“TO THE MOON”
By Bret Bowerman, Larchmont, NY

“You’ve probably seen them bagging groceries,” said the geneticist attempting to explain to my wife and me that our one-day old daughter, Ellie, had Down syndrome and what that meant for her future. Her age was measured only in hours and already, expectations for Ellie’s potential had been capped.

Just hours earlier we were sitting in a recovery room holding Ellie, hosting visitors, emailing pictures along with requisite weight and length statistics and basking in the afterglow of a seamless delivery and the addition of a beautiful, healthy daughter. Then visiting hours ended, our guests were ushered away and Ellie was carted off to the “well baby” nursery for a routine examination by an attending pediatrician. We exhaled and exchanged a silent smile. A brief window of unmitigated joy.

I recall our debate over which take-out food to order for dinner because “hospital cafeteria food would just not do justice to the occasion.” The trivial nature of that conversation underscores our blissful ignorance to the commotion that surrounded our daughter in a brightly lit exam room down the hall. We did not know our calm would soon break.

As we would learn, Ellie had been relocated to the hospital’s neonatal intensive care unit (NICU) because of a heart condition suspected by the pediatrician. Her prognosis was encouraging but her immediate condition was tenuous, needing supplemental oxygen and medication to help her heart and lungs work properly. And,

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Call for Nominations to NDSC Board

The National Down Syndrome Congress is looking for people who have an interest in serving the Down syndrome community as a member of the NDSC Board of Directors. Board members have the opportunity to shape policy, lead initiatives and make a difference through rewarding work as a team.

Board members are elected at the NDSC’s annual meeting, which will be Saturday, July 12, 2014, during the NDSC Convention in Indianapolis, Indiana.

Any NDSC member in good standing is eligible for nomination to the Board of Directors. Self-nominations are welcomed as well as nominations by third parties. The Nominating Committee is chaired by Immediate Past President F. Brooks Robinson, Jr. with representation from the general membership. Members can express interest in learning more about board service without making a commitment to complete and submit an application for this year, by sending an email to info@ndsccenter.org.

The NDSC seeks wide representation in its board membership and considers factors such as areas of expertise, prior experience on not-for-profit boards, geographical representation, age of person or family member with DS, parent/professional status and ethnic representation. The Nominating Committee is particularly interested in adding persons of color to the board, as well as those with backgrounds in accounting, finance, higher education, fundraising and conference program planning.

A Nominee Information Form as well as a description of the board selection process is available on the NDSC website, ndsccenter.org, or by calling the Center at 1-800-232-6372. To submit a name for the Nominating Committee to consider, please send a completed form by mail, fax or email to: F. Brooks Robinson, Jr., NDSC Center, 30 Mansell Court, Suite 108, Roswell, GA 30076; 1-770-604-9898; or info@ndsccenter.org.

Deadline for nominations is Friday, May 16, 2014.
we were told, a geneticist would visit us to discuss an additional diagnosis.

That “additional diagnosis” was hardly the afterthought it sounded at the time. Down syndrome, also known as Trisomy 21, is a chromosomal condition caused by the presence of a third copy of the 21st chromosome. Down syndrome is the most common chromosome abnormality, affecting more than 250,000 Americans, and is associated with delayed cognitive ability and physical growth.

For three weeks, NICU angels cared for Ellie while my wife and I relied on a chorus of beeping monitors and exhaustion to dull the potent cocktail of shock, grief and fear that we struggled to stomach. And it would be dishonest if I didn’t admit to secretly hoping that it was all just a bad dream. But instead of awaking to relief, each morning was greeted with a pounding hangover of guilt for wishing that Ellie was any different than the miracle she was destined to be.

We coped with the stress of her heart complication and began to accept the challenges associated with Down syndrome that lay ahead. But the visual painted by the geneticist of Ellie as an adult, wearing a name tag and struggling to load a milk carton into a grocery bag, was etched in our minds. That description of Ellie’s diminished outlook, delivered as a foregone conclusion, was difficult to accept. Her promise, stolen. It was an injustice that took time to fully appreciate and gnaws at me even today.

Soon, Ellie’s doctors said she was ready to head home. And Ellie’s 15 month old brother was ready to play with his little sister. If only my wife and I were as ready to face our new reality. Those once seemingly daunting tasks of learning how to change a messy diaper or install a car seat took a back-seat to the new challenge of learning how to change an oxygen tank and install a feeding tube.

Fortunately, those skills were fleeting as Ellie’s heart fully recovered ahead of expectations. On her three-month birthday, she no longer needed oxygen so we untethered her from the tank and shed it like the Space Shuttle releasing an empty fuel tank after launch. Free from life’s initial gravity, Ellie was on her way.

