

Down Syndrome News

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NEWSLETTER OF THE



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Raising Awareness of Keratoconus in the Down Syndrome Community

Article provided by Glaukos Corporation - an ophthalmic medical technology and pharmaceutical company focused on novel therapies for the treatment of glaucoma, corneal disorders, and retinal diseases. More information can be found at www.glaukos.com.

Each year, approximately 6,000 babies are born with Down syndrome, and some form of an eye disease is reported in more than 50 percent of the community. Fortunately, these vision issues can often be treated if they are detected early. For this reason, it is recommended that people with Down syndrome, even if they are without symptoms, should see an ophthalmologist every one to two years, sometimes even more frequently.

Vision Issues in People with Special Needs

Experiencing visual changes, such as blurry or distorted vision, can be an unsettling experience for anyone. While everyone processes changes in their health differently, people with special needs, particularly Down syndrome, may have difficulty communicating with caregivers and can be less likely to report changes in vision. Even if a loved one is not complaining of vision challenges, there are small signs that may indicate a problem.



Photo provided by SPECS4US

Any noticeable behavioral changes – holding objects and screens closer to the face or squinting more – may be a sign that they are having some trouble with their vision. It's important to connect with a physician to see if there are any other potential issues or vision changes they should be screening for or monitoring.

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Letter From the President

Dear NDSC Families,

As we approach the end of 2020, I think that we can all agree that this year has been one like no other any of us have ever seen. Although this year has brought us many challenges, it has also brought many triumphs. I could not be prouder to be a part of an organization that does so much for the people who count on us. From the immediate pivot to our first virtual convention to the swift response and creating of webinars to assist parents with the difficult adjustment to digital learning, our team of staff and volunteer board members pulled together to address our member families' needs. We not only worked as a team within our organization, but we also worked with other national organizations to provide the "Q&A on COVID and Down syndrome," an essential resource to the Down syndrome community. We acted quickly to bring together a group of community leaders to provide a platform for open communication around racism as this national issue received much attention this year. Our impact in Washington, D.C., ensured that the rights of people with Down syndrome and other disabilities were protected and that they were cared for properly. This year has brought so many challenges to so many families, but these challenges allowed us to step up for our members like never before. Now, more than ever, we understand that our work is not only important, but it is essential.

The NDSC staff and Convention committee are hard at work planning and preparing for the 49th Annual NDSC Convention

to be held July 8-11 in Phoenix, AZ. We are closely monitoring the latest information around COVID-19 and will make decisions based on what is in the best interest of our members. Thank you to all who completed the first convention survey. Your input helps us in our planning. Be on the lookout for a second survey after the first of the year. We hope you will take a moment to give your feedback so that we may plan for your needs in 2021.



Although we are best known for our annual "Giant Family Reunion," please know that we are here for you 365 days a year to provide resources and support. No matter what lies ahead, know that the NDSC will continue to work with you, and for you, to promote the interests of people with Down syndrome

I wish you and your family a very Happy Holiday, and prosperous and healthy New Year! I hope to see you in 2021. It is my pleasure and privilege to serve you and your family.

Gratefully,

A handwritten signature in blue ink, appearing to read "Shauntel Neal-Howe".

Shauntel Neal-Howe

Raising Awareness of Keratoconus in the Down Syndrome Community Continued from Page 1

Keratoconus and Down Syndrome

Keratoconus, often referred to as 'KC', is an eye condition in which the cornea weakens and thins over time, causing the development of a cone-like bulge and optical irregularity of the cornea. Keratoconus can result in significant visual loss and may lead to corneal transplant in severe cases.

What many people don't know is that research shows 5-15% of people with Down syndrome are affected by keratoconus. With enhancements in diagnostic tools and increasing awareness of keratoconus, more people are being diagnosed earlier and more accurately. Many parents and caregivers aren't aware of keratoconus, and that, combined with a person who is less likely to report vision changes, creates an often-difficult combination. Ultimately, keratoconus can impact an individual's ability to function at their highest level, especially since it is a progressive condition and may continue to affect a person's vision over time.

Standard Vision Testing for People with Down Syndrome

To diagnose vision issues as early as possible, caregivers of children with special needs should schedule yearly (or bi-yearly) eye exams beginning in infancy to monitor any vision changes. By checking a loved one's vision yearly, eye care professionals will be able to notice any abnormalities or changes and take proactive action in treating them.

With a higher prevalence of keratoconus in people with Down syndrome, it's important to talk to an ophthalmologist about keratoconus and request that screenings become part of yearly exams, especially in the teen and early adult years. While keratoconus can be a challenging condition to diagnose and treat, it can be managed with the proper steps. Detecting keratoconus early provides people with a greater number of treatment options, including the chance to slow or halt the progression of the disease.

