



Doug, Louie, Zach, and Liam Herrera

NADS News

Newsletter for the National Association for Down Syndrome

March, 2015

Profile of Louie Herrera

Louie is 28 and is the oldest of four boys. Louie has a very busy life. He participates in the Monarch Academy through RGA; he has a job at Elmhurst Photo Boutique; he takes part in Gateway Special Recreation programs, is involved in his church, and is a member of the Next Chapter Book Club through UPS for DownS. As his mother wrote us recently, "He has a full, rich life."

Louie also enjoys spending time with his brothers. Younger brother Doug is a special education teacher at Kirk School in Palatine; Zach is a student at North Central College, and his youngest brother, Liam, is a junior at York High School. When Louie is not busy with his own activities, he enjoys watching Zach and Liam compete in Cross Country and Track meets at their schools. His mother describes

He has a full, rich life.

him as "the heart and soul of the Herrera household!"

Over the years, Louie has had the chance to meet a number of celebrities, either through meet and greet occasions or at book signings. He has met The Wiggles several times; the Imagination Movers twice; Cho Cho Soul from the Disney Channel; singer Natasha Bedingfield; former Bears coach, Mike Ditka; and actresses Jenny McCarthy and Bella Thorne (who told him her cat is also named Louie!). These encounters were fun and exciting for Louie, and the celebrities were warm and welcoming to him and, as his mother observed, "very receptive to Louie's sweet personality."

World Down Syndrome Day

March 21 is World Down Syndrome Day. If you are looking for ways to celebrate, the National Down Syndrome Congress (NDSC) has put together a World Down Syndrome Day Toolkit to help you promote Down syndrome awareness in your community. The Toolkit is available at www.ndsccenter.org. The NDSC, in conjunction with 6 other Down syndrome organizations, is also promoting a "Random Acts of Kindness" campaign. If you liked the Lots of Socks theme from last year, Down Syndrome International (DSI) is encouraging people to wear them again. DSI will also post videos from WDS Day events across the world (www.ds-int.org/wdsd-2015). Perhaps yours will be one of them!



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

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Speech Intelligibility: Helping Children and Adults Develop and Maintain Understandable Speech

Libby Kumin, Ph.D., CCC-SLP

PHONOLOGICAL PROCESSES

As young children first develop speech, most use what are called “phonological processes.” These are sound simplifications or substitution patterns children discover, usually on their own, that make their speech production easier. It enables them to make a variety of different sounds, even when they can’t make all of the sounds. It is a step in learning sounds and the sound patterns (where do sounds go, what sounds can be combined, etc.) of their language. For example, a child may say “tootie” instead of “cookie” because he still can’t make back sounds. Or he may leave off all of the final consonant sounds in words, saying “ca” for both “cat” and “cap”. At the same time, he may say “po” for “pot” and “to” for “top,” proving that he is capable of saying the final consonants of cat and cap. So sometimes the problem is that he doesn’t know when to use these sounds, not that he can’t say them.

What can you do at home?

The most common phonological process used by children with Down syndrome is final consonant deletion— leaving off the final consonant sound in words. You can help bring the need for using final sounds into awareness. Make a card game with the goal of collecting pairs of cards, or use the cards to plan a matching memory game, where you search

for the pairs. The pictures or photos that you choose should be of words that differ only in the final sound in the word, like “boat, bone, bowl” or “can and cat” or “book and boot”. If your child can read, write the word under the picture, and make the final sound in bold letters. The players take turns asking, “Do you have any _____?” If your child says “bow,” you tell him that you don’t know which card he wants. Then you model the correct pronunciation. “Do you want bone or boat?”

VOICE

Your child’s voice quality, and the volume and pitch he uses when speaking can also affect intelligibility. In children with Down syndrome, voice quality is often described as hoarse, rough, or breathy. For voice difficulties, an examination by an otolaryngologist (ENT) is needed before any speech treatment begins. There may be medical reasons for the problem— such as allergies or anatomical differences in the larynx (voice box), which would require medical treatment. Voice quality can also be related to low muscle tone.

Pitch

Pitch refers to how high or low the voice sounds. Generally speaking, the range of pitches that children and adults with Down syndrome are able to use is similar to the range used by people without Down syndrome.