Ellie has tackled life head on, making friends and enjoying childhood while enduring endless hours of physical, occupational and speech therapies to track milestones that come naturally for her older brother. To borrow a sports analogy, Ellie has braved “two-a-days” her entire life, showing up every day, on time and ready to play. Never have I been more proud than witnessing Ellie walk for the first time. Knees wobbly and body trembling, she gave the Heisman to the outstretched arms reaching to support her while shooting a look that signaled, “I’ve got this.”

In the nearly five years since Ellie’s birth, we’ve experienced vast misunderstandings about the potential for individuals with Down syndrome. Too often, people look at Ellie and see ‘Disability.’ They see ‘Can’t.’ Even highly educated clinicians are not immune to misconception, electing to chart her against diminished benchmarks of success and suggest that Ellie should

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settle for less because “that’s just the way most kids with ‘Downs’ are.”

And yet, we’ve met adults with Down syndrome who can check the box on being a successful student, accomplished athlete, productive employee, prom king or queen, or husband or wife. And while scientific breakthroughs and novel therapies should further advance the potential of Ellie’s generation in the long-term, her daily accomplishments demand that we discount her disadvantages now. They demand that we focus on her abilities and expect more from her.

The contradiction between Ellie’s accomplishments and the geneticist’s misguided projection has shaped how we parent all three of our children (Ellie now also has a younger brother). We believe that children, whether they have Down syndrome or not, tend to perform to the level of expectations placed upon them. Expectations are often misconstrued as setting a floor on performance. Rather, expectations typically serve as a ceiling, so we’ve learned the trick is to set high expectations balanced with reassurances that it is okay to fail. And the only true failure is not testing the boundaries of our capabilities, wherever that may be.

From early on, we’ve educated Ellie’s brothers about Down syndrome and what that means for her—“Ellie can do everything you can do; it just may take her longer or require extra help; but she’ll get there eventually.” Her older brother, then 3, retorted, “Can she go to the Moon?” “Yes,” we responded. “Maybe someday she can go to the Moon.”

We’ve tried to instill in our children a belief that “if you put your mind to something, try your hardest, and never give up, then you can do almost anything.” And we hope that message and our belief in them will one day translate to an inalienable belief in themselves.

Of course, it’s important to recognize challenges and provide resources to address them. It’s true, Ellie needs support—and lots of it. But, too often, people focus on her disadvantages and lose sight of her strengths. Even school administrators try to classify her, listing her deficits, setting expectations low and building a case to separate her from her typically developing peers despite numerous studies that would suggest including her with her peers is mutually beneficial. But pigeonholing her is the path of least resistance. Low expectations are, after all, the easiest to meet.

The people closest to Ellie know the truth. They know that she braves hours of therapies every day, that she’s worth the extra effort and capable of much more than what most expect of her. That they shouldn’t be fooled by her infectious smile, capable of lighting up a room, because behind that cute façade is a fiercely determined girl. Ellie proves that every Saturday during her rock climbing class. Sure, she is intimidated by the 30 foot walls, struggles with the climb and rarely makes it all the way to the top. But after a brief break, she’ll look at me and say, “Again, Daddy.”

And, perhaps, equally important, the people closest to Ellie also know she is just like most of the four year old girls in her pre-school class. She is a princess at heart, loves to host play-dates and go swimming at the pool. She enjoys playing catch with her brothers but occasionally catches flak for teasing them. She’s more alike than different.
Recently, we asked Ellie’s older brother, “Do you remember what it means for Ellie to have Down syndrome?” “Yes,” he answered, “It means she can go to the Moon. But it’s not fair, why does Ellie get the extra chromosome?” referring to her 47th chromosome. Priceless. If only our society could look through that same lens of ‘advantage,’ and focus on abilities rather than disabilities.

A prenatal screen pegged the odds of Ellie having Down syndrome at less than one in 3,000, so we like to think Ellie has defied expectations from the very beginning. And we trust she will continue to do so from here on out. Though, we hope one day, she won’t have to. We hope one day our expectations of her, as a society, are more limitless than they are limited.

Ellie has taught us many lessons about parental love, but perhaps the most important of which is not letting societal expectations dictate all that a child can be. October is Down syndrome awareness month—let’s use this month to leverage that lesson by together, recalibrating expectations. Let’s recognize the disadvantage, but not overcompensate for it by setting the bar too low. Let’s, for this month and all that follow after, see the ‘Can’ in those children affected by Down syndrome, not the ‘Can’t.’ In fact, let’s do that for all our children—extra “chrome” or not.

