At the age of 96 and at the end of almost six decades of advocating for persons with cognitive disabilities, I find it important to share our experiences as a family still pursuing answers to the challenges of daily life for persons who share the same or similar diagnosis.

Our son Kevin was identified at birth as a person with Down syndrome—although in 1960 this diagnosis carried another name which we choose to forget. Throughout his life we have identified the need for changes in medical acceptance, mainstreamed educational opportunities, employment with support, and on and on.

As these changes have occurred, the longevity of our special sons and daughters has increased. They are outliving their parents. Surprisingly this has created new challenges. How many are able to live independently? If not, are siblings available? Or are there agency contacts? And many other questions.

Those of us who continue to believe in independent living are keenly aware that we, once again, are pioneers in our quest for new patterns of housing and daily activity for our middle-aged population who have cognitive disabilities. Our personal path still is ongoing with no absolute assurance of successfully reaching the target of “moderately” independent living, but I will share a few thoughts.

After the death of my husband John more than a decade ago,
Kevin and I continued to maintain our familiar household. Although some maintenance items were handled by our condo association, other chores were ours. The time had come to analyze future needs. After careful weighing of pros and cons, socially and financially, my decision was to select an apartment in an independent living center for seniors. Special permission was granted for Kevin although he is younger than the minimum age for residents. More important was the assurance of continuity for Kevin after my demise if “appropriate”. This is not an absolute guarantee but is comparable to the assurance for the elderly residents as well.

How independent is Kevin? His degree of independence includes his role as an excellent housekeeper and he is great with his own personal care. His only needs are cooking and transportation – both of which are met for all residents here. In addition to nutrition, breakfast and dinner sessions provide good social interaction with other residents and staff. Transportation is available on the center’s mini-bus, which is available for special field trips and for individual medical appointments or shopping needs. A convenience store and café is available within the center for miscellaneous shopping or a great sandwich for lunch. All are available to him without assistance. Currently two volunteer jobs have been made available. These provide meaningful activity for him – dining room chores and internal mail room activity – a satisfying daily life.

Age mates are available in an unusual way. At the age of 57 Kevin’s peers are the members of the administrative staff. Some are his age, some are younger. All of them have welcomed him as a friend. Hopefully this will continue. Kevin’s siblings continue to be a major part of his life although geographically scattered in locations such as Omaha, Boise, Seattle and Denver. Contact with them includes daily interaction by phone and numerous visits in person. Many such visits are related as support for medical appointments or recreational weekends. If Kevin continues to live in our senior apartment alone, these visits may become part of his support system. An additional factor may be the possibility of an apartment mate – young or old depending on which may be acceptable to the rules of the senior center. Funding is essential and we are prepared. Although opportunities have been potentially available for public assistance, we have maintained family support for Kevin. His special needs trust hopefully will safeguard his long-term care.

We have many bridges to cross but we look to the future with optimism. New challenges promote greater creativity and result in successful outcomes if courage and persistence are the order of the day. There has been for me an overriding item of comfort. My son Kevin, who is a middle-aged person with Down syndrome, has been welcomed with me into our senior center with a degree of assurance that this will be his home when I am no longer here as his housemate. What more joyous reason for our happiness here!!

Editor’s Note: Marjorie Lee was one of the founding members of NADS. Her late husband, John, was NADS’ first President.
A HUGE thank you to the Alzamora family for continuing to support NADS through their Designer Genes Fundraiser! The 9th annual event took place in April and raised over $20,000 for NADS. Some of the proceeds will go towards a special party for all of our adult PAC group self-advocates, as appreciation for all of their hard work and dedication in the programs and services they assist with throughout the year (including all NADS events, speaking engagements, fundraising, service projects, and more). Some funds will also go to support the upcoming conference in August. We are so grateful to Sarah and Mike Alzamora, pictured above with board member Don Hubert and NADS staff members Linda Smarto, Deb Kracik and Chris Newlon.

Thank you to PAC Member Ali Barr and her mom Lari for representing NADS at the Palatine High School Resource Fair this spring.
I Still Wish You Did Not Have Down Syndrome

By Randi Gillespie

A few years back, I penned an article about my youngest child, Liam (then 7) and his older sister, Maddy (then 10) that ran in the Chicago Tribune Perspective Section. The heart of the article was that Maddy had Down syndrome and her younger brother, Liam, was angry that she had Down syndrome. He made it perfectly clear one morning by revealing to her, “I wish you did not have Down syndrome.” I chronicled the relationship between the two and the events which led up to Liam’s honest yet painful words. I wrote that I expected that their relationship would evolve over time and that growing up with a sister who had a disability would not only positively shape him in ways that he could not imagine but the benefits of their sibling relationship would enable him to examine and interpret the world differently. His eyes would see things in ways that others do not have a sibling with a disability cannot. He would remind people that his sister has the right to be valued, respected and accepted—just like anyone else. Simply put... he would develop into a more caring and compassionate young man because he had a sister with Down syndrome.

