

# Down Syndrome News

NEWSLETTER OF THE

Volume 39, Number 4

Winter 2016



## Keratoconus...Seeing Things More Clearly

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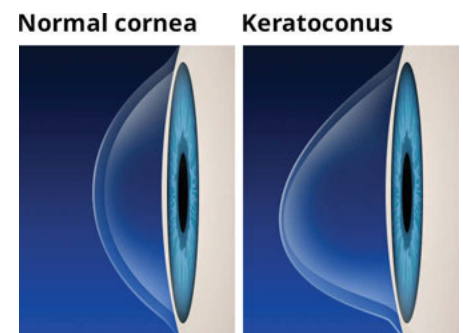


In recent months we have received several calls at the Center about keratoconus. Keratoconus, often abbreviated to KC, is a non-inflammatory eye condition in which the normally round, dome-shaped cornea progressively thins causing a cone-like bulge to develop. This results in significant

visual impairment. Symptoms include fluctuations in visual acuity, and an increased sensitivity to light and glare. Even with the best pair of glasses, a patient may not achieve good vision. Until recently, most cases of KC have gone undiagnosed; however, with more diagnostic tests and treatments becoming available, ophthalmologists are finding and treating patients sooner.

The actual incidence of KC is not known. It is not a common eye disease, but it is by no means rare. Keratoconus is generally first diagnosed in young people at puberty or in their late teens. It has been estimated to occur in 1 out of every 2,000 persons in the general population; however, the incidence in the Down syndrome community is estimated at 1 out of 67!

It has been found that the twenty-first chromosome is where several collagen-encoding genes are located. Patients with Down syndrome show an



*continued on page 51*

# Letter from the President

Dear Families,

It is hard to believe that we are approaching the end of 2016. What a year it has been! The National Down Syndrome Congress has been hard at work on Capitol Hill working on your behalf regarding ESSA funding regulations and implementation; The Higher Education Act; IDEA; Medicaid; and many other issues that affect people with Down syndrome. Be assured we are diligent in our efforts and will keep you informed via our Governmental Affairs Newsline.

In addition, the NDSC staff and Convention committee are hard at work planning and preparing for our 45th Annual NDSC Convention that will take place July 20-23, 2017 in beautiful Sacramento, California. Be on the lookout for registration and hotel information in the Spring! You won't want to miss it — there will be many new and exciting workshop topics, awesome presenters, and, of course, wonderful parents, self-

advocates, siblings, educators, and volunteers! We look forward to "Livin' The Dream" with you and celebrating our Sapphire Year.

The Board of Directors continues to work on our Strategic Plan initiatives that include educating and empowering self-advocates and their families of all backgrounds to influence public policy, increase NDSC's presence in the medical/education communities, provide educational services for parents and educators through our Center for Educational Excellence, develop a Self-advocate Leadership Academy, and, continue to increase awareness about Down syndrome and NDSC. We are making great strides and look forward to sharing more of our plans and initiatives with you in July!

Although we are known for our "Family Reunion" each year, remember that we are here for you 365 days a year to provide resources and support. We continue to work with and treasure our relationships with



our Affiliates and are always available for whatever you might need.

As we begin to put the finishing touches on 2016 and prepare for 2017, I wish you and your family a very Happy Holiday and a very prosperous and healthy New Year! Hope to see you soon! It is indeed my pleasure and privilege to serve you and your family.

My best,

Marilyn

## Down Syndrome News

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### Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

### Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

### Statement of Policy and Disclaimer:

This newsletter reports items of interest relating to Down syndrome and provides a forum for others. The NDSC does not promote or recommend any therapy, treatment, etc. NDSC will not espouse any particular political or religious view. Individuals or organizations referred to are not necessarily endorsed by this publication or its editor. The National Down Syndrome Congress works to educate, advocate and empower. We are the leading national resource of support and information for people seeking to learn about Down syndrome.

The editor reserves the right to make corrections as are appropriate and in accord with established editorial practice in material submitted for publication. Submitting an item to the editor to use in *DSN* gives permission to do so.

### Reprints From DSN:

We invite editors of other newsletters to reprint items from *Down Syndrome News*, provided proper credit is given to the source. Please delineate clearly the material you are reprinting and indicate that it comes from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108, Roswell, GA 30076, [ndsccenter.org](http://ndsccenter.org)

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## Keratoconus

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increased rate of collagen-related disorders, among them KC, which presents a major challenge to the eye specialist, because treatment options are limited. In most of these patients, corneal transplanting is not an option, because patients would rub their eyes after surgery, putting the transplant and the entire eye at risk.

### Cross-linking: Eye-opening Treatment

Cross-linking (CXL) is a method to mechanically stabilize the cornea, inducing an increased number of bonds between the collagen fibers of a connective tissue. This can be compared to a net that receives additional links and becomes mechanically more resistant. CXL is not a cure for keratoconus. The aim of this treatment is to arrest progression of keratoconus, and thereby prevent further deterioration in vision and the need for corneal transplantation. Glasses or contact lenses will still be needed following the cross-linking treatment (although a change in the prescription may be required) but it is hoped that it could limit further deterioration of vision.