And, as for Ellie, she’ll see you on the Moon…

An edited version of this article first appeared on CNN.com. Bret Bowerman is Ellie’s dad, and serves on the Board of Directors of the National Down Syndrome Congress. You can find more information about serving as a director of the NDSC with amazing people like Bret on page 2.
Children, adolescents and adults with Down syndrome have a lot to tell us. But, many times, we cannot understand what they are saying. Speech intelligibility is the term used to describe whether a person’s speech is understandable to a listener. Intelligibility sounds like an objective scientific term, but it is not. It is a subjective judgment made by a listener which can be affected by many factors. Not only is the speaker and his speech an important factor, but so are the familiarity of the listener, the type of message being communicated and factors in the environment such as noise. That’s why mom, dad, and siblings can understand someone better than someone meeting the person for the first time. That’s why an adult with Down syndrome may be understandable saying “hi” and “what’s up?”, but less understandable when he is trying to tell you about something that happened at school or work.

Intelligibility is not static; it can vary greatly from one situation to another. It is frustrating for a child when we cannot understand what she is trying to tell us. It is also frustrating for parents, families, teachers, and friends to try to guess what the person is saying, to pretend that they understand, nod their heads and respond, when they are not really sure that they got the message right.

Up until the mid-1990’s, speech intelligibility difficulties in people with Down syndrome were rarely discussed in the research literature. Although parents saw evidence of the difficulties every day, it was hard to find services for speech intelligibility because it was not documented as a problem. In 1994, using a survey of families, I was able to document that speech intelligibility was a major problem for individuals with Down syndrome. Over 95% of the almost 1000 families responding reported that their children had difficulty being understood by people outside of their immediate circle sometimes or frequently. (58.2% of parents reported that their children frequently had difficulty being understood and 37.1% reported that their children sometimes had difficulty being understood.) So we have documentation that speech intelligibility is a widespread problem in children with Down syndrome. But, does that help us know what to do to improve intelligibility?

“Speech intelligibility difficulty” is a global diagnosis. Using the label of “speech intelligibility difficulties” gives us no information on what to do to help the child. There is no one speech pattern typical of all children with Down syndrome. For one child, a soft voice and many articulation errors may make their speech difficult to understand. Another child may speak very rapidly and stutter and leave off the final sounds in words. Still another child may produce sounds inconsistently; sometimes he can say /b/ and /f/ and other times, he can’t. He may also leave out syllables and reverse
sounds (for example, “efelant” for “elephant”). The specific speech difficulties affecting intelligibility of speech must be individually evaluated and treated for each person.

How can SLPs help an individual child with speech intelligibility? We need to have a framework/checklist to evaluate each of the factors that might affect speech intelligibility and then determine which ones are affecting speech in that individual child. A comprehensive treatment plan can then be designed by the SLP to target the specific difficulties encountered by the individual. The treatment plan for intelligibility could involve other specialists in addition to SLPs. For example, hearing loss would be tested by an audiologist (hearing specialist). Sensory processing or sensory integration difficulties can be treated by physicians and occupational therapists (OT). Speech is an output system, but it is based on hearing, vision and other sensory input systems. So, the input systems need to be functioning well for the person to be able to speak. Parents have reported wonderful treatment sessions in which the SLP and OT collaborate.

The most important first step in planning treatment is to obtain a comprehensive evaluation of the factors affecting intelligibility in the child. For example, if the child had difficulty with the /s/ sound, articulation therapy would focus on the /s/ sound. If low muscle tone was a factor, therapy would focus on strengthening the muscle tone in the face, lips, and cheeks through practice with whistles, blowing bubbles and lip and tongue exercises. If the child did not look at the speaker’s face, therapy would focus on eye contact. If staying on the topic was a problem, language therapy would focus on topic maintenance. There is no specific treatment plan recommended for intelligibility treatment. Rather, the treatment plan should include objectives to address each factor that is impacting on intelligibility of speech for that child, and benchmarks to measure progress for each factor affecting that child’s speech. A formal test that may be used is the Children’s Speech Intelligibility Measure. Usually, the evaluation is informal and samples all of the factors that may be influencing the person’s speech intelligibility.

WHAT ARE THE FACTORS THAT SHOULD BE EVALUATED?

Anatomical and Physiological Factors

The SLP will observe and examine the structures that affect speech production. The diagnostic evaluation will include an analysis of the structure and functional movement of the lips, tongue, teeth, upper and lower jaw, hard and soft palate, larynx related to voice, and breath control. The SLP may also ask you about related oral issues including difficulties with feeding and swallowing, drooling, teeth grinding, tics or tremors or other involuntary facial movements.