Fast forward 3 years. Guess what? Their sibling relationship has never been better. They are thick as thieves and remain each other’s confidants. They share intimate secrets with one another that only loving and devoted siblings share. They never argue, they never provoke one another with name calling and that whole, “I wish my sister did not have Down syndrome” is no longer an issue.

This is so not true.

Three years later, Maddy still has Down syndrome (no surprise) and Liam is still trying to figure out his feelings surrounding their brother-sister relationship. There are days he confesses he “does not love her” and days when he tells me that he “does not like her.” To be fair, Maddy has expressed similar sentiments toward Liam. I will go out on a limb here and speculate that most siblings at some point have similar attitudes toward their brothers and sisters, whether a disability exists or not.

Surprisingly, their relationship is not an adversarial one. Liam does show affection, tenderness, and joy towards Maddy. He just does not love that she has Down syndrome. He does not love all the “stuff” that comes with her condition. Although my heart aches to hear him admit how he feels, I cannot fault him for having the good sense to express himself and to talk openly about his feelings. Although their relationship continues to parallel that of an emotional pendulum, his ability to remain open in discussing what he is not getting from Maddy and the challenges that come with having her as a sister continue to amaze me. I admire his candor.

Throughout the years, there have been many rays of sunshine between them. They play together. They have real conversations with one another. They unite and come together when it suits both of their needs. They jump on the trampoline together without any yelling, screaming, or tears. Liam will tell Maddy to “hop on” his electric scooter to give her a ride to the neighborhood playground. Liam will read Maddy her favorite book, Pinkalicious, to her at bedtime while reminding her to stay out of his room and to “never, ever go into my room and touch my stuff...or else.” They shoot each other with nerf guns, they have pillow fights and they argue over which inappropriate TV show to watch. Despite below freezing temperatures coupled with snow and wind in their faces, they enjoy sledding down the largest sled hills together while laughing and giggling on their way down.

When I am preoccupied and pretending not to have eyes in the back of my head (like all moms do), I am able to see and hear the best versions of their sibling bond. I see Liam sneak Maddy an additional piece of chocolate during the day or slide her an additional slice of pizza during dinner, while whispering, “don’t tell Mom.” I overhear him teaching her addition and subtraction and I hear them playing Connect Four and UNO. He performs these small acts of kindness because he knows it will make Maddy happy. It was only recently I recognized I no longer felt the need to step in and engineer their sibling relationship. I have come to the realization that if Liam truly did not enjoy being Maddy’s brother, he would not go out of his way to make her happy.

I have watched Liam mature over the years. He has grown to accept everything that makes Maddy who she is. Creating meaningful moments between the two of them requires fortitude, resolve and a lot of patience. It also requires friendship and devotion. Fortunately, Liam embraces those qualities and is fulfilled by...
Thank you to all of the PAC members who came out in April to pack meals at Feed My Starving Children. The adults packed 42,768 meals, which will feed 117 children for a year. Great job!

BUSINESS SPOTLIGHT:

We Grow Dreams

We Grow Dreams is a year-round, not-for-profit greenhouse and garden center, providing job training for individuals with disabilities. We Grow Dreams supplies a variety of annual and perennial plants, vegetables, and herbs, available for retail and wholesale purchase. They also have a gift shop where craft products made by staff are sold. Their mission is to provide people with disabilities the opportunity to lead fulfilling lives and to train and work in a supportive, safe and caring environment while producing and providing products and services to the community. You can learn more at www.wegrowdreams.org or visit the greenhouse and garden center at 1055 W. Washington St., West Chicago, IL.

FREE Parent Advocacy Training for Legislative Change

Family Resource Center on Disabilities (FRCD) and the University of Illinois at Urbana-Champaign are offering a free training to parents and family members of children with disabilities. The purpose of this program is to educate and empower parents of children with disabilities about legislative advocacy. The training will enable you to:

- Participate in the legislative process to change special education policy.
- Become more comfortable speaking to legislators and sharing concerns.
- Develop an understanding of special education policy and practice.