Volume

To be intelligible, your child needs to be loud enough

for the listener to hear, and appropriate to the situation. Often, difficulties are not due to respiratory or voice production difficulties, but related to the child’s lack of awareness of volume. So, what your child may really need to learn is when to be loud and when to use a quiet voice. This is best taught at home (or in the community) in real-life situations. At home, you can let your child know that you are having difficulty hearing him and that he needs to speak more loudly. You can let him know when you are on the phone and he needs to use a soft voice. You can also discuss and practice different situations. Practice may be all that is needed to increase or decrease his volume.

Home Activities

- Talk about loud and soft voices. Label voices as your “inside” and “outside” voices.
- Practice using a loud voice in a tunnel so you can hear the echo.
- Demonstrate using a soft voice, from a whisper to a quiet voice.
- Comment on loud and soft noises in the environment. For example, when you hear the lion at the zoo, comment on the loud roar. Listen to quiet sounds in the environment, such as water dripping and birds chirping, and comment on them.
- Talk about places where you need to use a soft voice, such as at school or church, and places where you can use a loud voice, such as at a baseball

game or on a roller coaster.

- Read books about whispering and loud and soft sounds. Some favorite books for talking about volume include:
 - *Mr. Brown Can Moo, Can You?* by Dr. Seuss,
 - *Noisy Nora* by Rosemary Wells,
 - *SHHH!* by Suzy Kline,
 - *Noisemakers* by Judith Caseley,
 - *Helen and the Great Quiet* by Rick Fitzgerald,
 - *The Quiet Noisy Book* by Margaret Brown, and
 - *The Very Quiet Cricket* by Eric Carle

Play games where your child has to use a loud or soft voice or a whisper. "Telephone" is a good game to use, but remember to keep the messages short. Several children stand in a line. The first child whispers a message in the ear of the next child in line, and so on down the line. The last child has to repeat the message he heard and compare it to the message the first child sent.

When your child has learned how to control volume, but doesn't remember to do so, use a sign or cue at home as a reminder.

RESONANCE (ORAL/NASAL BALANCE)

Resonance refers to how full and vibrant a voice sounds—the tone of the voice. When someone sounds as if they are all stuffed up or "twangy," you are noticing the quality of vocal resonance. Many children with Down syndrome have resonance problems based on medical conditions. If your child has allergies or enlarged tonsils and adenoids, he may breathe through his mouth. As a result, sounds

may never be resonated through his nasal cavity. He will sound stuffed up, as if he has a perpetual cold. This is known as hyponasal resonance or hyponasality. An ENT or an allergist can treat the problem. If your child has a short velum (soft palate area), a high palatal vault, or velopharyngeal insufficiency (difficulty using the soft palate and throat wall muscles to seal off the nasal cavity to keep air/sounds out of the nose, and to send air through the mouth), this is known as hypernasality. With hypernasality, your child's speech would sound "twangy." The speech-language pathologist can give your child muscle strengthening exercises to help him improve velopharyngeal closure. If the hypernasality is severe and affects intelligibility, it may be necessary to seek treatment from a maxillofacial team. These teams are usually made up of dental, medical, and speech specialists and are located in hospitals. They might prescribe a speech appliance, similar to a dental bridge that would make velopharyngeal closure easier. Or they might recommend pharyngeal surgery, which would also aid in the closure.

RATE

The rate of speech, or how fast we talk, is an important factor in whether we can be easily understood. Children with Down syndrome may have a rapid rate, slow rate, or uneven and changing rate of speech. Rate patterns have not been documented in the literature. In my experience as a speech-language pathologist, I

have found that children with Down syndrome often speak rapidly or in spurts. They may start out at a comfortable rate for the listener, but often speed up as the conversation progresses. Fast or spurted rate may result in slurred or difficult-to-understand speech, because there are no pauses between words, and words tend to run into each other. If your child has trouble speaking at an appropriate rate, there are a variety of activities you can try at home.

Home Activities

A pacing board may be used to help your child develop a more regular rhythmic pattern. If your child is typically using five words, the pacing board would have five circles or five stickers. Your child would put his finger on the first circle as he said the first word, the second circle as he said the second word, and so on. This acts as a visual reminder to speak

more rhythmically.

Lightly beat a drum as your child speaks and have him try to match his speech rate to the drum. For example, have your child practice saying a phrase such as "Hi! How are you? I'm fine. Bye now!" to the accompaniment of a drumbeat. You can also use a metronome for this type of practice.

Have conversations with your child in which each of you sings your words to a musical rhythm. You can use a song that your child already knows or make up a different tune. You can use slow and fast songs. You can also sing to a specific rate and rhythm using a metronome and a specific tune.