The SLP will also examine the movement of the articulators (physiology) and the strength and range of motion of the muscles. She will ask your child to imitate or to follow instructions to make certain movements so that she can make specific observations, e.g. throwing a kiss, smiling, moving the tongue from side to side. When the SLP finds anatomical and/or physiological difficulties, she will evaluate further to determine whether those difficulties are related to oral motor issues and/or childhood apraxia of speech issues.
Neurofunctional Level
In my experience, many children with Down syndrome exhibit symptoms of oral motor problems (dysarthria), some exhibit symptoms of childhood apraxia of speech, and some exhibit symptoms of both. In a survey of over 1620 families of children with Down syndrome that I conducted, results indicated that 61 percent of parents had been given a diagnosis of oral motor difficulties in their children. When survey responses on speech characteristics of the children were analyzed, a higher percentage of children showed characteristics of oral motor difficulties. Results of the survey indicated that just 15 percent of children had been given a diagnosis of apraxia. When responses to specific questions on the survey were tabulated, it became clear that more children show signs and symptoms of apraxia characteristics, who have not been given that diagnosis. There is no doubt that, when present, both oral motor difficulties and apraxia affect speech intelligibility.

Neuromotor Component/Oral Motor Skills
When a child has difficulty with oral motor skills, also known as dysarthria, he usually has difficulties with chewing and swallowing in addition to trouble articulating speech sounds. Children who have dysarthria are very consistent in the types of speech problems they have and the speech errors that they make.

An oral motor evaluation looks at the anatomical and physiological functions of speech, as described above. Usually, checklists and informal testing are used. A formal test that may be used to evaluate both oral motor and childhood apraxia difficulties is the Verbal Motor Production Assessment (VMPAC).

Oral motor therapy
Activities, exercises, and games that help children learn to move the muscles for speech are used in therapy. Activities such as blowing bubbles, blowing horns and whistles are used to help children develop awareness of the mouth and the speech articulators, and to learn movements that are needed for speech sounds, e.g. rounding the lips and closing the lips. Movements with sounds such as smacking the lips or making popping and clicking sounds may be used. Work on jaw stabilization may use bite blocks. Different kinds of activities such as icing, massage, vibration, and mirror work may be used. Non-speech tasks should be phased out as the focus of therapy as soon as the child is able to make speech sounds.

HOME ACTIVITIES: WHAT CAN YOU DO AT HOME?
If you are working with an SLP, ask them to suggest home activities that reinforce what your child is learning in therapy sessions. Here are some suggestions.

1. Look in a mirror together with your child and have fun moving your lips and tongue.
   - round your lips
   - blow kisses
   - smack your lips
   - smile and then pucker
   - say /oo/ as in “soup” and then /ee/ as in “meet”
   - frown
   - open your mouth wide
   - close your mouth tightly
   - reach for the sky with your tongue (move your tongue up as if to touch your nose)
   - lick your lips (try smearing peanut butter, jelly, or ice cream on your child’s lips to encourage him to lick)
   - say “mmmm”
   - yawn
   - sigh

2. Once your child can make those movements, do the same activities without the mirror. Look at each other when you make the sounds and then imitate each other.
3 Blow bubbles. For a long time, your child will not actually blow bubbles. It’s the lip rounding that you’re practicing first. The bubble blowing will start as your child gains additional breath control.

4 Whistles and horns provide excellent practice for the lip rounding and lip compression needed for making sounds such as /p/, /b/, /m/, and /w/. When you begin practice, you will need a whistle with a large, round mouthpiece. If your child cannot seal his lips around the whistle, increase the circumference of the mouthpiece. This can be done in two ways:
   • Take the rod out of a foam hair curler.
     Stretch the foam curler over the mouthpiece of the whistle.
   • Wrap a piece of sponge around the mouthpiece.
     Secure it around the mouthpiece.

To make practice more interesting, get a variety of intriguing types of whistles. You can find a variety of horns and whistles in the Sarah Rosenfeld-Johnson horn hierarchy (Talk Tools); MORE whistle sets available from PDP Products; or whistles from Therapro. The Talk Tools whistles are arranged in a hierarchy of difficulty. Play rhythms with the whistles, take turns blowing, or simply blow long and loud. The lip compression and lip rounding practice helps strengthen the lip muscles.

5 Use real or toy musical instruments such as harmonicas or kazoos for work on lip movements, as well as breath control. Try blowing the toy instrument yourself to be sure that it is not too difficult or frustrating to blow. The recorder is an instrument that many children with Down syndrome play and enjoy.

6 For the older child, design a lip and tongue Olympics. Have events such as the activities used for mirror practice above. Add higher level activities. For example:
   • Hold your tongue up right behind your teeth for a count of ten.
   • See how high the coach (you) can count while your child holds his tongue up.
   • Round /oo/ and retract (smile) the lips alternately ten times.
   • Open your mouth a little, then a little wider, and then close.
   • Open and then close the mouth, increasing the number of times and increasing the speed.
   • Move the tongue from one corner of the mouth to the other.
   • Lick the entire perimeter of the lips (slowly and carefully).
   • Touch the outside of your child’s cheek; have him move his tongue to that spot on the inside of his cheek.

