

NADSNEWS



Katia Crawford with big brothers Sean and Aidan

The Newsletter of the National Association for Down Syndrome

March, 2009

The Down Syndrome Community Lost a True Friend — Dr. Bill Cohen

By Sheila Hebein

It is with great sadness that we report the death of a leader and true friend of the Down syndrome community.

Dr. William I. "Bill" Cohen died of a heart attack on Friday, Feb. 6, 2009. Dr. Cohen was a well-known leader in the international Down syndrome community. He was the Medical Director of the Down Syndrome Center of Western Pennsylvania and co-founder and co-chair of the Down Syndrome Medical Interest Group (DSMIG), which produced the health-care medical guidelines for individuals with Down syndrome. Dr. Cohen was a member of the Clinical Advisory Board of the National Down Syndrome Society (NDSS) and the Scientific Advisory Board for the Down Syndrome Research and

Treatment Foundation. He was also Associate Professor of Pediatrics and Psychiatry at the University of Pittsburgh School of Medicine.

NADS members who attended our 2006 conference will remember Dr. Cohen's wonderful keynote address and his workshop on challenging behaviors. He was a tireless worker for children and adults with Down syndrome — giving of himself to groups throughout the country, serving on boards, and providing critical leadership within the medical community. Dr. Cohen was respected throughout the world and was actively involved in planning and presenting at international conferences.

I have known Bill Cohen for more than 20 years, and it is hard to believe that I won't see him at the next Down syndrome conference,

where I could always count on a warm greeting and a bear hug. Rest well, dear friend, and know that you really made a difference in so many lives — in the lives of thousands of children and adults with Down syndrome and their families and in the lives of many professionals with whom you so willingly shared your knowledge and insight.

We send our condolences to the family of Dr. Cohen and also to the staff and families who had come to count on him for guidance and great care for many years.▲



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NADS Nominating Committee

Successful organizations need good front line people and good people behind the scenes, and NADS is no exception. We're looking for people who want to contribute to the mission of NADS by serving on our Board of Directors. We need people with a variety of skills and talents, especially those who like to work with numbers and finances, but we welcome anyone who is interested in serving. If you are a parent or a professional member of NADS and would like to be considered for our Board of Directors, please call our office at 630-325-9112, and we'll send you a nomination form. Or you can download a PDF version from our website at www.nads.org/docs/board_nomination.pdf. The completed form must be received in our office by March 21, 2009.▲

PUNS — The Basics

From the ARC of Illinois Family to Family Health Information & Education Center:

- PUNS stands for Prioritization of Urgency of Need for Services.
- PUNS is a list of the people in Illinois with developmental disabilities who need services.
- PUNS is for everyone who may need help from the government to pay for developmental disability services now or in the future.
- PUNS is the first step toward getting services in Illinois. If you are not on the PUNS list, you are not on the waiting list for services.
- To get on PUNS, you need to set up a date to meet with a Pre-Admission Screener. These screeners will ask questions about you and your needs. These questions are part of the PUNS survey. All screeners work for Independent Service Coordination Agencies or ISC's. To get on the PUNS list, you must have a developmental disability. If you don't know if you have a developmental disability, the screener will help you.
- To find your ISC, you can call Illinois Life Span at **1-800-588-7002**. You can also call DHS at **1-888-DD-PLANS**.
- When your PUNS survey is done, you are on the list. This doesn't mean that you will get the services you need. It just means that you have made the first step.
- Some of the services that people may need are:
 - In-Home Supports
 - Respite Care
 - Job Coaches
 - Group Homes
 - And many others
- There is not enough money to give everyone in Illinois the services they need. Right now, many people are working on a fair way to choose who gets services.
- Don't forget to update your PUNS form every year. Only people (families) who have completed the PUNS - and keep it updated - have a chance of getting "picked" to receive services.
- If you have questions or need help, you can call Illinois Life Span at **1-800-588-7002**.
- If you want more information about PUNS or Home-Based Services, go to the Family Support Network website at www.familysupportnetwork.org

Winter's Child

By Christopher Garcia

Not long ago a friend left our firm, and he passed along a familiar definition of success from Ralph Waldo Emerson as a general, if somewhat clichéd, benediction:

- To laugh often and much;
- To win the respect of intelligent people and the affection of children;
- To earn the appreciation of honest critics and endure the betrayal of false friends;
- To appreciate beauty;
- To find the best in others;
- To leave the world a bit better, whether by a healthy child, a garden patch, or a redeemed social condition;
- To know even one life has breathed easier because you have lived — this is to have succeeded.

