

## DOWN SYNDROME

## News

## A REMARKABLE WOMAN

Paula Hirschhoff

*(Editor's note: Paula Hirschhoff wrote this piece in December as a holiday letter to friends. In this adaptation, it became a tribute to her sister Heidi who died last year. A sister who had an enormous influence on the writer's life.)*

My sister Heidi died on March 15, 2014, after a long decline. Another sister and I had been her guardians since 2000, but as big sisters, we'd been loving her and helping with her care for 55 years.

Heidi was born with Down syndrome (Ds) in 1958, a time when doctors still advised parents to expunge memories of such newborns by institutionalizing them. Instead, our folks brought her home. It was never a question. That was a crucial decision in shaping our lives, both as individuals and as a family.

Stereotypes about people with Ds abound, even today. They are characterized as simple folk, good natured and loving. At Heidi's celebration of life service, her caretakers spoke of her golden smiles and warm hugs. Without doubt, she gave those in abundance. Her smile could light up a room. Her joyful welcome could make you feel like you were the most spectacular human in all creation. I concurred with those tributes.

Yet Heidi was more complicated than most people realized. She never talked much, but her mind was full of ideas; it was frustrating for her to be unable to express them in words. She would get agitated and difficult. I longed to know what she was thinking.

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PAULA AND HEIDI  
HIRSCHHOFF

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## LETTER FROM THE PRESIDENT



It is hard to believe that as I write this it's already May, and our annual convention is just around the corner! I can't wait to see so many of you again as well as meet new families and self-advocates in Phoenix. For those of you who are first time attendees, I know you will find a gathering place of like minds, high hopes, and realized dreams. As you can imagine, our staff and Board of Directors are working feverishly to make sure everything is in place so you can fully experience our "Giant Family Reunion," filled with learning, laughter and love for all children and adults with Down syndrome.

Your Board of Directors has been hard at work this year, collaborating with other national and international partners to ensure we are moving the Down syndrome movement forward. The passage of the ABLE Act, the nationwide debut of the movie "Where Hope Grows," improvements to the Adult Sibling Toolkit, as well as dedicated staff for African American and Spanish outreach are some of the highlights in the Down syndrome community.

The NDSC's website has a beautiful and engaging new look with updated navigation tools and additional resources, materials, and information that is only a click away. We are committed to continuing to create more new programs to better serve our members, enhance communications and advocacy for greater information sharing, and improving and developing more programs for self-advocates. The NDSC is excited about the future, and we are honored to serve as your national organization focused on families and creating a better world for individuals with Down syndrome.

I'm looking forward to seeing so many of you in Phoenix! If you are unable to attend, stay in touch via our website, Facebook and Twitter. Together, we can change the world for individuals with Down syndrome and make the world a better place!

My best,

Marilyn Tolbert, President

**Mission**

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

**Vision**

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.



## A Remarkable Woman

*continued from page 17*

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She had a range of passions. Music was one of the most intense. With a remarkable memory for songs, she could name what was playing on the radio before it registered on our subconscious. She could identify instruments in the orchestra by sight and sound. She loved Broadway musicals and ballet. I once watched her perform ballet steps, trancelike, across the living room floor. It was beautiful but mystifying, as if emanating from a source beyond our reach. As a child, she had said she wanted to become a ballet dancer.

Girl Scouting was another love. When her troop began meeting less often, she drew on her fantasy world and began running imaginary meetings on Wednesday nights, complete with recitation of the Girl Scout Promise. The marathon meetings would last until she fell asleep in the early morning hours, exhausted from her leadership responsibilities.

That fantasy world hid some danger as well, a lesson I learned one day when she was 12. We were home alone when she told me she was going over to the old house that we'd left several years earlier. We never drove, let alone walked that route, so I assumed she was taking one of her pretend trips on the exercycle. Mom and Dad got home just as I started to panic. Soon neighbors and police were scouring the neighborhood. No one had seen her. I didn't recall what she'd told me because it was inconceivable that this child who

never went alone beyond the driveway would try to find the old house by herself.

After an hour or so the phone rang. Former neighbors were calling to ask whether we'd sent Heidi over to visit. Relief collided with astonishment. With her favorite doll Mattie tucked under her arm, she had negotiated busy streets, traffic lights and 16 long city blocks. I wondered then what else she might be able to do if she and Mattie just strode out into the world together.

Heidi had always lived with our folks, but as they aged, I worried that she was isolated at home and that we had no plans for her future. With much effort and the help of a social worker, we found her a place in a group home and a day activity center. We thought weekends with Mom and Dad would ease the transition for everyone.

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**“I worried that she  
was isolated at home  
and that we had no  
plans for her future.”**

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But after weekend visits, Heidi would refuse to return to the group home. She found the new arrangement unacceptable. The love and interdependence that bound Mom and Heidi were more powerful than we had realized. It was a time of terrible tantrums (Heidi) and desperate doubts (me).

Then Heidi protested the only other way she knew how. She went on a hunger strike; her weight dropped to under 85 pounds. The situation

was deeply troubling. In fact, it was horrible. We were agonizing over what to do when suddenly and quietly, our beloved, caring mother passed away.

In the midst of mourning, the task of telling Heidi seemed formidable. I feared an extreme reaction. Yet when I finally told her, she accepted the sad news stoically, as if she already knew. If Mom was gone, she no longer needed to come home to be there for her. She began eating again. I brought her home to spend a couple days with Dad, Lori (our caretaker), and me.

That evening Heidi was busy, as always, bent over pen and paper. Before going to bed, we found the note that she had painstakingly printed. This time she had found the words to express what was in her heart: “Dear Mom. Missing you. Love Heidi.”