Award prizes for each event mastered, or use a checklist and check off each skill mastered.

7 For children preschool age and older, design a “Make That Face” game board to help practice the movements. Opened manila folders make wonderful game boards and are easy to store. Use a spinner and game pieces. On selected spaces, draw in cartoons or pictures and instructions such as “Make a kissing sound with your lips.” Another variation is to put the instructions on cards and have the game board spaces say, “Pick a red card” or “Pick a yellow card.”

8 Use a hopscotch grid on the ground. In each square, place a card listing an activity involving the tongue or lips. Wherever the stone is thrown, everyone has to do what it says, e.g. click your tongue 3 times.

This is the first in a series of three articles that will discuss the factors that could affect speech intelligibility for children and adults with Down syndrome, with the goal of helping families and SLPs identify and work on the specific factors affecting the understandability of speech for your child.
Resources: Book Reviews

Each month, we receive multiple requests to review books for Down Syndrome News. Many are written by parents or other family members of a person with Down syndrome, who want to share their story. Others are academic in nature, and would be most beneficial to professionals in educational settings. While we wish we could review them all, it is impossible to do so. Our goal is to present books here that will directly benefit our primary reader: parents and family members. Some criteria we consider when reviewing books are:

- Does the publication promote a positive image of people with DS?
- Does it use people first language?
- Does it enhance the dignity of people with DS?
- Does it avoid stereotyping?
- Does it present accurate information?
- Does it recognize the value of person with DS?

With that in mind, we are pleased to share the following books with you!

GROSS MOTOR SKILLS FOR CHILDREN WITH DOWN SYNDROME

By Patricia Winders, PT

At last, the second edition of Pat Winders’ amazing resource is here! Every child with Down syndrome should be evaluated for physical therapy intervention as an infant, and nearly every child with Down syndrome will receive physical therapy services at some point. Pat Winders sees children with Down syndrome exclusively, which makes her a unique expert in treating our children. This book is for you AND for your child’s physical therapist, who will benefit tremendously from Pat’s experience.

Gross motor development in children with Down syndrome is hindered by low muscle tone, increased joint flexibility, other medical issues, and decreased strength, but physical therapy can help overcome these challenges. It’s not so much about helping our children meet their physical milestones sooner, but helping them meet them in the right way—in a way that will serve them best as they grow. As Pat writes, “There are certain crucial results that need to be accomplished early in your child’s development so that he will have a body that is fit and functional throughout his life.” The focus in physical therapy should be on how and what your child learns, not how fast she learns it. (A hard lesson for all parents who like to meet those milestones!)

This book is for parents of children from birth through early elementary school, and we recommend you share it with your child’s physical therapist. The information here can be read cover to cover, but also as a resource when you need help on a specific area or skill. It’s a book you’ll pull off the shelf again and again as your child learns new things. – SJ
RAISING HENRY, A MEMOIR
OF MOTHERHOOD, DISABILITY, & DISCOVERY

By Rachel Adams
Yale University Press, 2013, 272 pages, hardcover, $26.00

Rachel Adams is a gifted writer. Professionally, she’s a professor of English at Columbia University, so you’d expect that to be so, right? This book is a pleasure to read—it truly comes alive on each page, and you’ll believe you are right in the room with the author. The birth of her son Henry, who is diagnosed with Down syndrome, is a story that so many of us can relate to. But because Rachel really knows how to write, she tells the story in a way that most of us are unable.

I’ll admit, I was a bit scared to read this book, seeing that another book she had authored is titled, Sideshow U.S.A.: Freaks and the American Cultural Imagination. How would a person with a professional interest in “freaks,” people born with physical deformities who were then exploited in side shows and the like, write about raising her son with Down syndrome? Fortunately, my fears were unjustified. It was actually her interest in disability that made it easier for her to grasp her son’s diagnosis. When another parent is considering facial reconstruction for her own son, Rachel tells her, “What’s wrong with it is that Down syndrome isn’t a disease that needs to be cured. The problem is with the world, not our kids.” Yes, she’s speaking our language.