One line always stands out in stark relief for me: “To leave the world a bit better, whether by a healthy child, a garden patch, or a redeemed social condition.” Emerson’s progression is telling: redemption of the body politic depends on a literal healthy body and its flourishing, natural world counterpart (a “garden patch”). There appears to be no place for the notion that redemption and grace can be found in the life and

the care of a child that many would not describe as precisely “healthy.”

Eight years ago my daughter, Sarah, was born with Down Syndrome. She has since been diagnosed with Autism. After two heart surgeries and a hip brace to keep her femurs inside their sockets, she can walk; she can run (sort of); she can climb; and she can certainly dance. She spins in a kind of ecstasy, eyes nearly closed, in a trance-like state that resembles descriptions of early church mystics—hands out, as if she were blessing the room.

There was a well-intended essay being circulated not long ago comparing the raising of a special needs child with a trip to Holland, rather than a trip to Italy. The essay was predictably parodied by some who care for such children—reminding us that for some it feels more like a jog through Beirut, Iraq, or Siberia. But at this time of the year, the season in which she was born, I am daily reminded of the unique blessing of being her father.

I am reminded especially by the image of Sarah trying to ascend the staircase, one excruciating step at a time. I was at the top, encouraging her, watching that little hand wrap itself around the wooden banister, lifting each step as if her foot weighed 100 pounds, her feet struggling against the braces, a look of quiet determination on her face, those singular identifying eyes locked on mine, and



those feet moving toward each new step. A journey of perhaps 12 feet that may as well have been a mile. What would it be like to possess a tenth of her focus and courage?

To care for a child with special needs is to be reminded daily that every step, every grasp of a wooden block or toy, every full sentence uttered is a miracle. Each step, word, and act results from hundreds of hours of care, encouragement, and hard work. It is a unique privilege to be her legs, her arms, her voice and, at times, her body and breath.

Some people stereotype children with Down syndrome as perfectly behaved little angels, but they are just children. Yet

in the school yard they often inspire awe, compassion, and humility. Sarah and those like her present the possibility of true social and personal redemption not because they cause us to “breathe easier” but because they cause us to work harder at our essential humanity: *if you have cared for one of these, the littlest of my children, then you have cared for me.* Sarah reminds me on a simple (yet profound) level that we have today: this step, this word, this smile, this dance. ▲

New Arts Program for Children with Special Needs

The School of Performing Arts, which has locations in Naperville and Plainfield, is now offering a series of workshops for children with special needs through their Very Special Arts Program. Classes include an introduction to music, theater, and dance for children ages 3 to 6, an art class for children age 5 and older, and A Very Special Musical, open to children in grades 4-12, in which class members put on their own musical. Continuous enrollment is accepted. For more information, call (630) 717-6622 x128 or go to their website at www.schoolofperformingarts.com.

Other Arts Resources

Art Ventures (Crystal Lake)
(815) 477-9368

Center Stage Dance Studio (Bloomington)
(630) 529-9080; www.centerstagedanceonline.com

Come Children Sing Institute
(online music program)
(708) 957-SING; www.comechildrensing.com

Community School of the Arts (Wheaton)
(630) 752-5567; www.wheaton.edu/csa

Impact Dance Studio (LaGrange)
(708) 354-5867; www.impactdancestudio.com

Special Gifts Theatre (Northbrook)
(847) 564-7704; www.specialgiftstheatre.com

Special Recreation Associations (Chicago area)
www.il-ipra.org/resources/links

Special Music by Special People (Chicago)
www.specialmusic.org

VSA (Very Special Arts) of Illinois
(317) 974-4123; www.vsarts.org/x301.xml

SAVE THE DATE:
NADS Annual Meeting
Tuesday, May 19, 2009
Topic: Transition



Knights of Columbus Make Donation in Honor of Austin Cleary

The Knights of Columbus of St. Joseph Catholic Church in Manteno, IL recently donated \$1,218.92 to NADS on behalf of Austin Cleary. We are very grateful to the Knights of Columbus and to the Cleary family for this generous donation.▲

