



Down Syndrome News

NEWSLETTER OF THE

Volume 39, Number 1

Spring 2016



About my sister

By Eilish Kelderman

My sister, Kailin, is the most amazing person I've ever known and will ever know. She looks at everything with a positive attitude and always manages to find the good in even the worst situations. She's always there to give me the best advice or to give me bear hugs when I'm feeling down. She is undoubtedly the most inspiring person I know and every day I thank the Universe for not only putting her in my life, but making her my older sister.

There's a lot of things I wish the world could understand about my sister. Like how instead of declining an invitation to go out, she'll say, "I need to take care of my cat...at home". Or how she clasps her hands together and squeezes her eyes shut when she's happy. Or that you shouldn't treat her differently because she's a little more unique than the rest of us.

What makes her so unique?

One extra copy of her 21st chromosome.

My sister has Down syndrome. Kailin was born on November 22, 1994 at some wee hour of the morning. About a minute after she was born, the doctor said to my mom, "I highly suspect that your daughter has Down syndrome."

Growing up, I never really felt like Kailin (KK and/or Keeks for short) was any different than the rest of my peers. I knew KK got held back in first grade, making it so that we were always in the same grade, but I never really thought much of it.

Something people ask me a lot is, "When did your parents tell you that KK was different?"

My answer is, they never did, because she's not. She's just like me and you. I understand that yes, she has Down syndrome, but so what?

My sister is just like everyone else, if not better. Sure math and science aren't her strong suits, but my sister is an incredible artist.

She's protective over her younger sister.

She's in her second semester of college at the University of Nevada, Reno. She lives on her own in a house near campus with a friend.

In this issue

| | |
|--|----|
| Letter from the President | 2 |
| Greg Rogers, a living act of kindness..... | 4 |
| Employee of the month, Tony Piontek | 5 |
| Remembering... Judith Ann Smith..... | 6 |
| What I have learned from persons with Down syndrome..... | 8 |
| A little NDSC history lesson..... | 9 |
| Recommended reading and viewing | 10 |
| NDSC at the American College of Medical Genetics and Genomics | 11 |
| Self-Advocate Corner | 12 |
| Esperar la perfección | 13 |

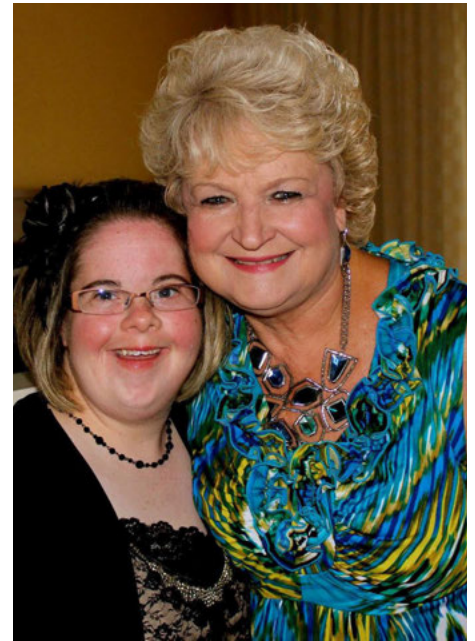
Letter from the President

Happy Spring! I hope you all had a wonderful winter and are now looking forward to warmer days, sunshine and fun! The NDSC has been busy all winter setting the course for new and enhanced resources for you and your family. The Board met in November and again in January to set out an ambitious Strategic Plan that offers more opportunities for learning and growth. We are excited about the next years and can't wait for you to join us in these new endeavors.

We are also busy planning for the NDSC Convention – or what we like to call “Our Giant Family Reunion”! This year will be truly magical as we are back again in Orlando at the J.W. Marriott Grande Lakes. The accommodations are beautiful and will be a wonderful place to celebrate with other NDSC families and friends. The convention committee is hard at work finalizing all the plans, workshops and ensuring that all the details are perfect when you arrive. We are expecting record attendance, so book your registration and hotel early to ensure your family will be there!

We look forward to seeing you soon! In the meantime, if you need anything from the NDSC, we are here for you. Please contact our Center Staff at info@ndsccenter.org or 800-232-6372. Keep up with us on our social media pages, too. We're on Facebook, Twitter, Instagram and YouTube!

It is indeed an honor and pleasure to serve you and your family. Thank you for your continued support of the NDSC!



Marilyn Tolbert

Down Syndrome News

ISSN 0161-0716

Publisher: National Down Syndrome Congress

Executive Director: David Tolleson

Editor: Sue Joe

General Correspondence and Memberships:

National Down Syndrome Congress

30 Mansell Court, Suite 108

Roswell, GA 30076

phone: 800.232.NDSC fax: 770.604.9898

email: info@ndsccenter.org

website: ndsccenter.org

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.

Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in *DSN* gives permission to do so.

Reprints From *DSN*:

We invite editors of other newsletters to reprint items from *Down Syndrome News*, provided proper credit is given to the source. Please delineate clearly the material you are reprinting and indicate that it comes from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108, Roswell, GA 30076, ndsccenter.org

Please note that for material which the *DSN* reprinted with permission you must contact the original source.

Board of Directors:

Marilyn Tolbert, Ed.D. – President
Andrew Bean – Vice President
Carole Janine Guess – Vice President
Kishore Vellody, M.D. – Vice President
Kate Dougherty – Vice President
Shawn W. Hardister – Treasurer
Julie Harmon – Secretary

Bruce Bennett • Christopher Bennett
Bret Bowerman • Regina Britt
Daniel Chaplin • Viviana Fernandez
Kathleen Forney • Dana Halle, Esq.
Raymond Jancso • Nadine C. Maes
Mitchel Rothholz • Jessica Smart
Sean Smith, Ph.D. • Chandra Torry, Pharm.D.
Jeannie Visootsak, M.D.

About my sister

continued from page 1



She started her own business at 16 years old and travels across the nation to sell her work.

She is independent.

My sister has taught me so many things. Something I say all the time and truly believe is that if Kailin wasn't my sister, I would probably be a terrible person. Kailin has taught me patience. She's taught me to embrace and promote diversity. Not only has she made me a better person, she has opened up so many doors for my family and me.