While it is most definitely the story of Rachel and Henry (and to a lesser extent, her husband and older son Noah), it is a story that other parents of children with Down syndrome will appreciate. But bigger than that, this is a book to share with others, too; those who have not experienced the realities of raising a child with Down syndrome. – SJ

WHO’S THE SLOW LEARNER?
A CHRONICLE OF INCLUSION AND EXCLUSION

By Sandra McElwee
Outskirts Press, 2014, 336 pages, paperback, $17.95

Another parent-written book, Who’s the Slow Learner? chronicles the education life of Sean McElwee, a young man with Down syndrome in the California public education system. Although this is just one story of one student, there are many lessons to be learned here, and parents of school-age children will find it to be beneficial. If you are currently struggling to make an inclusive education setting work for your child, you’ll feel Sandra’s pain and frustration as she fights for the best for Sean. With this book, you have the opportunity to take her lessons and make them work for you. Here are three lessons that we feel are terribly important, but you’ll read many more.

One, there is no requirement that your child be doing grade level work to be included in a general education classroom for that grade. That’s what modifications are for.

Two, a collaborative relationship with the teachers, administrators and other staff is always better than an
adversarial one. Do everything you can to make those relationships work.

Three, always be aware of the power of general education students. They can be your best allies in the fight for inclusion.

While the lists of Sean’s goals from each year’s IEP can be long to read, they may just trigger a new goal or new idea to help you with your next IEP. Another example of parents helping parents—it doesn’t get much better than that! – SJ

WILDERNESS BLESSINGS, HOW DOWN SYNDROME RECONSTRUCTED OUR LIFE AND FAITH

By Jeffrey M. Gallagher

Jeff Gallagher is an ordained minister, serving a church in Kittery Point, Maine. He is also husband to Kristen, and dad to Noah and then Jacob—who was born in 2008 with Down syndrome. Jeff is able to take us back to the time of Jacob’s birth and first year of his life because there is a record of that time on CarePages, a web service he used mostly to keep his family and friends informed of Jacob’s hospital stays. Because he had that printed record of his world, it’s easy for him to return to the thoughts and feelings of that time, and for us to put ourselves in his place.

Many of us have experienced difficult medical situations with our children with Down syndrome. The cardiac consults, the team meetings, the surgical waiting rooms, and the “other parents” who were coming unglued over a tonsillectomy (while our own children were on a heart-lung bypass machine). Jeff details it all. He says he could have easily called this book “Everything I Learned About Life with a Child with Down Syndrome I Learned First While at Children’s Hospital.” (So, he’s funny, too.)

As Jeff says, we all have a story, and sometimes in the telling we are able to create bonds with others that will enrich each of our lives. We see families do that constantly at the NDSC convention each year. Jeff and Jacob’s story is not particularly unique to our community (grandparents stepping in to care for other children, friends supporting us with food and prayer). Fathers everywhere will connect to his idea of “just being a Dad,” when he makes it his mission to know what every pump, machine, and monitor in the cardiac intensive care unit is responsible for. But it’s Jeff’s connection to a welcoming faith community that holds a lesson for us all. Maybe this book isn’t just for us, but for the leaders of our faith communities, as well. – SJ
“Probablemente los hayas visto embolsando alimentos en un supermercado”, dijo el genetista en un intento por explicarnos a mi esposa y a mí que nuestra hija, Ellie, tenía síndrome de Down y lo que eso significaba para su futuro. Ellie tenía apenas unas horas de vida y ya le habían puesto un tope a las expectativas sobre su potencial.

Un par de horas antes estábamos sentados en la sala de recuperación cargando a Ellie, recibiendo a las visitas, enviando fotos por correo electrónico junto con los datos obligatorios de peso y longitud. Estábamos felices por el hecho de que no habían habido complicaciones en el parto y por la adición de una hija hermosa y saludable a nuestra familia. Luego terminó el horario de visita, y se llevaron a Ellie a la sala de recién nacidos “saludables” para que el pediatra de cabecera le realizara un examen de rutina. Exhalamos e intercambiamos una sonrisa silenciosa. Un breve intervalo de felicidad absoluta.

Recuerdo que tuvimos un debate sobre qué comida ordenaríamos para la cena porque “la comida de la cafetería del hospital no estaba a la altura de la ocasión”. La naturaleza trivial de esa conversación pone de manifiesto que ignorábamos por completo la conmoción que rodeaba a nuestra hija en una sala de examen bien iluminada al final del pasillo. No sabíamos que nuestra calma duraría poco.

Después nos enteramos de que habían trasladado a Ellie a la unidad de cuidados intensivos neonatales del hospital (UCIN) porque el pediatra sospechaba que tenía una cardiopatía. El pronóstico era alentador, pero en ese momento estaba frágil, necesitaba oxígeno y medicamentos para que su corazón y sus pulmones funcionaran correctamente. Y nos dijeron que un genetista vendría a vernos para hablar sobre otro diagnóstico.

