaviours better. Understanding them doesn't make the behaviours easier, but it does reassure us that it is not our fault that she behaves in the way she does. Olivia is also showing more and more autistic characteristics. She showed many of these when she was much younger

but things seemed a little better for a couple of years once her language developed. At a recent appointment with a psychologist, it was suggested that she has 'Autistic Emotions'. She will jump, flap and hum in situations like over-stimulation both auditory and visually, too many people, unfamiliar places or generally when unsure of what's expected. She can become very anxious and that usually sets off the PDA behaviours. For this we use social stories and Mayer Johnson Board Maker Symbols, so that she has visual cues for sequencing the day's events in small chunks, as Olivia has no concept of time. If none of this works she will lie down on the floor in the fetal position and rock back and forth.

Epilepsy is still probably one of the more worrying difficulties of idic15 she has. In spite of the cocktail of anti convulsion medications, her seizures are not controlled. Apart from 'drop seizures' Olivia now has the full range of seizure types. Last

year she started having Grand Mals, which were a very scary experience the first time she had one; we now have an emergency protocol in place and a medication called 'Midazolam'. After four EEG's that all came back 'normal', her latest one showed 'Focal seizure discharges on the right side of her brain in the temporal lobe region'.

I feel that because of the increase in seizure activity and the possible effects of medication, her education has been affected. At her last school review in July, the general feeling from all concerned was that she had made no significant progress. She has real difficulties staying on task and has 'lost' interest very quickly. She still can not read or write and has no concept of math. On those side of things I am not trying to kid myself – I would rather she is taught basic life skills. She is now in her last year at Primary level at school and moves up to High School in September 06. We are lucky in the respect that her present school has a foundation group for those who have very low abilities and it is there that Olivia will be placed.

"People without a disability are like wildflowers. All you need is some sun and some rain and sometimes a little weeding. We are more like orchids. We need more care, but we are just as beautiful."

— A quote from a young adult with a rare chromosome disorder

2006 Regional Gatherings

Several IDEAS Regional Gatherings Planned for 2006

● Northwest Families

Labor Day Weekend

Maryhill State Park

Contact:

Nicole Cleary 503-253-2872

● Northeast Families

Labor Day Weekend

location TBA

Contact:

Cindy Johnson 609-723-7731

● New England Families

Labor Day Weekend

location TBA

Contact:

Kathy Wise 603-635-9077

● Chicago Area Families

Labor Day Weekend

location TBA

Contact:

Ruth Kross 708-691-0378

Let's plan more!

If you would like to coordinate a regional family gathering in your area, please contact Heather Bruce, IDEAS Board Member at 317-862-8581 and she can help you get started.



IDEAS

is a non profit organization dedicated to providing information, education and support to families with individuals affected by isodicentric and interstitial duplications of chromosome 15. **IDEAS** unites families, researchers, and professionals; and promotes research, awareness and understanding of Isodicentric 15 and related disorders.