When Nikki Hafezi learned that leading cross-linking experts had treated only a handful of patients with Down syndrome, she recognized an imminent need: patients with Down syndrome are almost never diagnosed with KC and treated by CXL, because of a lack of information and screening on multiple levels.

Nikki has been working in ophthalmology for more than 10 years. Working in Switzerland as an intellectual property specialist, she helps academic researchers protect their ideas, supporting them in creating patents, founding spin-off companies, and developing new medical products and pharmaceuticals. She had a partner for this enterprise in her husband, Farhad Hafezi, MD, PhD, one of the world's leading ophthalmologists. Trained in Switzerland, he is a member of the team that had developed the first CXL device and had brought CXL technology into ophthalmology in 2003.

The result was the Zurich-based charity, *Light for Sight 21*. The mission of *Light for Sight 21* is to increase awareness about KC among Down syndrome families and to educate



health professionals and primary care eye doctors who manage these patients about the importance of



screening for KC and treating the disease.

Internationally, ophthalmologists have been eager to join the Hafezis to help *Light for Sight 21* succeed. In more than 25 countries, education and advocacy takes place. Only eye surgeons who have extensive experience with cross-linking are invited to participate as Light for Sight Ambassadors. These ophthalmologists perform CXL on patients with Down syndrome according to a set protocol (the Light for Sight protocol) that takes into account how cooperative the patient will be during the procedure and post-op period. Also, these eye surgeons contribute patient follow-up information to an international research database that will yield useful information about CXL outcomes in the Down syndrome community.

Cross-linking received FDA approval in May 2016 and *Light for Sight 21* is working to identify ophthalmologists and eye centers in the U.S. to join in their important work. To search for a provider, you can visit <http://avedro.com/en-us/patients/find-a-physician/>.

**Thank you to our friends at the National Keratoconus Foundation for allowing us to share this information with you. To learn more about keratoconus and cross-linking, visit [www.nkcf.org](http://www.nkcf.org).**





# “The Perfect Child” Revisited

by Frank H. Boehm, M.D. (reprinted from *The Tennessean*)

Last August marked 13 years since the birth of my grandson, Seth, and his twin sister, Marly. It was on that day, a few hours after their birth that doctors informed us that Seth had a genetic disorder known as Down syndrome. Our initial reaction upon the twins’ birth was pure joy but that soon turned to concern for Seth. Many emotions bombarded us, but mainly it was fear of the unknown. There were so many unanswered questions.

Down syndrome was first described by Dr. John Langdon Down in 1866 as a condition in which a child is short of stature with mild to moderate intellectual disabilities, as well as often being associated with other physical problems such as heart defects. Down syndrome is one of many possible issues parents may face with the birth of a child.

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We were so very proud of all our grandchildren but also understood what enormous effort it had taken to get Seth to this time and place. His family and friends had all played such a big part in this moment and I was so very touched by all that I was witnessing. Seth had fulfilled what I had hoped for him so many years ago. He is indeed, a “perfect” child.

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As a specialist in high risk pregnancies, I have spent my entire career counseling patients on the risks and issues involved when delivering a child with birth defects. I try to emphasize to my patients that “normal” is in the eye of the beholder, despite the many differences, and that the

uniqueness of each of us is what makes us special. I also try to help them see that the gift of life can be “perfect” even in the presence of serious problems.

Thirteen years ago it was now my family who had to confront the many problems associated with a child

born with a significant genetic disorder. It was one year later that I wrote an op-ed column for *The Tennessean* on the subject of “The Perfect Child.” In that column I wrote, “Holding Seth in my arms and gazing into his angelic face, I was overcome with unconditional love for my grandson. As tears rolled down my cheek, I understood that despite his diagnosis, to me and those who love him, Seth is a perfect child, to be loved and nurtured, the same as his sister Marly. Our dreams and expectations for him may now be different from those for his sister, yet they are dreams and expectations nonetheless.”

Now 13 years later, I can report that those words have become truer than I could ever have imagined. As Seth has grown, we have watched as his uniqueness evolved. He is a happy and loving child with a sense of humor that brings joy to those around him. He has learned to read and write and has shown a love for music since he was old enough to hold a spoon and hit a pot!

Seth and his brothers, Max and Sam, began taking piano lessons six months ago and recently performed in their first recital, along with Marly who has been playing the violin for six years. Julie and I attended that recital and it was this event that made me realize how those words I wrote so many years ago have come true.

