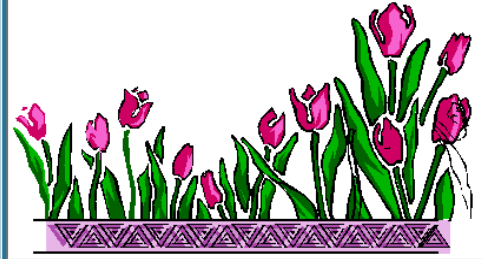


THE MIRROR

The Newsletter of IDEAS - IsoDicentric 15 Exchange, Advocacy and Support

Spring
2000

Good Things Are Happening at IDEAS!



To date, over 140 families of people with idic15 have joined our mailing list, and the number grows weekly. We expect many more families to learn about IDEAS when our Internet website is unveiled in April. The idic15 email listserv has blossomed into a supportive online community for families from around the world. For those of you without computer access, IDEAS will continue to keep you updated through The Mirror newsletter. In this issue, look for information about recognizing and responding to seizures. We've also included [a seizure questionnaire](#) which will help us begin to answer questions about the connection between idic15 and epilepsy. The results will be reported in a future issue of The Mirror.

TABLE OF CONTENTS

(Spring 2000)

- [Seizure Recognition](#)
- [Family Portrait:](#)
[Cheyenne Rain Jackson](#)
- [Mirror News](#)
[Communication Document](#)
[Birthdays](#)
- [Virginia Special Ed Proposal](#)
- [Therapeutic Horseback Riding](#)
- [Skiing with Style](#)
- [Idic\(15\) Smiles](#)
- [Parents' Resource Page](#)





**UPDATE JUNE 2004: THANK YOU FOR YOUR INTEREST. THE
SEIZURE STUDY IS NOW DONE AND WE ARE NO LONGER
ACCEPTING SURVEYS.**

[CLICK HERE TO SEE THE RESULTS](#)





[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

SEIZURE RECOGNITION AND FIRST AID

Seizure disorders are common among children and adults with idiopathic 15. Parents often have questions about how to recognize different types of seizures. The information below is excerpted from the website of the [Epilepsy Foundation \(www.efa.org\)](http://www.efa.org)

*****HELP US LEARN MORE ABOUT SEIZURES IN IDIC15
BY COMPLETING OUR [ONLINE SURVEY.](#)**

GENERALIZED TONIC CLONIC SEIZURES

(also called GRAND MAL)

What the Seizure Looks Like:

Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control. The seizures usually last a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.

What To Do:

Look for medical identification.

Protect from nearby hazards.

Loosen ties or shirt collars.

Protect head from injury.

Turn on side to keep airway clear unless injury exists.

Reassure as consciousness returns.

If a single seizure lasted less than 5 minutes, ask if hospital evaluation wanted.

If there are multiple seizures, or if one seizure lasts longer than 5 minutes, call an ambulance. If person is pregnant, injured, or diabetic, call for aid at once.

What Not To Do:

Don't put any hard implement in the mouth.

Don't try to hold tongue. It can't be swallowed.

Don't try to give liquids during or just after seizure,

Don't use artificial respiration unless breathing is absent after muscle jerks subside, or unless water has been inhaled.

Don't restrain

ABSENCE SEIZURES

(also called PETIT MAL)

What the Seizure Looks Like:

A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. The child or adult is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. It may result in learning difficulties if not recognized and treated.

What To Do:

No first aid necessary, but if this is the first observation of the seizure, medical

evaluation should be sought.

SIMPLE PARTIAL SEIZURES

What the Seizure Looks Like:

Jerking may begin in one area of body, arm, leg, or face. it can't be stopped, but the person stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure. Partial sensory seizures may not be obvious to an onlooker. The person experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.

What To Do:

No first aid is necessary unless the seizure becomes convulsive, then follow Generalized Tonic Clonic seizures first aid (described above).

No immediate action needed other than reassurance and emotional support.

Medical evaluation should be sought.

[CONTINUED ON NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

Family Portraits



CHEYENNE RAIN JACKSON

by Erica Jackson

Her name is Cheyenne. I first found out that I was pregnant with her really by accident. I had been discussing the option of having my tubes tied because I already had three other children, and this was a very good time in my and my husband's life. Things around the house were quiet and calm; money was good then because I was working; and my husband and I were doing favorite things that we had not had the opportunity to do before: riding our horses and camping out in the mountains. It just seemed that life was at its best.

