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Behavior Challenges in idic(15)

JANE TRUE

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AS PEOPLE WHO CARE ABOUT AND FOR SOMEONE WITH IDIC15, we have all been witness to problem behaviors. In this issue, we attempt to dig into these behaviors in the hope that we can uncover a few strategies that will make dealing with behaviors more manageable.

To kick off our discussion, we will look at:

Things You Can do to Support a Person with Difficult Behaviors

(Adapted from "10 Things You Can Do To Support A Person With Difficult Behaviors"; David Pitonyak; posted on www.dimage.com; January, 2002; by permission)

● Remember that all behavior is meaningful

Difficult behaviors are "messages" which can tell us important things about a person and their quality of life. In the most basic terms, difficult behaviors result from unmet needs. The very presence of a difficult behavior can be a signal that something important that the person needs is missing. Some examples of the kinds of messages a person might be conveying with his behavior are: "I'm lonely";

"I don't feel safe"; "Something hurts".

Even the most difficult behaviors do not occur without reason. All behavior, even if it is self-destructive, is "meaning-ful".

● Don't assume anything

It is easy to make the mistake of underestimating a person's potential because of her labels or because she has failed to acquire certain skills. This is a mistake. Always remember that people with disabilities are people first. Speak directly to the person and explain things as clearly as you can, even if the person's labels suggest that he cannot understand (at the very least the person will understand your tone of voice).

● Relationships make all the difference

Loneliness is the most significant disability of our time. Many people with disabilities, young and old, live lives of extraordinary isolation. Remember that there are many people in your community who will benefit from knowing your child. Be confident that he or she will make someone's life richer again and again and help them create relationships with others.

● Instead of ultimatums, give choices

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).

Choice is a powerful alternative to punishment. If your child's behavior challenges you, help him to find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices. Allow your child to make decisions throughout the day. If he has trouble making choices, find a way to help. Don't assume that helping the person to have more choices means letting him do whatever he wishes. Limit-setting is an important and fair part of any relationship.

● Help your child to have more fun

Fun is a powerful antidote to problem behaviors. Ask yourself, "Is my affected child having fun? Is she experiencing enough joy? Is this an interesting life with things to look forward to?"

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Creating Order Out of Chaos: Functional Behavior Assessments



ADAPTED WITH PERMISSION FROM FUNCTIONAL BEHAVIORAL ASSESSMENTS:
NEW DEVELOPMENTS, BY RICK ALBIN, UNIVERSITY OF OREGON

MANY FAMILIES RAISING A CHILD WITH IDIC(15) FIND THAT AS A CHILD GROWS OLDER, THEIR BEHAVIORS BECOME MORE CHALLENGING.

These behaviors often interfere with a child's ability to participate in school and community events, and can throw family life into chaos. Fortunately, there are ways for families to understand and manage these difficult behaviors. This article will provide an overview of a useful tool in understanding behavior challenges, the **Functional Behavioral Assessment**.

Functional Behavioral Assessment is a process for identifying the events that predict and maintain a child's problem behaviors. A functional behavioral assessment looks beyond the problem behavior itself and provides a context for the behavior. It can help families better understand why their child engages in these behaviors, and improves the effectiveness of behavior support efforts. Functional Behavioral Assessment is a means, not an end in itself. An effective Behavior Support Plan is the outcome (end). There are six steps in a functional assessment:

1. What is the problem behavior?

The first step is to clearly define the behavior in observable terms. Often the process of clearly defining a behavior can help strip away the anger, guilt, and fear that families feel about the behavior and help them to look at the behavior more objectively.

2. What is happening immediately before the behavior occurs?

The person conducting the assessment identifies the immediate predictors for the problem behavior – what are the cues, situations, or events that trigger the behavior?

3. What function does the behavior serve for the child?

What happens after the behavior occurs? What does the child get or avoid doing that keeps this problem behavior occurring over and over? Is the child meeting a sensory need? Is the child using a behavior to communicate something she or he wants? It's important to identify what "payoff" the child is getting from the problem behavior – it is this "payoff" that maintains the problem behavior. Sometimes one behavior may have several different functions. For example, pinching may serve as both a way to express frustration (communication function) and as a way to get input into the hands (sensory regulation function).

4. What are the conditions that make it more likely that the behavior will occur?

What are the conditions or events that "set the child up" for problem behavior when a "triggering" cue or event occurs? For example, does the behavior only occur when the child is tired? Hungry? Bored? After taking a prescribed medication?