Kailin owns her own business called "Kelderman Klassy Glass" (check out her Facebook page). She creates glass jewelry pieces and sells them as pendants, earrings, and other creative pieces of glass art. For the past seven years, my family and I have traveled to and attended the National Down Syndrome Congress (NDSC) convention to sell her jewelry.

In addition to selling Kailin's jewelry for her business, I have attended the Brothers & Sisters conference every single year at the NDSC convention. The B&S Conference is a conference within the NDSC convention that is specifically for the siblings of people with Down syndrome. I started attending this conference when I was in 7th grade and continued up until I was a senior in high school. I can honestly say this conference changed my entire life. I never felt like there were any people that not only understood the benefits of having a sibling with Down syndrome, but also understood some of the harder

times. Throughout the years of being an attendee at the B&S conference, I've met some of my best friends and also learned how to explain things about my sister without becoming angry or offended by people's lack of knowledge on the subject.

The leaders I had for this conference are some of the people I look up to the most. They really helped me become the advocate I am today, and I won't ever be able to thank them enough for that.

After I graduated high school, I was asked to join the Sibling Leadership Team (SLT). The SLT basically plans and leads the entire Brothers & Sisters conference at the NDSC convention every year. So, obviously I wanted to be a part of the team. This summer will be my third conference being a part of the SLT, and my eighth year attending. We will be traveling to Orlando, Florida for the convention.

Without my sister, none of these amazing opportunities would have been possible. I wouldn't be who I am today without my sister. She has helped me become a better advocate. She even helped me decide that I want to go to law school and become a lawyer. I want to become a lawyer because a lawyer is basically a really intense version of an advocate and I want to do everything I can to ensure that my sister has equal rights and is provided with the resources and tools to be able to live a happy and full life.

KK is the best thing that has ever happened to me. She's the best big sister I could have ever imagined having. I honestly don't know how I got so lucky. Kailin is pure happiness and love, and for that, she is my inspiration and my role model.

So Keeks, thank you. Thank you for being the person I can always look up to. Thank you for showing me that anyone can do anything they set their mind to. Thank you for inspiring me each and every day. I am so proud of all your accomplishments, and I am so proud to call you my big sister. I LOVE YOU.

This originally appeared as a post on Eilish's blog, <https://eilishkeld.wordpress.com>



Greg Rogers, a living act of kindness

A collaborative group of national Down syndrome organizations, including the NDSC, encourage people to participate in Random Acts of Kindness on World Down Syndrome Day (March 21st) each year. This way, people have the opportunity to bestow a kindness on someone else, in honor of those with Down syndrome.

Greg Rogers, a young man who describes himself as "born a different way" has been bestowing Random Acts of Kindness long before it became "a thing." Greg lives on his own in Portland, Maine, and is known as "Mr. Right On It."

While he was walking his beloved dog one day, he noticed a neighbor's Christmas tree was half buried under ice and snow and he felt it was unlikely to be picked up by the trash crew in Portland, Maine. So, after taking care of his dog, he tried to pull the tree out, but it was stuck. He went and got a shovel and dug it out, then dragged it across to his place. He inclined it so it would be clearly visible and then, just to make sure, he put his purple trash bag next to it. This "Random Act of Kindness" was entirely unprompted by anyone else.

In an instance a few years ago, he won an award from his local Down syndrome group for helping a young man who was in danger of drowning! The young boy was screaming and thrashing in the water. After Greg tried to alert the lifeguards by waving his hands over his head (never mind what that says about how they processed signals coming from him!), he swam out into the water where the young boy was, who then flung himself on Greg. Greg had no instruction in life-saving and was briefly submerged. When he came to the surface, the young boy put his arm around Greg's neck and draped himself across his body. Greg then backstroked him to shore, where

"He may have been intimidated by his own event, but was quick to respond to a perceived need in another athlete."



another young man helped Greg get him to shore when his family came rushing down.

Another time at a Special Olympics competition, Greg was not feeling great and didn't think he would do very well and win a coveted medal in his event. Equivocating about entering the event, he disappeared. When he came back a little out of breath, his mom asked where he had been. "Nothing important, Mom," he replied. Later she learned via email that Greg had helped a fellow athlete make it to the finish line, after she had "stalled out" about 3/4 of the way around the track. He may have been intimidated by his own event, but was quick to respond to a perceived need in another athlete.

Greg's mom writes, "There are varieties of intelligence not measured by IQ (Greg's is 50) that our culture tends not to celebrate, or cultivate, much to our world's diminishment and possible danger. In less random ways, Greg grows food for the hungry and is environmentally conscious. He is a very active participant and volunteer in a local program "Garbage to Garden" that converts food waste to useable compost.

Employee of the month

On February 5, 2016, Tony Piontek celebrated five years of employment at Lowe's Improvement Center. Tony is a former Director on the Board of the National Down Syndrome Congress, and currently serves on our Self-Advocate Council. We are proud to share this honor that Tony received last fall:

Quarter 3, 2015

ANTHONY PIONTEK LOWE'S OF NEW IBERIA, #1107

Dear Anthony,

Congratulations and great job! Your work has recently been recommended by a Lowe's Customer who took the time to let us know about the outstanding service you provided. On behalf of the Lowe's South Division Team, I'm proud to present you with the enclosed Customer Service Focused pin for the third quarter.



This pin signifies that everything you do every day truly does matter. Customers depend on you to help them take care of their homes and their communities, and ultimately their families, friends and neighbors. That is why the enclosed pin speaks volumes to the work you do and the impression you make every time you go above and beyond to help Lowe's Customers.

Thank you for the outstanding Customer Service! Keep up the great work, and wear the pin with great pride. Let it always serve as a reminder that we all play an important role in helping Lowe's Customers love where they live.

Bill Edwards
Senior Vice President, Store Operations
South Division



Find us on Facebook:
National Down Syndrome Congress

Read more about Tony Piontek here, excerpted from an original article by Vicky Branton, which appeared in the Daily Iberian, June 15, 2015.

Tony Piontek is a walking miracle, but he is someone who might remain nameless if you only walk by him in the parking lot at Lowe's Home Improvement Center where he works as a Customer Service/Loader Level 1.

Born in 1974 and raised in a small town outside San Juan Puerto Rico, Tony Piontek came into the world a fighter. Critical at birth in a hospital 50 years behind the United States, he had to fight to overcome not only the issues at birth, but an unseen genetic condition that happened before he was born.