Nutrition Webinars

Joan Guthrie Medlin, a registered and licensed dietitian and author of **The Down Syndrome Nutrition Handbook** (as well as the mother of a son with Down syndrome), is offering a series of four webinars in March in honor of World Down Syndrome Day:

1. Begin at the Beginning: Nutrition-Related Concerns for People with Down Syndrome from Birth and Beyond
March 3, 2009; 10-11:30 Pacific Time
2. Setting the Stage for Successful Mealtimes for Young Children with Down Syndrome
March 10, 2009; 10-11:30 Pacific Time
3. Creating Successful Mealtimes for Children With Down Syndrome: The Feeding Relationship
March 17, 2009; 10-11:30 Pacific Time
4. Food, Feeding, Family . . . Freedom! Supporting Healthy Lifestyles for Teens and Adults With Down Syndrome: An Overview
March 31, 2009; 10-11:30 Pacific Time

The cost of each webinar is \$30. For more information or to register, go to www.downsyndromenutrition.com or contact Joan Guthrie Medlin at (503) 246-3849.▲

Fashion Show Models

Here are some more stars from last year's Fashion Show:



Carly Kauz

Carly Elizabeth Kauz was born July 29th, 2001. At three months old she had re-constructive heart surgery and has not stopped progressing since. She started the Early Intervention program at eight months and always pushed herself to succeed. She has unlimited energy and loves to play. Her personality lights up any room, and she can really put on the charm. She attends Lester school in Downers Grove and is in the second grade. She attends Church on Sundays and loves going to Sunday School. Carly has an amazing memory, which really adds to her learning skills. She loves music and dress-up and gets everyone in on the act. She touches the heart of everyone she meets and is an absolute blessing to our family and all who know her.

Colleen Altman

Colleen is an active 11 year old Chicagoan with a

strong sense of independence and a wonderful sense of humor. Colleen is the oldest of four, who appreciates her birth placement, as she enjoys telling her siblings where they are headed each day and directing them as an older sister should. Colleen likes to know the agenda for each day and enjoys the anticipation of each activity as much as her participation in it.



Colleen is going into 5th grade, where science and reading are favored subjects. Colleen is able to express her enjoyment for music and drama through piano and special gifts theater. This past year she debuted as Pepper in the production of Annie. Colleen, going into her 4th year as a Special Olympics athlete, has also been able to showcase her athletic ability by out-ranking the family in tennis and boxing on the Wii.

Colleen's most treasured

memories are those spent with family and friends. Colleen flips through dozens of photo albums, which remind her of wonderful vacations, beach/pool outings, concerts, parties and holidays.

Colleen, we love you very much!!



Christopher Nichol

Christopher Nichol is 13 years old. He lives in Chicago with his parents and 2 siblings (Lauren 22 and Mark 11). He is a typical teenage boy: he loves sports, TV and video games, and being with his friends and family.

Since he was very young, Chris has always wanted to do the same things his brother Mark did. Therefore, with the exception of Tomahawks Hockey and Conquerors Special Needs Swim team, Chris has participated on "regular" baseball, basketball, and football teams. We do

admit he's a bit of a ball hog - - e.g. in basketball he will immediately take that outside shot. But we love watching his games, and we are always so proud of him. We especially enjoy watching him swim, and he loves that he can beat the neighborhood kids in a race.

Chris likes to go out with his brother and other friends, and he wants to be independent. We get a bit nervous when he rides his bike in the neighborhood along with the other boys, or when he walks to the park at the end of the block, but we let him do it anyway. He is great about calling or texting us on his cell phone to let us know he has arrived safely. We know this is mostly because he LOVES to use the phone, but we don't complain.

Currently in 7th grade at Wildwood school, Chris looks forward to going to high school. He's good at math and reading, but claims his favorite subjects are gym, recess, and "going home." Of course, Chris would rather be playing videogames on his Xbox, or watching reruns of Everybody Loves Raymond or Friends (don't even think about challenging him in a trivia contest).