5. Create a Hypothesis Statement

Hypothesis statements identify the conditions that set the child up for problem behaviors, the immediate

triggers, a clear statement of the problem behaviors, and the function of the behavior for the child. If problem behaviors serve multiple functions, then separate hypothesis statements are developed for each function.

6. Confirm the Hypothesis

Confirm your hypothesis (or hypotheses for problem behaviors that serve multiple functions) through observation. Of the times that you saw the problem behavior occur, what proportion included the triggers and consequences predicted by your hypothesis?

● After the Assessment

Creating a Behavior Support Plan

The information from a functional behavioral assessment is used to design a behavior support plan. The assessment provides the means to create a behavior support plan that directly targets the causes and effects of problem behaviors. A behavior support plan will help children learn how to meet their needs more positively, and will help families reduce the chaos that comes with challenging behaviors.

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.

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Lessons from the Classroom: Behavior Support Plans in Action

MICHELLE HOKENSON, a cross-categorical special education/social skills teacher, mom to Hannah, Klara (idic15), and Holly Ann, lives with her family in Rosendale, Wisconsin



SPECIAL EDUCATION TEACHERS know that every behavior has a purpose. There may be a direct payoff, it may meet a child's needs for sensory input, or it may be an attempt to communicate something that the child can't find another way to communicate. In the classroom, teachers and staff invest a lot of time in analyzing the when, where, how and why of problem behaviors. Once these are understood then classroom staff can begin to offer alternative choices to help the child stop the damaging or unwanted behavior. The formal name for this is usually a behavior support plan. Families can use behavior support plans to encourage more positive behaviors in their family lives too. Here are some examples of behavior support plans that I have used with Klara in our home.

● Severe posturing to cut off circulation to her feet

Some of Klara's unwanted behaviors are due to her sensory needs. For example, she wraps her legs tightly together and cuts off the circulation to her feet. We use a weighted blanket to give her the deep pressure that she needs. This strategy works very well.

● Hitting, Kicking, & Pinching

Klara hits, kicks and pinches her sisters and our pets. I believe she perceives things differently and sees her sisters and pets as a threat to her. If she is not expecting Holly Ann to come running by her, Klara will hit,

kick or pinch her in an effort to protect herself from what she sees as a threat. I have taught Holly Ann and Hannah to announce their plan before they pass by Klara. For example, Holly may say, "I'm going to the kitchen now." Klara is "warned" that Holly will be passing by her and she leaves her alone. Just saying hello to Klara before you pass by works!

When Klara demonstrated physically aggressive behaviors at school they used "scripting" techniques. We have just started using "scripting" at home. We draw simple stick figures doing what Klara was doing just before the behavior occurred. Then, we use thought bubbles above the stick people to find out what Klara was thinking and feeling and to point out what the other people involved might be thinking and feeling.



We only use natural consequences that happen because of the behavior itself. For example: People are sad when they get hit. We miss out on free time if our jobs are not done.

These strategies work well when Klara has chores to do. I wait for her to express a want. "Mom, can I play play-doh?" I answer with, "Yes, as soon as your dishes are put away. I will get the play-doh out and you put the spoons away." We give Klara very specific directions to help with chores. Instead of "put the dishes away" we say "put the spoons away", "now get all the bowls stacked up" and "where do all those plates go?" She understands these simple, direct statements and is happy to be helping her family.

● Unresponsiveness to requests

We also use a when _____, then _____ strategy. "When the racecars are put away, then we can go to the store." "When you are clean from your bath, we will have popcorn."

We also have a behavior plan to teach Klara time limits. I give her three verbal cues so she can measure time. For example: "When I have my shoes, coat and purse, I will leave for the store." "I have my shoes, are you cleaning up?" "I have my coat are you cleaning up?" etc. If she does not clean up I don't take her with me. When she misses out on things she really enjoys, she learns to follow directions in a timely manner even though she does not understand time. I use verbal commands and directions because Klara understands them but these strategies can be made into visual schedules as well.

Behavior support plans really can help to decrease problem behaviors. Remember that our kids are not making these choices to drive us crazy! Good Luck!