El “otro diagnóstico” no era algo menor que se les había ocurrido después, como sonó en ese momento. El síndrome de Down, también conocido como ‘trisomía 21’, es una condición cromosómica causada por la presencia de una tercera copia del cromosoma 21. El síndrome de Down es la anomalía cromosómica más frecuente (afecta a más de 250,000 estadounidenses) y está asociada con retrasos en el desarrollo cognitivo y físico.

Durante tres semanas, los ángeles de la UCIN cuidaron a Ellie mientras mi esposa y yo nos refugiábamos en el coro de pitidos de los monitores y el cansancio para aliviar el potente cóctel de conmoción, dolor y temor que intentábamos digerir. Y mentiría si no admitiera que, en secreto, albergaba la esperanza de que todo fuese un mal sueño. Pero en lugar de despertarnos aliviados, todas las mañanas teníamos una resaca de culpa por desear que Ellie no fuera el milagro que estaba destinada a ser.

Lidiamos con el estrés de su complicación cardíaca y empezamos a aceptar los desafíos asociados con el síndrome de Down que teníamos por delante. Pero la imagen visual de la Ellie adulta que había esbozado el genetista, con una etiqueta con su nombre y luchando para meter un cartón de leche en una bolsa de supermercado, había quedado grabada en nuestras mentes. Esa descripción de un panorama tan limitado
para Ellie, presentada como un final inevitable, era difícil de aceptar. Le habían robado su potencial. Me llevó tiempo comprender plenamente tal injusticia, y me corroee incluso hasta el día de hoy.

Al poco tiempo, los médicos de Ellie dijeron que estaba lista para irse a casa. Y el hermano de 15 meses de Ellie estaba listo para jugar con su hermana pequeña. Ojalá mi esposa y yo hubiésemos estado igual de listos para enfrentar nuestra nueva realidad. Las tareas que una vez nos habían parecido tan intimidantes, como aprender a cambiar un pañal sucio o instalar la silla del bebé en el automóvil, pasaron a segundo plano frente al nuevo reto de aprender a cambiar un tanque de oxígeno e instalar una sonda de alimentación.

Afortunadamente, sólo precisamos esas habilidades por poco tiempo, ya que el corazón de Ellie se recuperó por completo antes de lo previsto. Para cuando cumplió los tres meses ya no necesitaba el oxígeno, así que la “desenchufamos” del tanque y lo tiramos como cuando el transbordador espacial se desprende de un tanque de combustible vacío después del lanzamiento. Una vez liberada del peso inicial de la vida, Ellie estaba encaminada.

Ellie ha abordado la vida de frente: hace amigos y disfruta de la niñez a la vez que soporta horas interminables de fisioterapia, terapia ocupacional y terapia del habla para poder alcanzar los logros que su hermano mayor ya ha alcanzado naturalmente. Si me permiten tomar prestada una analogía deportiva, Ellie ha afrontado “dos entrenamientos al día” toda su vida. No falta nunca, llega a tiempo y está lista para jugar. Nunca me he sentido más orgulloso que cuando vi caminar por primera vez a Ellie. Se le doblaban las rodillas y le temblaba el cuerpo pero, al ver los brazos extendidos que querían ayudarla, hizo el gesto del trofeo Heisman y dijo con la mirada: “Tengo todo bajo control.”

En los casi cinco años que han pasado desde el nacimiento de Ellie, hemos experimentado enormes malentendidos sobre el potencial de las personas con síndrome de Down. Con demasiada frecuencia, la gente la mira a Ellie y ve “discapacidad.” La gente ve “no puede.” Ni siquiera los médicos con un altísimo nivel de educación son inmunes a las ideas erróneas. Deciden medir su progreso en función de estándares de éxito limitados y sugieren que Ellie debería conformarse con menos porque “así es como son la mayoría de niños con síndrome de Down.”

Y, sin embargo, hemos conocido adultos con síndrome de Down que son estudiantes exitosos, atletas consumados, empleados productivos, reyes o reinas del baile de graduación y esposos o esposas. Y si bien los avances científicos y las terapias novedosas aumentarán aún más el potencial de la generación de Ellie en el largo plazo, sus logros cotidianos nos exigen que no les prestemos demasiada atención a las desventajas que tienen ahora. Nos exigen que nos concentremos en sus habilidades y esperemos más de ella.

La contradicción que existe entre los logros de Ellie y la proyección equivocada del genetista ha moldeado la manera en que criamos a nuestros tres hijos (ahora Ellie también tiene un hermano menor). Creemos que los niños, tengan síndrome de Down o no, tienden a desempeñarse al nivel de las expectativas que se tienen sobre ellos. A menudo se cree, erróneamente, que las expectativas le ponen un piso al rendimiento. Más bien, las expectativas suelen funcionar como un techo, por lo que hemos aprendido que lo mejor es fijar expectativas altas y equilibrarlas recordándoles que no pasa nada si fracasan. Y el único verdadero fracaso es no poner a prueba los límites de nuestras capacidades, donde quiera que estén.