Tony has Down syndrome, but you probably wouldn't notice any differences walking by Tony in a parking lot, unless you spend some time with him. When you do, you realize what an exceptional young man he is.

With four older brothers and two older sisters, Tony's parents, Diane and George Piontek said he didn't have time to be different. His siblings never treated him any different and neither did they. Like their other children, the Pionteks expected him to do his best at whatever he tried.

"Tony wanted to keep up with his brothers and sisters, we expected him to try," the elder Piontek said. "Like any typical child, if you expect nothing, you'll probably get nothing."

Socially, his parents said they are constantly amazed when around town with their son. Everywhere they go he greets people by name and knows to ask about their families and details that lets you know he remembers everything about them. Although there have been limitations, like driver's education and money or time management, Tony has excelled in the things he loves. When he began attending elementary school, an announcement was made asking if any students were interested in joining Cub Scouts.

Not only did Tony join, he remained active and achieved Eagle Scout without modification in 1992. He continues to be active in Scout Troop 17, often giving workshops or talks about the impact the Scouting program has had on him.

"Scouting was the only place with a structured program. It gave Tony a chance at leadership," Mr. Piontek said. "Scouts are given a chance to grow and the families in scouting have the same values. Most children have a tolerance and understanding for different children."

One of Tony's favorite slogans is: "We're more alike than

continued on page 7

Remembering...Judith Ann

Judith Ann Smith passed away on March 8, 2011 at the age of 64. While cleaning up old papers recently, Judy's mother, long-time NDSC member Norma Smith, found copies of beautiful messages written for Judy's celebration of life service.

This one, written by Norma is a wonderful reminder how far we've come since 1947. Remember, IDEA did not come to pass until 1975...

My husband Woodward, daughter Barbara and her husband John, and our son Roger thank you all for coming to share in this celebration of Judy's life.

Sixty-four years ago, when Judy was born, thoughts and feelings were different from those today, especially about having a child with a mental disability. It was thought then to be a terrible misfortune with many children like her placed in an institution.

At Judy's first month visit to the pediatrician, I was asked if I saw anything different with her from her older sister. He then told me his diagnosis, Down syndrome. Later, when I tried to explain it to my husband he said, "She'll always be loved". For her first year, when anyone asked me about her, I said she had a heart condition, which was true, but there was more. If we went to public places, I hoped she would not speak, which could alert passersby who might stare at us. Even when living on an Army post, it was suggested to us that we find some other place for her.

In 1953, we found "the School of the Chimes" in Baltimore and enrolled her. For the first time we met other parents who had similar children. Our lives changed and we began to work toward the acceptance of these children and to become aware of all the avenues open for them.

The program, now known as "Heart Light," originally brought our family to Towson Presbyterian during the 1960s. Judy attended the Sunday Class for over forty years and really liked to participate in all its activities and joined this church in 1970.

We now believe that Judy's task here on earth was to help pave the way for community acceptance of all these children. Her winning personality, her guilelessness, her kindness, her smile, wanting to please, her goodness and her love of life have been a beacon to those who knew, lived and worked with her.

We now realize that God had only loaned her to us for a while and now has claimed her. We are very grateful to Him for sharing her with us, as a member of our family.

And this one written by her sister, Barbara Ann Smith-Law, will touch every sibling's heart:

My name is Barbara Law and I am Judy's older sister. Everyone knows what sisters are supposed to do — they share jokes — they help each other with nails and hair-dos, talk about boyfriends and share secrets. But everything changes when you have a sister with Down syndrome.

At first, you don't notice any difference. Judy does the same things you do. She takes swimming lessons and learns to swim in deep water. She goes camping and has to climb up mountains. She goes to the dentist and learns how to sit in a chair and keep still. She goes to school. She learns to write her name. She learns how to ride a two-wheel bike. The only thing is, that it takes her longer to learn these things than it takes for you.

You tease her and call her "Oodle." When you are mad you tattle on her — but she has a comeback. She says "Judy not bad — Barbara is bad." And she was right.

When you are a teen, you go to camp with Judy. But you are a counselor and she is a camper. You are amazed at the things she can do that other campers can't.

When you go to college, you start to write papers about Down syndrome, and you finally begin to realize what a hard job your parents have had teaching her all of the things that came so easily to you.

When you get married, you are happy to have her be a bridesmaid, and she performs her duties to perfection.

As the years pass, you become more and more aware of the place she has in the hearts of her parents. Judy was a Daddy's girl — he could get her to do things when no one could. Her mother was the one who was the patient teacher — something I could never do. They get all of the credit for how she turned out and what a sweet girl she was.

When Judy didn't want to do something, she was "won't going." She was "won't going" to Alaska — but loved the trip. She was "won't going" to Paris, France, where she met her Aunt. She was "won't going" on an intercoastal cruise where they sang Happy Birthday to her. She was "won't going" to the ballet and to see plays at the Lyric. When she

got older, she was definitely "won't going" to the group home run by Gallagher, but she stayed there for 20 years, and gradually it became her new home. I appreciate all the care they provided for her.

Now, Judy is "won't going" to Heaven. I will miss her and know that I will get a chance to see her again when I am "won't going" there, too.

Tony Piontek

continued from page 5

different." It's part of the mantra from the National Down Syndrome Congress, which has given Tony another shot at leadership. Tony and his mother attended their first national conference in 2008 when the local Down Syndrome Association of Acadiana elected him to the board as a self-advocate.

A fire was lit in Tony to become a member of the national board, which he accomplished after three years of campaigning at the national level to achieve name recognition. His three-year term did not diminish Tony's commitment on the local level. He continues to be a self-advocate on the advisory board of DSAA.

Tony was a lobbyist for Down syndrome in Washington D.C., during one of the national conventions held there. As an employee with Down syndrome, Tony has been limited in the amount of money he can make and save without losing his disability.

The ABLE Act, signed into law in 2015 by President Barack Obama, covers people who have been diagnosed with a disability before the age of 26 and are receiving or are deemed eligible for disability benefits under the Social Security Act.

Families like the Pionteks will be able to set up a tax-sheltered account at a financial institution, depositing up to \$14,000 annually, to save for long-term needs such as education, housing, transportation, employment training and support, assistive technology and personal support services and any other expenses approved under regulations. The contributions would be in after-tax dollars but earnings would grow tax-free.