Heidi was a remarkable woman, fierce in her loves and loyalties and often unfathomable. Life with her was not easy. But she pushed us to raise the standards for what we expected of ourselves, especially our acceptance of eccentric behavior and human foibles. She helped us realize that everyone has a deep interior life and hidden talents. Our reservoirs of patience and empathy are far deeper because of her. Life with Heidi was one of the greatest gifts that our parents could have given us. She is part of me, part of all of us who loved her.

*If you'd like to contact Paula Hirschhoff, you may reach her at [phirschhoff@gmail.com](mailto:phirschhoff@gmail.com).*

# Siblings. Brothers and Sisters.

They are your first friends.

They are there with you for all of life's ups and downs. They are the people who will love you even when they are angry at you; the people who will most likely be your longest lasting relationship.

When you have a sibling with Down syndrome, the relationship takes on added significance, especially as you and your sibling get older. Our cover story in this issue, written by sibling Paula Hirschhoff, is a testament to the special sibling relationships we experience in our community.

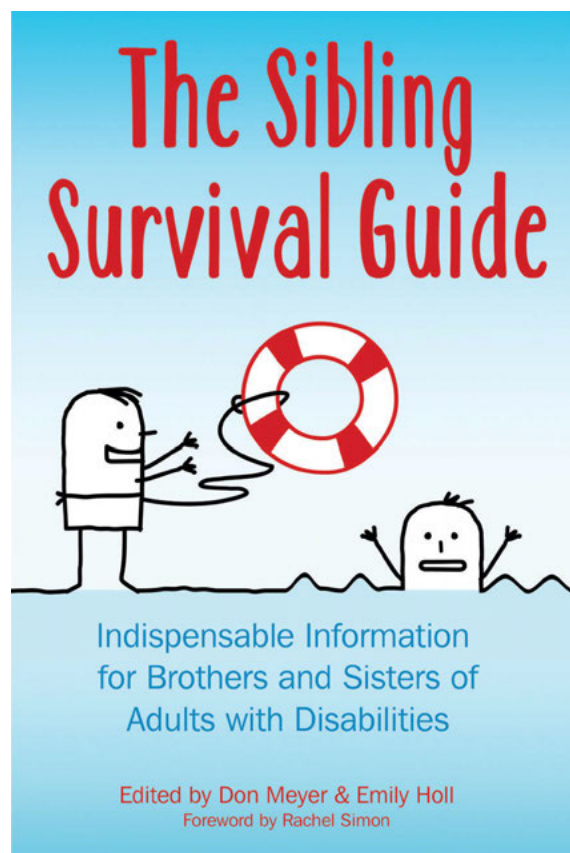
Thirty years ago, people with Down syndrome were not expected to out-live their parents. Yet with advances in medicine, coupled with improved living conditions (by living at home instead of in institutional settings), people with Ds are now often living into their 60's and 70's, long after their parents are able to care for them.

If you are a sibling of someone with Down syndrome, *The Sibling Survival Guide*, edited by Don Meyer and Emily Holl, is a valuable resource. It explores the many topics you need to know about and discuss with your parents now. Don't wait until a crisis occurs; decisions made during stressful times can sometimes have long-lasting ramifications.

*The Sibling Survival Guide* is an indispensable resource for families who are just beginning to discuss the future of their sibling. Where will he

live after he leaves the family home? How much support can you provide? What types of support should you provide? It contains advice on how to find day programs, respite, trusted attorneys, estate planners and other community supports. The contributors are siblings themselves and speak to the feelings, concerns and situations that may occur. While the book is written for adult siblings of anyone with special needs, not just Down syndrome, it will make an excellent companion to the NDSC's *Adult Sibling Toolkit*, by providing practical tips on how to talk with your parents, what to do if disagreements arise, and how to take care of yourself, even as you take care of your sibling. This book is a must!

Don Meyer, is an internationally known speaker and author. He is the also the creator of the Sibshop model, which provides peer support and information to thousands of young brothers and sisters of children with special health and developmental needs. He is the award-winning director of the Sibling Support Project, and has presented on issues facing families of people with special needs all over the world. He created SibKids,



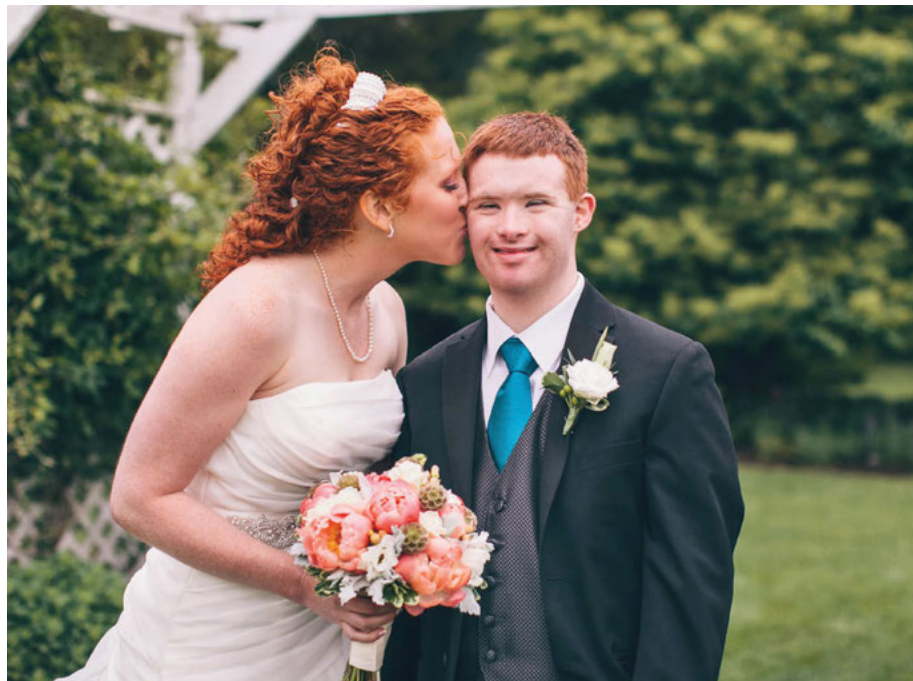
SibTeen, and SibNet, the internet's first and largest Yahoo groups and Facebook groups for young and adult siblings of people with disabilities, reaching over 3000 siblings every day. NDSC is pleased to be working with Don about sibling issues.