Desde un principio, hemos educado a los hermanos de Ellie sobre el síndrome de Down y lo que la condición...
significa para ella: “Ellie puede hacer todo lo que pueden hacer ustedes; la única diferencia es que puede llevarle más tiempo o puede precisar ayuda adicional, pero a la larga lo logrará”. Su hermano mayor, que por aquel entonces tenía 3 años, replicó: “¿Puede ir a la luna?” “Sí,” respondimos. “Tal vez algún día pueda ir a la luna.”

Hemos tratado de inculcarles a nuestros hijos la creencia de que “si te propones algo, te esfuerzas y nunca te das por vencido, puedes hacer prácticamente cualquier cosa.” Y esperamos que ese mensaje y la confianza que les tenemos algún día se traduzcan en una confianza inalienable en sí mismos.

Sin dudas es importante reconocer los desafíos y proporcionar recursos para hacerles frente. Es cierto que Ellie necesita apoyo, y mucho. Pero, con demasiada frecuencia, la gente se concentra en sus desventajas y pierde de vista sus puntos fuertes. Incluso los administradores de la escuela intentan clasificarla: confeccionan listas de sus déficits, fijan expectativas bajas y le “arman una causa” para separarla de los compañeros que tienen un desarrollo normal a pesar de los numerosos estudios que indican que integrarla con sus compañeros resulta mutuamente beneficioso. Pero es mucho más cómodo encasillarla. Las expectativas bajas son, después de todo, las más fáciles de cumplir.

Las personas más cercanas a Ellie saben la verdad. Saben que ella soporta horas de terapia todos los días, que vale la pena el esfuerzo extra y que es capaz de mucho más que lo que la mayoría espera de ella. Saben que no deben dejarse engañar por su sonrisa contagiosa, que es capaz de iluminar una habitación, porque detrás de esa fachada tierna hay una niña con una determinación de hierro. Ellie lo demuestra todos los sábados en su clase de escalar rocas. Claro que las paredes de 9 metros de altura la intimidan, que le cuesta subir y que rara vez llega a la cima. Pero después de un descanso breve, me mira y dice: “Otra vez, papá.”

Y, tal vez, igual de importante es que las personas más cercanas a Ellie también saben que es igual a la mayoría de las niñas de cuatro años de su clase de preescolar. Ella se siente una princesa, y le encanta invitar a sus amigos a jugar en su casa e ir a nadar a la piscina. Le gusta jugar a la pelota con sus hermanos, pero de vez en cuando la critican por fastidiarlos. Es más parecida que diferente.

Hace poco le preguntamos al hermano mayor de Ellie: “¿Te acuerdas de lo que significa para Ellie tener síndrome de Down?” “Sí,” respondió, “Significa que puede ir a la luna. Pero no es justo, ¿por qué el cromosoma extra es para Ellie?” (en referencia a su cromosoma 47). Ese comentario no tiene precio. Si tan sólo nuestra sociedad pudiese ver a través del mismo lente de ‘ventaja’ y concentrarse en las capacidades en lugar de en las discapacidades.

Un chequeo prenatal indicó que las probabilidades de que Ellie tuviese síndrome de Down eran menores a una en 3,000, por lo que nos gusta pensar que Ellie ha desafiado las expectativas desde el principio. Y confiamos en que seguirá haciéndolo de aquí en más. Sin embargo, tenemos la esperanza de que algún día no tenga que hacerlo. Esperamos que algún día las expectativas que tenemos sobre ella, como sociedad, sean ilimitadas.

Ellie nos ha enseñado muchas lecciones sobre el amor de padres, pero quizás la más importante sea que no hay que dejar que las expectativas sociales determinen todas las cosas que un niño puede ser. Octubre es el mes de la concientización sobre el síndrome de Down; usemos este mes para aprovechar la fuerza impulsora de esa lección y recalibrar las expectativas todos juntos. Reconozcamos la desventaja, pero no la compensemos en exceso bajando demasiado las expectativas. Veamos, este mes y todos los que siguen, el ‘si puede’ en los niños con el síndrome de Down y no el ‘no puede’. En realidad, hagámoslo con todos nuestros hijos, tengan o no un “cromosoma” extra.

Y en cuanto a Ellie…ella lo verá en la luna.

Bret Bowerman tiene una hija con síndrome de Down e integra la Junta Directiva del National Down Syndrome Congress, organización que defiende los derechos de las personas con síndrome de Down a nivel nacional.
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