Participation in this training will build advocacy skills and provide important feedback that can help guide, expand, and strengthen special education policy. To learn more and register, go to https://www.surveymonkey.com/r/DisabilityAdvocacy by August 20, 2018. If you have questions or want to complete the survey over the phone or via hard copy, please contact: Meghan Burke at meghanbm@illinois.edu or 217-300-1226.
Profile of: Jimmy Keen
If You Build It They Will Excel: Positive Work Environment Enables Jimmy Keen to Succeed Beyond Expectations
By: John Huthmacher, The Hastings Tribune, Hastings, Nebraska

When it comes to demonstrating what a supportive work environment can mean in the life of someone diagnosed with Down syndrome, Jimmy Keen has become a walking billboard of advocacy on campus at Hastings College.

Keen, 21, is part of the Fresh Ideas Food Service team that serves meals to students and staff each day in the cafeteria dining area located inside the Hazelrigg Student Union. It is his responsibility to keep the eating area spotless and attractive for those who partake of food and beverages there. From scrubbing down tables and sweeping floors to keeping the salt and pepper shakers aligned in proper order, his position keeps him hopping during his 10-2 shift Monday through Friday.

It is one of two jobs Keen works during the year; the other is a summer position at Hastings Aquacourt Water Park. Both positions enable him to keep busy while earning a paycheck in environments that are inclusive and enjoyable.

His transition from student to employee has been nothing short of amazing since joining the Fresh Ideas team in August. After completing alternative assessment courses at Hastings Senior High School, he continued to explore potential employment opportunities through Project Search, a component of the district’s 18-21 training program. Told he probably would never be able to transition into a gainful employment situation based on assessment test results, he has — with the help of Shirley Ginn, state vocational rehab job coach, and his mother, Connie Gendville-Keen — risen above expectations to become a productive and much-valued asset in the workplace.

“This is the best setting in the world for Jimmy to work in,” Ginn said of the Fresh Ideas program. “They’ve welcomed him with open arms. I’m hoping to be able to transition out of his life after the first of the year. He knows the routine and is doing a splendid job.”

Exceeding expectations is nothing new to Keen, who is the youngest of six children, five of them girls. Having earned a black belt at South Central Taekwondo, he is also a competent pianist after 10 years of practicing at least 15-20 minutes per day most days.

“He’s been fortunate enough to have never met anyone less than supportive and enthusiastic in aiding him,” Gendville-Keen said. “The past 21 years have been filled with medical personnel, therapists, teachers, social workers and employers that have all had an important role in making his life full and happy. “When Jimmy was diagnosed with Down syndrome at just a few weeks old, his sisters joyfully announced it to the world as if they’d won the lottery. A nurse at Mary Lanning Memorial Hospital (where he was born) said to me, ‘I think your son is just perfect. Let’s just look at him.’ So began his life, with those words engraved on my heart.”

You can read the full article from the September 30, 2017 Hastings Tribune at goo.gl/6HQ8NY. This portion was reprinted with permission.

DOCTOR’S CORNER

By Erin B. Dominiak, M.D. Adult Down Syndrome Center, Director of Medical Education

Summer is here! I have some quick reminders for staying healthy in the sun and heat. People with Down syndrome tend to sweat less and have problems regulating body temperature, so they are more prone to overheat and potentially pass out. Also, many people with Down syndrome do not have as much thirst drive and may need reminders to drink more fluids. So, it is important to find ways to stay cool like staying in the shade when possible, cool water mists, and wearing light but protective clothing. A good moisturizing sunscreen should be used for sun exposure. I recommend a fun water bottle and tracking fluids closely. Water is best, but many people prefer some flavor so you can add in a non-calorie mix-in like Crystal Light. Enjoy being outside and be safe!
Welcome to the 2018-19 Board of Directors

Officers

KATIE WOOD – PRESIDENT
Katie is a financial consultant and has been involved with NADS for the past six years. This will be her fifth term on the Board and her second term as President, with all preceding terms served as Treasurer. When Katie is not working she enjoys traveling with her husband, Dan, and preparing for the newest addition to their family this August.

LUCAS STAIB – VICE PRESIDENT
Lucas is an architectural and graphic designer and has been on the NADS board for three years. He is currently Vice President and Chair of the Communications Committee. Lucas’ cousin, Avery, has Down syndrome. When Lucas is not working at Moment Design or helping with NADS, he enjoys spending time with his wife, Deidra, and his baby girl, Charleigh.