Medications Used for Behavior Management

JAMES TRUE, MD,

is a psychiatrist and father of young woman with idic15

SEVERAL GENERAL CAVEATS concerning medications in individuals with idic15 warrant discussion before more detailed information is considered. First, parents should be aware that any medication may have an unexpected effect or side effect, with no guarantee of benefit or outcome. One may be allergic to or intolerant of a substance without knowing it. Any new medicine is essentially a “trial”. Second, individuals with special needs often do not react typically to medicines, especially medicines used for “behaviors,” moods, or unusual presentations. The neurochemistry of the brain is extremely complex and not fully understood even in “typical” people. In individuals with idic15 it is much more complicated and not yet fully characterized. Third, drug interactions, chemicals in food, amino acids, and herbal products all have effects on behaviors and moods. This makes finding the right medicine even more complex. Fourth, people are not always aware of the effect of medicine on themselves. Our children, especially, cannot usually tell us how they feel in reaction to a medicine; we have to observe and interpret the effect. Finally, people with special needs have a high rate of paradoxical

reactions to medicine. That is, the medicine may cause a change opposite to the expected or desired one, or a totally unexpected one; sometimes, lower or higher doses than normal are required.

However, for our children with troubling behavior problems, we must try to help and it is important to understand the range of treatment options. General tranquilizers are antipsychotics but are also used for bipolar symptoms and often for intrusiveness or obsessive behaviors (frequently as an add-on). Some common ones are Risperidol, Seroquel, Abilify, Geodon, and Zyprexa. All have different side effects—some can cause weight gain, change prolactin levels, cause increased blood fats or sugar problems. Some generally do not. Some cause sleepiness. Abilify and Geodon have novel and complicated receptor binding in the brain and may have special advantages in avoiding side effects.

Anticonvulsants (seizure meds) are used for bipolar symptoms and sometimes for other behaviors, as well as for seizures. In general they have calming effects and along with antipsychotics tend to reduce the amount of stimulating input into the processing centers of the brain. Each anticonvulsant has side

effects—Tegretol can cause liver problems and bone marrow suppression, as can Depakote. Dilantin is usually not used for “behaviors.” Other anti-convulsants are Trileptal, Gabitril, Neurontin, Zonegran, and Phenobarb. Usually anti-convulsants affect either glutamine receptors or GABA receptors. Children with idic15 have unusual GABA receptor profiles that are being studied right now.

Antidepressants come in several categories. These are used not only for depression but also for obsessive compulsive disorder and anxiety. The old tricyclics, such as Elavil (amitriptyline), Tofranil (imipramine), and others can cause weight gain, constipation, and dry mouth. The SSRIs include Prozac, Zoloft, Paxil, Celexa, Lexapro, and Luvox. SSRI stands for selective serotonin reuptake inhibitor. These can help but can cause unexpected and atypical reactions, such as worsening behaviors. Anecdotally, they can also cause seizures in some individuals. Selective norepinephrine/serotonin reuptake inhibitors include Effexor and Cymbalta. They may work for depression and anxiety and cause side effects similar to the SSRIs. Wellbutrin is usually activating and can cause seizures. Luvox and clomipramine, a tricyclic, are used for obsessive-compulsive disorders but have similar class side effects and many drug interactions.

So-called **minor tranquilizers** include the benzodiazepines—

Medications Used for Behavior Management

Valium (diazepam), Xanax, Ativan, Tranzene, and others. They are addictive and can cause seizures if stopped abruptly; in people with special needs they can cause paradoxical reactions including tantrums, worsening of anxiety, etc. Other meds used for “anxiety” include Buspar and sometimes Benadryl or Atarax. In my opinion, unless needed as a seizure adjunct, benzodiazepines should be avoided. Sleep medications include Ambien, Sonata, and others (nearly benzodiazepines). Any of the previously mentioned medications can cause sleepiness. Benadryl and Seroquel are sometimes used. Rozerem is new and closely resembles melatonin. Melatonin itself can be used for sleep; it is

metabolized into a molecule resembling serotonin.

Medications for hyperactivity are sometimes used in children with idic15 due to their apparent lack of focus and hyperactivity. These are stimulants and include Ritalin (methylphenidate) and its offspring (Concerta, metadate, Focalin, etc.) or d-amphetamine (Dexadrine, or a mixture—Adderal). If these work, it’s great. However they can cause paradoxical sleepiness or actually increase “hyper” behaviors. Other medications used for hyperactivity include Strattera (nearly identical to Prozac) and sometimes Wellbutrin.