Here is what Don had to say about our *Adult Sibling Toolkit*: "Brothers and sisters will have the longest-lasting relationship with a family member who has a disability. And nothing keeps adult siblings up at night more than worrying about the future well-being of their brothers and sisters. I have met too many families who have not made plans for the future or the plans they have

made have been inadequate. Adult brothers and sisters desperately need information and resources that will help them support their siblings. The National Down Syndrome Congress' *Adult Sibling Toolkit* makes a valuable contribution to families as they plan for the future. One last thing: Parents, don't wait for your adult children to download the *Adult Sibling Toolkit*. Read it today and begin the discussion this week!"

NDSC is committed to providing brothers and sister of all ages with the tools they need through all stages of life. If you have not had the opportunity to connect with other siblings you are missing out on valuable support!

If you'll be attending our convention in Phoenix, we urge to take a look at the Adult Sibling Track we have planned. This track of workshops is designed to give adult siblings the tools they'll need, whether the day



has come when their parents are not able to care for their sibling or whether it's well in the future. Packed with experts in financial planning, adult transition, community inclusion, employment, independent living, aging and mental health, along with a few social networking opportunities,

adult sibs will leave feeling prepared, supported and empowered. There will be a sharing session led by an adult sib, and you'll have a chance to meet members of the NDSC Adult Sibling Task Force. You'll learn how to be involved with Sibnets and receive an *Adult Sibling Toolkit* for your family if you don't already have one!

Not able to attend the convention this year? Call us! We will answer any questions you may have.

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*The Sibling Survival Guide* is published by Woodbine House; [www.woodbinehouse.com](http://www.woodbinehouse.com).

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NDSC's Adult Sibling Toolkit can be downloaded from our website at [www.ndsccenter.org](http://www.ndsccenter.org) or you can request a hard copy by contacting us at 800-232-6372; [info@ndsccenter.org](mailto:info@ndsccenter.org).





# An Uncomplicated Life

by Paul Daugherty

William Morrow

[www.harpercollins.com](http://www.harpercollins.com)

March 2015, New York, NY

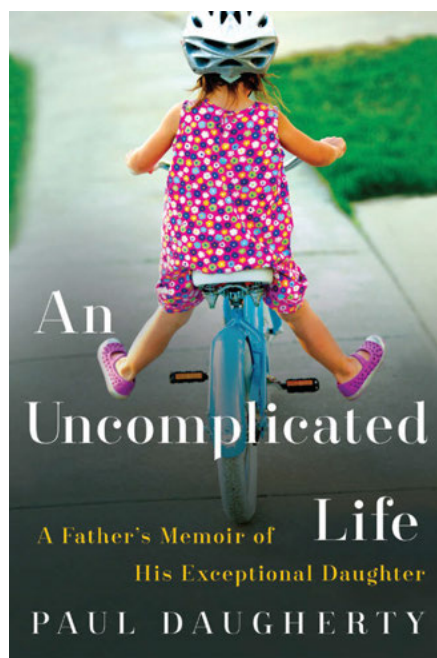
Hardcover: 384 pages

## Chapter 4, Therapy

“What they don’t tell you about having a child with Down syndrome, what they can’t possibly know, is that very quickly, you develop a syndrome of your own. It is equal parts fear and determination, anguish and love. It produces an alchemy of hope and sadness, a strange human metallurgy that stiffens your spine as your heart cracks. You don’t know what to do. So you do everything, and even then, everything isn’t enough. But its purpose is to sew you tightly so the worry doesn’t win.

We chased information. We kept moving. That way we eased our grief. We knew we couldn’t cure Jillian. We also believed it was worth the attempt. We became wrapped in a measured mania. Not an obsession, just constant motion. You can’t drown in sorrow when you’re spending all your time swimming.

We stayed afloat on the hope of the present. What can we do today to make Jillian better? The future became immediately and forever constricted. Our lives became a sports cliché. We took it one play at a time.”



This is just part of one of many relatable chapters in Paul Daugherty’s book, *An Uncomplicated Life: A Father’s Memoir of His Exceptional Daughter*. And this is one of many reasons we recommend you read it. Paul Daugherty has been a sports columnist for the *Cincinnati Enquirer* since 1994, and he’s been Jillian’s dad since 1989. Paul writes a daily blog on [Cincinnati.com](http://Cincinnati.com), and his followers are no strangers to Jillian and her life. She’s been the topic of his column many times, and now, she’s the star of an entire book.

Parents of children with Down syndrome, particularly fathers, will connect with Paul and his family. But how exciting that since Paul is already a popular writer with a built-in following, he has the opportunity to reach beyond the Down syndrome community, and

help other fathers, other families, see what we see. This makes us very happy!