He is also part of the Global Down Syndrome Foundation started by the Sie family who established a research center in Denver strictly dedicated to Down syndrome.

These types of achievements are exceptional for anyone, but for a child born with only 10 percent chance of survival, Tony has done rather well. Oh, and almost as an aside, his mother said, having momentarily forgotten, Tony is a cancer survivor.

At an early age he was diagnosed with leukemia. Now in total remission, Mrs. Piontek said Tony is a walking miracle. Having spent time with him, you might agree.

Next time you are at Lowe's and see Tony, he won't be nameless. You can congratulate him on a job well done, deservedly so.



Narrative Language Intervention

A study by Drs. Lisa Schoenbrodt & Libby Kumin

Do you want to learn how to use books to increase reading and language skills in your child? Join our online parent training study to learn how!

In order to participate you must:

- Have a child between ages 6-18 who is using speech
- Have access to a computer, YouTube, and two books (TBD)
 - Be able to email investigator weekly
 - Complete Pre- and Post- Surveys online

| | |
|--|---|
| <p>Goals & Objectives</p> <ul style="list-style-type: none"> - Identify and define vocabulary words related to the story - Brainstorm words and concepts that relate to the target word - Identify the problem and sequence events in the story - Understand events in the story and make predictions about the story - Predict consequent events from pictures in the story | <p>Things you will learn to use:</p> <ul style="list-style-type: none"> - Picture Walk - Semantic Word Map - Story Grammar Map - Learn Vocabulary - Wh questions - Appropriate/related comprehension questions - Art projects |
|--|---|

More Information

Contact Dr. Lisa Schoenbrodt at
lschoenbrodt@loyola.edu

What I have learned from persons with Down syndrome

by Brian Chicoine, Medical Director of the Adult Down Syndrome Center

It is truly an incredible time in history to be serving people with Down syndrome and their families. An amazing time to be learning from them, to be exploring new vistas, and sharing what we have learned.

About 25 years ago, Sheila Hebein, then Executive Director of the National Association for Down Syndrome (NADS), came to Advocate Lutheran General Hospital in Park Ridge, Illinois. She asked the hospital president to develop a clinic for adults with Down syndrome. The parents in NADS were finding that their sons and daughters were getting good care as children, but not the same quality of care when they became adults.

Through a series of events, that request went through the family medicine chairman at Lutheran General Hospital at the time, to me, the newest faculty member, but also the one with the most experience working with adults with intellectual disabilities. Nearly 25 years and more than 6,000 patients later, the Adult Down Syndrome Center is the nation's largest Center specifically serving adolescents and adults with Down syndrome and until the last few years, the only one providing primary care. And we keep growing and we keep learning.

Around the time the Center was being developed 25 years ago, my 5-year-old daughter asked about the Center. I explained to her that people with Down syndrome have 47 chromosomes while she, and most people, have 46. Her response was, "What a jip!" In the eyes of a 5-year-old and her understanding of the blessing of abundance, 47 was clearly more and better. Many times since I have reflected on both the prophetic and insightful nature of her comment.

A few years before the Center opened, Robert Fulghum wrote *All I Really Need to Know I Learned in Kindergarten*. I have often thought that I should write a companion book, *All I Need to Know Can Be Learned from People with Down Syndrome*. In it I would describe some of the many lessons that I have learned.

Our former social worker, Dennis McGuire, PhD, described "empathy radar" in people with Down syndrome. He told a story that

a patient's mother shared. While attending a parent-student-teacher conference one evening, the mom and son were listening to the teacher discuss the academic progress of the student with Down syndrome. Suddenly the boy stopped the conversation by asking the teacher, "How are you doing?"

Concerned that he didn't understand the purpose of the meeting, his mom went to correct him but noticed the teacher started to cry. Mom was mortified, but the teacher quickly stopped her from redirecting her son. The teacher shared that her best friend from her home town had died the day before, and she would be leaving for the funeral right after the conferences. She hadn't told anyone because she thought it would make it more difficult to get through the evening. However, the boy with Down syndrome had clearly picked up on her feelings. The rest of the conference was spent discussing his empathy and his sense of reading and being sensitive to others' feelings. That is one of scores of similar stories. Empathy radar.

Being in touch with one's own feelings is important, just as is being in touch with those of others. When I give a patient a compliment, such as, "I hear you are a good swimmer," the most common response I hear is, "I know." Not "thank you." Not the common, "Oh, it's nothing," "No, I don't have that talent," or "That's not true." No false modesty. Just a realization of who they are and the talents they have. As a person, a teacher, a doctor, and a parent I have asked myself many times, "How much do I accept and how much do I encourage or strive for improvement?" The joyful balance in the lives of so many of our patients is both admirable and a lesson.

While acceptance is a fine quality, striving is equally so. One of the joys of seeing patients with Down syndrome is asking them what activities they are doing and participating in.

There always seems to be something new. Awhile back, a patient came into the office and reported he was scuba diving. Now perhaps I was projecting my own fears, but I hadn't really thought of a person with Down syndrome doing that. A week later another patient reported she was also scuba diving. Another day, another new activity, another hurdle jumped.

When I graduated from medical school in 1984, the life expectancy of people with Down syndrome was less than 30 years. No wonder I don't recall anyone in medical school teaching us about adults with Down syndrome. They weren't around in great numbers. Now the life expectancy is about 60 years. How many other physicians can say that the life expectancy of their patient population has doubled during their career?

The realization is that it is truly an incredible time in history to be serving people with Down syndrome and their families. An amazing time to be learning from them, to be exploring new vistas, and sharing what we have learned. In 2017, we will be celebrating the 25th anniversary of the Center and we're planning a number of events. This has given me an opportunity to reflect on these past 25 years and on the future. The steep ascent in the life expectancy of people with Down syndrome is matched by the knowledge we are learning from and about them. What will the next 25 years bring? I know there is no need to think that far ahead. The next five or 10 will surely be inspiring.

This article first appeared as a blog post for World Down Syndrome Day on the Advocate Healthcare website.

The steep ascent in the life expectancy of people with Down syndrome is matched by the knowledge we are learning from and about them.