Other medications Lithium carbonate is used for bipolar disorder. It can be effective in stabilizing moods, but can cause

decreased thyroid functioning and requires blood level monitoring. It can cause acne and sometimes mild weight gain. Clonidine and Tenex are medications for adult hypertension but used for impulsivity in children. Side effects are decreased blood pressure, decreased pulse, and sleepiness.

In general it is best to identify as specifically as possible the problem needing treatment and use as little medicine as possible while trying to give your child a chance to function at his or her highest level. Remember, the doctor most likely has never treated a person with idic15 and your input and observations will be critical for finding the right medication for your child.

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Deb Case

| Cody & Corey's mom

"Since Cody was nonverbal, when he started school his teacher had us fill out a communication dictionary. [It helps] figure out what is going on with your child.

There are 3 columns. First column is a behavior/action... Second column: what he is trying to communicate... [Third column] How I respond... This helped the teacher in many ways. And the consistency of home and school has done amazing things for him!"

Jo-Ann DiBiasio

| Christine's mom

"My daughter does have a diagnosis of obsessive behavior that comes and goes. She responds well to sensory activities and I agree with what others said about trying to substitute her behavior with something else. However, I have also come across certain [behaviors] that I cannot seem to substitute and for those I have insisted that she goes into her room alone. Sometimes she does not want to be alone so she will stop the behavior on her own. If the behavior gives her lots of attention it always worsens."

Mari O'Connor

| Christopher's mom

"We tried time outs (and it worked!)... When he is "caught in the act" I used to plop his butt down in a special chair that we had ready for this moment... I held him in place and talked to him in simple words about how sad I was about what he had done... Sometimes he actually would say, 'sorry.'

"In the kitchen I always have a very special toy. I show him the picture of the toy and say, "here is your ball, play nicely." He knows that if he's a wild man that he will lose the ball and that time will be all over... These are simple techniques that just require consistency and repetition."

Amy Turner

| Ryan's mom

"...when I'm in the mood to explain [Ryan's behaviors] with humor, I say it's like [the movies] *Rainman* and *Forrest Gump* all rolled together."

Samuel Duxtator, age 11

| Cheyenne's (idic15) sibling

Most people don't understand kids with idic15 so they treat them like babies, but as a sibling of a sister with this disorder I know her behaviors and

understand them. Like for example, when my Mom's friend comes over and does crafts and activities with my sister Cheyenne. So she says to Cheyenne, "These are called scissors. We use them to cut stuff" and shows her how to use them. She then says, "This is called a glue stick and we use it to stick stuff together," and shows her how to use it. While that was happening I was sitting close by and I wanted to jump in because Cheyenne always takes the scissors and glue stick and uses them all the time but I didn't say anything since I didn't want to be rude.

One thing about kids with idic15 is that they listen and copy words they hear (so be careful what you say!). Also I'm not sure about other kids but I think that kids that have idic15 will start copying animals. Like my sister copies a parrot and always repeats herself over and over. She always says, "Squawk... I'm a parrot, squawk!" Also, when she was a baby the doctors said she would never walk, talk, see, or hear, but now she always runs, has pretty good hearing, she has fairly good vision and we have to constantly tell her to be quiet.

When my sister starts screaming or crying, I feel sorry for my Mom because she's the one who has to deal with it and in public my feelings intensify because people don't understand Cheyenne so they automatically believe that the source of the problem is my Mom even though it isn't. Plus I feel a tinge of embarrassment. Practically whatever Cheyenne does, I feel that way but I hardly ever feel embarrassed though. Like when Cheyenne's in public and she just keep talking loudly but I don't get embarrassed but I do get annoyed. Yet when Cheyenne is bad and my Mom has tried everything to settle her down and my Mom will ask me to help, 99.9% of the time I can settle her down. Dealing with my sister's behaviors is tough, but we love her anyway.



What great IDEAS!

Help meet our fundraising goals!

IDEAS is trying to raise \$28,000 this year to support the idic(15) registry, our upcoming 2007 conference, and meet our operating costs. Thanks to the efforts of many families, we've already raised over \$5,000 in 2006.

