My oldest brother, Ray Strzewski, was born on 4/19/1979 and after an extremely difficult 48 hours he hit the ground running and never looked back. I recently had the pleasure of attending a NADS charity event sponsored by Windy City Women in HVAC with Ray and was asked to write an article discussing my brother and his work history. I am extremely fortunate that I am not only able to work with Ray on a daily basis but also our other brother, Ralph. We all currently work for Porter Pipe & Supply Co., a pipe valve and fitting wholesale distributor in Addison IL. Porter Pipe was founded in 1976 on the principles of Faith, Family and Integrity.

Ray has held many jobs prior to coming to work at Porter Pipe, which included 5 years at Fuddruckers as well as 5 years at Portillos. Neither of these jobs was a good fit for Ray, and I don’t believe Ray found his work exciting or challenging enough to truly succeed there—however he did enjoy the free food. On January 24th, 2005 Ray was hired by Jim and Bud Porter to work as part of the facility maintenance team. He is responsible for a variety of job tasks, which include making sure the front office is kept spotless, and he is also required to attend the Monday managers meeting to fill us in on his progress and to deliver “the good news of the week.”

I can’t tell you how proud I am of my brother Ray. He is my biggest inspiration. His level of work ethic and drive is unmatched by anyone I know. He is an inspiration to many of his fellow Porter Pipe family members. I often remark that Ray is the ambassador of Porter Pipe & Supply and I truly mean it. He was also responsible for helping me and my brother Ralph get our jobs here. Ray has excelled at Porter, and he is a valued member of the team. He is held to the same standards as every other team member, which allows him the structure he needs to be successful. When I spoke with my mother about this topic, she said, “People with disabilities need advocates for them when they enter the work force. Porter Pipe is a rare place in that regard. Ray has never needed that while at Porter. They accept him as he is, for the person...
that he is, along with all his quirks, and everyone has been willing to make adjustments to help him be successful. It's one of the important pieces that makes Ray feel good about himself. He feels valued and is a contributing member of society. That comes from the top down. I have always felt that Porter Pipe should be the star that companies should model themselves after when it comes to giving a person with a disability the opportunity for successful employment.” Ray still faces daily challenges, including finding economically acceptable transportation to and from work every day and also his increasingly deteriorating speech. These hurdles will not hold Ray back. He is a strong, independent and blessed man and nothing can hold him back from success!

Windy City Women Fundraiser

Our sincere thanks to the Windy City Women, an organization of women in the HVAC industry, who this year chose NADS to be the recipient of their annual charitable fundraiser. Their event raised over $15,000 for NADS. We are honored to have been chosen and very grateful for this generous donation. Thank you to all involved!

Call for Volunteers

NADS is looking for volunteers to help plan a Hispanic Disability Resource Fair. If you are able to help, please contact us at the NADS office at 630-325-9112 or info@nads.org.

Editor’s Note: Many thanks to the following Self-Advocates who took part in the event: Tommy Vargulich, Kelly Wesolek, Michelle Anderson, and Jane Kracik. We appreciate their participation.

NADS News is a publication of the National Association for Down Syndrome (NADS).

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Exec. Director  Diane Urhausen
President        Steve Connors
Editor          Ann Garcia

UPCOMING EVENTS

Chicagoland D.A.D.S. Holiday Party
December 5, 2015
www.chicagoland-dads.org

NADS Bowl-A-Thon
March 6, 2016
Stardust Bowl
Addison, IL
www.nads.org

2016 Buddy Walk Conference and Buddy Walk on Washington
April 10-12, 2016
Washington, DC
www.ndss.org
My son was nine years old the first time he heard someone call his sister retarded.

He was sitting in the school cafeteria and the boys across the table were talking about some other children, referring to them as retards. Another boy leaned over and said, “You guys, be quiet. Luke’s sister is retarded.”

That boy actually had good intentions. In a way, he was trying to look out for my son and protect his feelings. But in another way, he hurt Luke even worse. Someone Luke considered a friend had just used a horrible, offensive word to describe his sister. It may have been the first time that he had to confront his feelings about hearing that word. But it will most likely not be the last.