Paul’s memoir includes big moments and small ones. Jillian learning to ride a bike, leaving the yard on her own, dates, proms, graduation, college, Jillian’s engagement. Mothers who read this are sure to get goosebumps, if not teary-eyed. Dads...who knows? Paul says he didn’t shed a tear at her graduation or 21st birthday celebration...but some fathers will for sure, just by reading his account.

Paul is honest about lots of things, including how scared he was about the diagnosis. And that all of the hard work done to keep Jillian out of segregated classrooms really fell to his wife Kerry. And that it’s painful to see your child excluded from typical social activities because she has Down syndrome. But he also gives us these words, “If you are anything other than terminally pessimistic, you believe the extra chromosome has some beneficial reason for being. Number 47 contains a lot of what makes us good. It has to. Somewhere in that bonus wiring is a connection to compassion and kindness—a plan for how to be better. Number 47 puts out the fires of ego and envy and vanity and guile. It filters anger. Thanks to 47, Jillian lives a life of joy, giving and receiving in equal time...It’s an extra storage tank for all her good stuff.”

There is sure to be an amazing column written after Jillian's wedding this summer. We can't wait to read it.

*Note: We have reviewed other exceptional books written from a father's perspective about raising a child with Down syndrome. In 1996, Michael Berube's book, Life As We Know It, was published, and chronicled his family's life since the birth of his son Jamie in 1991. In 1997, football coach Gene Stallings published Another Season, about life with John Mark, and recounted the influence his son had on his entire family, from birth to adulthood. More recently, George Estreich wrote about his daughter in The Shape of the Eye, and Jeffrey Gallagher recounts his son's birth and first year in Wilderness Blessings. We recommend each of these. [SJ]*

# 10 Defusing Phrases to Use at IEP Meetings

by Amanda Morin, Understood.org

*Amanda Morin is a writer specializing in parenting and education. She draws on her experience as a teacher, early intervention specialist, and mom to children with learning issues.*

## 1. "I may be misunderstanding."

IEP meetings can get heated when there is disagreement about how to interpret laws or test results. You can defuse that by taking a step back and giving the school a chance to explain its position. If you're certain you're correct, don't worry—you'll get a chance to say so.

**Sample response:** "I may be misunderstanding. Can you show me a detailed interpretation of that law? Here's the information I have on hand that speaks to this issue."

## 2. "I can show you."

If someone tries to shut conversation by telling you she's not sure where your information is coming from, that's easy enough to defuse. Simply show her.

**Sample response:** "I can show you where I've highlighted that information in the report and progress notes. Can we make each team member a copy?"

## 3. "How can we work together to make this happen?"

It can be frustrating (to say the least) to hear someone at your child's school tell you it doesn't provide a certain service or doesn't have the staff to implement it. But the law is on your side, so make the conversation about collaboration.

**Sample response:** "How can we work together to make this happen? The law says services must meet my child's unique needs, and this is the recommended service."

## 4. "May I see a copy of the written policy?"

Someone from the school might say, "This is how we've always done something." But that doesn't necessarily mean it's a policy.

*Continued on page 24*

**321**  
**dance**



June 27, 2015

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## 10 Defusing Phrases for IEP Meetings

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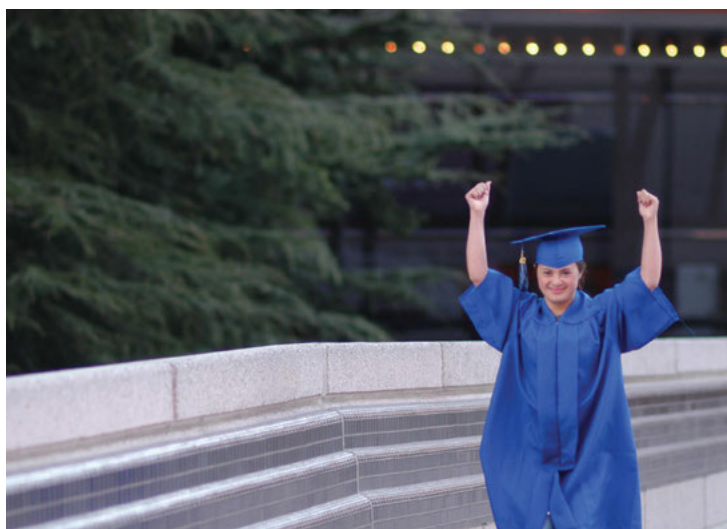
Defuse any arguments about it by asking to see in writing that this is how they handle the situation.

**Sample response:** “I understand this is how you do things. May I see a copy of the written policy that outlines this procedure?”

### 5. “Let’s ask him to join us.”

Federal law says that the IEP team needs to include someone who is able to make decisions about staff and funding. But in practice you may hear, “I’m not in a position to make that decision.” Instead of getting upset, get practical.

**Sample response:** “Is it Mr. Smith who has that authority? Let’s call him and ask him to join us.”



### 6. “I understand.”

It may surprise you how this simple phrase can defuse tense situations. Keep in mind it doesn’t mean the same thing as “I agree.” It just means you’re hearing what’s been said.

**Sample response:** “I understand you only have 15 minutes left for this meeting. While we’re all here, why don’t we set up another time to continue this conversation?”

### 7. “I’ve noticed...”

Parents are equal members of the IEP team. If you feel like your concerns aren’t being heard, take a breath and then calmly speak up. Be specific about what you know about and see in your child.

**Sample response:** “I’ve noticed that at the end of the day, Olivia isn’t able to focus on her homework without getting frustrated. I’d like to talk about how to make that easier for her.”