A little NDSC history lesson

The Down's Syndrome Congress was formed in 1973 by a group of people who had been meeting as a committee of the Association of Retarded Citizens, now known as The Arc. Out of this meeting came the decision to become a self-sufficient organization dealing specifically with Down syndrome, which is now known as the National Down Syndrome Congress. In Anaheim that year, more than 800 parents and professionals interested in Down syndrome came together at the NARC Convention.

In 1975, we published our first newsletter, **News & Views of the Down's Syndrome Congress**. In 1977, an existing newsletter, **Down's Syndrome News**, merged with **News & Views** to become the one official newsletter of the Down's Syndrome Congress.

At our Annual Membership Meeting in Providence, Rhode Island in October, 1983, a vote was taken to add the word "National" and we became the National Down's Syndrome Congress. The following year in San Antonio, the membership voted to remove the "apostrophe s" from our name.

In 2002, we rolled out a completely revamped look for **Down Syndrome News**, and then in 2004 we unveiled an updated NDSC logo. Fast forward to 2015, when our logo got a bit of an update along with a totally re-designed website.

Since then, we've tinkered with the look of **Down Syndrome News** a few times, but you should notice a big change in this issue! We hope you find the look to be bright, engaging and friendly – just as we hope you find the NDSC and its staff to be welcoming and accessible to you and your family. We are here to serve you and appreciate your commitment as members of the NDSC!



National Down Syndrome Congress

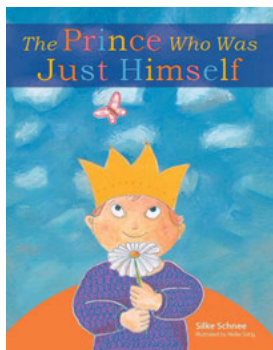


NATIONAL
DOWN SYNDROME
CONGRESS



NATIONAL
DOWN SYNDROME
CONGRESS

Recommended reading and viewing



The Prince Who Was Just Himself

Author, Silke Schnee; Illustrator, Heike Sistig

From the Publisher: "At first when Noah was born, we were shocked and sad," comments Silke Schnee on the birth of her third son in 2008 who was diagnosed with Down syndrome. Schnee is the author of *The Prince Who Was Just Himself* (Plough, September 2015), a new book that celebrates our differences. "The catalyst for this book was witnessing the effect Noah has had on many people, despite being categorized as disabled."

In this whimsical children's book, the royal couple is looking forward to the birth of their third child. "He looks a little different," muses the king at Prince Noah's arrival. "He is not like the others," agrees the queen. Soon they notice what a special person he is, even though he can't do everything his brothers can. When Prince Noah disarms the cruel knight Scarface with an act of compassion, everyone finally realizes how good it is that each person is unique.

In a recent review, Kirkus said the book "offers a special-needs child in a positive, starring role and can be read simply as a satisfying fairy tale or as a beginning introduction to Down syndrome."

Schnee, the cofounder of a school in Cologne, Germany that welcomes all children regardless of their ability and disabilities, is thrilled with the positive reviews surrounding the book. "Our little prince brings much love, joy, and sunshine not only to us, but to all around him. Children are a wonder, and we



must see them with the eyes of our heart: each child just the way he or she is," says Schnee.

The Prince Who Was Just Himself is a great tool for parents and teachers to use with their children to explain Down syndrome and other disabilities, teaching them to appreciate the differences that make each of us unique.

Plough Publishing House; 3-9 years old; hardcover; \$16.00; 32 pages; Sept. 1, 2015.

Reasons to Smile: Celebrating People Living with Down Syndrome

Edited by Andrea Knauss & Elizabeth Martins, Foreword by Keith Harris

From the Publisher: "This compilation of 56 encouraging and eye-opening short writings by a variety of authors across the globe celebrates the lives of people living with Down syndrome. Together with 56 inspiring "slice of life" photos, these candid true stories, including the renowned "Welcome to Holland," provide inspiration and connection. Parents and families of children living with Down syndrome will discover a wealth of positivity and valuable guidance. Special education teachers, social workers, mental health professionals, and policy makers will find helpful information and insight from stories regarding behavioral health. And anyone who is looking to learn more about Down syndrome will discover a world full of possibilities they never knew existed."

Schiffer Publishing, Ltd., hardcover, 56 color & b/w photos, 128 pages, February 22, 2016.



Jerome Lejeune, To the Least of These My Brothers and Sisters

A Film by Francois Lespes

From the Lejeune Foundation, USA: *To the Least of These My Brothers and Sisters* chronicles the life of Dr. Jerome Lejeune, the Father of Modern Genetics, and contains numerous interviews with former colleagues and parents whose lives were changed by knowing Jerome Lejeune. The film discusses the importance of his discovery of the genetic cause of Down syndrome, and presents the controversies that arose in France during his opposition to his discovery being used to selectively terminate Down syndrome pregnancies. Attorneys representing both parties in the Davis case in Maryville, TN, the first legal test of the person-hood of the human embryo, are interviewed, as are current researchers who reflect on the important legacy of Jerome Lejeune.

Filmmaker Francois Lespes conducted extensive interviews with those who knew Jerome Lejeune, or have been affected by him in some way. He combined these interviews, conducted in both France and the U.S., into a beautiful professional documentary.

This DVD contains:

- The documentary with English voices dubbed over the French.
- The original French version.
- A version with Spanish subtitles.
- Bonus material that includes additional recollections by friends, family, and former colleagues who reflect on Dr. Lejeune's genius, his faith, and ultimately his profound humanity.

The DVD is available from the Jerome Lejeune Foundation for \$16, plus shipping.

This film also includes footage filmed at the 2014 National Down Syndrome Congress Convention in Indianapolis, Indiana.

NDSC at the American College of Medical Genetics and Genomics

In March, 2016, the NDSC participated at the ACMG Annual Clinical Genetics Meeting in Tampa, which provides genetics professionals with the opportunity to learn how genetics and genomics are being integrated into medical or clinical practice.

We believe it is critical to have information about Down syndrome presented to these professionals on behalf of our constituents. Often, medical professionals provide information to families who have received a diagnosis of Down syndrome based only on their experiences in a classroom or in a laboratory, not from their experience with an actual person with Down syndrome. That's why we partner with our amazing self-advocates at these events, and provide physicians and genetics professionals with an opportunity to meet and speak with someone with Down syndrome. Since 2007, we've been attending medical conferences like this one, such as the annual meetings of the American College of Obstetrics and Gynecology and the National Society of Genetic Counselors, whenever our budget allows us to do so.