When Luke came home and told me about the experience, I was heartbroken. I wanted to take away the hurt in his eyes and the worry in his voice. But I was also very proud of him. He wasn’t upset because he was embarrassed about having Lily for a sister. He was genuinely upset about the use of the word retard, and how it negatively impacted his sister and anyone like her. And he wanted me to help fix it. He wanted me to make sure that the kids at school wouldn’t use the word again.

My initial reaction was to call the school, to have the boys punished and their parents contacted. I emailed the principal and the homeroom teacher and explained what happened. But I didn’t give the boys’ names or ask about consequences. I didn’t get angry or upset. Instead, I explained that I am a public speaker for NADS and asked about possible dates to present to the fourth and fifth grade students. I used the experience as an opportunity . . .

“I have been a public speaker for NADS for seven years, presenting mostly to nurses, nursing students, residents, and medical students in and around Chicago. However, the thought of speaking to a classroom full of children always intimidated me more than speaking to a room full of pediatricians. Questions from fourth and fifth graders can be unexpected. They can render you speechless or have you fumbling for the right explanation.

But despite my apprehension, I couldn’t ignore what happened to Luke. His experience forced me to see the need to speak to the children, not just about Down syndrome, but about all disabilities . . . about respect . . . about kindness. I wanted to ensure that they knew how to treat all of their peers, regardless of ability. I especially wanted to explain how powerful words can be and how badly they can hurt another person. I realized that it was my responsibility to tell children that people with Down syndrome have the same interests, hobbies, dreams and needs as themselves, just as I’d been telling doctors and nurses for years.

And just like the doctors and nurses, the children also needed to meet someone with Down syndrome and hear about her amazing life. NADS started a self-advocacy program a few years ago, so I am now accompanied by Michelle Anderson to all of my presentations. She is a remarkable young woman who captivates her audiences with her style, charm and wit. She’s a tough act for me to follow, but I love having her there and I wouldn’t want it any other way.

Michelle tells about her life and then uses photos to help illustrate that she is incredibly active and happy. Inevitably, she gains the respect and admiration of all of our audiences, whether they are nurses or nine year olds.

At our presentations to the students at my son’s school, Michelle explained about going to school and growing up, doing all of the same things as the children in the audience. She became an instant celebrity and they asked questions like “what’s your favorite movie?” and “where’s the most exciting place you’ve been?” From the front of the classroom I could see the expressions change on the students’ faces as they realized Michelle is someone to admire, not ridicule or insult. Boys called out things they had in common with her. “My favorite color is blue too!” Girls came up and asked to hug her and gave her gifts. I followed Michelle’s presentation by showing the 13 minute video “Just Like You – Down Syndrome.” It uses the friendships of three young people with Down syndrome and their typically-developing peers to explain different aspects of the disability. They give tips on how to get to know and better understand someone with Down syndrome, and they touch on the offensiveness of the ‘R-word.’

I used the video to lead into a discussion about words and how dangerous they can be. I recited a verse from Sarah Bareilles’ song Brave (“nothing’s going to hurt you the way that words do”), and I quizzed them about the word in Harry Potter that is so hurtful and offensive that it causes others to shudder or react with violence when someone uses it (“mudblood”). I held up a crisp sheet of paper and did an exercise that illustrates someone’s feelings as they are insulted or called names. I pretended that I was a student and I detailed the hurtful things that were said to me throughout a day at school and at soccer practice. With each hurtful word or experience I crumpled parts of the paper. Then I pretended that everyone who insulted me came back to apologize the next day. As I described the apologies, I smoothed the paper out. We talked about how everything should be okay now, because people

Continued on page 11

R-Word Presentation Nancy Goodfellow

NADS News — November, 2015 3
Fathers Find Fellowship with D.A.D.S.  