Talk about slow and fast speech and demonstrate slow and fast speech. Play a game in which you say sentences or read a story while your child moves a car along a toy road. When you

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Speech Webinar

Down Syndrome Education International is hosting a webinar: Supporting the Development of Clearer Speech for Children with Down Syndrome on April 21 at 8:30 am EDT. It will cover speech development in children with Down syndrome and resources for improving speech clarity. To register, go to www.dseinternational.org.

New Assistive Technology Program

The Arc of Illinois has developed a new program to help provide assistive technology equipment to individuals with developmental or intellectual disabilities. Individuals must have received an evaluation from a qualified professional and the device must not be covered by a medical insurance plan. The maximum grant will be \$500. For more information, go to www.thearcfillinois.org or call 815-464-1832.

RESOURCES FOR THE YOUNG CHILD

Old Town School of Folk Music

New Exceptional Wiggleworms class for young children (ages 1-3) with special needs. 773-728-6000; oldtownschool.org

iPad Apps Webinar

The Center on Technology and Disability will be hosting a webinar: "iPad Apps for Foundational Literacy Skills & Language Development: Application & Implementation." The presenter will be Diana Petschauer, of Assistive Technology for Education, LLC, and the webinar will be held April 7 from 4-5. EST. She will cover the best educational apps for young children to help them acquire foundational reading, writing, and math skills. For more information, go to ctdinstitute.org.

Early CHOICES

Early CHOICES was established by the Illinois State Board of Education to encourage and support inclusion at the preschool level. Early CHOICES provides research-based information and technical assistance for school districts and many resources for families. For more information, go to their website: eclre.org or contact Ann Kremer, the Project Leader, at ann.kremer@eclre.org or Sandy Ginther, Specialist, at sandy.ginther@eclre.org.

Speech Intelligibility

Continued from page 3

speak slowly, he moves the car slowly. When you speed up, he should make the car speed up. When this activity becomes familiar, have your child repeat phrases after you, and move the car along at the speed of speech. This activity can be varied with a toy horse on a trail or a toy boat on a river.

Read the story of *The Tortoise and the Hare*, and talk about slow and fast. You can say a rhyme or sing a song very fast and very slow.

FLUENCY

Fluency refers to the smoothness of speech—how easily one sound flows into the next sound, one syllable flows into the next syllable, and one word flows into the next word. Problems with fluency are sometimes referred to as stuttering. Children who stutter may have repetitions or blocks (periods of silence in which they seem to be struggling to emit a sound).

Stuttering or dysfluency is more prevalent in people with Down syndrome. At present, the best estimates are that approximately 45 to 53 percent of people with Down syndrome stutter. Sometimes fluency problems occur together with rate problems. If your child has fluency problems, it is important not to

draw attention to them. In general, you should maintain eye contact, be very patient, and listen to what your child is saying. Don't fill in the words that are giving him difficulty and don't tell him to slow down. Let him know that you will continue to listen to him until he is finished.

Fluency problems are complex and need to be treated by a speech-language pathologist. He or she will suggest home activities appropriate to the specific type of fluency problems your child has.

PROSODY

Prosody is the general term for the rhythm of speech. Prosody includes how pitch and inflection are used to convey meaning. For instance, in English the voice generally goes up at the end of the sentence for a question and down for a statement. I have observed clinically that prosody is often difficult for children with Down syndrome, especially as they begin to use longer sentences. They may emphasize the wrong word in a sentence or speak in something of a monotone.

Home Activities

Help your child learn more about the musicality

of language by singing words as a game, as if you were in an opera. So, sing "Good morning. How are you?" That emphasizes the inflection and rhythm.

Play a game where you pretend to be a robot or alien that speaks in a monotone on one pitch (or use a puppet). Your child's job is to teach you to speak more like a human. For example, you say, "May I have the ball?" robotically. Your child models, "May I have the ball?" with the pitch going up at the end. He doesn't give you the ball until you imitate his model correctly.

Use the same words with varying inflections. For example, you ask, "Ice cream?" Your child needs to respond, "Ice cream," with the inflection of a statement if he wants some. If he says it as a question (modeling you), you say, "Well, do you want ice cream?" Then change roles. Your child asks, "Baseball?" and you say, "Baseball," and put the TV on to begin watching the game.