We knew the boys were taking piano lessons and every time we went for a visit they were excited to show us how much they had learned. Although we had heard Seth practice, we were nervous for him when the time came for him to walk to the piano that day. But we were also very excited. We were not disappointed! As his name was called,



Seth stood straight and true and walked up the stage stairs with his hands in his pockets. He did not appear nervous as he took his seat and turned toward the audience and beamed a huge smile. Seth was happy, confident and excited. As he began to play his three minute piece "You Alone Can Rescue" by Matt Redman we could see the intense concentration in his face and body movements. His music was clear, precise and flawless and he was clearly enjoying the moment.

Tears rolled down my cheek as he played. Then when Seth finished his piece, he did something that revealed his uniqueness. He threw his right arm up into the air with a twist at the wrist so as to express a sense of completeness and flair. It was typical Seth and the crowd clapped and yelled as he stood, smiled at the crowd, bowed at the waist and ran off the stage and into the arms of his waiting family.

I thought my heart would burst with joy. We were so very proud of all our grandchildren but also understood what enormous effort it had taken to get Seth to this time and place. His family and friends had all played such a big part in this moment and I was so very touched by all that I was witnessing. Seth had fulfilled what I had hoped for him so many years ago. He is indeed, a "perfect" child.

*(Dr. Frank H. Boehm is professor and vice chair of the Department of Obstetrics and Gynecology at Vanderbilt University Medical Center. He can be reached at [frank.boehm@vanderbilt.edu](mailto:frank.boehm@vanderbilt.edu)).*



**NATIONAL  
DOWN SYNDROME  
CONGRESS**

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## ESSA Webinar in January

As a joint collaboration between NDSC, Down Syndrome Affiliates in Action, and NDSS, there will be a three-part webinar series on the Every Student Succeeds Act (ESSA), presented live on three consecutive Thursdays in January at 8-9 pm Eastern Time. The first webinar in the series will occur on January 12, 2017.

Presented by NDSC Senior Education Policy Advisor, Ricki Sabia, and NDSS VP of Advocacy & Public Policy, Heather Sachs, the objectives of the webinar are to explain why ESSA is important for students with disabilities, to explain ESSA's connection to IDEA implementation, and to provide some general tips for IEP meetings and state advocacy. The two subsequent webinars will get into much greater detail about how to use ESSA with IDEA to support high expectations at your child's IEP meeting and how to advocate in your state for strong ESSA implementation.

**Register now – <https://attendee.gotowebinar.com/register/8954137202621991938>**



**NDSC's Advocacy Team: Ricki Sabia, Stephanie Smith Lee, Susan Goodman**





## NATIONAL DOWN SYNDROME CONGRESS



July 20 - 23, 2017

# SACRAMENTO, CA

Sacramento is the star on the map of California - where you will find cultural attractions to inspire you, cutting-edge cuisine to impress you, history to enrich you and surprises to put a smile on your face. Venture out in any direction and you'll see why **"California begins here."**

NDSC attendees will be **"Livin' The Dream"** at the Sacramento Convention Center where nearly **4,000 people** will converge to celebrate our Sapphire Year.

Each year, thousands of people from across the globe attend the NDSC Annual Convention. For most, it's to hear the latest information from world-renowned experts. For others, it's a great vacation. But, for nearly all, there's the one-of-a-kind NDSC "giant family reunion" feeling that permeates the convention weekend.

**PARENTS:** Learn from the best, as internationally known experts come to Sacramento to share their knowledge across the life span of individuals with DS.

**SELF-ADVOCATES:** Join 300 friends from across the world to learn, share, become empowered and have an amazing time!

**SIBLINGS:** Share and learn alongside your peers, from each other, as well as from professionals.

**VOLUNTEERS:** Have the experience of a lifetime by volunteering your time at our convention.



**Save the Date:**  
**July 20-23, 2017**  
**Convention Registration**  
**Opens: April 2017**

Visit [www.ndsccenter.org/the-convention/](http://www.ndsccenter.org/the-convention/) often to view our growing schedule of activities. Convention registration will be required to access the

NDSC room blocks at the Hyatt Regency, Sheraton Grande and Residence Inn. Registration will go live in April.

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# 2017 NDSC Convention

## Award nominations accepted through January 30th

Each year at our annual convention we recognize individuals and organizations for outstanding achievement within the Down syndrome community. Nominations may be submitted by any person or organization wishing to direct the attention of the NDSC Board of Directors to outstanding achievement. Please use the form found at <http://www.ndsccenter.org/convention-history-and-awards/>

- **Exceptional Meritorious Service Award** – an individual whose service and contributions to people with DS and their families have had local, state and national significance.
- **Employer of the Year Award** – recognizes an employer for efforts in creating employment opportunities for people with DS.
- **Christian Pueschel Memorial Citizen Award** – recognizes an individual with DS whose achievements, service and contributions have enhanced the value and dignity of people with DS and their families.
- **Sig Pueschel NDSC Service Award** – recognizes an individual or organization for outstanding contributions to the NDSC.