Sherry Manschot

When Avery was younger, I remember coming back from a Special Olympics track and field meet. Avery did great! She got a medal in her event and was so excited,” recalls Steve Connors, Avery’s father. “I was so proud of her. She threw the tennis ball 8 feet.”

Connors explains that it was a huge accomplishment for Avery, now 18 years old, who has Down syndrome. He also explains that there are times when it can be difficult to share that type of excitement and the sense of pride he feels for Avery’s achievements with fathers of typical kids. All dads are proud of their kids. But when talking with dads whose kids are playing club sports, he wonders whether or not they can really relate to Avery’s struggle to achieve an 8-foot throw.

Six years ago, Connors, along with several other dads, started a support group of sorts where dads of children with Down syndrome can gather to listen, share and even brag a little (or a lot) to other dads who “get it.” This group is modeled after the national D.A.D.S. (Dads Appreciating Down Syndrome) organization.

The Chicagoland D.A.D.S. group is intentionally set up in a relaxed environment where dads can come to find fellowship among one another. The group meets the last Sunday of every month at Emmetts Ale House in Downers Grove. As it says on the National Association for Down Syndrome (NADS) website, dads can come together to “share what you know and learn what you don’t” … maybe even enjoy a beer at the same time.

For Aaron Huston, this is his time to unplug for a few hours. Like Connors, he too gets to brag about both his sons, 8-year-old Cody with Down syndrome and typically developing 5-year-old Ryan. What he really finds helpful though is sharing the challenges that come with raising a son with Down syndrome and learning from dads who are on the other side of those challenges.

“Sometimes it’s hard to hear what to expect. But, for better or worse, I want to know,” Huston said. “It has helped me ease into some things, made it a little less challenging.”

While there is mentoring that takes place, Connors is careful to explain that he doesn’t go so far as to give advice. “I am cautious about mentoring. Advice should come from professionals. I can only share what I went through with Avery. Every child is different and things, like therapies and special education, change over the years.” He goes on to say, “I try to listen more than anything else. There are a lot of I-know-what-you-are-feeling huddles that go on when we get together.”

Peter Vargulich, whose son, Tommy, also 18 years old with Down syndrome, finds himself in a bit of a different place than some of the dads in the group. As a member of this group, Vargulich has been tapped by NADS to reach out to the parents of a young girl who was going through heart surgery. About half of the infants born with Down syndrome have some sort of heart defect. For many, surgery is often necessary at a very young age. Vargulich was asked to connect with the family during a difficult time. “I was able to meet with them. They were struggling. I was honest about the good and not-so-good parts that come with heart surgery,” recounts Vargulich. “I tried to be constructive and hopefully help by reducing some of their apprehension.”

Connors is quick to point out that the conversations are completely free flowing. Rather than formal agendas or guest speakers they prefer to let the topics develop more organically. So at any given time they might be discussing what’s happening in schools, the importance of a dad’s active role in an IEP, the latest legislation affecting families with a child with special needs, who has a good dentist, or even the latest techniques used for potty training.

Sometimes their meetings are simply a beer, lively conversation and whatever game happens to be on the television. Beyond the D.A.D.S. group meetings, they get together for a family picnic in the summer, a holiday party with spouses and often provide the manpower for charity events supporting NADS and other similar organizations.

Huston, who coordinates the Chicagoland D.A.D.S. website, encourages more dads to check out the group. He says there are some dads who don’t make the meetings but still like the virtual fellowship offered
What Keeps Me Coming Back to the D.A.D.S. Group

Graham Traynor

January 18, 2012. That was the day my wife had her 20 week ultrasound. We learned that our youngest child would be our third son (Ryan) and that he had a major marker for Down syndrome, which was later confirmed through a prenatal diagnosis. Like so many of the people reading this newsletter, that day has a special meaning for us. After the initial shock subsided, I was made aware of the NADS website and researched many of the services they offer. One organization that caught my eye was the DADS group. I was drawn to its mission and laid back environment where fellow dads get together over beers for support in our collective efforts to help raise children with special needs, to discuss our children’s accomplishments, learn from other people’s experience, etc. Even though we had not had Ryan yet, I found myself looking forward to attending my first DADS meet up.