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Excerpted from Down Syndrome News, Volume 37 #4 (Winter 2014), the newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108 Roswell, Georgia 30076, www.ndsccenter.org. This excerpt is from the last article in a 3-part series on communication by Libby Kumin. The other 2 articles appear in the Spring 2014 and Summer 2014 editions.

Help for Medical Travel Expenses

Eli's Heart is a non-profit organization that helps families who may need to travel for surgeries or other medical procedures for their child with Down syndrome. The organization helps defray travel expenses for families by providing plane tickets, gas or meal cards, hotel rooms, etc. For more information, go to www.elisheart.org



The Benefits of Aquatic Therapy at Marianjoy

Has your child ever participated in aquatic therapy as part of their treatment plan?

A study published in the *Pediatric Physical Therapy Journal* (Vol. 19, Issue Number 4, Winter 2007), found that children 6 to 30 months old who received aquatic therapy made significantly greater gains

“...children 6 to 30 months old who received aquatic therapy made significantly greater gains in mobility.”

in mobility. Other potential benefits of aquatic therapy include improved flexibility, increased strength, increased core stability, better balance, improved respiratory capacity, greater cardiovascular fitness, and earlier progression in functional tasks, such as

standing and walking.

According to Ginny Girtten, Marianjoy Rehabilitation Hospital pediatric program liaison and physical therapist, “Water is a natural setting for children. In the pool, therapists are able to design creative and enjoyable water experiences for the child to help address

therapy goals that may not be as easily achieved through therapy in a traditional setting.”

Marianjoy, located in Wheaton, Illinois recently opened

a new Aquatic Therapy Center in January 2015. The therapeutic pool offers many significant features that can benefit both adults and children. It uses salt-water instead of chlorine, which is better for the skin and respiratory system, and the temperature is a

soothing 88 to 93 degrees, to improve muscle and joint flexibility and range of motion. In addition, the Center offers a lift system to transport patients into the pool who are not ambulatory, a new family locker room, and a secure waiting and viewing area for parents and caregivers.

Some things to consider when determining if aquatic therapy is right for your child:

- How does my child respond to bath time and water in general?
- Is my child able to actively and safely participate in therapeutic activities in water?
- Is my therapist trained in aquatic therapy or are there therapists in my area who are?
- Does the pool in my area meet the criteria for a therapeutic pool?

Girtten does caution that not all children may be appropriate for aquatic therapy. “Young children

with acute heart conditions need to be cleared by their doctor in order to participate in warm-water exercise. If a child has ear tubes parents should consult the child’s ENT. In addition, children with G-tubes are appropriate for aquatic therapy, but extra care is needed to make sure the tube does not open and the skin around the tube does not become irritated.”

For more information on Marianjoy’s Aquatic Pool Therapy Program, please call 630-909-7155.

Editor’s Note: The information in this article was provided by Ginny Girtten, Pediatric Program Liaison and Physical Therapist; Mandy Hammock-Cote, Physical Therapist; and the Marketing Department at Marianjoy.

Buddy Up Tennis

Beth Gibson

Spring is coming! Get FIT, learn to PLAY tennis and have a ball of FUN!



Buddy Up Tennis is having fun in the Northwest Suburbs!

Come and join us on the courts!

What Is Buddy Up Tennis?

Buddy Up Tennis, Fitness and Fun is a High-Energy Adaptive Tennis and Fitness clinic designed for individuals with Down syndrome. We feature 90-minute clinics that include fitness activities and professional tennis instruction, as well as participation by our volunteer Buddies, who work alongside our Athletes to maximize the experience. Anyone 5 years and older can join Buddy Up Tennis. We will provide tennis racquets, team shirts and fun! No prior tennis experience is required. Athletes have the opportunity to join a team, improve motor skills, enhance coordination, and build upon their confidence. Most importantly, both our Athletes and Buddies will make new friends and have a great time!

Interested? Want to Know Where to Find Us?

You can find us at our Chicagoland location:

Heritage Tennis Club
7 West College Drive
Arlington Heights, IL 60004

Winter and Spring Session meets from 4:00-5:30 PM

February 7 & 21 – March 7 & 28 – April 11 & 25 – May 2 & 16

How Can I Sign Up?

Contact: MaryBeth Bowman at NWChicago@BuddyUpTennis.com

Clinics are \$15 each or \$25/month, with scholarships available

Want To Know Even More About Our Program?