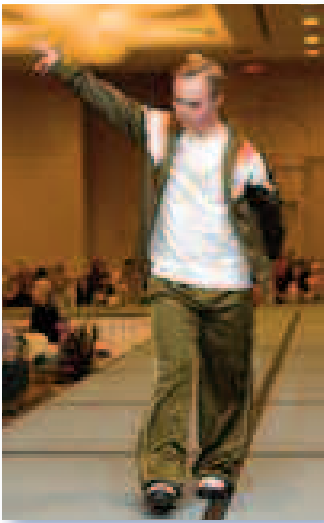
Chris is loving and funny and smart. If you're having a bad day, a warm hug or a funny comment from Chris will change your

Continued on page 6

Fashion Show

Continued from page 5

mood instantly. As an added bonus, he has a great memory and has memorized the phone numbers, birthdates, and addresses of our families, friends and neighbors. So it's like having a walking PDA when Chris is around! We feel so blessed to have Chris as a part of our family.



Peter ten Brink

Peter was born on March 5, 1992 at Evanston Hospital. We were lucky enough to have none other than Sheila Hebein as our "Parent Volunteer"! She saved our lives that day, and we will never forget her kindness and all the much needed information she provided us about having a baby with Down

syndrome. Since that day, Peter has continued to exceed all of our expectations. He has grown into a very energetic, kind and independent young man. Since Fourth Grade, Peter has been very involved in Special Gifts Theatre, where he has played the parts of the Tin Man in the Wizard of Oz, Rooster in Annie and Winthrop in the Music Man. Currently, as a sophomore at New Trier High School, Peter participates in the Drama program and Special Olympics.

Peter has a brother, Michael, who is studying Special Education at Indiana University, a sister Ana, in sixth grade, and a five year old Yellow Lab called Riley. He is also lucky to have fourteen fabulous and supportive cousins in the U.S. and Holland.

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Model bios written by family members for the Fashion Show Program.

Photos by Kelley Demas Photography, www.kelleydemas-photography.com; (847) 650-5163.

Editor's Note: Other Fashion Show models will be featured in future editions of NADS News.

Health Insurance Resource from the ARC of Illinois

When a parent is laid off, one of the first challenges is what to do about health insurance. Some workers may be eligible to continue existing coverage through COBRA for a limited amount of time. Another option is the All Kids Insurance program offered by the State of Illinois. It is open to any child not covered by another health insurance plan, and children can be enrolled regardless of health status or family income level.

The Arc of Illinois has put together a booklet for families to help them weigh their options. The pamphlet, *All Kids Insurance vs. COBRA Coverage—Which One Should I Pick?*, can be downloaded from their website through the following link: www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=839. It can also be requested by contacting the ARC office at (866) 931-1110 or by emailing familytofamily@thearcofil.org. ▲

Special Needs Advocacy Organization

Protected Tomorrows specializes in advocating for individuals with special needs. It is based in the Chicago area but has a network of advocates across the United States. Advocates can help families address the needs of a loved one with a disability in the areas of education, health care, government benefits, law, finance, residency, recreation, and vocation. In addition to helping families put together Future Care Plans, the organization also offers newsletters, workshops, and presentations, which cover such topics as funding sources and special needs trusts. For more information or to locate an advocate, go to www.protectedtomorrows.com or contact the Services Coordinator, Carol Carlsen, at (847) 522-8086 x229. ▲

Special Ed Advocacy Center

The Special Ed Advocacy Center (SEAC) offers free legal advocacy on special education issues to low-income families in the Chicago area. SEAC's mission is to help families obtain appropriate educational services for their child with a disability, as well as to educate parents and schools on their rights and responsibilities under current special education law. Through SEAC, families can obtain free legal representation in securing Early Intervention services for their child or in negotiating with school districts. For more information, call (847) 736-8286 or go to www.specialedadvocacycenter.org. ▲



New Year's Letter to Emily Pall

By Mary Pall (Emily's mother)