BRIDGET BROWN - 2ND VICE PRESIDENT
Bridget is a 32-year-old woman with Down syndrome and has lots of accomplishments. She is a national public speaker, as well as a person-centered planning coach who works with young adults with disabilities to help them find their own voice. Bridget is a strong self-advocate who believes in dignity of all self-advocates. She works with Linda Smarto with the PAC members and self-advocates to teach leadership skills.

DON HUBERT – TREASURER
Don owns a shipping business in Chicago with his brother and has been on the NADS board for one year. Don and his wife Jessica have 3 girls, Natalie (5), Samantha (4), and Lil (3). His oldest, Natalie, has Down syndrome. When Don is not working or helping with NADS he enjoys spending time with his wife and children. He also sneaks in some rounds of golf when he can.

PEGGY DELANEY – SECRETARY
Peggy has been involved with NADS for the past 10 years since the birth of her son, Jack, who has Down syndrome. She joined the board as the Executive Secretary in November 2017 and is Chairperson for the 2018 Creating Lifelong Learners Conference this August. Currently Peggy works in the Downers Grove school district supporting the Preschool RISE Program (Reaching Independence through Special Education).

Directors

RYAN BURKE
Ryan is a young man with Down syndrome who is new to the board this year. Ryan is a graduate of the Burke Scholar program at Notre Dame High School. He recently graduated from the ELSA program at Elmhurst College and currently works at Notre Dame High School during the school year. He is involved in Special Olympics for powerlifting and bowling, and he enjoys weightlifting, exercising, and swimming. Ryan especially enjoys Broadway plays. Ryan adds that he is “a best buddies member and the English teacher of the Burke family.”

KATIE FRANK
Katie is an occupational therapist at the Adult Down Syndrome Center and has been on the NADS board since early 2018. Katie’s younger sister, Tori, was born with Down syndrome. Outside of work, Katie likes to exercise, travel, and explore the new restaurants in downtown Chicago.

JEN HORA
Jen has been a first grade and special education teacher for 22 years in Huntley and has been involved with various aspects of NADS since her son Brogan was born with Down syndrome in 2004. This is her first year on the board. Jen is also the new chair of the NADS Fashion Show. When not teaching, she enjoys reading, spending time with her husband, Brian, and two sons, Brogan and Gavin, up at their cabin in Wisconsin. She also enjoys being involved in all of her boys’ extracurricular activities such as travel hockey, NISRA programs, and school sports.

ERIN KOMACKI
Erin has been an educator for the past 14 years. This will be her first term on the board. She volunteered as a NADS parent support volunteer for three years and then transitioned into volunteering for the Welcome Basket Program. Erin and her husband, Paul, have two children, Sarah Kate (7) and Hope (4). Hope

Continued on page 11
Establishing an Independent Special Olympics Athletic Team

By Lisa Benco

I can honestly say that “Athletic Director” was never one of the titles I ever envisioned for myself. It is, however, the role I assumed in order to provide my daughter, Abby, and her friends with a wonderful Special Olympics Rhythmic Gymnastics opportunity.

Abby has been a Special Olympics rhythmic gymnast for over four years. When scheduling conflicts forced us to leave the initial team we knew and loved, I was not confident we could find a suitable replacement in close proximity to home that could accommodate our hectic schedule. There were other established special rec programs (special recreation association programs affiliated with local park districts), but we were interested in keeping a core group of teammates together, and not everyone lived in the same town. Special rec residency requirements would have forced us to split up a team of girls that had bonded as athletes and friends.

Consequently, we considered the option of an “independent” Special Olympics team. Did you know that you can establish an independent Special Olympics athletic team for any sanctioned Special Olympics sport? This was uncharted territory for me, but with a little research and lots of generous assistance from a long-time Special Olympics volunteer, we made it happen.

Abby’s Buddy Baseball coach, Deb Guenther, is a tireless volunteer for the Special Olympics organization. She volunteered as a judge at the District Gymnastics Games in Palatine and as a floor coordinator at the 2017 Summer Games. She was the perfect candidate to approach about the possibility of coaching her own team. Without hesitation, she responded with an enthusiastic “Yes!”.

A big step in forming an independent team was complete - we had a volunteer coach! Now, we needed a location to practice. Unfortunately, this was tougher than procuring a coach. Finding an available gym that was conveniently located for athletes as far east as Oak Park, north in Elmhurst, and the Westmont/Downers Grove/Woodridge area was challenging. After much back and forth and re-arranging of schedules, we were fortunate to land gym space at the Butterfield Park District in Lombard. The gym is a perfect space for us: we have it all to ourselves with no distractions from other groups, which is important for our special needs athletes.