Visit us at BuddyUpTennis.com

Summer Camps in the Midwest

Illinois

Camp Callahan; www.campcallahan.com; 217-228-2707
Camp Hope; www.camphopeillinois.org; 312-401-HOPE
Camp Little Giant; www.ton.siu.edu; 618-453-1121
Camp New Hope; www.cnhinc.org; 217-895-2341
Camp Red Leaf; www.jcys.org; 312-726-8891
Easter Seals Camps at Timber Pointe; www.ci.easterseals.com; 309-365-8021
Keshet Special Needs Camps; www.keshet.org; 847-205-0274
Penguin Project Arts Camp at Timber Pointe; www.penguinproject.org or www.ci.easterseals.com; 309-365-8021
Shady Oaks Camp; www.shadyoakscamp.org; 708-301-0816
Special Camps; www.specialcamps.org; 630-690-0944
Special Touch Getaway Retreats; www.specialtouch.org; 715-258-2713
Walcamp Outdoor Ministries Summer Camps; www.walcamp.org; 815-784-5141

Indiana

Camp Anderson Woods; www.andersonwoods.org; 812-639-1079
Camp Millhouse; www.campmillhouse.org; 574-233-2202
Camp Riley; www.bradwoods.org; 765-342-2915
Camp Red Cedar; www.awsredcedar.com; 260-637-3608
SonRise Camps; www.bethesdalutherancommunities.org; 877-642-9902
Springhill Camps; www.springhillcamps.com; 812-497-0008

Iowa

Camp Albrecht Acres; www.albrechtacres.org; 563-552-1771
Camp Courageous; www.campcourageous.org; 319-465-5916
Easter Seals Camp Sunnyside; www.ia.easterseals.com; 515-309-2375

Michigan

Camp Fish Tales; www.campfishtales.org; 989-879-5199
Camp Grace Bentley; www.campgracebentley.org; 313-962-8242
Fowler Center for Outdoor Learning; www.thefowlercenter.org; 989-673-2050
Freddy's Friends Camp; www.pineridgecamp.com; 616-696-8675
Friendship Camp; www.cranhillranch.com; 231-796-7669
Friendship Circle Overnight Camp; friendshipcircle.org; 248-788-7878
Indian Trails Camp; www.indiantrailscamp.org; 616-677-5251
Joni and Friends Family Retreats; www.joniandfriends.org; 818-707-5664
Springhill Camps; www.springhillcamps.com; 231-734-2616
Skyline Camp; www.campskyline.org; 810-798-8240
St. Francis Camp on the Lake; www.saintfranciscamp.org; 517-688-9212
Summer Serve Camp; www.compheart.org; 616-748-6011

Wisconsin

Badger Camp; www.badgercamp.org; 608-348-9689
Camp Daniel; www.campdaniel.org; 715-757-3880
Camp Matz; www.bethesdalutherancommunities.org; 920-261-3050
Camp Pow Wow; www.waukshaarch.org; 262-542-9811
Camp SOAR; www.childstudy.org; 312-726-4011
Cristo Vive; www.cristovive.net; 763-263-1526
Easter Seals Camps; www.eastersealswisconsin.com; 800-422-2324
Easter Seals Respite Camps; www.wi-se.easterseals.com; 414-449-4444
Inspiration Ministries Retreats; www.inspirationministries.org; 262-275-6131
Special Touch Getaway Retreats; www.specialtouch.org; 715-258-2713

SELF-ADVOCATES

RESOURCES FOR TEENS & ADULTS

New Self-Advocacy Website

Self Advocacy Online (www.selfadvocacyonline.org) is a new website for people with intellectual or developmental disabilities developed by the Arc and the Research and Training Center on Community Living at the University of Minnesota. The website includes information on a variety of topics, including healthy eating and relationships, as well as stories from self-advocates, connections to self-advocate groups, and information on research.

TRANSITION RESOURCES

For some families, the transition of an individual with Down syndrome into adulthood can bring changes to how that person accesses healthcare, perhaps requiring different medical providers or different processes for managing appointments and medical decisions. Planning for that transition can make it easier, and families can find a number of resources to help with that process at www.gottransition.org.

The Developmental Disabilities Family Clinics offered by the University of Illinois Chicago's Institute on Disability and Human Development also offer transition planning help, including a Transition Consult Clinic. For more information, go to www.ahs.uic.edu/cl/familyclinics.