- ❖ She dances when everyone is looking, or no one at all.
- ❖ She smiles at strangers, often waving and giving a hug, things we don't dare do to strangers.
- ❖ She cries when someone hurts her...she forgives in a New York minute and never ever holds a grudge.
- ❖ She wakes up every morning to a new adventure. And if one is not available, creates it.
- ❖ She laughs so hard at all of us, and at herself perfectly appropriately.
- ❖ She would fly if she could, and not be afraid, ever.
- ❖ If she falls down, kissing the boo boo makes it perfect again, forever.
- ❖ She sings to her dolls or anyone who will listen. She often sings to herself alone, but I catch a glimpse without her knowing.
- ❖ She is happiest with family. She loves them all in very different ways.
- ❖ She climbs on my back when I am weary and tired and is never too heavy to carry upstairs.
- ❖ She pets animals that would scare the likes of me, for they are imperfect or scary to look at. She knows all creatures need to be loved, old and young, small and huge. She sees beauty in every living thing.
- ❖ She has the courage of a lion. And the compassion of the tiny animal who pulls out the hurting thorn.
- ❖ She possesses the purest heart I have ever seen. Or will ever see again.
- ❖ Her cheeks are softer than cotton, her complexion, perfection.
- ❖ There is not a color made that she cannot wear.
- ❖ She has a million friends, even when they don't realize it.
- ❖ She couldn't care less if you are red or blue or purple or green. You are just fine as you are.
- ❖ She may never experience the excruciating pain of true heart break, and for that I am thankful.

Disability Awareness in the Schools

Announcement from Seguin Services

Responding to the need for disability awareness education within the school community, Seguin Services has produced two instructive units addressing the issue for use in both elementary and middle schools. Seguin's Youth Leadership & Disability Awareness Units are designed to encourage school children to lead the way in promoting increased awareness and understanding of persons with disabilities in their respective schools and communities as well as to help foster good relationships with all classmates, regardless of disabilities. For elementary schools, a weeklong unit is being carried out with students participating in the reading of a short book titled, *What's Wrong with Timmy?* by Maria Shriver and numerous disability awareness activities. Middle school students will be reading from *The Man Who Loved Clowns* by June Ray Wood. Students will also engage in a question packet, quizzes, writing activities and disability awareness activities to coincide with the reading, all developed in partnership with teachers from Lincoln Middle School in Berwyn.

In addition to Lincoln Middle School, Oak Park's Julian Percy Middle School implemented Seguin's unit starting in the fall of 2008, while Cicero Public School District 99 will be utilizing both units in its classroom starting in March of 2009 to coincide with the kick off of The Town of Cicero's Disability Awareness Month.

If you are interested in learning more about Seguin's Youth Leadership & Disability Awareness Units or to receive a copy of either unit, please contact Ryane Kaucher at 708-222-5143 or rkaucher@seguin.org. ▲

Happy New Year our beautiful Emily!



A Special Friendship

Frank Smith and Tim Davis have been buddies through the NADS Mentoring program for almost ten years. During that time, they have formed a wonderful friendship, discovering what they have in common and trying out new experiences. They have a mutual love of 60's music, especially Elvis Presley. Tim has come to join in Frank's love of the Circus, Demolition Derbies and White Castle "sliders." Tim has shared his passion for miniature golf, which he always wins. Over the years, they have had fun attending local events or going out for dinner or to the movies. The evening is always topped off with ice cream. In November Frank and Tim attended the Ringling Brothers Barnum and Bailey Circus and got Circus Celebrity seats in which they were both part of the show. Frank said he's been going to the circus for years, but he has never experienced the happiness he had that night watching the excitement and joy on Tim's face. ▲



Birthday Donation in Honor of Ethan Burleigh

Dear NADS:

In November of 2005 our son Ethan was born with Down syndrome. That day changed our lives forever. The first days were a scary journey in uncharted water of the unknown, but now that we have begun the journey, it is a great and wonderful journey.

We thank God every day for Ethan. Our son has filled our hearts with love. He is a joy to be around and brings a smile to everyone he meets.

For his birthday, we had a gathering of friends and family celebrating three years of miracles with him—his smile, first step, first words, and all the little miracles he performs each day.

In honor of his third birthday, we collected donations to be split between NADS and Gigi's Playhouse. Please accept this donation in the amount of \$110.00 in honor of Ethan.

We are truly thankful for organizations like yours who are instrumental in making a difference in the lives of children and adults with Down syndrome.