*David Tolleson, Jeanette Pueschel Larson, Siegfried Pueschel/Theodore D. Tjossem Research Award Recipient Christopher Lemons, Marilyn Tolbert*



*Marilyn Tolbert, President's Award Recipients from ADOSID, David Tolleson*

- **National Parent Group Award** – recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with DS and their families. Parent groups will be judged on advocacy services, relationship to the NDSC, support to families, fundraising activities and local and regional programs and services.
- **Pueschel/Tjossem Memorial Research Award** – recognizes research, which has contributed to greater knowledge and understanding of DS and has improved the lives of people with DS or their families.
- **National Media Award** – honors outstanding national media efforts, which create better understanding of DS and people with DS. The award recognizes programs on network television and radio, national publications, serials and syndicated columns. National Media Awards may be presented for the categories of television, radio and print. The media efforts must have been broadcast or published before January 1, 2017.
- **Education Award** – recognizes outstanding performance on behalf of students with DS. Nominees will be judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with DS.

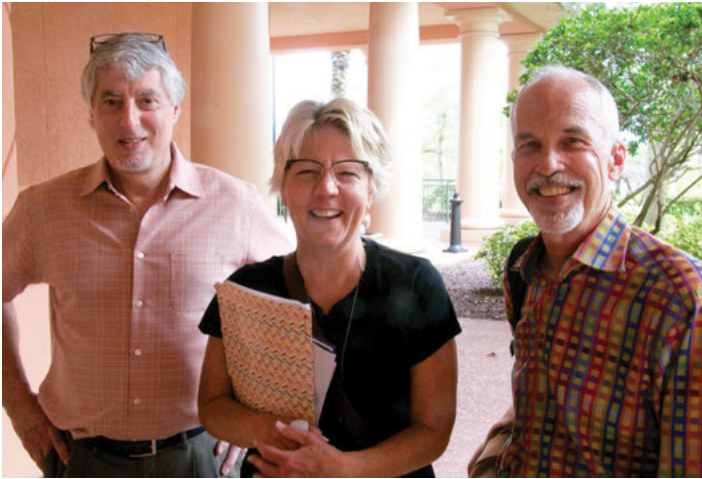


# Last Call for Speakers!

The Convention Planning Committee is seeking proposals for the general convention workshop cycles geared for parents, family members, and professionals. The deadline for submitting all speaker proposals is January 4, 2017. Proposals will only be accepted via the online form on the NDSC website. Incomplete, late, or incorrectly submitted proposals will not be considered.

Please be prepared to provide the following information when submitting a proposal:

- Workshop title
- Workshop abstract
- 3 Learning objectives
- Workshop outline
- Speaker name, title, company, full address, phone, email
- Speaker photo and short introduction
- Audio Visual requests
- Target audience



The Youth & Adult Conference Support Team is looking for engaging self-advocates (individuals with DS age 15 and older) to share their talents, experiences and perspectives with their peers.



## GENERAL CONVENTION

<http://www.ndsccenter.org/call-for-speakers/convention-workshop-proposal-form/>

## YOUTH & ADULT

<http://www.ndsccenter.org/call-for-speakers/ya-speaker-proposal-form/>



# Happy Holidays to Everyone!

As the season settles in, we hope that all of your holiday endeavors bring you, and your family, joy and prosperity! Please be assured that we at the NDSC are working diligently to wrap-up what has proved to be our biggest year to date, and as we head into 2017, we are preparing for what we know will be the largest year for growth in our 45 year history!

As you make your decisions for year-end giving and support, we ask that you not forget the National Down Syndrome Congress in your generosity. If you are a current donor, we hope you will consider a "level-up" in your current giving, and if you have never donated to us at year's end, it is our wish that you include us this year.

In 2017, we will be introducing our **NDSC Resource and Support Center**, which we anticipate will take over 12,000 calls, from over 30 countries! Within this center we will also print and mail (AT NO COST) thousands of written materials and brochures

(in both English and Spanish), and we will direct over 100,000 people to our website for material downloads and vital information. In addition, our **Adult Sibling Toolkit**, which has already been distributed to over 1500 families in English and Spanish, has tripled in requests for the product, and we are now adding Adult-Sibling programming across the globe, including support groups and training, and we will have an entire track at our convention just for this important endeavor. Our **Affiliate**

**Program** will see a host of new offerings and webinars, and two new endeavors for 2017 will be our **Center for Educational Excellence** and the **NDSC Self-Advocate Leadership Center**.

We wish you and your family the happiest holidays, and we hope you remember during your year-end giving! For more information follow this link <https://www.ndsccenter.org/year-end-giving/> or contact **Kathy Edwards** via phone (404-242-3640) or email [kathy@ndsccenter.org](mailto:kathy@ndsccenter.org).

the joy of



visit  
our  
online  
store



## Find the perfect gifts for your loved ones

in our online store. With apparel, mugs, greeting cards, our signature holiday ornament and more, our online store is the perfect place to shop and support the work of NDSC! Give a gift that also helps others – proceeds from all sales benefit NDSC.