Since Ryan’s birth, I have had the opportunity to attend a number of monthly meet ups over the past three years. I enjoy how welcoming the fellow dads are and the organic topics that come up. I especially value hearing from the dads that have older children. As we are very early in our journey to raise Ryan, I find these experiences extremely enlightening. But not all of our time is spent focusing on Down syndrome related topics. I enjoy how a lot of what we discuss does not revolve around Down syndrome. There is a certain comfort in being able to talk about other topics (e.g. a lot of sports discussions) over beers with fellow men who have been touched by Down syndrome. I appreciate how there is no pressure to attend every meet up. Everyone recognizes that we are a busy bunch and you are welcomed back like a “regular” no matter how long it has been between visits. The DADS group has become a key part of my journey and I look forward to our next meet up at a local pub on the last Sunday of the month!
Inclusion in Education  Lara N. Suleiman

NADS self-advocate Kelly Neville’s slideshow presentation to a local elementary school was a visual scrapbook of her life, with all its glory and glamour. She beamed as she talked about her jewelry business, Special Sparkle. She was confident, articulate and had a lot of spunk. “I make all the jewelry,” Neville said “Not my mom!”

No doubt this 24-year-old with Down syndrome had toured many schools like this before as part of her outreach efforts. But she can be sure she will always find a loyal fan base from the faculty and staff at Brook Forest Elementary School in Oak Brook, IL.

“Kelly was so poised and has such a zest for life!” said Sheila Elberts, a classroom aide for nearly 20 years. “At Brook Forest we only see our students when they are young,” Elberts said. “It was really great to see an adult with Down syndrome who has become a productive, positive member of society.”

Elberts was among the many who came to learn from NADS experts and advocates about inclusion strategies for students with Down syndrome. She is currently supporting a student with Down syndrome at the school.

In fact, NADS often comes to schools because a parent may have concerns about their child’s education. “There may be some tension, or they aren’t sharing the same vision,” said Linda Smarto, NADS Program Coordinator and mother of a daughter with Down syndrome. While that was not the case at Brook Forest, it has been nearly been 10 years since the school had a student with Down syndrome.

Approximately 10-percent of the 350 students at Brook Forest have Individual Education Plans (IEPs). The school is following an inclusion model. Research shows that inclusion results in significant gains in expressive language, social-emotional development and positive behavior among students with special needs. It also promotes respect for differences, leadership and mentorship among the school community.

“It is hard to imagine schools not wanting to have students with special needs in their schools...”

She works directly with the special needs population and believes it makes sense to have an organization like NADS help not only children and adults with Down syndrome, but also the families and the educational staff that work with them.

Karen Neville, Kelly’s mother, is a NADS parent volunteer and trained advocate. She shared with staff some of the specific modifications that aided in learning. As a former reading specialist in the schools, she often needed

TIPS FOR EDUCATORS

- **Collaborative team work**
  Communication is crucial. It could be daily, weekly or monthly updates. Whether it’s through a communication log, meetings or phone calls, it is important to keep the feedback stream flowing. This includes reassessing the IEP and making necessary curriculum amendments by the resource teacher.

- **Same expectations with modifications**
  Work toward altering the expected curriculum to suit the student’s needs. Reducing amount of spelling words or number of sentences written, a word bank, larger font and eliminating unnecessary information on worksheets.

- **Capitalizing on students’ strengths with encouragement**
  As visual learners, students with Down syndrome may need extra visual support or use of audio-visual devices like iPads to maximize learning.

- **Preview, Do, Praise, Review**
  A helpful strategy is to first introduce a concept. Practice it, and then praise the student for completing the task. Follow up with reviewing it.

- **Being proactive**
  Anticipating challenges or potential weaknesses before they arise. This may include previewing lesson plans from team members to make appropriate changes, or eliminating environmental distractions.

- **Behavior as communication**
  For a student that may have limited verbal skills, any form of behavior should be flagged as a form of communication. Look to see if they are seeking attention to gain friendships, are bored or the material is not at their level.