### 8. “How does that look in the classroom?”

Conversation about accommodations, behavior plans or instructional strategies, can easily turn to talk about theories or ideas. You can redirect by asking about how things will actually work.

**Sample response:** “I like the idea of checking in every 15 minutes to see if Olivia is on task. How will that happen in the classroom? Will the teacher be able to manage that?”

### 9. “What alternatives do you suggest?”

When you hear, “We don’t agree with that recommendation,” you may feel the need to push to defend your position. Instead, keep the dialogue going.

**Sample response:** “OK, you don’t think that will work for Olivia. What alternatives do you suggest to address that identified need?”

### 10. “Let’s talk about what’s working.”

Sometimes it can feel like an IEP meeting is a long conversation about what’s going wrong. It doesn’t have to be. In fact, focusing on what’s going well can help you discover ways to address other issues.

**Sample response:** “Let’s talk about what’s working. Maybe some of those strengths and strategies can help us find ways to address the trouble spots.”

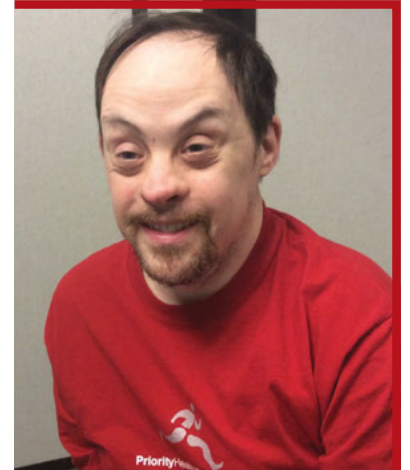
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## SELF-ADVOCATE CORNER

# Doug McBride



My name is Doug McBride. I am thirty-seven years old and I live in Kalamazoo, Michigan. I live with my mom and dad. I have two brothers, my brother Mike lives in California and my brother Jeff lives in Texas. At home, I like to color and trace in my tracing book but my favorite activity is making lists of sports teams and mascots on the computer.

In my free time I enjoy all types of sports. A long time ago (like Star Wars), I played softball in Challenger little league. Now I help coach a team with my dad. I now participate in the Special Olympics as an athlete and a coach. My favorite event is the Javelin. I also enjoy watching all sports. I used to go to many high school games, now I attend lots of Western Michigan University Sports with my mom and dad. At home, I watch sports on TV and listen to them on the radio. My favorite teams are the Detroit Tigers, Detroit Red Wings, Detroit Lions, Kalamazoo Growlers and the K-Wings. My favorite player is Justin Verlander his number is 35.

I am an active member in my church community. I used to sing in my church choir but now I sing with the Borgess Spirit Choir at Borgess Hospital. At church, I help out by sharing stories during the children's

worship. I also talk with my friends about grief and provide them with much needed hugs. I help out during church by greeting the new and old members and passing out church bulletins. At church, I get to see my favorite pastor Matt and his beautiful wife Cara and their son and two daughters. Pastor Matt and his family always bring a smile to my face.

I have many hobbies that I enjoy including relaxing and listening to music. My favorite artist is Tobey Keith but I also enjoy gospel, and pop music. On TV, I watch dramas, reality TV, comedies, but especially enjoy history, the news and WWE ("The Rock has come back"). My favorite wrestlers are Brock Lesner and his assistant Paul Heyman. One of my most favorite activities is visiting my friends at their group home R.O.I. At the group home, I play sports, hangout, horse around, and talk to girls.

Another activity that I enjoy is traveling. I have been all over the United States and really enjoy visiting state capitals. While on trips, I also visit many college and professional sports stadiums. My favorite stadium I have visited is Lucas Oil stadium in Indianapolis. I have also travelled to several National Down Syndrome Congress

conferences including conferences in Washington D.C., Indianapolis, Minneapolis, and Kansas City and hope to attend more in the future.

*Joe Kilpatrick supported Doug in the writing of this article for Down Syndrome News, and felt it would be beneficial to his work on communication skills. Joe writes, "Building communication skills can occur in many ways. Part of Doug's path to building his communication skills came through writing this letter, which involved many high level executive functioning skills. Doug was required to make some difficult decisions, such as deciding who he was and what he wanted his readers to learn about him. Throughout the past month he has worked diligently brainstorming, outlining, and drafting his "about me" letter; working through the same process that any successful writer does. In addition, this activity provided a fully functional opportunity to work on writing skills such as spelling and structuring sentences. Each day working with Doug was a pleasure. He was highly motivated to write this and it made the process run smoothly. It was a pleasure working with Doug, learning his story and helping him share it with the world."*

# Inclusion: Celebration of Diversity in Action

by Dr. Ilene Schwartz

Imagine a world where children of all abilities learn, play, and grow together. A world where ability does not stand in the way of making friends, or having fun, attending the school of your choice, or participating in your community in a manner that is meaningful to you.

That is what I spend my time working on every day at the University of Washington's Haring Center for Inclusive Education. That is, how to realize the promise, potential and power of inclusion.

But, what is inclusion? Inclusion is about belonging, membership and participation. It is about being part of the group—but it is way more than just being physically present. Haven't you all had an experience where you are physically part of a group but you feel like you do not belong? It is not a good feeling.

How does that change? It changes by someone making an accommodation so that your needs are met and that you can experience success in that setting. That is the key to inclusive education. Inclusive education provides the types and amounts of supports to students and teachers to insure that they can be successful. The goal is to make sure that everyone in the school is challenged, supported, and can participate in a meaningful way.