Shop now: <https://www.co-store.com/gigisplayhouseNDSC>



# A homecoming for Naia

By Tierney Temple Fairchild

*Editor's Note: Many of you may be familiar with the book **"Choosing Naia: A Family's Journey,"** by Michael Zuckoff, based on an award-winning series of articles, about a modern family and Down syndrome (including an award from NDSC). The book follows Greg and Tierney Fairchild, from the time they discover that their child will be born with Down syndrome through their decision to continue the pregnancy and into the baby's first years of life. Greg served on NDSC's Board of Directors and Tierney is a past NDSC Convention speaker. Nearly two decades later, Tierney wrote an Op-Ed for the Boston Globe last month, which is reprinted here.*

**In this election season, it's easy to** focus on what makes us different rather than our common bonds. As adults, we often have difficulties bridging cultural, racial, and other gaps that would make us stronger as a community, as a nation. Thankfully, our future isn't only dependent on us; our youth are paving a road for a brighter tomorrow.

On a warm Friday night in October, the Charlottesville High School community (home of Thomas Jefferson and the University of Virginia) offered a lesson in our shared experience, our common humanity, choosing my daughter, Naia Grace Fairchild, as the Homecoming Queen of the Black Knights. For the seniors who nominated her to the court, and the student body that voted her as queen, it may have been an obvious choice. Yet, to those of us who grew up in different times, overcame unspeakable odds, and experienced a more callous

school community, Naia's election is significant, even inspiring.

Cheers rang out in the crowd as my husband Greg and I escorted Naia across the football field to join the other members of the court and their escorts. The speaker listed Naia's high school accomplishments as we walked through the color guard, their flags twirling in the night sky. Her life sounded like any other aspiring college-goer: intern at the Virginia Discovery Museum and the YMCA Child Care Center, honors student, cheerleading team manager. Then, an unexpected twist — keynote speaker of the Massachusetts Down Syndrome Congress annual meeting.

As the announcement approached, Naia's excitement was palpable. Her hands left our grasp and folded prayerfully, her head bowed down awaiting the news. Those expectant moments felt like an eternity, and then they called her name. Naia leapt forward joyfully to claim her crown, the crowd erupting in her honor.

To us, Naia's election as Homecoming Queen was remarkable, and, during Down Syndrome Awareness Month, seemed only fitting. Eighteen years ago, we chose Naia after learning in utero that she would have Down syndrome and a major heart defect. At that time, we could not even imagine the possibilities for her life today — her pursuit of a standard diploma, expectations of community college, and an abundance of friends of every age and experience.

The Charlottesville High School student body reminded us of what community means, and how its



***Homecoming Queen Naia Grace Fairchild and Homecoming King Francis MacCall.***

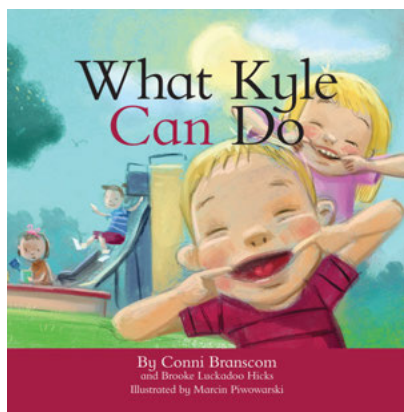
diversity is not only an asset, it's a defining and essential characteristic of our vibrant culture. Words cannot adequately express our gratitude to the community for choosing Naia to represent them this Homecoming.

In truth, Naia's path to this moment was paved with the hard work of so many teachers, therapists, family and friends who have taught, challenged, supported, encouraged, loved, and enjoyed her. That road began months before she was born and continues today.

Perhaps Naia's story is sounding familiar now. At Naia's first birthday, our family's journey was catalogued in a six-part series written by then-Boston Globe reporter Mitchell Zuckoff and photographed by his wife, Suzanne Kreiter. We exposed ourselves — our doubts, faith, concerns, and questions — in an effort to help others facing similar challenges. Nearly 20 years later,



# Recommended Reading



## What Kyle Can Do

by Conni Branscom and  
Brooke Luckadoo Hicks

In "What Kyle Can Do", Mya is about to have a baby brother and upon hearing he has Down syndrome, fears he won't be able to do all of the fun things she has planned for him. Beautifully illustrated, this 20 page book focuses on the great things that Kyle can do like swimming, making faces and playing in the sand. Mya learns that Kyle can do so many great things and makes her family, along with many other people, smile every day.