At this year's ACMG meeting, we were the only exhibitor space dedicated to providing information about Down syndrome, and our



staff and self-advocate team was able to talk with medical and clinical geneticists, genetic counselors, pediatric, and maternal fetal specialists. Thanks to the generosity of Kathryn Lynard, we were able to not only provide NDSC informational resources, but also copies of the book, *Gifts 2: How People with Down Syndrome Enrich our World*.

With our self-advocate representatives and these resources, we feel certain we made a big impression on medical practitioners from all over the world, who provide care to newly diagnosed families. After all, it's one thing to view an extra chromosome as a scientist, and quite another to have a conversation with a person who has that extra chromosome!

SELF-ADVOCATE CORNER

2016 Self-Advocate Book Project

This project began in 2003 when self-advocate Tracy Hile introduced the idea of self-advocates presenting books on Down syndrome to the NDSC convention host community. Self-advocates donate money for books that positively portray individuals with Down syndrome. They present these books to libraries in the NDSC Convention host city.

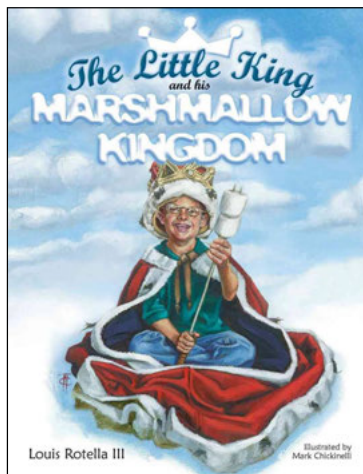
The project accomplishes several goals set by self-advocates:

- The public sees self-advocates as productive and as giving back to the community
- Self-advocates increase disability awareness for students K-12
- Self-advocates increase leadership opportunities as they implement the project
- Communities become more inclusive places for people with Down syndrome

How can you help?

- During on-line convention registration, check the box to have \$1.00 or more added to your registration fee to be donated to the Self-Advocate Book Project.
- For a donation of \$100.00, you may receive a "bundle" of all the books listed below. You might do this by having a special fundraiser to honor a self-advocate or educator in your community and donating this bundle in their name.

Send check (made payable to NDSC) to NDSC Center, 30 Mansell Court, Suite 108, Roswell, GA 30076.

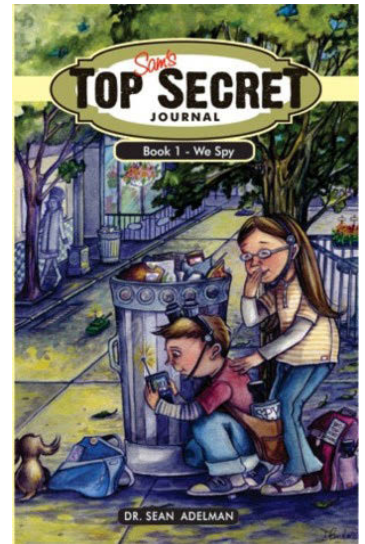


2016 Book Project List

Sam's Top Secret Journal (3 Book Series)

by Sean Adelman –

This is a set of three delightful books about the adventures of Sam, a middle school girl with Down syndrome. They solve mysteries, have adventures, and deal with the world and its conflicts. Each book has a different setting that allows the plots to be unique and fresh.



ABC Building Blocks for Growing Up with Down Syndrome by self-advocate Meredith Martin, outlines some of the key components that led her to independent living.

Donovan and the Big Hole by Nancy Lambert Davenport – This delightful fiction Texas adventure is narrated by fourteen year old Donovan who happens to have Down syndrome. He and his neighborhood friends don't ask for trouble, but manage to find it at every turn.

The Little King and His Marshmallow Kingdom

by Louis Rotella III – This beautiful book encourages children to be themselves with confidence, and challenge pressures to conform.

Why Are You Looking At Me?

by Lisa Tompkins – A child with Down syndrome only wants to be a friend and have friends. She wants them to learn that she has likes and dislikes, not unlike theirs, and as a result, embrace their relationship.

Esperar la perfección

Por Holly Christensen

*Holly y su familia viven en Akron, Ohio.
Holly es escritora del blog Whoopsie
Piggle, www.whoopsiepiggle.com*

Hace dos años, Max y yo asistimos a nuestra primera convención del National Down Syndrome Congress (NDSC). Lyra tenía 11 meses por aquel entonces, y yo estaba aterrada. Sentía que teníamos muy poco margen de error a la hora de ayudarle a desarrollar su mente, de enseñarle a mover su cuerpo óptimamente, y de sentar las bases que necesita para la inteligibilidad del habla. Salimos de nuestra primera convención con muchísima información y con una caja de plástico de Talk Tools, repleta de juguetes para morder. En cuanto regresamos, compramos de inmediato una colchoneta para comenzar hacer ejercicios de motricidad gruesa y empezamos a asistir a sesiones semanales de terapia física, ocupacional y del habla en el Akron Children's Hospital (Hospital para Niños de Akron). Gracias a esto y a más iniciativas que tomamos en una edad temprana he perdido (mayormente) mis miedos a cometer errores.

Lyra tiene ahora 3 años: camina, habla, come ella solita, se viste con ayuda y está aprendiendo a usar el baño. Hace todo lo que se esperaría de cualquier otro niño de su edad. Mientras tanto, Max y yo seguimos aumentando nuestros conocimientos acerca del síndrome de Down leyendo libros, reuniéndonos con médicos y terapeutas, asistiendo a programas y conociendo a otras familias como la nuestra. Pero Lyra es igual de importante que todo lo anterior. No solo hemos podido ir viendo de qué formas afectaba el síndrome de Down a sus habilidades (mucho menos de lo que pensábamos el día que nació), sino que durante estos tres años hemos podido ver cómo su personalidad iba floreciendo: es una niña valiente, dulce y, sí, inteligente. Lyra es nuestra pequeña amante de la música, protestona y totalmente desastrosa cuando come. Adora a sus hermanos, a sus perros y a sus gatos y los llama a todos por su nombre. Le encanta ir a la guardería y al preescolar, pero pelea con uñas y dientes cuando le cambiamos los lentes de contacto, cuando



Holly y su hija Lyra

hay que hacerle un análisis de sangre o cuando le cepillamos los dientes. Es una niña de papá, llora cuando Max tiene que irse al trabajo y se come todo lo que haya en el plato si él se sienta a su lado, habiéndose negado antes a probar un solo bocado que viniera de mí.