- **Unlimited experiences with productive participation**
  There is a difference between listening and learning. A student may be in a classroom listening but educators must assess whether they are actively learning by ensuring they are actively participating. Look for opportunities for leadership or helper roles in the classroom. It is not enough to say they are included for inclusion’s sake. Think beyond.

- **Inclusion in Education**
  She worked directly with students with Down syndrome at the school. The school had a student with Down syndrome, which was not the case at Brook Forest.

- **TIPS FOR EDUCATORS**
  - collaborative team work
  - same expectations with modifications
  - capitalizing on students’ strengths with encouragement
  - preview, do, praise, review
  - being proactive
  - behavior as communication
  - unlimited experiences with productive participation

- **Inclusion in Education**
  - collaboration
  - same expectations with modifications
  - capitalizing on students’ strengths with encouragement
  - preview, do, praise, review
  - being proactive
  - behavior as communication
  - unlimited experiences with productive participation
to troubleshoot when teachers were not thinking creatively or using alternative teaching tools. She rewrote books using larger fonts, made flashcards and developed creative games to make learning more meaningful for her daughter.

“Most of the strategies they mentioned help all students, not only those with special needs,” Elberts said.

From Smarto’s experience, inclusion challenges come from staff who fail to set high standards for students with Down syndrome.

“Teachers sometimes don’t give our kids enough credit,” she said. “The assumption is that because expressive language may be low, that receptive language is similar.”

Her favorite teachers were the ones who thought of creative ways to teach the material.

“They came up with a song or a poem because they knew my daughter loved music.”

According to Voliva, as academics get more difficult in upper grade levels, so does paralleling the curriculum. However, finding the right staff member to do those appropriate modifications makes the process easier.

She was both inspired and hopeful after hearing Kelly’s progress through the formative years of education.

“Never give up on learning,” Voliva said. “As adults all the hard work will pay off with getting jobs in the community.”

Elmhurst Learning and Success Academy

The Elmhurst Learning and Success Academy (ELSA) is a four-year non-degree certificate program at Elmhurst College which provides academic and vocational training for young adults with intellectual and/or developmental disabilities. Students experience college life on the Elmhurst College campus, participating in academic and career exploration courses, learning strategies to improve independent living skills, and having the chance to participate in college organizations and activities along with other Elmhurst College students, some of whom serve as peer mentors and education coaches. ELSA students appreciate the inclusive environment, and some are also eligible to live on-campus if they choose. ELSA helps prepare students for employment through job shadowing, internships, and other opportunities and also offers a Certificate Program for qualified students.

An Interview with ELSA student, Ryan Burke:

How many years have you been in the ELSA program?
I am a junior and I have been in ELSA 3 years.

How is ELSA different from high school?
The class schedule is different from high school to college because I have free time in between my classes to do homework, eat lunch and work out at the fitness center.

What do you like about being part of ELSA?
I love to be an ELSA student because it lets me be part of a college community of Elmhurst College.

What were your favorite classes?
My favorite classes are business writing and educational coaching and service learning.

What did you like about them?
I like getting good grades and learning to be independent.

Have you been involved in any groups or activities on campus?
I am in Best Buddies and student assisting animal shelters. I am still looking up a few more to get involved with.

What would you like to do after you graduate from ELSA?
I would like to get a good job and I will be rich and I will get married.

PAC Kick-Off at Elmhurst College

On November 22, 2015, we will be launching our new service leadership program for adults with Down syndrome, the Partnership Advocacy Council, with a Kick-Off event from 2:00-5:00 pm at Elmhurst College. To RSVP or to find out more about the program, please contact Diane Urhausen at 630-325-9112 or durhausen@nads.org.
Healthy Smiles - Because Every Smile Matters!