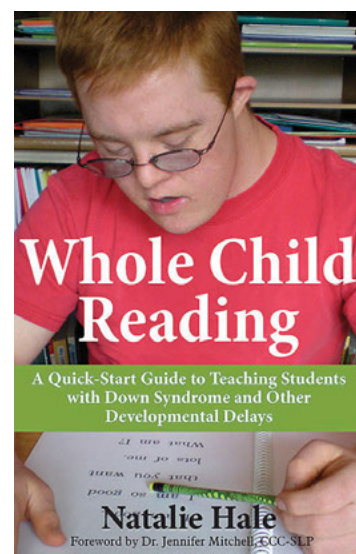
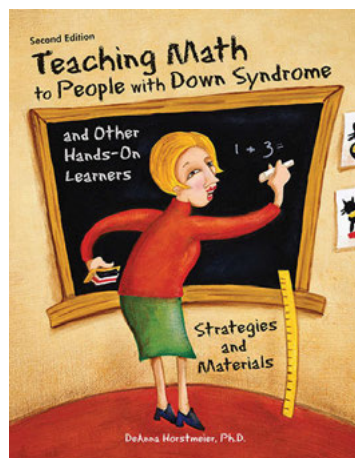
Proceeds from the book benefit Kyle's Korner Inc., a nonprofit established by Conni, which provides adaptive bikes for children with special needs. Their mission is to "develop awareness, promote public inclusion, and provide an educational platform regarding the benefits, challenges

and opportunities of those with Down Syndrome and other disabilities". More information about Kyle's Korner can be found online at: [www.kyleskornerinc.org](http://www.kyleskornerinc.org).

## Teaching Math to People with Down Syndrome and Other Hands-on Learners, 2nd Edition

by DeAnna Horstmeier, Ph.D.

Children and adults with Down syndrome need math for the real world – counting with meaning, adding the scores in a game, and tracking time in order to keep to a schedule. Written in a straightforward and user-friendly style, this new, second edition provides strategies and activities that are relevant to daily living, are concrete and practical, offer hands-on practice, and provide opportunity for successful completion.



## Whole Child Reading: A Quick-Start Guide to Teaching Students with Down Syndrome and Other Developmental Delays

by Natalie Hale

Our longtime friend and award-winning author, Natalie Hale, has a new book for today's busy parents and teachers. This easy-to-use guide explains how to *go in through the heart* to hook beginning and struggling readers, but then how to *teach to the brain*, so that learning is fast and permanent. The methods in the book can be adapted for learners of any age who are reading at a third grade level or below. If you have at least five minutes a day to work on reading, you have enough time to get started!

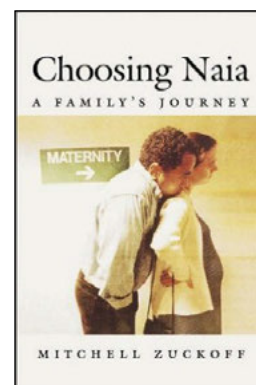
we can now reach back to share the joy we have experienced as Naia's parents and the awe and appreciation we feel in watching the community embrace her.

Naia, in a local television interview, said, "A lot of people with Down syndrome don't get to become homecoming queen, so this is a big honor for me." Her Homecoming King, Francis MacCall, noted, "A lot of people

asked if it was a communal effort to vote Naia as homecoming queen, but everyone sees how great she is and made that conclusion themselves."

Naia's election has given us a glimpse of what we all strive for as parents – to have our children accepted and included, and working to be their best selves.

*Tierney Temple Fairchild is the executive director of Resilience Education.*





# Join LP Online™ Now!

DSF and the NDSC Center for Educational Excellence are partnered to provide educational support to students with Down syndrome, their families and the professionals who work with them. We invite you to participate in LP Online™ 2016-2017, an online learning community based on The Learning Program™.

LP Online™ sessions support development of reading, comprehension and math skills, and address general topics related to accessing curriculum, fostering independence and memory. Sessions are geared towards supporting parents in the educational process, sharing strategies, resources and activities to improve academic outcomes for students with Down syndrome. Administrators, teachers and therapists are also welcome to join.



Level choice depends on the developmental stage of each student, but generally:

- **Level 1** is appropriate for students in preschool through 1st grade (ages 3-6)
- **Level 2** is appropriate for students in 2nd or 3rd grade (ages 6-8)
- **Level 3** is appropriate for students in 4th through 6th grade (ages 9-12)

Tuition is \$200 for 10 sessions (\$20 per month) and includes access to monthly live and recorded webinar presentations\*, membership to the LP Online™ website (which houses handouts, recording links and videos) and membership to the Learning Program

Facebook Group. Sessions last approximately 1.5 hours. (\*Attend live or access the recordings anytime during the program year.)



# Queratocono...Ver las cosas más claramente

En los últimos meses hemos recibido varias llamadas en el Centro preguntando sobre el Queratocono. El Queratocono, a menudo abreviado a KC por sus siglas en inglés, es una condición no inflamatoria del ojo en la cual la córnea -normalmente redonda en forma de cúpula- se adelgaza progresivamente haciendo que se forme una protuberancia parecida a un cono. Queratocono



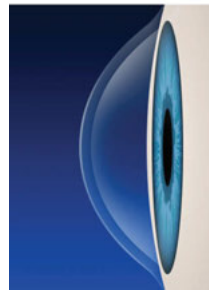
literalmente significa "córnea en forma de cono".