Lyra no sufre o padece síndrome de Down; Lyra es una persona como tú y como yo. Una persona que tiene síndrome de Down.

Con vistas al futuro

Como nos hemos centrado en que Lyra adquiriese sus habilidades básicas, la única terapia que necesita por ahora es la logopedia. Lo confirmamos el

pasado verano en Phoenix, en la convención del NDSC. Durante tres años seguidos Pat Winders, terapeuta física, ha evaluado en la convención las habilidades motoras gruesas de Lyra. Este año, Lyra caminó y corrió para hacia Pat, tanto con las férulas (y zapatos) como sin ellos. «¡Lo está haciendo genial!», dijo Pat. «Sus talones están rectos, sus pies se flexionan como deberían y sus piernas se mueven correctamente según camina. Que continúe con las férulas de Sure Step durante un par de años más y después cambiaremos a unas plantillas ortopédicas como las de Chipmunks. Recuerda que no queremos que nuestros niños estén en terapia física toda su vida. Todo va como debería en el desarrollo de la pequeña. (¡Yuh!)»

Ya no nos aterra explorar opciones para la educación de Lyra, ni tampoco saber cómo abogar por ella. Actualmente sigue avanzando cada día en preescolar y aún hay tiempo de buscar cuál será el siguiente paso. Después de tres años de actividades y de lo que, en ocasiones, parecía una carrera universitaria dedicada al síndrome de Down, ahora podemos mirar con vistas al futuro de Lyra. Y no hay mejor sitio para visualizar su futuro como adulto que la convención del NDSC.

Autogestores

«¡Mira, allí está Aaron!», le dije a Max. Después de un estupendo desayuno el día de inauguración de la convención de este año, entramos al pasillo del hotel reservado para eventos a los que asisten los jóvenes y

adultos con síndrome de Down, eventos que incluyen las elecciones para la junta directiva del NDSC. Cada año, Aaron nos saluda y se presenta, nos da un apretón de manos y nos pide que le ayudemos a ganar las elecciones.

La convención anual del NDSC es tanto un lugar para que los padres de niños (de todas las edades) con síndrome de Down obtengan información valiosa, como para que establezcan vínculos significativos con otras familias. Pero esta convención es igualmente importante para adolescentes y adultos que tienen síndrome de Down. La misión de la NDSC es mejorar el mundo para las personas con síndrome de Down a través de una colaboración organizada de las familias de las personas con síndrome de Down, las comunidades en las que viven y, sobre todo por medio de los autogestores. Y su junta directiva es un buen ejemplo de esto. Cada convención anual tiene salones dedicados a las elecciones y comités para los autogestores.

«¿Qué edad hay que tener para votar en las elecciones para la junta, Aaron?», pregunté, pensando en cuándo podría participar Lyra. Aaron desconocía la respuesta, así que nos acercamos a una pareja joven que pasaba junto a nosotros con material para decorar una mesa. Como muchas otras personas autogestoras en la convención, se presentaron inmediatamente. Los cuatro estábamos hablando sobre de dónde veníamos cuando de repente, la mujer le dio a su pareja un golpecito con una pequeña caja de cartón. «No te quedes ahí hablando y ayúdame a abrir esto», dijo ella, burlonamente. Ambos tenían unos veintitantos y ninguno de ellos recordaba cuándo fue la primera vez que participaron en las elecciones del NDSC, ya que llevaban votando muchos años.

Entonces, nos volvimos hasta una mujer de aspecto delicado que trabajaba en una de las mesas contiguas. Su cabello canoso estaba recogido en un peinado digno de una Gibson Girl. «No recuerdo cuándo pueden votar por primera vez, ha pasado mucho tiempo desde que mi hijo votó. ¿A los quince años, quizá?», dijo. Después preguntó, «¿Cuántos años tiene tu hija? ¿Tres? ¿La llevas al logopeda? Es muy importante que trabaje bien el lenguaje. ¿Has conocido a mi Tony? ¿No? Parece ser que todo el mundo conoce a mi Tony. Tiene 27 años. Oh, tienes que conocerlo, ¿dónde estará? Bueno, estoy segura de que nos encontraremos de nuevo y, entonces, te lo presentaré». Nos encontramos varias veces esos días con la madre de Tony, pero nunca pudimos conocerlo. Siempre estaba por ahí con sus amigos exprimiendo al máximo ese fin de semana en el que el síndrome de Down es lo normal y no la excepción.

Verme reflejada en Sarah

Lo que una vez fue nuevo, ahora es algo normal. Después de dejar ese pasillo, entramos a la sala principal para buscar a nuestros amigos. Dimos un abrazo a los fundadores de la Red de Diagnóstico del Síndrome de Down (DSDN por sus siglas en inglés), una organización que hace un trabajo tan importante que es difícil imaginar que solo lleve existiendo unos pocos años. De la DSDN nos trasladamos hasta otra joven organización, nombrada en honor a la hija de los fundadores, Tim y Liz Plachta. Ruby's Rainbow concede becas para educación

“Lyra tiene ahora 3 años: camina, habla, come ella solita, se viste con ayuda y está aprendiendo a usar el baño. Hace todo lo que se esperaría de cualquier otro niño de su edad. Mientras tanto, Max y yo seguimos aumentando nuestros conocimientos acerca del síndrome de Down leyendo libros, reuniéndonos con médicos y terapeutas, asistiendo a programas y conociendo a otras familias como la nuestra.”

postsecundaria para personas con síndrome de Down, ya sea para la universidad, formación laboral o programas de enriquecimiento personal. Esto que antes era algo desconocido se está convirtiendo cada día en algo muy importante tanto para el futuro de las personas con síndrome de Down como para las personas que acaban de graduarse de la escuela preparatoria. Y es por una buena causa. Cada vez más adultos con síndrome de Down son independientes y la educación post secundaria contribuye a aumentar sus opciones laborales (como pasa con todo el mundo). Con frecuencia escucho decir a adultos con síndrome de Down lo importante que es para ellos el ser miembros productivos de sus comunidades.