Juveria Hussain, Student, UIC College of Dentistry
Blase Brown, Clinical Assistant Professor, UIC College of Dentistry

The series on oral health in patients with Down syndrome continues! Having a ‘dental home’ with caring professionals along with regular dental visits can help influence and develop the self-esteem and general well-being of an individual. The key element for understanding and relating to the oral health issues seen in patients with Down syndrome is a family centered cumulative approach. The purpose of this article is to examine features commonly seen in children with Down syndrome, ages 0-6 years, and to consider their oral health effects.

Oral cavity and dental concerns:

PALATE

In many children with Down syndrome, the palate has a high-arch (V-shaped) and is short in length. This is due to delayed development of the mid-face (a condition called mid-face hypoplasia) which leads to reduced length, height and depth of the roof of the mouth (palate).

Dental concern - Constricted palate creates less space for the tongue which affects speech, chewing efficiency, and tooth positions.

LIPS

In children with Down syndrome, often the mouth is open and the lips do not touch due to relatively narrow passages in the throat and nose and enlarged tonsils and adenoids, which contribute to mouth breathing. It can also be secondary to the enlarged size of the tongue or altered tongue posture.

Dental concern – This can lead to altered development of the jaws and tooth position, drooling of saliva, angular cheilitis (cracked corner of the mouth) and chapped/cracked lower lips. Mouth breathing can be a contributing factor to gum disease and respiratory tract infections. Excessive drooling of saliva could be due to malpositioned teeth and muscular imbalance within the mouth, aggravated by the reduced control of head posture and narrow passages in the throat and nose.

TONGUE

The tongue can be enlarged (macroglossia) and exhibit low muscle tone (hypotonia). The shape of the neck, together with narrowed airway passages in the throat and nasal cavity often results in an altered position of the tongue, postured forward, that allows mouth breathing. Mouth breathing often leads to the development of deep grooves in the tongue, which can contribute to “bad breath” and impact oral hygiene.

Dental concern - The pressure from the enlarged tongue/ altered tongue position can cause mandibular (lower) teeth to move forward, affect the lip seal, and create spacing between the teeth. Tongue size and position can also be a contributing factor in obstructive sleep apnea (OSA), which has been reported to be a significant health concern in individuals with Down syndrome.

TEETH

The baby teeth can have delay in their eruption. Normally in all children, the first of the baby teeth, lower incisors, begin eruption between 6 to 10 months, with all 20 teeth completing eruption between 25-33 months. The literature reports that the most common first tooth to erupt in a baby with Down syndrome is an upper first baby molar, not a lower incisor. The average time for this first eruption has been reported to be 14 months. This varies quite a lot between individual children with Down syndrome. Baby teeth in children with Down syndrome are typically wider than average, and can exhibit altered shapes and position in the dental arch. The high and narrow palate and altered tongue position cause alterations in jaw growth and tooth position (malocclusion).

Dental concern – The delayed eruption of the baby teeth can impact the future eruption of permanent teeth, but on a positive note may be a factor contributing to the high number of children with Down syndrome who are free from decay. The overall tooth position together with factors impacting jaw development will be a concern for the child developing bite problems (malocclusion), which is significant for older children and adolescents with Down syndrome.

An inter-disciplinary approach involving the child’s pediatrician, the pediatric dentist, speech therapist, otolaryngologists and orthodontists is important for improving overall function and health. Prevention of dental disease through effective home care is achievable with family support, just as with any child in the 0 to 6 age range. Regular dental check-ups can help in early recognition of developmental features and provide intervention, if appropriate. Early and regular dental visits will also enable the child to get familiarized with a dentist visit and help them to develop coping skills for continued care in offices and clinics in your own communities.

Remember – Every smile is special, and together we can make a difference!

References:
Jack Larson’s Graduation

Connie, Emma, and Julia Larson

Congratulations to our son and brother Jack Larson! Another milestone achieved even though he still considers himself a high school senior! Moving on to the Transition school program has been uneventful but Jack was hesitant none the less. He misses his school friends, some of them are still at the high school, but most moved on to College. He really misses the size of the high school and all the many people he would interact with throughout the day as he made his way around the school. He misses the activities such as Choir and the dances – he couldn’t believe there was a Homecoming dance and other activities without him! One thing that won’t be going away thankfully is Special Olympics basketball. District 99 has several teams. Last season all 3 teams went to State at ISU. Jack’s team got 2nd place and it was awesome! All the teams stayed in the same hotel and it was a blast.