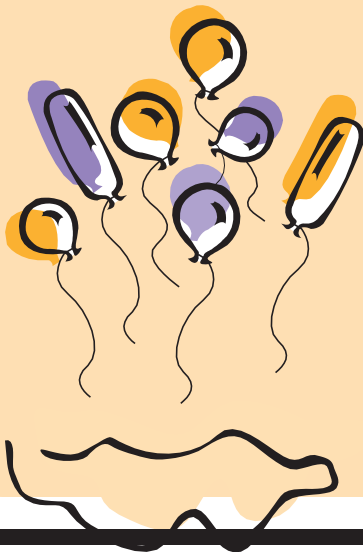
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For more fundraising tips, check the **Support IDEAS** link on the IDEAS website at www.idic15.org.

Thanks for helping IDEAS!

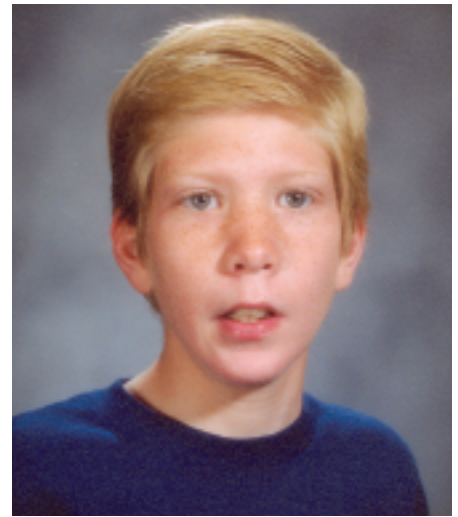
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Finding Our Way Through Behavior Changes

KAYE KITZMILLER,
is mom to Jason (idic15), and adult children Debra and Chad. Jason's father, Joel, passed away in 2004. The family lives in Woodland, California.



Our son Jason was a “perfect” baby and toddler. He did not display any aggression. At four years of age, he had a grand mal seizure. Soon after the start of seizure medication we began to see some significant behavior challenges, with pinching being his “behavior of choice.” I talked to the neurologist, but was assured the medication was not the culprit. He said Jason was frustrated because of poor communication skills.

I remember that Jason would scream and be agitated. There were times in the car where he would even reach me in the driver’s seat and pinch my arm. I would stop the car, firmly hold his hands, and tell him that was NOT okay but it did not phase him. When his behaviors were in the “attack” mode, I would put him in his room and shut the door. I had to hold the door closed because he would not stay voluntarily. He seemed to be a “devil” child intent on hurting everyone. It took about a year to realize that the behaviors were indeed a result of the seizure medication. We finally got him on a different medication where his behaviors became more manageable. We also added Dexedrine and Zyprexa into the mix of medication which was to help with behavior control. It has been several years now that we his behaviors

have been well controlled. I truly believe that, in Jason’s case, the seizure medications and/or seizures were a significant variable affecting his challenging behaviors in his earlier years.

Throughout the years, I have used many different techniques for managing Jason’s behaviors. When Jason was on the original seizure medications, these techniques were not terribly effective. After his medication was adjusted, these techniques proved to be much more successful.

At the first signs of agitation, it helps to firmly massage the palms of Jason’s hands or the bottom of his feet. I use this while out in public (the hands anyway!) and I find it helps a lot. It helps Jason to calm down a little bit and take charge of his emotions. At the same time, I drop my voice down to a nice even tone, sometimes almost to a whisper so he has to try hard to hear me. When he was younger, I would carry around food items I knew he liked. The act of his sucking or chewing on them would sometimes help to divert his behavior and he would “forget” that he was agitated. I made sure when I used this technique I rewarded him at a “good” behavioral moment. Even if

Finding Our Way Through Behavior Changes

there were only two seconds where he was not pinching, I would say “good not pinching, do you want a candy?”.

We also always have a place for Jason to go for a “time-out.” This is at the end of the hall where it is dark and quiet. When he was younger and more challenging, I would have to hold him there to make him stay. Now I can say “go to time out” and he walks to the end of the hall. This is usually all it takes to divert whatever behavior he is doing. There are times where he will go to that area himself. It is great that now Jason knows it is calming and is able to decipher when he needs to calm himself.

Another strategy I use in serious situations is to “talk with Jason on the couch.” It is something I use when I hear from teachers and others that his behaviors hits a level and can not be controlled in any other way. If he does not stop the behavior, they tell me and I follow through with it at home. I always follow through with what is said. Jason gets very serious for these talks and will sit still on the couch and listen intently. When I first used the couch-talk I did not understand why it was so effective. One day while I was talking to Jason,

he touched my eyebrows, said “eyebrow” and scrunched up his eyebrows. I realized that it was my facial features being firm with scrunched up eyebrows that he did not like. The couch-talk was VERY successful in his younger years when he would not behave at school. Now I only use it in worse case scenarios. Jason is warned it will happen if he continues his behavior and most of the times that will stop the behavior.