Sincerely,

The Burleigh Family
(Gordon, Eva, Phillip, & Ethan)

Thank you to the Burleigh family and to the friends and family members who donated on Ethan's behalf—and happy birthday to Ethan!

Upcoming Events:

Legal and Future Care Planning for Your Relative With a Developmental Disability

Theresa M. Varnet, M.S.W., J.D., Presenter
Friday, March 27, 2009, 9:30 am - 4:30 pm
Lansing Library, Lansing, IL
Sponsored by the ARC of Illinois and hosted by LARC
Registration at www.thearcofil.org or call (708) 206-1930

Disability Rally Day at the Capitol, Springfield, IL
May 21, 2009, 9:00 a.m.
Information: (309) 693-8981

The 37th NDSC National Convention
July 31-August 2, 2009
Sacramento California
Registration information: www.ndsccenter.org;
(800) 232-6372

2009 Midwest Conference: Bridging the Gaps;
Sat. April 18th, 2009, 8:00 am - 3:00 pm
Isle of Capri Conference Center, Bettendorf, IA.
Chris Burke, Keynote speaker.
More information: (563) 271-3524;
www.dsfamilygroupqc.org.

A Sibling Perspective

The following essay was sent to us by NADS member Lisa Masucci, whose son, Jack, is friends with Max Metcalf, the boy featured in this story. The essay was written by Max's older brother, Jordan.

My Best Teacher

By Jordan Metcalf

Picture this. It's a nice sunny day. All seems perfectly well, especially when you're at the age of no worries (2nd grade). You go inside after a long day of coloring, playing with your friends, maybe even some school work, and you look for your mommy. Now as everyone knows, at 2nd grade, your mommy is your hero, your fallback plan, your favorite person. You look around for a while and then finally you hear her in the kitchen. You bust through the door and you're about to say, "Hey mom what's for dinner!" but you end up saying nothing, not even breathing. She's weeping. The person you thought was the strongest and bravest person in the world is weeping about something that was obviously for her to know and for you to find out eventually because your dad shoos you out of the room. You go outside to think things through and get it off of your mind by playing with your neighbors, but you still have that lead block at the pit of your stomach. I remember that day so well. Even though it was not a very happy day, it created one of the most important people and the best teacher in my life.

Autism. No one knew what it was until my little brother Max was "diagnosed" with it. Even though every day I wish that things were different, I'm so grateful for all of the things that he's taught and given me. Max is definitely one of the most important people of my life.

If you've ever been close with a

child with Autism, then you know that they are a full time job.

Even though my mom is still my hero, every once in a while she wants to throw her little kryptonite out of a window. That's when she needs me or my older brother to step in and help out. One thing that I do for Max sometimes is take him up to bed only after he has fallen asleep a flight of stairs away. I usually do this because my parents are getting a little bit old to be doing that. Even though it can be a drag sometimes to take care of Max, I love it because sometimes it makes me feel like I'm his dad and he's my responsibility.

Max has taught me many things about social issues, but the one that sticks has to do with reading people's emotions. Sometimes when Max is angry, he screams for an hour. Now that is most definitely not a good way to express anger but that's the thing with autism is that he doesn't know how. Therefore if Max is screaming, or crying, I confront him about it and say things like "What's wrong?" or "Does something hurt?" because otherwise he can't compose a sentence to say what he's upset about. This is an important lesson to me because it has become apparent to me that girls appreciate it when you ask them about how they're feeling, and they like it even better if you can just tell that something is wrong and you talk to them about it. It's a great way to make and keep friends, and it's all from my little brother.

Lastly, my brother has introduced me to some of his pals, teachers, acquaintances, and more, and the more of them I meet, the more I



Jack, Jordan, and Max

learn of their stories. For example, Max has a friend named Jack. My mom met his mom at some meeting, you know how that goes, and ever since our families have been friends. Now Jack has Down syndrome, which is somewhat like autism but there is more of a visible difference between them and a regular functioning kid. Something that I learned from him is that you have to become good at body language if you interact with someone in his case because his speech is very impaired. There have been so many times where I have had absolutely no idea what he was talking about. A lot of people would say, man that sounds like no fun at all, but he always puts a smile on my face.