Another transition for Jack is readjusting his life since twin sister Emma is at college. When is she coming home? He gets the concept having experienced this previously with his older sister Julia. Julia is out of the house, working and living fairly close but he misses his sisters greatly. Thank God for FaceTime. He can’t see and talk to her whenever he wants but pretty regularly. We’re hopeful he’ll find a job that he likes and be happy….just like anyone else.

NADS Fashion Show

This year, we celebrated the 10th anniversary of the NADS Fashion Show. Stacey Baca returned as host and received an award for her many years in that role and her longstanding support of NADS. At the end of the show, she was presented with a plaque featuring a picture of her with Corey Crawford from a previous Fashion Show and including the text, “With Heartfelt Appreciation from the National Association for Down Syndrome. Thank You for Your Time and Commitment to our Annual Fashion Show.” This year, she was joined in introducing the show by NADS Self-Advocate, Alex Tello, who welcomed guests in English and in Spanish. Also new this year was the premiere of a professionally shot video about NADS, which featured interviews from many families who have benefited from NADS’ services. As in the past, the event showcased the talents of many individuals with Down syndrome.

Chris Hebein entertained guests with his piano music, Steve Gotsis was the featured vocalist and shared one of his favorite One Direction songs, and models of almost every age delighted the crowd with their joyful procession down the runway. Who could resist dancing by the end?

We appreciate the hard work of everyone who helped make this year’s Fashion Show a success. We are also grateful for the many donations from families and local businesses, the planning work of the Fashion Show committee, and the participation of the models and their families. Many thanks to all involved.

Marissa Bloodgood at the Fashion Show

This year marked Marissa Bloodgood’s 10th year as a model in the NADS Fashion Show. We are grateful for her faithful participation and her longstanding support of NADS. At the end of the show, she was presented with a plaque featuring a picture of her with Corey Crawford from a previous Fashion Show and including the text, “With Heartfelt Appreciation from the National Association for Down Syndrome. Thank You for Your Time and Commitment to our Annual Fashion Show.”

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Marissa is the most incredible girl I know. There is no one who has as much love and heart as she does. She is a passionate cheerleader, dancer, actor, and basketball star. But the most important thing about Marissa is that she cares so much about everyone. When you are sad she makes you happy and when you are down she will turn that frown upside down.

In this last year she’s proven once again what a Rock Star she truly is, she not only got on every roller coaster at six flags, but she dare-deviled her way through all 17 roller coasters at Cedar point in Ohio. I’m telling you, my sister is fearless!

On this day, it is my beautiful sister MARISSA “You have been the BEST sister since the day you were born”

Marissa Bloodgood

Marissa Bloodgood at the Fashion Show

This year marked Marissa Bloodgood’s 10th year as a model in the NADS Fashion Show. We are grateful for her faithful participation and for all the support and contributions of her family. Here are her brother’s reflections on this milestone, which were printed in the Fashion Show booklet:

To my amazing sister MARISSA
“You have been the BEST sister since the day you were born”

Marissa is the most incredible girl I know. There is no one who has as much love and heart as she does. She is a passionate cheerleader, dancer, actor, and basketball star. But the most important thing about Marissa is that she cares so much about everyone. When you are sad she makes you happy and when you are down she will turn that frown upside down.

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On this day, it is my beautiful sister’s 10th anniversary “Rockin’ the Runway” for the NADS Fashion Show. It has been an honor to walk it alongside her for many years. We started when I was just 3 and she was 4.

Please give her a grand round of applause because she deserves it!

I love you to Infinity and beyond crazy girl, and remember, don’t let anyone dull your shine!!!!