Self-Advocates at the Magic Show

Julia Smarto, Michelle Anderson, Alex Tello, Lindsey Pazerunas, and Rachel Giagnorio help out before the show

POSTSECONDARY RESOURCES

Think College Illinois

Think College Illinois (www.thinkcollegeillinois.org) is the local branch of Think College (www.thinkcollege.net), a national initiative to create postsecondary education opportunities for individuals with intellectual or developmental disabilities. The Illinois website includes a list of inclusive programs in Illinois as well as access to the Think College national database and other resources.

Inclusive Campus Communities Webinar

March 24 3-4 pm ET

Presented by: Melissa Jones, Northern Kentucky University and Molly Boyle, Think College
www.thinkcollege.net

POSTSECONDARY SCHOLARSHIPS

- Ruby's Rainbow Scholarships (for individuals with DS): www.rubysrainbow.org
- O'Neill Tabani Enrichment Fund Scholarships (for individuals with DS): www.ndss.org
- Katie MacDonald Memorial Scholarships (for individuals with DS or individuals pursuing disability-related degrees): www.upsfordowns.org
- Eric Martinez Memorial Scholarships (for individuals with DS or siblings): www.upsfordowns.org
- Linda Cronic Institute Undergraduate Scholarship Program (for individuals pursuing DS research): globaldownsyndrome.org

RECREATION RESOURCES *continued from page 6*

Down Syndrome Camps

May 31-June 5 Camp Hi-Lite (Camp Riley program), IN; www.rileykids.org; 317-808-8557 or 877-867-4539

June 14-18 Down Syndrome Foundation Camp, MN; www.downsyndromefoundation.org; 612-799-0254

June 14-19 Rising Stars/Shining Stars Camps (Easter Seals Camps at Timber Pointe; www.ci.easterseals.com; 309-365-8021)

July 5-10 Destination Smiles Down Syndrome, Camp Eden Wood, MN; www.truefriends.org; 800-450-8376.

July 26-Aug 1 Camp PALS Chicago, Elmhurst College, Elmhurst, IL; www.palsprograms.org

August 4- 8 Camp Super Smile, VA; www.brainycamps.com; 202-476-5142

September 11-13 Pretty Place Stargazers Family Camp; www.campgreenville.org/pretty-place-stargazers.php; 864-836-3291 x107

Believe in Magic

The 2015 “Believe in Magic” show was a moving tribute to its founder, Paul Lee. This year’s show successfully carried on the tradition Paul Lee established, providing a magical afternoon of entertainment, music, and magic tricks. We would like to extend a special thanks to the members of the planning committee (Char Lee, Terri Mate, Diane Urhausen, Mary Lou Miller and Steve Chezaday), who worked hard to carry out Paul’s vision. We are also grateful to all the performers--magicians Steve Chezaday, Dennis Debondt, Jania Taylor, Anthony Stockton, and Trent Rivas, singer Karen Burris, and assistants Carol Hendrix and Jessica Peterson—for ensuring the success of this event, as well as to strolling magicians Plaz Garcia, Raime Townsend and Steve Joyce, and face painter, Melody Pekarek for entertaining the crowds before the show. We would also like to thank Mike Engle & Dragon Design for designing the promotional materials and the program, Ozzie’s Deli in Melrose Park for donating sandwiches for the performers, and the staff at the Arcada Theater for donating the space and providing support the day of the event. The show could not have gone forward without your dedication and generosity!

Sarah Goes to the Magic Show

Ann Garcia

It is bed time at our house, but my daughter, Sarah, is spinning on the floor, looking far from sleep. “Time for bed,” I say. She

advancing, and so back to her bedtime ritual she must go. Fortunately for us, she loves routines almost as much as she loves spinning. Soon she was snuggling

she starts beaming from the moment we enter the parking lot. Her enthusiasm is contagious.

Sarah can be playful and affectionate, but she does not need others to be happy—a gift with a dark side, as anyone raising a child with Autism knows. We understand why “Bye!” is her favorite word, but we are not willing to let her always dance alone. We have explored different ways to help her develop socially. When she was little, saying “hello” was a goal on her IEP. She complied (with prompts) but never embraced its purpose. Now, suddenly this year, when it is her idea and not ours, she has started saying “hi” spontaneously. Her sister gets an enthusiastic “hi” when we pick her up from school. Even the houses on our street get a joyful greeting as we drive past.

Music has been the most effective bridge to others. When she was young, her Musikgarten class taught her to imitate sounds and movement as well as the other children in her class. Now she is involved in an instrumental and choral program at our church. Music has given her a chance to be part of a group and taught her how to share something she loves.