I had called the doctor's office to arrange to have the procedure done. I had absolutely no reason to think that I was pregnant because it wasn't time yet (ladies, you know what I mean); but after making the call, I couldn't stop thinking about one thing that the nurse had said to me on the phone: "Are you sure you're not pregnant?". For some reason, I just could not get that thought out of my head. I decided to pick up a pregnancy test, just to be on the safe side. I went to the store and bought the absolute "cheapest" one that I could find on the market. I came home and took the test, alone, because I had not said anything to my husband about the nurse's question, and yes, it was positive! I couldn't believe my eyes! I ran

around the house like a crazy women, crying and wailing all over the place. I am just so glad that my other children were not at home at the time. I pulled myself together and thought, "Well this test was a fluke. I'll go and get another and do it at work tomorrow." And I did, and the EPT that I took said "YES" again! This time I was at work, and I had to try to be cool, but I was miserable inside. I kept thinking the whole time that my husband would not believe me when I told him that "I had no clue", and that he would yell at me because we had already discussed it, and on and on and on. So many things kept whirling around in my mind, but, through my tears, I made it through the day and went home fearing what I had to say. On the way home, I decided to stop at the barn where we kept the horses, and my husband just happened to be there. That is where I broke the news to him that we were going to have another baby. He looked at me with disbelief in his eyes, just the look that I had been fearing. He didn't want to believe that I really didn't know but, I guess he was too shocked to fight about it. He then asked me, "What are we going to do with another baby?", and I simply said, "Have it". What else could I say? We went home that day and he was far more understanding than I had imagined him to be, and we talked about it into the night.

He asked if I was really going to go through with the pregnancy, and of course, this hurt my feelings severely, and I brushed him off and said that I didn't know what I wanted to do, even though I really did. I knew that God had given me this child and I was going to have it, with or without my husbands blessing. I went into early labor at 30 weeks and was put into the hospital for 3 days and my labor was successfully stopped and was sent home with medicine to control contractions that I refused to take because she stopped moving when I would take them and so they told me that it was OK to discontinue , and she was born 6 weeks later. I had already agreed to have a hysterectomy at the time of birth to minimize the risk of reoccurring cell growth and also because I was satisfied with my family number. Four hours later after they took her from me, they wheeled me into the recovery room and I was awakened by the doctor and then my husband was allowed to come in. The doctor had told me that there were some small complications with the baby and for me not to worry that they would take good care of her and that she was doing fine and that he needed me to get better because I gave them a scare in the OR because of heavy bleeding.

Finally, when my husband came in I could tell right away that there was something wrong other than his concern for me. I could see it in his face, but, he wouldn't say a word. Then finally they wheeled my bed into the baby ICU unit and let me see her, her sweet face and tiny body was surrounded by wires and tubes but, all I could see was her. I reached out to touch her hand and she opened her eyes and looked right at me when I called her name "Cheyenne," I said, "I love you." I hadn't noticed her legs, but, then as the nurse came over and was checking her and talking to us, I did. Her legs looked like they were broken at the knees. They just flopped around, she could not straighten them out, they would only fold towards her in the wrong direction. My heart cried out in silence. I thought that she would be crippled and never be able to walk, I thought that others would make fun of her and be teased and taunted. But, then I said, "Thank you Lord, she is sooo beautiful" and then I didn't care what she was anymore, I just knew that I loved her and was glad that she was alive.

They did all the tests that needed to be done, the usual apgar, which was 8 & 9 and then x-

rays to check her hips and legs and saw that it was something that they could fix really easily, and all they did was put casts on her legs for about 3 to 4 weeks and her legs were the way that they were supposed to be. To us that was a miracle! If we only knew than that there would be obstacles far greater than that, that we would face that would not be so easy to fix. Looking back now, how petty I must have seemed to one mother, all she wanted was just to hold her child, she was praying that the baby would just survive. I am not ungrateful for what God has given, She is my prize, my life and my joy, and I wouldn't change anything about her or the way that things have happened, for you have to experience life in order to grow and be Thankful and that is just what my husband and I have done...a lot of growing and learning.