Through all of the tantrums, the embarrassment, the waking up at 5 in the morning, Max has taught me so much. He's taught me how to be as responsible as a father, reading people's emotions like street signs, and he's given me the pleasure of meeting his fellow teachers (friends). If you think about your teachers and what subjects they teach, you will probably come up with math, science, English, history, and maybe a language. I can get one of those at school, but not many people have a personal teacher at their house who teaches them lessons that aren't taught from a book. I have a teacher for the lessons of life, and I wouldn't trade him for anything. ▲

NADS familyalbum



Ava Farrell



Kristi Ozelis



Brianna Archbold



Conor Cahill



Alita Eubanks



Elijah Hsu

Standardized Tests

Being Developed for Individuals with Down Syndrome

Dr. Lynn Nadel, a Regents' Professor in the Department of Psychology at the University of Arizona who has been researching the cognitive aspects of Down syndrome for 25 years, is working with a team of researchers to develop a new battery of standardized tests to assess the cognitive abilities of individuals with Down syndrome. The team hopes to isolate factors which may play a role in common problems associated with Down syndrome. They are hoping that the earlier they can provide an accurate assessment of a child's particular challenges, the earlier that child can receive appropriate educational or medical interventions (including, potentially, drug therapies).

The team is currently working on a battery of tests for 8 to 18 year-olds but plans to develop additional tests for all age ranges. The current test series has been developed over the last year and a half and will likely be completed later this year. Nadel believes that having standardized tests will be helpful to other researchers—especially to those developing new educational or drug therapies and for clinical trials which require a before and after comparison. He has also found support from some parents of children with Down syndrome, who recognize the potential for these tests to establish scientifically which interventions actually make a difference and which do not.

For more information about Dr. Nadel's research, see the press release published on the University of Arizona's website: www.uanews.org/node/23348.▲

New Postsecondary Resource

Coastal Carolina University will offer a new inclusive postsecondary program for students with intellectual disabilities beginning in the fall of 2009. The four-year program, LIFE (Learning Is For Everyone), will be sponsored by the College Transition Connection, the state of South Carolina, and the NDSS. The program will accept up to 6 students each fall. They will be offered both on and off-campus residential options and the chance to participate in classes on a college campus, with appropriate supports. Through the program, participants will be able to strengthen specific academic skills, develop independence, participate in a college community, and prepare for employment. For more information, go to: www.coastal.edu/cec/LIFEprogram.html.▲

New Publications

Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters

By Brian Skotko & Susan P. Levine
Woodbine House, 2009; \$18.95

Dr. Brian Skotko is a physician at Children's Hospital in Boston who focuses on children with intellectual disabilities. He also has a sister with Down syndrome. Susan Levine is a social worker and co-founder of Family Resource Associates, Inc. in New Jersey, and she has 30 years of experience working with families and siblings. The two have joined forces to produce this book for teenagers who have a brother or sister with Down syndrome. The book addresses more than 100 questions posed by actual teenagers and covers a variety of issues, including dealing with their sibling's behavior, sorting out their own feelings, wondering about the future, and finding resources.

Street Gang: The Complete History of Sesame Street

By Michael Davis
Viking, 2008; \$27.95

Michael Davis, a senior editor and columnist for TV Guide from 1998-2007, tells the story of how Sesame Street was created and developed over the years since it first aired in 1969. The book was written with the cooperation of one of the show's cofounder's, Joan Ganz Cooney, and it details the creative ups and downs of the show from era to era. Emily Pearl Kingsley, the author of "Welcome to Holland," is a long-time writer for Sesame Street and has pushed for greater inclusion of children with special needs in the episodes, some of which have featured her son with Down syndrome. This book provides a thorough history of what went on behind the scenes as well as in front of the cameras and allows us to witness the evolution of a legendary children's program.

Up Close: A Mother's View

By Fiona Yaron-Field
Bunker Hill, 2008; \$35

This literary and photographic memoir records Fiona Yaron-Field's life with her 13-year old daughter, Ophir. The author, who is a professional photographer and art psychotherapist, began taking pictures of her daughter at her birth, and from that point on, her camera was never far from her reach. The photographs of Ophir show her engaged in activities from different periods of her life, from playing to dressing up to running, and the pictures are accompanied by text which captures the author's thoughts and feelings about her daughter.



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