We have also tried to include her in family outings, especially when they involved music. Those efforts were less successful, as I could never convince Sarah that the audience at concerts is not supposed to participate. We usually ended up listening to her



Sarah with her sister, Rachel

knows what that means and goes into her room, turns off the light and shuts the door, but I am not deceived. Sure enough, when I look in, there she is, still spinning. Seeing her, I might have thought of her Autism and the constant craving for motion it seems to bring. Or I might have wondered if another sleepless night lay ahead. But instead, I was held by the expression on her face: pure bliss.

I have seen that look many times, especially when she is dancing to music. Spinning there, she seemed to be moving to a melody only she could hear. I was reluctant to break into her private joy, the dance which circled in place, as if she could keep time there as well, but the evening was

under the covers, giggling as I tucked her in. “Bye,” she pronounced as I left. Dismissal words (goodbye, goodnight, all done) have always been her favorites.

Later, my husband and I laugh together over her creative solution to parents who would interrupt her fun. It has surprised us how much laughter she has brought to our family. We enjoy her partly because she is joyful. Not that she is always happy. She has had her share of traumas (multiple surgeries) and trials (combs and brushes, unexpected change, encounters with animals—sorry, dogs, Sarah will never be a fan). But she also has a gift for appreciating the blessings in her life. When we go out to eat,

sister's programs from the hall. Then there was the time we decided to include her in our annual Christmas trek to the Joffrey "Nutcracker." With all that music, we thought, she is sure to enjoy it. We were right. She did love the music. She made herself right at home, immediately kicking off her shoes. Literally kicking, we realized, as we watched one hurtling towards the balcony edge. We caught it just before it went over the railing and landed on someone's head. For the rest of the performance, we were on the edge of our seats, but Sarah was thoroughly—and uninhibitedly—enjoying herself. She danced in her seat. She clapped. She especially liked the energetic pieces. Unfortunately, when the tempo slowed, she was not so pleased. On came the Sugar Plum Fairy to dance her beautiful pas de deux, but Sarah was ready for the Russian dancers to come back. "Bye," she called, and then, when the dancers did not take the hint, "Bye," more loudly. Well, maybe the Nutcracker was not such a good idea . . .

After that experience, I was hesitant to take her to

public performances, but one day, I had the chance to talk to Paul Lee about the NADS Magic Show. During our conversation, he asked if I had taken Sarah to see it. I confessed I had not. "Why not?" he asked, fixing me with a direct look which made the explanation I offered seem like a lame excuse. I realized he was right. Where else could I find a more welcoming audience? I took her the next year, sitting in the last row so I could slip out quietly if she became disruptive. I soon realized it would not matter if she did, as the performers were actively involving the audience, and many members of the crowd were enthusiastically responding. Here at last was an audience which was allowed to participate! No one turned around to glare at Sarah for making a noise. No one minded when she danced in her seat. Sarah was in heaven. We did not have to leave the auditorium once.

This year I took her to the Magic Show again, though I knew the mood would be more somber, as the show would also be honoring Paul's life. I was a little concerned she might not be sufficiently

quiet during the slide show tribute at the end, but she surprised me by behaving perfectly. Though the day was emotional for many, the magicians brought a spirit of celebration to their performances of Paul's favorite tricks. The show also featured singer Karen Burris, so Sarah had plenty of music to enjoy. At the end, audience members rose to their feet and so did Sarah, without any prompting from me. She had been watching the people around her as well as the people on the stage.

That night at bed time she was still happy from her trip to the Magic Show. After her bath, I prepared to comb out her hair—a task we both usually dread—but she barely noticed as the comb approached her head. I managed to remove all the tangles without a single protest—a minor miracle. She was not thinking about her hair but laughing up at me, and suddenly goals seemed less important than sharing this moment with her. For, I realized, we were sharing it. She gave me a smile which seemed to rise from her toes. "Hi," she said—her new favorite word.

2015 NDSS Buddy Walk Conference and Buddy Walk on Washington

April 13-15
Washington D.C.
www.ndss.org

9th College Work Transition Summit for Youth and Young Adults with Disabilities

April 18
MOPD Field Office
2102 West Ogden
Chicago, IL
312-746-5743
Sponsored by the Mayor's Office for People with Disabilities

NADS Annual Meeting

May 12, 6-7pm
NADS office
1460 Renaissance Drive,
Suite 405
Park Ridge, IL

NDSC Convention

June 25-28
Phoenix, AZ
convention.ndscenter.org

Institute of Special Education Advocacy Conference

August 2- 7
William and Mary Law School
Williamsburg, VA
www.wrightslaw.com/speak/15.08.va.wm.htm

Sibling Survey

The Sibling Leadership Network is studying the support needs of siblings of individuals with disabilities. The survey is for the following individuals to complete:

- Siblings of people with disabilities
- People with disabilities
- Parents of people with disabilities
- Professionals working with people with disabilities and their families

This is an online survey; it will take less than 30 minutes to complete.