How do we make this happen? Through teaching. Through the high quality implementation of effective instructional practices. In other words, teaching is important. It is important if you are a young child trying learn how to negotiate the world, a child with disabilities attempting to learn how to use words to communicate, a child learning to conquer two digit addition or riding a bike, or even if you are a 50-something non-digital native attempting to figure out how to use her new iPad.

As adults, however, we often forget the power and importance of high quality instruction when we are learning new skills. We spend so much time doing what we are good at or at least what we are comfortable with, that we rarely learn new skills. Every year I challenge my graduate students to take the time to learn a new skill. They look at me perplexed and remind me that they are in graduate school and are spending every day learning new skills. I agree, but remind them that by the time they have gotten to graduate school, they know how to "do" school and challenge them to do something in an area that they are not good at. I challenge myself in the same way and every year or so try to learn or accomplish something in an area I find challenging. That is



DR. ILENE SCHWARTZ

how I ended up doing a triathlon for my 50th birthday and discovered or rediscovered the importance of instruction.

Effective instruction helps learners to be confident and competent. It provides them with opportunities to practice with feedback that improves their performance. It is motivating. Most importantly, it is intentional. Effective instruction does not just happen—good teachers whether they are in a classroom, a kitchen, a sports field or elsewhere in the community, plan the type of instruction that they provide. They evaluate their students' current performance and figure out what type of support is needed to get them to the next step. They look at the data on students and make decisions based on those data.

But, good instruction is only valuable if it is used to teach socially important skills and behaviors. Often when visitors observe our inclusive preschool program at UW they remark how nice it is that

children naturally play and help each other. I correct them and say it is great that children with and without disabilities play and work together, but it is because of carefully planned instruction. If you want children to be helpful and inclusive you need to create classroom and community environments that provide the opportunities and teach children how to support each other, what it means to communicate with someone who has limited language skills, and how to make accommodations so that everyone can participate in an activity.

In our work on inclusion we followed a number of children with severe disabilities from preschool to high school for five years, observing them at the school, in the community, talking to their teachers, parents, and to them, when possible. We were interested in answering the question “what do children learn from being involved in inclusive education.” In our work we heard lots of stories and observed some remarkable transformations. One of my favorites is what I call the birthday party story. Here is how it goes—Ryan is a 3rd grader with severe disabilities who has always been in a segregated classroom. This year his school has made a commitment to inclusion and he is in a general education classroom with support. A few months into the school year, an invitation to a birthday party for one of Ryan’s classmates comes home in his backpack. Ryan had never been

invited to a birthday before. Being invited to a birthday party is an indicator of inclusion—by itself it is not an outcome, but points to some important outcomes. We identified three primary outcomes of inclusion: membership, relationships and skills. Membership describes how a student interacts with a group. We look for indicators of membership—these are accommodations that people in a group make to facilitate the meaningful participation of students



with disabilities. We look at membership in classroom, school, and community groups. The second outcome domain is relationships. Whereas membership looks at interactions with groups, relationships examine 1:1 interactions. We are interested in observing the range of relationships a student demonstrates including peer/ companionship, helper/helpee, and conflict. We don’t include friendship

because we believe that being a friend means demonstrating that full range of relationship. Finally we have skills—the cognitive, communicative, social, motor, and adaptive skills that are part of an educational plan for all children.

Simply put, **inclusion is the celebration of diversity put into action.** If we abandon our commitment to inclusive education and inclusive communities, we lose the rich diversity of experiences that only happen when children, families, and teachers learn and participate together.

If we give up on inclusion, it leads to a culture where learning will not happen for all and communities do not connect. Where children don’t have access to opportunities and support that they need to succeed, instruction works to make learners more successful and confident. Effective instruction used to teach valued outcomes in valued rituals, routines, and activities is what we need to achieve the promise of inclusive education. Inclusion is a right, not a privilege.

*This article was originally posted on Kansas University’s Hawk Hopes Blog, and is reprinted with permission. Dr. Ilene Schwartz is a professor in the Area of Special Education at the University of Washington and the Director of the Haring Center for Research and Training in Education at UW. She earned her Ph.D. in child and developmental psychology from the University of Kansas and is a board certified behavior analyst (BCBA).*



# Infantile Spasms in Children with Down Syndrome: Investigating a Rare but Serious Condition

**Infantile spasms can occur in children with Down syndrome and typical children alike. Ongoing research at the Anna and John J. Sie Center for Down Syndrome at Children's Hospital Colorado examines the relationship between infantile spasms and Down syndrome in hopes of improving diagnosis and treatment.**

The spasms, characterized by a stiffening of the extremities and an arching or folding at the waist, are also known as West's syndrome after the first known description of the condition's symptoms—a letter penned by Dr. W. J. West describing his son's attacks. Dr. West's son would heave forward from the waist for a moment, then return to an upright position. These episodes would occur in clusters of as many as 20 spasms in a row in rapid succession.

While infantile spasms are serious, they are not common. Estimates suggest 1 to 3 percent of children with Down syndrome will develop infantile spasms, while the highest estimate places that figure around 13 percent.

## WHY SO SERIOUS?

Children with infantile spasms stop progressing toward developmental milestones and may lose motor skills they have already mastered, such as sitting up or crawling. They may experience cognitive and speech regression as well.

Unaddressed infantile spasms may permanently impair functionality and impact children's abilities—a serious concern for children with Down syndrome who may already have developmental delays.

"It is imperative to diagnose infantile spasms early to promote appropriate treatment and the best possible



outcome," said Dee Daniels, R.N., C.P.N.P., Program Director at the Sie Center.