Cheyenne was fine up until her first birthday and she went to have her checkup with the pediatrician. The doctor and I were both concerned with her not walking and not being able to sit on her own. I thought that she was a "good" baby, she didn't cry much and she was just so "laid back" and smiley. The doctor ordered some metabolic tests to find a physical reason as to maybe why she was behind. There was nothing, so we were referred to Early Childhood Intervention. Not thinking clearly, I couldn't accept that there might be something else wrong with her, so I decided to take her back to Baptist Hospital to see the ENT there because she was at that time having lots of ear problems and I really wanted that to be the problem, and not what I feared secretly. They put tubes in her ears which did help with her balance, and she began to walk by 23 months, it was then clear to me by the time that the ENT wanted us to follow up with Early Intervention that there was more to it than her ears.

In March of 1998, we began services with them. At first, it was very hard to swallow when they came out to evaluate her and they told me that she was bout a year behind and that she needed therapy, but, I loved her so much that I put the pain away and began an intensive search to find out everything that I could to get her what she needed. What ever services she needed, I wanted to get for her and whatever doctors she needed to see, made sure that she was there, and after months of searching and pounding the pavement everyday, searching the internet everyday, making phone calls everyday, and writing letters to whoever I thought could help, on March the 5, 1999, we got the answer.....Inverted Duplication (15), type three. Cheyenne is healthy, and we are so Thankful. She so far, does not have seizures or any physical problems in that way except for her not sleeping very well, and being hypotonic. She falls a lot and has autistic like characteristics as well as developmental delays, limited speech and oral sensory problems like chewing and mouthing things like a baby, and she is not potty trained. But, unless you put next to another 2 1/2 year old, you would not be able to tell right away because she looks so "normal". I currently have her enrolled in a school for special needs children called Gateway Education Center that has also been a blessing to us. They have done so much for her and she enjoys being there.

I don't know what the future holds for us but, I do know that she has changed and enriched our lives so much, we see this world through new eyes and it is my pleasure and honor to love and care for my Special Angel that God has given to me. My husband and I have learned so much from her and others that we meet, I wouldn't go back to the "good" life that I thought that I had before, for anything....I like it here just fine.

[CLICK HERE TO READ A POEM BY ERICA JACKSON](#)

[CLICK HERE TO GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

THE MIRROR NEWS PAGE

Communication in People with Isodentric 15

Many thanks to parent, Nicole Iseli, of Portland, Oregon for compiling a descriptive survey of communication in idic15. The document is a collection of communication profiles of children and young adults with idic15, ranging in age from 3 to 23. Nicole excerpted the descriptions from ongoing discussions posted to the idic15 email listserv. To access the document online, register for the [listserv](#), then view the file called "ID15-communication.doc" under the 'Files' section.



Happy Birthday!

Allison 03/01/97
Dylan 03/01/94
Jackson 03/08/94
Samuel 03/08/83
Shawn 03/09/93
Delancy 03/14/97
Michael 03/17/80
Kathryn 03/18/95
Christina 03/20/85
Joseph 03/21/88
Jason 03/23/90
Katherine 03/24/97
Chad 04/08/94
Jeffrey 04/10/95

Tatiana 04/11/86
Jaime Lee 04/12/93
Bobby 04/14/78
Allora 04/19/96
Cody 04/19/93
Suzy 04/20/89
Coleen 04/23/93
Elisabeth 04/27/95
Paige 04/28/92
Robert 04/28/94
Matthew 04/29/88
Crystal 04/30/87

Joelle 05/02/94
Shelby 05/05/93
Jillian 05/06/92
Albanelia 05/08/84
David 05/08/93
Anna 05/09/88
Austin 05/13/92
Jaylin 05/15/92
John 05/20/94
Brendan 05/24/91
Joanne 05/27/88
Jarrett 05/28/91

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 Donna Bennett, c/o I.D.E.A.S., 416 Big Mount Road, Thomasville, PA 17364, Or if possible, email your newsletter items to Brenda Finucane <brenda@craftech.com>

[GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

VIRGINIA CONSIDERS SPECIAL ED PROPOSAL BROUGHT BY IDEAS MOM AND FRIENDS

Patti Rubel, parent of a son, Adam, who has idic15, recently sent us this update on her activities with the Virginia State legislature. Congratulations Patti!