The survey is available in English and in Spanish. The link to the survey is:

<http://bit.ly/SiblingSurvey>. If you have any questions or concerns, please contact Meghan Burke at 217-300-1226 or meghanbm@illinois.edu.

family album



Avery Connors



Miles Evans

Photo courtesy of Katie Discoll



Abby Benco and her brother Kevin Skrabacz



Sarah Buzby



Blake Garner



Michelle Anderson and Alex Tello

We Need Photos!

Send your
Family Album
photos
to NADS!

shebein@nads.org

NADS Welcomes New Staff Member

Welcome to **Deb Kracik**, who has joined our staff as our Office/Bookkeeper Assistant. Deb has volunteered for us in the past and has been active in the Down syndrome community. She has 4 children, and her youngest, Jane (age 8), has Down syndrome. We are delighted to have her on board!

Debbie Taus-Barth, our long-time Office Coordinator, will remain with NADS but will shift roles to become our Development Coordinator, managing membership, events, and fundraising. Congratulations to both on their new positions!



NADS Public Speaker Training

NADS will be conducting its next public speaker training Tuesday April 7th at 6:00 pm and Tuesday April 21 at 6:00 pm in the NADS office, 1460 Renaissance Drive, Suite 405 in Park Ridge. Attendance at both sessions is required. If you are interested in becoming a public speaker, please contact Linda Smarto at lsmarto@nads.org or 630-779-4245.

NADS Parent Support Training

Training for new parent support volunteers will take place Saturday, May 2 from 9-3 in the NADS office, 1460 Renaissance Drive, Suite 405 in Park Ridge. If you are interested in serving as a mentor in our Parent Support program, please contact Ann Garcia at agarcia@nads.org or 630-325-9112.

NADS Retreat

The next NADS Retreat will be Saturday, April 18. NADS offers the Retreat twice a year for families who have a child with Down syndrome and an additional diagnosis, such as Autism or ADHD. If you are interested in attending, please contact the NADS office at 630-325-9112.

DEVELOPMENT

Notre Dame Impact Partner Program

We are delighted to announce that NADS has been chosen as a non-profit partner for Notre Dame's Impact Partner Program. The program involves developing a project which Notre Dame alumni help to implement. Thank you to Patrick Crawford for submitting our application. We are honored to be chosen by Notre Dame and look forward to working with Notre Dame's alumni volunteers.

FUNDRAISING

Strider Bike Donation

We are grateful to the Strider Bike organization for donating 6 Strider bikes to NADS. Many thanks to Josh Morrow for helping to coordinate the donation and distribution of the bikes. We are grateful for the generosity of all involved.



Buddy Walk Donation

Many thanks to Down Syndrome Support for donating \$18,000 to NADS from the proceeds of the 2014 Chicagoland Buddy Walk, which took place October 12 in Cantigny Park. We are very grateful for their ongoing support and for the assistance they have provided to the Down syndrome community in the Chicago area.



1460 Renaissance Drive, Suite 405
Park Ridge, IL 60068

Change Service Requested

www.nads.org

Membership Application

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

Name:

Address:

City: State: ZIP:

Phone (home) Phone (work)

Email Address:
 Please add me to the NADS e-mail alert list

Category of Membership (check one)
 Parent: \$25.00 (1 Year) \$70.00 (3 Year) Child's birthdate/...../.....
 Professional: * \$30.00 (1 Year) \$85.00 (3 Year)

*Please indicate professional involvement:

Donation level: Contributor (\$100 +) Benefactor (\$500 +) Patron (\$1000 +)
 Check if Renewal

Make checks payable to: **NADS** and send to:
1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068

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

NADS GIFT MEMBERSHIP
 Please send a NADS gift membership to:

Name:

Address:

From:

Phone:

Relationship:

\$20 per recipient should be enclosed and sent to:
National Association for Down Syndrome (NADS), 1460 Renaissance Drive, Suite 405, Park Ridge, IL 60068

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