After we had gym space and definite practice times reserved, it was time to get the word out and let other athletes know about our newly formed team. After reaching out to families via e-mail, creating a Facebook group page and posting flyers, we happily added two new members. Five members followed from our prior location for a manageable seven-member team, spread across two practice sessions/week.

One of the more creative aspects of this process was naming our team. We initially brainstormed options starting with “R” for rhythmic, such as Rebels, Rainbows, and Rosebuds. We loved the concept and beauty of the butterfly and its meaning of transformation/transition. Since “Rhythmic Butterflies” seemed a little too generic, we thought about specific types of butterflies. After some Google internet research, we found that “blue” monarchs are rare and unique. Hence, our team name “Blue Monarchs” was born. Coach Deb designed an awesome logo with flowing, ribbon-like font that represents the most popular rhythmic event - ribbon. It was a nice touch to have welcome certificates and a “theme” to present to the girls on their first practice day with their new team.

As SOAD (Special Olympics Athletic Director) of this team, I am responsible for scheduling the practices at the gym, managing the financials, meeting Special Olympics competition entry paperwork deadlines, and coordinating the equipment and accessories required. The most challenging aspect so far: COSTUMES!

The Blue Monarchs’ first season is soon coming to a close. Two of our athletes will compete in the 2018 Summer Games. I reflect on all we have accomplished in our first year and am proud of what we have built.

If you see a need for a Special Olympics program that is not offered in your area or have unique scheduling demands that require some flexibility, consider the possibility of forming your own team. Class A training for Special Olympics volunteers is available online and you are required to attend a Coaches’ meeting once a year. Each team needs a coach and a SOAD. It is a very rewarding experience!
Creating Opportunities

Lisa Benco wrote in her Recreation Spotlight article that she created a Special Olympics team in order to provide the best opportunity for her daughter and her teammates. Sometimes, as parents of children with special needs, we may find that it is necessary to look beyond the programs and resources that are available to us and actually create the opportunities we want to see for our kids.

In the May 2018 issue of NADSNews, I wrote about Lily’s summer plans. I mentioned that she will be working for the first time as a clerk at our local pool. I stated that “I made it clear that I didn’t expect her to be a paid employee, but she will be assigned shifts and expected to do the same job as everyone else.”

I should have included that Lily is only 15 years old as of May 26, and she does not yet have the skills necessary to complete the required responsibilities of the position. The clerk jobs at our pool are highly sought after, with over 50 applicants for 12 positions. I did not mean to imply that individuals with Down syndrome should not be employed and paid just like their typical peers. I meant to explain that for this summer, Lily is volunteering as a sort of ‘intern’ so that she can get the necessary experience and learn the job skills, which will hopefully lead to paid employment opportunities in the future. Lily is also volunteering as an usher at the local children’s theater this summer. Both are places where everyone knows her and she feels comfortable. Hopefully with this exposure to the jobs and the opportunity to become fully independent to complete the required tasks, these can become future places of employment for her.

As Lily gets older, I keep looking a few years into the future and envisioning what I want for her. Just like Jimmy Keen, who is featured in this issue’s Adult Profile, I want Lily to work as an adult in a job that she enjoys, in an environment where she is accepted and supported. I hope that by creating opportunities for her now, we are giving her the chance to try different types of jobs at different places that will eventually lead to even more opportunities. I know that as Lily continues in school (I still can’t believe she’ll be a sophomore next fall!), she will have the opportunity to explore different jobs in the community. However, those opportunities won’t really start for another year or two. Rather than wait for her to be introduced to new jobs through school, we are looking carefully at her existing relationships in the community to create as many opportunities for her as possible right now.

So, whether it’s becoming a Special Olympics Athletic Director, finding new volunteer opportunities that may someday lead to employment, or countless other efforts, we never stop looking for ways to help our kids and create valuable experiences for them.