“Here in Virginia, Standards of Learning (SOL) tests are now required and the idea, ultimately, is that all kids will have to pass the SOLs to receive a diploma. This is true for children in special education as well (the greatest number of children in special ed, of course, are those with learning disabilities). We saw a need to look at how the State was doing with regard to SOLs and those children. Two other Moms and I formed a group called CASE (Citizens Advocating in Special Education). Since we feel that high standards should apply to all children, we started to look at this issue. We saw the SOLs as a way to make the school system accountable for actually teaching our children. Currently, most of the kids ‘opt out’ of taking these tests. The schools seemed to be encouraging parents to opt their kids out of taking the tests, and we thought something should be done about it. If kids are exempted or opted out of the testing, it doesn't affect the accreditation of the school. However, if the kids take the tests and fail, that can adversely affect school scores. You can see why it was in the schools’ best interest to get kids with special needs to opt out.

We made a proposal to our state delegate to have a study done that would look at this issue. We wanted the State to agree to modified testing for kids who follow a modified curriculum (this would include quite a few kids in special ed). That way, they wouldn't have to opt out. They would take tests based on the curriculum they're studying. The teachers would be accountable and the parents would have something to measure their children's progress by. We would also like to see another kind of diploma added to the system to go along with the "Modified SOLs". We hope this would help a great many kids in Special Ed go on to higher learning institutions. Right now an IEP Diploma won't get them anywhere.

The proposal (HJ302) went before the Virginia Senate for a vote on Feb 28, 2000. It passed unanimously! The State Board of Education has a year to look at the issue and make recommendations. We hope that one of us will be assigned to the task force that studies it, to ensure they stick to the program. The task force will study many questions: Is the system fair? Are special education students being given the proper accommodations and/or

modifications? Are they even being encouraged to take SOLs or are they being exempted (we know they are right now)? A system needs to be put in place that will encourage schools to require the kids to take the SOLs, but before that, a modified test needs to be developed. There are many things to iron out, but the bottom line is we want our kids to have the opportunity to take the SOLs the same as all other kids do. We want teachers to be accountable to our kids just like they are to the kids in general education. This is probably an issue that will affect many children around the country as more and more states are looking at improving their standards of learning. We need to make sure that children in special education are included in those plans.”

[GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

THERAPEUTIC HORSEBACK RIDING

A Parent's Perspective....



The following exchange recently took place on the idic15 listserv.....

There was an article in our Sunday paper about a center that offers therapeutic horseback riding to special needs children. I have seen that some of you do this with your kids. A few questions: When (what age) did you start? What are your goals with this activity? What changes have you seen in your children? What has been your overall experience?

Johanna started riding when she was about 11. It was offered during the day through her middle school and because of her love of animals, we said "Why not?". She's been riding ever since, though now her lessons are after school, semi-private, and we pay for the lessons. The cost is quite reasonable, however, considering she's with the horses for about two hours each week. She grooms the horse before and after she rides and is on the horse an average of about one hour each lesson. I see these lessons accomplishing a number of goals:

- Johanna's self-esteem is greatly improved by her sense of accomplishment in riding and the competitions she participates in, winning blue ribbons and trophies, etc.
- Her tone is improved by the need to squeeze her thighs and position her body in the appropriate positions.
- Her attention span and cognitive skills are helped because she needs to listen and follow directions during the lesson. She's motivated to do both because of her love of the horses.
- She's provided with an opportunity to interact and connect with a number of new kids her age and older (who volunteer as 'walkers') and with adults in a new setting.
- Her independence is clearly evident because she wants to do this 'by myself'!
- It provides an opportunity for just Jo and me to spend some time all to ourselves. She seems to enjoy that special attention.
- It provides Johanna with another activity where she's the focus of attention . . . she's usually tagging along to her siblings' events and that gets boring for her!

Diane Creeley, Mother of Meghan (21), Johanna (18, idic15), Brian (16), Sean (16)



Eighteen year old Johanna Creeley shows off her horseback riding ribbons and trophy.



[GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

SKIING WITH STYLE

Bob Wiederwax of Glen Mills, Pennsylvania recently shared these photos of himself and his son, Bobby, on the slopes. Twenty-one year old Bobby, who has idic15, makes use of adapted equipment to help him enjoy this activity. Bob used a tether and a device called a ski bra which keeps Bobby's skis from crossing as they glide down the slopes together.