Esto da como resultado un deterioro visual significativo. Los síntomas incluyen fluctuaciones en la agudeza visual, una mayor sensibilidad a la luz y el deslumbramiento. Incluso con el mejor par de anteojos, un paciente puede tener problemas con su visión. Hasta hace poco, la mayoría de los casos de Queratocono no habían sido diagnosticados. Pero con más pruebas diagnósticas y tratamientos disponibles, los oftalmólogos están encontrando y tratando a los pacientes más pronto.

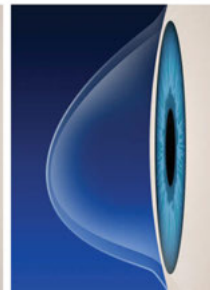
La causa real del Queratocono no se conoce. No es una enfermedad común de los ojos, pero no se puede catalogar como extraña. El Queratocono generalmente se diagnostica por primera vez en la pubertad o en la adolescencia. Se ha estimado que ocurre en 1 de cada 2.000 personas en la población general, sin embargo, en la comunidad con síndrome de Down se estima que hay una persona afectada en 67!

Se ha encontrado que el cromosoma veintiuno es donde se encuentran varios genes que codifican el colágeno. Los pacientes con síndrome de Down muestran un aumento de la tasa de trastornos relacionados con el colágeno, entre ellos el Queratocono, que presenta un gran reto para el oftalmólogo debido a que las opciones de tratamiento son limitadas. En la mayoría de estos

Córnea Normal



Queratocono



pacientes el trasplante de córnea no es una opción, ya que tienden a frotarse los ojos después de la cirugía, poniendo en riesgo el trasplante y la salud del ojo en general.

## Reticulación: Tratamiento para abrir los ojos

La reticulación o "cross-linking" (CXL por sus siglas en inglés) es un método para estabilizar mecánicamente la córnea, induciendo un aumento del número de enlaces entre las fibras de colágeno de un tejido conectivo. Esto se puede comparar con una red que recibe enlaces adicionales y se hace mecánicamente más resistente. La reticulación no es una cura para el Queratocono. El objetivo de este tratamiento es detener la progresión del Queratocono y, por tanto, prevenir un mayor deterioro de la visión y la necesidad del trasplante de córnea. Se necesitarán anteojos o lentes de contacto después del tratamiento de reticulación (aunque puede ser necesario un cambio en la prescripción), pero se espera que pueda limitar el deterioro de la visión.

Cuando Nikki Hafezi aprendió que los principales expertos en reticulación habían tratado sólo a un pequeño grupo de pacientes con síndrome de Down, reconoció una necesidad inminente: los pacientes con síndrome de Down casi nunca son diagnosticados con Queratocono y tratados con CXL debido a la falta de información y de detección en múltiples niveles.

Nikki ha estado trabajando en oftalmología por más de 10 años, ha trabajado en Suiza como especialista en derechos de autor, brindando asesoría a los investigadores académicos en cómo proteger sus ideas, apoyándolos en la creación de patentes, creando compañías derivadas de investigación aplicada y desarrollando nuevos productos médicos y farmacéuticos. Su socio en esta empresa es su esposo, Farhad Hafezi, MD, PhD, uno de los oftalmólogos más reconocidos a nivel mundial. Con formación en Suiza, fue miembro del equipo que desarrolló el primer dispositivo CXL y quien llevó la tecnología CXL al mundo de la oftalmología en 2003.

*Continúa en la página 62*

Como resultado de este trabajo surgió la organización no gubernamental conocida como *Light for Sight 21* en Zurich. La misión de *Light for Sight 21* es despertar la conciencia sobre el Queratocono entre las familias que tienen un miembro con síndrome de Down y educar a los profesionales de la salud y los médicos de atención primaria que manejan a estos pacientes sobre la importancia del diagnóstico para detección del Queratocono y el tratamiento de la enfermedad.

A nivel internacional, los oftalmólogos están ansiosos de unirse a los Hafezis para ayudar a *Light for Sight 21* a tener éxito. En más de 25 países, la educación y la promoción se lleva a cabo. Sólo los cirujanos oftalmológicos que tienen una amplia experiencia en la reticulación están invitados a participar como Embajadores de Light for Sight. Estos oftalmólogos realizan la reticulación en pacientes con síndrome de Down de acuerdo con un protocolo establecido (el protocolo de Light for Sight) que tiene en cuenta cómo el paciente va a colaborar durante el procedimiento y el período post-operatorio. Además, estos cirujanos oftalmológicos aportan información del seguimiento realizado al paciente a una base de datos internacional de investigación que proporcionará información útil sobre los resultados de la reticulación en la comunidad del síndrome de Down.