Después de visitar a nuestros amigos, Max y yo nos dimos una vuelta por la sala principal. La escritora Sarah Savage Cooley se encontraba allí, vendiendo sus libros en una de las mesas. En su libro *Of Love & Loss, Poetry or*

Tears? (Sobre el amor y la pérdida, ¿poesía o lágrimas?) utiliza la poesía como medio para contar la historia de cómo se enamoró, se casó, las dificultades por las que pasó, su divorcio y los sentimientos de pérdida asociados a este. Los escritores, normalmente, superan los grandes retos de sus vidas escribiendo sobre ellos (yo escribí un libro de 300 páginas hablando sobre el final de mi matrimonio). Nada es diferente en el caso de la señora Cooley, que tiene síndrome de Down. Pero lo que me llevó a pararme delante de su mesa fue *The Selected Essays of Sarah Savage Cooley (Selección de ensayos escritos por Sarah Savage Cooley)*. En «Following My Dreams» («Siguiendo mis sueños»), critica el trato que recibió de niña en un programa de educación especial:

"Cuando iba al colegio yo era una persona normal, igual que los demás. Sin embargo, me pusieron en un programa de educación especial para recibir una atención especial. Tenía un ayudante en cada clase a la que iba. Yo, que soy una persona muy trabajadora, quería ser independiente. Pero en vez de esto, tenía una persona siempre que me ayudaba con las tareas de clase y que hablaba con los profesores. Incluso mis deberes eran especiales, diferentes a los de los demás. Siempre me iba de clase con la ayuda de esta persona, aunque me quisiera quedar en el aula para hacer los mismos trabajos que hacían los otros compañeros... Cuando tenía un ayudante en cada clase, me sentía realmente incómoda. Quería ser una persona que va a la escuela secundaria con sus amigos, que va a clase. Pero a cada clase que iba, tenía una persona conmigo para ayudarme, una persona que no me dejaba tener mi propio espacio".

Guau. Escuché la voz de Sarah, ronca, como la de Demi Moore. El resto del fin de semana asistimos a diversas sesiones sobre educación. ¿Acabaría tomando decisiones por las que Lyra me resentiría? Sin lugar a dudas. Las he tomado con todos mis hijos. Pero nadie debería hablar de ella en tercera persona cuando está sentada justo al lado, tal como hicieron los profesores y ayudantes de Sarah. Lyra tendrá el mismo poder de decisión que tienen todos mis hijos.

En *Found Out What My Future Will Be (Descubrir cuál será mi futuro)*, Sarah describe la frustración que siente por tener que trabajar en vez de poder hacer la carrera que quiere:

"Solo desearía que todo el mundo dejara de tratarme de manera diferente y que me dejaran crecer y continuar mi camino en la vida, centrarme en mi sueño... Es muy importante para mí llegar a ser escritora. Es lo que he

querido toda mi vida y es lo único que quiero hacer en el futuro... Trabajar en el Centro de los Derechos de las personas con Discapacidad durante el resto de mi vida no entraba en mis planes... Quiero estar en un lugar que ame, ir a la universidad, estudiar lo que me apasiona, trabajar en el lugar de mis sueños, ser quien realmente quiero ser, llegar a ser una escritora profesional y descubrir el mundo que me rodea".

«Ya sabes, Sarah», dije mientras cerraba su libro. «Yo soy escritora y lo único que deseo hacer es trabajar en mi libro. Pero tengo otro trabajo porque necesito ganar dinero».

«¡Yo también!», dijo ella mirándome a través de sus gafas de montura metálica. «¡Lo único que deseo es escribir mi libro!».

Compramos dos de los libros de Sarah firmados para Lyra. Un poco después, conocimos a un investigador médico del Centro Thomas para el síndrome de Down, del hospital de niños de Cincinnati, que actualmente está llevando a cabo una investigación sobre la depresión en personas con síndrome de Down. Le dije que debía conocer a Sarah Cooley y leer sus libros, ya que aportan un relato conmovedor acerca de la vida de una persona con síndrome de Down en primera persona. «Por supuesto que conozco su trabajo», me dijo el joven doctor. «Son libros de lectura obligatoria en el Centro Thomas».

Actualmente escribo un libro para personas que no conocen a nadie con síndrome de Down, porque quiero erradicar las ideas erróneas que surgen al saber que alguien tiene una copia extra del cromosoma 21. Sarah Savage Cooley, usando el mismo medio que yo, la escritura, lo ha conseguido. Sus libros, en manos de las personas que llevan esta investigación y de las que cuidan de personas con síndrome de Down están consiguiendo cambiar perspectivas. La vida de Sarah no ha sido siempre fácil, pero ha sabido canalizar sus penas y frustraciones a través de su profesión, consiguiendo de ese modo un efecto positivo en la vida de innumerables personas a las que nunca ni siquiera conocerá. Es lo máximo a lo que un escritor puede aspirar.

Para continuar leyendo el artículo "Esperar la Perfección" ingrese al blog del NDSC en español

<http://www.ndsccenter.org/bienvenidos/>

Traducción al español realizada por Carolina Bermejo, dentro del proyecto PerMundo para la traducción gratuita de páginas web y documentos para ONG y asociaciones sin ánimo de lucro. Proyecto dirigido por Mondo Agit. Revisión realizada por Gema Arce Raya.

Down Syndrome News is a benefit of your annual membership in the NDSC. To renew or join, visit ndsccenter.org. To update your contact information, call 800-232-6372 or email info@ndsccenter.org.

2016 Convention

44th Annual NDSC Convention
in Orlando, Florida
www.ndsccenter.org/register-now/



30 MANSELL COURT, SUITE 108
ROSWELL, GA 30076
NDSCCENTER.ORG

NON-PROFIT ORG.
U.S. POSTAGE
PAID
SACRAMENTO, CA
PERMIT NO. 1491

Down Syndrome News

A newsletter published throughout the year
by the National Down Syndrome Congress

2016 Convention in Orlando!



Photo credit: JW Marriott Grande Lakes

July 21-24, 2016

This year's convention site
is the beautiful JW Marriott
Grande Lakes Resort in
Orlando, Florida.

**Registration
Open on April 11!**

Don't miss this opportunity
to join with more than 3000
friends and family members
as we "Imagine the
Possibilities" for people
with Down syndrome.

Visit our website to register!