Bobby and his proud dad



Bobby enjoys skiing with the help of adapted equipment and a hand from his father

For more information about adapted skiing, including information on where to purchase equipment, contact:

**National Sports Center
For the Disabled
P.O. Box 1290
Winter Park, Colorado 80482
Phone: 970-726-1540
Website: www.nscd.org**



[GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)



Nicole Iseli of Portland, Oregon is the mother of Corrina (3 yrs., idic15) and Sierra (1 1/2 yrs.). She writes:

“Corrina's little sister has always been an annoyance to her (to say the least). When Sierra was an infant, Corrina used to try to climb in my lap and essentially sit on Sierra while I was nursing - completely oblivious to Sierra's presence (or so it seemed). As Sierra has grown and acquired skills at lightning speed, Corrina's attitude seems to have shifted from annoyance to active dislike. Corrina whines whenever Sierra is in the same room and repeatedly hits her sister on the head whenever Sierra does something she doesn't like. Given that this has been the basic sibling relationship up to this point, I am full of smiles because we've seen the relationship take a turn. We like to dance with the kids; we ask them to "hold hands" and we pick them both up and do a quick dance. Corrina now initiates the hand holding and reaches for her sister's hand! Last week, both girls took great delight in playing peek-a-boo around a chair. Corrina slowly leaned around the chair, Sierra squealed with delight, and Corrina hid back behind the chair - giggled - and then leaned out again! Moments like this are precious and few, and I'm happy to be able to share them with all of you who appreciate the simple magic of peekaboo between siblings.”

Do you have a “smile” to share?

*Send it to IDEAS, c/o Donna Bennett, 416 Big Mount Rd, Thomasville, PA 17364; or email it to:
IDEAS@craftech.com*

[GO TO NEXT PAGE](#)



[SPRING 2000](#)



[NEWSLETTERS](#)



[HOME](#)

PARENTS' RESOURCE PAGE

Upcoming Conferences

- **New Jersey COSAC (Center for Outreach and Services for the Autism Community)** will be holding its 18th annual conference in Atlantic City, NJ on May 12 - 13, 2000. IDEAS' Brenda Finucane and Elliott Simon are scheduled to present an overview of genetic causes of autism, including idic15. For more information, call COSAC at 609-883-8100 or email them at njautism@aol.com.
- The **Autism Society of America** is sponsoring its annual conference this year from July 2-5, 2000 in Atlanta, Georgia. The conference will be held at the Hilton Atlanta Towers in the heart of the downtown area. For more information, call 1-800-3AUTISM or visit their website at autism-society.org. IDEAS parent Patti Rubel has attended ASA's national conference in the past and can give anyone interested general information about how it's run, how good it really is, etc. Call Patti at 703-273-3011 or email her at rubels@email.msn.com
- **The National Association for Dually Diagnosed (NADD)** will hold its fourth international conference in Philadelphia on June 14-17. NADD is an organization which provides information about behavior management, medication, and advocacy for people with developmental disabilities and behavior disorders. Find out more by writing NADD, 132 Fair Street, Kingston, NY 12401-4802, or visit their website at www.thenadd.org
- The **American Association on Mental Retardation's** 124th annual meeting will held in Washington, D.C. on May 30 - June 3, 2000. For more information, call 1-800-424-3688, or visit their website at www.aamr.org.

Autism:

- **FEAT Email Newsletter:** For those of you who are interested in subscribing to the FEAT (Families for Early Autism Treatment) email newsletter, simply go to the website, which is full of interesting stuff as well as a very quick form to fill out. Then you will get 2 or 3 emails per day on the latest and greatest stuff on autism. To register, go to: www.feat.org/FEATNews
- **Autism Society of America**, 7910 Woodmont Ave., Ste. 300 Bethesda, MD 20814-3015. 1-800-3AUTISM, www.autism-society.org
- **(CAN) Cure Autism Now**, 5225 Wilshire Blvd., Ste. 226, Los Angeles, CA 90036, Phone: 323-549-0500, www.canfoundation.org
- **Autism Research Institute** 4182 Adams Avenue, San Diego, CA 92116, FAX: 619-563-6840, www.autism.com/ari/

Seizures

- **Recommended Book:** Freeman JM, Vining E, & Pillas DJ: **Seizures & Epilepsy in Childhood - A Guide for Parents (2nd ed.)** Baltimore: Johns Hopkins University Press, 1997.
- **Epilepsy Foundation of America**, 4351 Garden City Drive, Landover, MD 20785, Local Phone: (301) 459-3700, Toll Free: (800) EFA-1000, Fax: (301) 577-4941, www.efa.org

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