Forever, Michael
family album

Miles Evans

Ashley & J.C. Fortman

Jagen Family

Ramsburg Family

Sophie Mannino

Blake, Brett & Noelle Weber
Fluency Disorder in Down Syndrome
Laura Drower M.S., CCC/SLP, C/NDT

People with Down syndrome are at risk for a variety of speech language difficulties. One of these is dysfluency or stuttering. Dysfluency is described as repeating whole or parts of words, long pauses in the middle of utterances, use of multiple interjections (um, er) or the inability to get a word out. People with Down syndrome may have a higher likelihood of being dysfluent when compared to typical peers. This can be the result of slower development of speech language skills and greater difficulty with speech and language production in general.

When we think of stuttering, we typically think of trouble getting words out but not about the process that needs to be in place before the words come out. In the person with Down syndrome, difficulty with producing sounds, formulating language and carrying on conversation are all factors that can impact fluent speech.

So what can be done for stuttering? Speech Pathologists use both formal and informal techniques to increase fluency. Before therapy for the person with Down syndrome is considered, however, we want to look at several factors. Is the person aware of the problem? Are they upset or embarrassed by it? Do they avoid certain sounds or avoid talking altogether? Does the stuttering impact communication more than other areas like sound production or language? If the person is not bothered by or aware of the stuttering, then the best approach may be to improve speech and language skills and to educate parents and others in the person’s environment in ways to assist the person with getting their message across.

The other issue to consider is the possible negative impact of treating the stuttering. Will the emphasis on smooth speech production increase anxiety in the person and worsen the fluency issue? Often, improving speech language and social skills will in turn improve fluency without directly treating the stuttering. Addressing articulation, phonological skill, pragmatics, and self-esteem may all positively impact smooth speech production.

The Stuttering Foundation is a great resource for information, research and ideas: www.stutteringhelp.org/downs-syndrome.

New WDSRA Lekotek Family Play Program

The room is painted and decorated. Staff are hired and trained. The toys have arrived…and arrived. The NEW Lekotek purposeful play sessions and toy lending library is OPEN!

Lekotek is the family centered play program designed to help families in the development of the very youngest children with special needs from birth to 8 years old. Cognitive, physical, communicative or sensory limitations may block the engagement inherent to play for a child with special needs. Through Lekotek purposeful play sessions and toy lending library, parents learn to engage their child and build the important bonds necessary to meet developmental milestones. Families take part in private, customized therapeutic play sessions where they receive the guidance, support and confidence they need to engage in purposeful play together. Siblings and other family members are always included.

The toy lending library lets families continue the learning by taking home the same toys they used in each play session. For more information, go to: www.wdsra.com/Programs/lekitok.html.

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R-Word
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said they were sorry or tried to take back their hurtful words. But the paper was no longer crisp and smooth. It was wrinkled and damaged and would never be the same again. We discussed the old adage “Sticks and stones may break my bones, but words can never hurt me.” And we all agreed that this is far from the truth. We talked about how bruises and broken bones heal. Words cut on the inside and those wounds may never go away.

Michelle and I spoke to every fourth and fifth grader at my son’s elementary school over the course of two days. After one of our presentations, a neighbor called to thank me. She said that her son had been teased for years by another boy in his class. After Michelle and I left their room, the boy had approached her son and apologized. He said that he was sorry for all of the hurtful words he’d used and he wouldn’t do it again.

I may not be able to protect my son from ever hearing someone call his sister retarded again, but I can try to teach children why they shouldn’t use that word or other hurtful words. Because regardless of how nervous I may get about talking to them . . . it’s well worth it.

If you’d like us to come to your child’s school, please contact Linda Smarto at lsmarto@nads.org or call the NADS office at 630-325-9112.

Editor’s Note: Additional resources for raising awareness about use of the R-word can be found at www.r-word.org.
Membership Application

Membership dues can be paid online at www.nads.org

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- $70.00 (3 Year)

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A NADS Membership is the perfect gift for grandparents, aunts and uncles and even your child’s favorite teacher!

Memberships can be paid online at www.nads.org!

Special Gift!