## THE INFANTILE SPASMS RESEARCH STUDY

Currently, the most effective treatments for infantile spasms are pharmaceutical.

"Once, while working with children who have Down syndrome and infantile spasms, I noticed that children with Down syndrome were more responsive to treatment, and many times, their infantile spasms resolved quickly," said Daniels, who was previously a nurse practitioner on the epilepsy team in neurology at Children's Hospital Colorado. "They also often did not go on to have other seizure types, which was not always the case in typical children who had infantile spasms."

In the first phase of the *Improved Outcome of Infantile Seizures in Down Syndrome Population* research project, researchers at the Sie Center are examining the records of 28 patients with Down syndrome and infantile spasms who were cared for at Children's Hospital Colorado between April 2005 and April 2013. Thus far, researchers have examined the response to

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## Unaddressed infantile spasms may permanently impair functionality and impact children's abilities.

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various anticonvulsants—including adrenocorticotrophic hormone (ACTH) and vigabatrin—to determine their effectiveness.

The research is planned to continue as a 10-year longitudinal study.

“While ACTH treatment for infantile spasms is effective, it can be potentially costly and time consuming. Each type of treatment, ACTH or vigabatrin, has unique side effects,” said Tim Benke, M.D., Ph.D., Director of Research at the Neuroscience Institute at Children’s Hospital Colorado, and Associate Professor of Pediatrics, Neurology, Otolaryngology, and Pharmacology at the University of Colorado School of Medicine. “We want to provide clear information and guidelines for families so they can make informed decisions about what’s right for their children.”

### SPOTTING THE SIGNS

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Daniels and Dr. Benke also hope this research will help to increase awareness of infantile spasms in children with Down syndrome, so those who are experiencing this condition will be identified early and treated appropriately to improve their medical and developmental outcomes.

“Sometimes infantile spasms in children with Down syndrome are not always recognized early, and treatment is delayed,” Daniels said. “Children with Down syndrome already have a range of development delays prior to diagnosis, as well as low muscle tone and other medical issues. Subtle early symptoms of infantile spasms are often attributed to Down syndrome.”

Raising the awareness of the child’s healthcare providers, parents, and caretakers about the risk and

presenting features of infantile spasms in children with Down syndrome is imperative to improving outcomes, Daniels added.

*The Sie Center was founded in 2010 with the support of the Global Down Syndrome Foundation. It serves as a hub of care and research for children with Down syndrome and has the added benefit of being connected to Children’s Hospital Colorado, a top 10 children’s hospital. For more information, visit [siecenter.org](http://siecenter.org).*

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## NDSC 2015 Annual General Membership Meeting

**Saturday, June 27, 2015**

**5:30 to 6:00 pm ET**

**Wildflower A, Level 2  
JW Marriott Desert Ridge  
5350 E. Marriott Drive  
Phoenix, AZ 85054**

The General Membership Meeting will include the introduction of our newest self-advocate board member (elected by his/her peers and the Youth and Adults Conference); reports from our Foundation Trustees, NDSC Treasurer, and an overview of 2014 activities by our Executive Director. The Nominating Committee will present its slate of candidates, and the election of new board members will take place. Other business of the organization will be conducted as warranted. All NDSC members are invited to attend.



**NATIONAL  
DOWN SYNDROME  
CONGRESS**

# Espasmos infantiles en niños con síndrome de Down: Investigación de una condición poco frecuente pero grave

**Los espasmos infantiles pueden presentarse en niños con síndrome de Down y en el resto de los niños de manera similar. La presente investigación llevada a cabo en el Centro Anna y John J. Sie para el síndrome de Down del hospital Children's Hospital Colorado analiza la relación entre los espasmos infantiles y el síndrome de Down con la esperanza de mejorar el diagnóstico y el tratamiento.**

Los espasmos, que se caracterizan por rigidez en las extremidades y un arqueamiento o flexión de la cintura, se conocen también con el nombre de síndrome de West, a partir de la primera descripción que se conoce de los síntomas propios de esta condición—una carta escrita por el Dr. W. J. West que describía los ataques de su hijo. El niño se inclinaba hacia adelante desde la cintura por un momento y luego regresaría a una posición vertical. Estos episodios se producirían en grupos de hasta 20 espasmos consecutivos en sucesión rápida.

Aunque los espasmos infantiles son graves, no se producen de manera frecuente. Las evaluaciones sugieren que entre el 1 y 3% de los niños con síndrome de Down desarrollarán espasmos infantiles, mientras que los valores más altos sitúan esa cifra alrededor del 13%.

## ¿POR QUÉ SON TAN SEVEROS?

Los niños con espasmos infantiles tienen una interrupción en las etapas de crecimiento y es posible que pierdan las habilidades que ya han dominado como sentarse o gatear. También podrían experimentar un retraso cognitivo y oral.

Los espasmos infantiles no tratados impedirían permanentemente la funcionalidad y causarían un impacto en las habilidades de los niños—una gran preocupación para niños con síndrome de Down, quienes posiblemente ya poseen retrasos del desarrollo.

«Es imprescindible diagnosticar los espasmos infantiles de manera temprana para llevar a cabo un tratamiento adecuado y obtener el mejor resultado posible», establece Dee Daniels, enfermero registrado (R.N.), enfermero profesional pediátrico certificado (C.P.N.P.), Director del Programa en el Centro Sie.

## ESTUDIO DE INVESTIGACIÓN DE LOS ESPASMOS INFANTILES

Actualmente, los tratamientos más efectivos para estos espasmos son farmacéuticos. «En una ocasión, mientras trabajaba con niños con síndrome de Down y espasmos infantiles noté que aquellos con síndrome de Down

«Es imprescindible diagnosticar los espasmos infantiles de manera temprana para llevar a cabo un tratamiento adecuado y obtener el mejor resultado posible.»