La reticulación o "Cross-linking" recibió la aprobación de la FDA en mayo de 2016 y *Light for Sight 21* está trabajando para identificar a oftalmólogos y centros oftalmológicos en los EE.UU. que deseen unirse a este importante trabajo.

Para buscar un proveedor, puede visitar <http://avedro.com/en-us/patients/find-a-physician/>.

Gracias a nuestros amigos de la **National Keratoconus Foundation** por permitirnos compartir esta información con ustedes! Para obtener más información sobre el Queratocono y la reticulación, por favor visite [www.nkcf.org](http://www.nkcf.org).

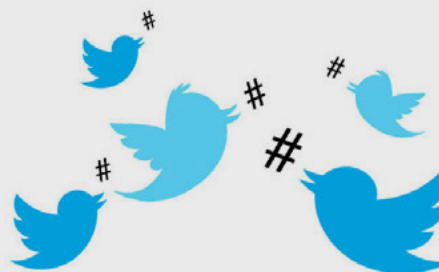


## #NDSCchat

El próximo 12 de enero del 2017 seguiremos con nuestro Mensual Twitter Chat, a través del cual podremos compartir preguntas y sugerencias con otros padres de niños y jóvenes con síndrome de Down acerca de la inclusión en las escuelas.

### Twitter Chat

Fecha: Enero 12, 2017  
Hora: 12:00 am - 1:00 pm Hora Miami  
Invitados: Todos  
Tema: La inclusión en las escuelas



### 4 pasos para ser parte del Chat del NDSC:

1. Ingresa a tu cuenta de Twitter, si no tienes una es momento de crearla.
2. Busca el hashtag #NDSCchat
3. Busca las preguntas publicadas por el NDSC. Aparecerán enunciadas P1, P2, P3, etc.
4. Comparte. Cada vez que compartas tu twitter, usa el hashtag #NDSCchat y el número de la respuesta así: R1, R2, R3, etc.

Si tienes dudas de como participar escribe a [juliana@ndsccenter.org](mailto:juliana@ndsccenter.org).





# Convocatoria de ponencias Convención Anual del NDSC Sacramento, CA Julio 20-23 2017

**Fecha límite de envío: 4 de enero, 2017**

Te invitamos a enviar tu propuesta para ser ponente durante la Convención Anual del NDSC 2017 en la ciudad de Sacramento. Las propuestas serán recibidas hasta el 4 de enero del 2017 para ser consideradas. No todas las propuestas serán aceptadas, y deberán ser aprobadas por el Comité de Programación de la Convención (CPC). Cada año el NDSC recibe un gran número de propuestas; de hecho son más de las que se pueden aceptar.

Buscamos conferencistas con un amplio conocimiento sobre el síndrome de Down y que tengan facilidad para comunicarse con las familias.

El ponente deberá tener disponibilidad para exponer su taller el viernes 21, sábado 22 y el domingo 23 de julio. La disponibilidad durante los días mencionados nos permitirá poder ofrecer una programación más equilibrada, llenando las expectativas de los asistentes. Si no le es posible exponer su taller en las fechas sugeridas entonces le pedimos que no envíe su propuesta. El domingo 23 de julio los talleres terminarán aproximadamente a las 12 del día;



favor de no reservar su vuelo de partida antes de las 3 p.m.

Nota: Si tu propuesta es aceptada y planeas asistir al Simposio Médico DSMIG, no tendrás que exponer un taller el viernes 21 de julio.

Los talleres tendrán una duración de 90 minutos. Las presentaciones deben ser interactivas, prácticas y abarcar las diferentes etapas de la vida de la personas con síndrome de Down.

Por favor, ten en cuenta lo siguiente: Si tu propuesta es aceptada, no existen honorarios o pago alguno para ti. Esta política ha permitido que el NDSC mantenga las tarifas de inscripción a la convención a un costo accesible para los asistentes.

Enlace: <http://bit.ly/2dnLCPy>



## Down Syndrome News

is a benefit of your annual membership in the NDSC.

To renew or join, visit [ndsccenter.org](http://ndsccenter.org).

To update your contact information, call 800-232-6372 or email [info@ndsccenter.org](mailto:info@ndsccenter.org).

When we **empower** individuals and families from all demographic backgrounds, we **reshape** the way people understand and experience Down syndrome.



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## Down Syndrome News

A newsletter published throughout the year  
by the National Down Syndrome Congress

Happy Holidays  
¡Felices Fiestas!



## GRANDPARENTS

Did you know there is a Facebook group – **Grandparents with Grandkids with Down Syndrome (GWGWDS)**? They share stories and offer support, education and information. They are not affiliated with NDSC, but they ask for our input from time to time. Ask to join (but only if you're a grandparent!)

Photo credit: Helena F Portela Fotógrafa