Current behaviors we deal with are screaming and other “loud” noises. He will still occasionally pinch. I ask him if he needs a time out and mostly that will stop the behavior. If not, then Jason gets a time out and that will divert the behavior.

Now I can take Jason anywhere and trust I will not have to deal with negative behaviors. When he was younger I would worry whenever we went somewhere that he would act out and we would have to leave. I still use the rubbing of the hands, and the food reinforcers. Rarely Jason needs a time out in a store. I have him stand for only a minute facing the shelves and that is enough for him. It is nice to be free of worries of what he might do.

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We have 70 completed surveys, but we'd like even more!

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RESEARCH

The Human Genetic Cell Repository

at the Coriell Institute for Medical Research holds the world's largest collection of human cell lines for use in research, including about 2000 different genetic disorders. They are collecting both idic(15) and int dup(15) cell lines. If you would like to add your child's cell lines to this important research collection, please contact:

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BITTERSWEET MEMORIES

It is with a heavy heart that we honor the memory of one of our own precious children. Breana Edwards succumbed to organ system failure and passed away in January after struggling with numerous medical challenges for many of her ten years.

Breana loved water and enjoyed her bath. School was a pleasure for her when she was able to attend and she especially loved to swing. Popsicles and peppermint sticks were special treats for her. Her 14 year-old brother Aaron has fond memories of a Dream Factory trip he took with his sister to Disney World in 2000, where they met the Chamberlin family from San Diego.

Like many other children with idic15, Breana came alive around music and it was a big part of her life. She particularly liked classical music and nursery rhymes, and would crawl over to the keyboard when her dad was playing. Hymns and children's songs were personal favorites.

Her dad Wayne is proud to have delivered Breana (with mom Angie's help?) on September 15, 1995. Fittingly it was the three of them together in their home at the end as Breana "danced into heaven" on January 14, 2006. Her parents describe their feelings as "bittersweet." Along with the sadness of missing Breana, they have ten years of beautiful memories that will stay with them forever.

The IDEAS family holds Breana in our hearts and sends our thoughts and prayers to the Edwards family at this difficult time.





Emma

Emma's Story

PAULA & BEN DAVIS

are parents to Emma (idic15) and two typical boys. The family lives in Westford, MA.

EMMMA WAS BORN February 9, 1999. She was full term and delivered via c-section. Emma was born with a cleft lip and palate. During Emma's first 12 hours of life, she had difficulty breathing so she was taken to Boston Children's Hospital for further evaluation. I didn't get to see my baby for 3 more days. Doctors ran all kinds of tests on Emma and determined that aside from the cleft, she was absolutely perfect....nothing to worry about, because they could easily fix the cleft with 4 or 5 surgeries over her first year of life (which they did, and her lip and nose look just about perfect.)

Emma was unable to breast feed because with the cleft, she was unable to close her lips to create suction. She used Haberman nipples and drank breast milk from a bottle. Because the Haberman

allowed us to squeeze the milk into her mouth, she was a hearty eater and ate whatever we gave her. To this day, she is still a terrific eater.

At 5-6 weeks old, Emma was not smiling, not really looking at me, and always gazing up at the ceiling. She frequently crossed her eyes and showed signs of low muscle tone. She was a laid-back baby, very quiet, a great sleeper, never cried, and very complacent. At 6 weeks she had her first cleft surgery, at 12 weeks her second.

At 14 weeks, I spoke with our pediatrician concerning all of the expected things that I felt Emma wasn't yet doing and he referred me to Early Intervention. As a result, at 4 months old we started OT and PT. At around 9 months, Emma was seen by a pediatric ophthalmologist because of eye crossing and what appeared to be a lazy left eye...in fact, Emma's

entire left side was weaker than her right side. The doctor said her vision was fine, but she had "delayed visual maturation" and that we should see a neurologist to figure out why she still wasn't really looking at us and not yet smiling. At 10 months, we went to the neurologist and they decided to run some blood tests. Voila!...we all know what the results said...Emma had idic15.