— Dee Daniels



respondían mejor al tratamiento, y en numerosos casos sus espasmos se solucionaban rápidamente», determinó Daniels, que anteriormente fue enfermero profesional del equipo de epilepsia en neurología del *Children's Hospital Colorado*. «Tampoco tenían otro tipo de convulsiones, que no era el caso del resto de los niños con espasmos infantiles».

En la primera etapa del proyecto de investigación *Improved Outcome of Infantile Seizures in Down Syndrome Population*, especialistas del Centro Sie examinan los registros de 28 pacientes con síndrome de Down y espasmos infantiles que recibieron asistencia en el *Children's Hospital Colorado* entre abril de 2005 y abril de 2013. Hasta el momento, los especialistas han analizado la respuesta a varios antiepilépticos—como la hormona adrenocorticotropa (ACTH) y la vigabatrina—para determinar su efectividad.

Se planea que la investigación continúe como un estudio longitudinal de 10 años. «Aunque el tratamiento con ACTH para espasmos infantiles es efectivo, puede ser potencialmente costoso y prolongado. Cada tipo de tratamiento, con ACTH o vigabatrina, posee efectos secundarios únicos», estableció Tim Benke, Doctor en medicina, Director de Investigación del Instituto de Neurociencia del Hospital de Niños de Colorado, y Profesor Asociado de Pediatría, Neurología, Otorrinolaringología y Farmacología de la Universidad de la Escuela de Medicina de Colorado. «Deseamos brindar indicaciones e información precisa a las familias para que puedan tomar decisiones fundamentadas sobre lo que es adecuado para sus hijos».

## DETECCIÓN DE LOS SIGNOS

Daniels y el Dr. Benke también esperan que esta investigación ayude a incrementar el conocimiento sobre los espasmos infantiles en niños con síndrome de Down, de manera que aquellos que tienen esta condición sean identificados de manera temprana y reciban un tratamiento apropiado para mejorar sus resultados evolutivos y médicos.

«En algunas ocasiones los espasmos infantiles en niños con síndrome de Down no se reconocen de manera

**«En algunas ocasiones los espasmos infantiles en niños con síndrome de Down no se reconocen de manera temprana y el tratamiento se retrasa.»**

**– Dee Daniels**

temprana y el tratamiento se retrasa», determinó Daniels. «Los niños con síndrome de Down ya poseen un desarrollo más lento previo al diagnóstico, así como también bajo tono muscular y otros problemas médicos. Los síntomas sutiles tempranos de los espasmos infantiles siempre son atribuidos al síndrome de Down».

«Es imprescindible crear conciencia en los médicos, padres y cuidadores sobre los riesgos y las características existentes de los espasmos infantiles en niños con síndrome de Down para obtener resultados favorables», agregó Daniels.

*El Centro Sie fue fundado en 2010 con el apoyo de la Global Down Syndrome Foundation. El mismo consiste de un centro de cuidado e investigación para niños con síndrome de Down y posee el beneficio adicional de estar vinculado con el Children's Hospital Colorado, uno de los 10 mejores hospitales de niños. Para más información visite [siecenter.org](http://siecenter.org).*

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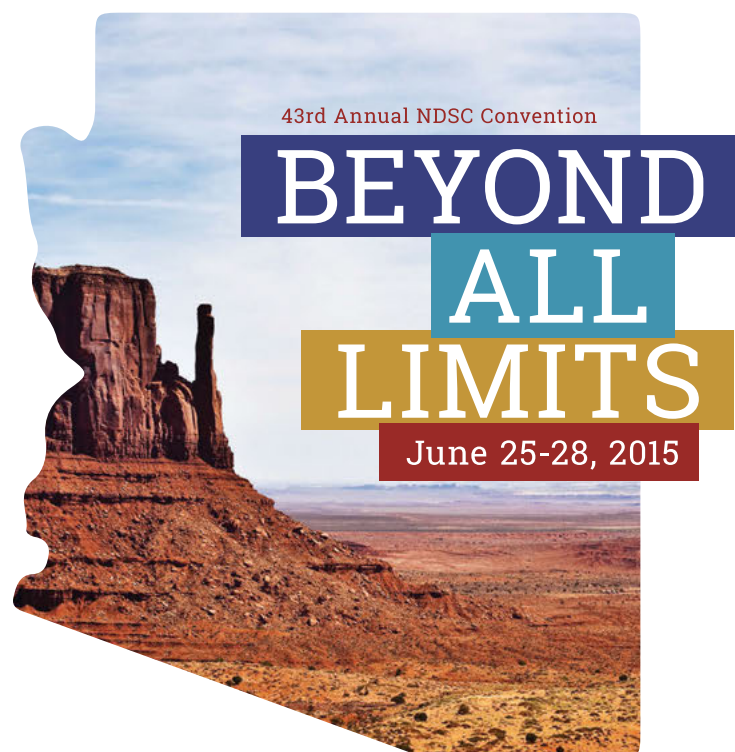
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Even if you can't make it to Phoenix, you can share in the experience by purchasing the audio recordings of the workshops and plenary sessions. For \$70.00, members can purchase online access to these recordings, which are synced to the presenters' PowerPoint presentations. (Convention attendees will have access to these recordings as part of their registration fee.)

Visit our website for complete information about all of the general convention workshops and how to register for the online recordings. (Recordings will be available approximately two weeks after the convention.)