**OT TIPS**

By Katie Frank, PhD, OTR/L, Registered Occupational Therapist at the Adult Down Syndrome Center

Sensory processing is a topic that comes up a lot at the Adult Down Syndrome Center. We all have sensory processing issues, but most of us are able to regulate our bodies or avoid input that we don’t like. For instance, eating an orange feels like fireworks going off in my mouth so I choose to avoid oranges and no one is the wiser to my sensory needs! We actually have eight sensory systems. Did you know that? Most people are aware of the senses of sight, taste, hearing, smell, and touch. These are considered the FAR sensory systems. We actually have three NEAR sensory systems that include vestibular (balance), proprioception (body awareness and input into our muscles and joints) and interoception (awareness of pain, hunger, thirst, and bowel and bladder functions). When there are difficulties with our NEAR sensory systems, it can impact our FAR sensory systems. The NEAR systems require activities (often involving therapy) in order to treat while the FAR sensory systems can be addressed by providing accommodations. For instance, if a person has deficits with their proprioception, we want to incorporate heavy work activities that encourage them to use their muscles and joints more to increase their body awareness. If that same person doesn’t like to be in gymnasiums during basketball games because of the loud noises (whistle, buzzer, fans, etc.), we can make an accommodation by encouraging them to use sound reducing headphones. Often times school therapists are able to help with making accommodations for sensory needs (i.e. the FAR sensory systems), but don’t have the time or resources to address the NEAR sensory systems. Therefore, if you believe your loved one with Down syndrome has sensory needs that aren’t being addressed by your school therapists, I encourage you to seek out the assistance of a private outpatient therapist to address this specific need.
2018 Bowl-a-Thon & Family Fun Day

Thank you to all of our bowlers at this year’s new Bowl-a-Thon & Family Fun Day! We would especially like to recognize the individual bowlers and teams who raised the most money:

**INDIVIDUALS**
- Chris Hebein: $6643
- Julia Smarto: $3740
- Kristin Malkowski: $1075

**TEAMS**
- Jacob’s Crew: $2984
- Spiewak Spares: $1550
- Irish Bowlers: $1015
Making Sense of Government Benefits
By Mary Anne Ehler

If you’re a parent of a child with special needs, or a caregiver of an adult with a disability, government benefits and legal options are often confusing. Here is a brief explanation of government benefits that in the future your loved one may or may not be eligible for, but you may want to investigate:

- **SSI – Supplemental Security Income:** A Federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind and disabled who have little or no income. It currently provides a maximum of $750 per month to be used for basic needs such as food, clothing and shelter. It is generally for people who have little or no work history.

- **SSDI – Social Security Disability Insurance:** Social Security Disability Insurance is a federal cash benefit that may be available if a person has a disability. It pays benefits to the individual and certain members of the individual’s family if you are “insured,” meaning that you worked long enough and paid Social Security taxes.

- **Medicare:** A federal health insurance program for people 65 years of age or older, individuals receiving SSDI will be automatically enrolled two years after receiving SSDI payments, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.

- **Medicaid:** This program provides medical assistance for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are actually established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs.

It is important to evaluate your loved one’s entire picture and take a few more things into consideration:

- Although you may be dealing with a child at this time, what do you see for him/her in the future? Supported employment? Part time employment? Residential living?
- In the case of planning for a child with special needs, does your existing health insurance remain in effect when your child turns 21 and is no longer a full-time student?
- What assets are presently in his/her name? Example: savings bonds, life insurance, stocks, mutual funds, homes, etc.
- Is there a possibility of inheriting any money or assets?

Once you’ve answered these questions, you can then look at what benefits he/she may be eligible to receive and how to best position his/her assets and income. These issues are often confusing. The important thing is to be patient and do your homework so that you are better prepared for the future.

Mary Anne Ehler is the founder and President of Protected Tomorrows®, an advocacy company that provides comprehensive life planning that addresses the educational, residential, financial, legal, health care, government benefits, employment, ABLE Act and recreational needs of individuals with special needs. Mary Anne will be speaking on all these subjects plus more at the NADS conference on August 11th. For more information on Protected Tomorrows® visit www.protectedtomorrows.com.

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Get More Doctor’s Tips and Information

Did you know that Dr. Brian Skotko, Board-certified medical geneticist and Director of the Down Syndrome Program at Massachusetts General Hospital, has started an email newsletter? You can sign up to receive helpful Down syndrome-related information and tips at his website – www.brianskotko.com. Past topics have included the importance of fiber, how to prevent #metoo, and vitamin supplements. Past newsletters can be viewed at http://brianskotko.com/publications/.
www.nads.org

Register at

1460 Renaissance Drive, Suite 405
Park Ridge, IL 60068

www.nads.org

Remember to register for the
NADS 2018 Conference –
Creating Lifelong Learners!

NEW LOCATION!

Saturday, August 11, 2018
St. Ignatius College Prep
1076 West Roosevelt Road
Chicago, IL 60608

Register at

www.nads.org