This diagnosis was a huge surprise in some ways, but no surprise in others. I knew something was wrong with Emma from the beginning, and now I had a name for it. The day I got her diagnosis was the worst day of my life. All I could think was why me? Why my little girl? I don't know how to take care of a "special child". However, I did know that that I had to learn what it meant, and try to explain it to my family.

The doctor gave me an IDEAS brochure, and my learning experience began.

Emma has two older brothers, 3 and 4 years older than her. They were too young at the time to understand anything beyond the cleft issues. My parents and my in-laws were the hardest to tell. All they kept asking is “what does it mean long term?”...If only I had some answers for them. If only I had answers for myself and my husband! I think it took a good 3 years for both sets of grandparents to really understand that this wasn't something that Emma was going to “outgrow.”

In terms of developmental steps, at 12 months old Emma could sit up unassisted and babble “mama.” At that time, we started speech therapy and sign language. At 14 months, Emma started to crawl. At 16 months, she pulled up to stand, and at 22 months she took her first steps. Emma signed her first sign at about 24 months old. She used the word mama correctly at about 2 yrs. At 3 she had 10 words and 10 signs and she started an integrated preschool for 2 full days and 3 (1/2 days)

per week.

The next year we switched her to a PDD class that was 5 full days. She received 1 hour each of OT, PT, and speech through all 2-1/2 years of preschool, and we supplemented with Private OT, Speech, Sensory, and Hippo therapy. Emma did very well in the PDD classroom. She learns much more using discrete trial training in a small environment. She learned all her colors and shapes and was speaking in 4 word sentences (age 4).

However, she was missing out on so much socialization with the “typical” kids. For kindergarten, I wanted her to spend more time with the typical kids in an inclusion classroom. Emma loves being around other kids, and has some very nice social skills and was talking in full sentences, but her articulation was poor. We tried inclusion, and, with 20/20 hindsight, I can say it was too soon to make the switch. She had an awful year. She didn't make any friends (the other kids thought she needed too much help for them to be able to play with her), and she made very little academic progress.

Emma is now in first grade, and is back in the PDD classroom, with 2 hours of inclusion each day. This year is turning out to be a great year. She has made several friends in the typical 1st grade. She is learning her letters, beginning phonics sounds, can rote count to 11. She talks a blue streak when she wants to, but her language skills are far from age appropriate. She is toilet trained for urine, and we're working hard at getting her to do a BM on the toilet.

Emma has an unbelievable relationship with her two older brothers and her father. She follows them around, asks for them when they aren't around, and snuggles in bed with them for story time. Her brothers will do anything for Emma too. They play the role of therapist when necessary, and discipline her when warranted. They tolerate her many idiosyncrasies, though they have moments like the rest of us when the feeling of their unique family weighs them down. Most of all, they treat her like a typical little sister. Emma is a happy little girl and has grown to be the sunshine in many people's lives

2006 Regional Gatherings

● California

Late August/Early September TBA
Golden Gate Park, San Francisco
Contact:
Evelyn O'Dell 925-827-9054
evelynodell@astound.net

● Midwest

Date & Location TBA
Contact:
Ruth Kross 708-691-0378
lenasmom@sbcglobal.net

● New England

Labor Day Weekend
Paula & Ben Davis' home
Westford, MA,
Contact:
Paula Davis 978-392-8474
xpdavis@comcast.net

● Northeast

July Date TBA
Cindy & Andrew Johnson's home
Central New Jersey
Contact:
Cindy Johnson 609-723-7731
cynthiaj100@verizon.net.

● Northwest

August 25 – 27
Camp Prime Time
Clear Lake, WA
Contact:
Greg Keller 360-270-3167
gregkeller1887@msn.com

● Texas

Date & Location TBA
Contact:
Linda Meagher
Linda.Meagher@shell.com

● Germany

September (September 9)
Bersenbrück, Northern Germany
Contact:
Christian Reiter
lissypapa@yahoo.com

SAVE THE DATE!

June 28–30, 2007
Seaport Hotel in Boston, MA

*The 4th International
IDEAS Conference
Sharing the Journey*



IDEAS

is a non profit organization that provides information, education and support to families affected by isodicentric and interstitial duplications of chromosome 15. **IDEAS** promotes research, awareness and understanding of isodicentric 15 and related disorders.

If you'd like to coordinate a regional family gathering in your area, and need help getting started contact:

Heather Bruce 317-862-8581
IDEAS Board Member