Diagnostic and Treatment Challenges

Many caregivers of people with Down syndrome are not aware of the prevalence of keratoconus, and how it can impact an individual's ability to function at their highest level. Often, keratoconus goes undiagnosed or even misdiagnosed, resulting in a more progressed stage of the condition. As a result, finding corrective lenses can be a challenge.

If progressive keratoconus is diagnosed, an eye care professional may then struggle to determine the best available treatment option. Historically, invasive treatments – such as a corneal transplant or grafting a cornea – were used. However, people may want to rub their eyes after surgery, which can put the transplant and the eye at risk. Now, there are less invasive options, including FDA-approved corneal cross-linking.

Available Treatment Options

While keratoconus can be a challenging condition, it can be managed effectively when detected early. Contact lenses or glasses can be used to help correct vision, while FDA-approved corneal cross-linking is a non-invasive treatment to slow or halt keratoconus that is progressive. When progressive keratoconus is diagnosed late, a more invasive corneal transplant can be required, which often results in a prolonged recovery time and need for rehabilitation.

Hear from an Expert

Dr. Erin Stahl, a Pediatric Ophthalmologist at Children's Mercy Hospital Kansas City, discusses the unique considerations for families with children who have special needs and keratoconus, specifically how to determine the best treatment options and recovery process.

How can I best prepare my family member with special needs to receive necessary eye tests to determine if they are living with keratoconus?

As a pediatric ophthalmologist, I am very comfortable working with pediatric patients of all abilities and levels of fear surrounding medical visits. There are a few necessary steps in achieving a good eye exam. The first is using one of many techniques to check vision. This ranges from following a lighted toy to checking vision on an eye chart. The next important step is to dilate the pupil with eye drops. After the pupils have been dilated (which takes about 30 minutes so bring something to entertain your loved one) we use special lights and the "red reflex" from the reflection on the back of the eye to determine glasses prescription, and to get a very good view of any corneal irregularities including early and late keratoconus.

If your loved one has done well with these tests which are done with flashlights from about a foot away from the patient, we can move to more measurements. Using a microscope called a slit-lamp we can get a close-up view of the cornea and look for scarring and subtle corneal changes, as well as signs of allergy. If your loved one is comfortable with all of these tests, then we try to obtain measurements of the cornea including a topographic map (corneal topography) and corneal thickness measurements. These tests use machines that do not touch the patient and do not hurt.

In some cases, we get more information from each visit as the patient has less fear with subsequent exams.

You can best prepare your loved one for these tests by telling them that they will get eye drops which will make their vision blurry. You can tell them to expect a number of different flashlights but nothing painful. Many young patients worry that they will get shots or have painful tests at the doctor. As a pediatric ophthalmologist, I have many distraction toys – lighted toys, movies, moving animals and stickers. Many think a trip to the eye doctor is pretty fun!

My loved one has Down syndrome and keratoconus. What do we need to take into consideration when looking into treatment options?

Pediatric ophthalmologists are very experienced in working with all children and

adolescents. There are also adult eye doctors who work often with these age groups. Children and adolescents with special needs should be cared for by someone who is comfortable examining young patients and have the tools in their office to make the exam fun and easy.

One of the most limiting factors in choosing a treatment option is the availability for different levels of sedation during the treatment. Most patients with special needs will need sedation for corneal cross-linking treatment. The procedure takes about an hour, so sedation can be needed to ensure the patient is calm and has no pain or discomfort during the procedure. Anesthesia for the procedure can range from topical numbing drops to general anesthesia. Pediatric anesthesia is safest when done by pediatric anesthesiologists in a monitored setting. These decisions are made with your family depending on the needs of your loved one.

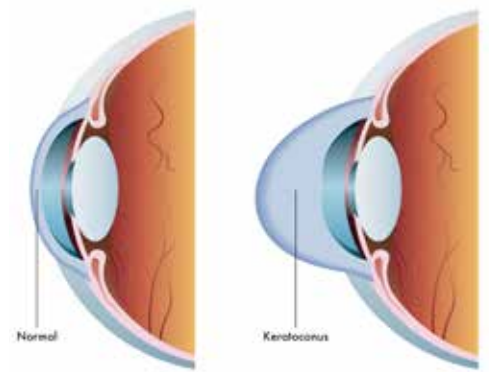
What is the best way to help my loved one with special needs prepare for and recover from the cross-linking procedure?

Corneal cross-linking, approved for patients 14-65 years of age, can cause post-operative light sensitivity and discomfort. There are many steps we can take to reduce these symptoms. In more cooperative patients, a contact lens will be placed and removed in clinic 3 days after surgery. This lens acts like a bandage and reduces pain. In more fearful patients, a dissolvable contact lens can be placed on the eye and does not need to be removed after surgery.

Gel ice packs can be applied to the eyelid after the procedure to reduce pain and can be very effective in reducing pain if your loved one will allow placement. Tylenol and ibuprofen can also be helpful to reduce discomfort.

As the eye heals after the procedure, it is important that your loved one does not rub their eye. We tape a clear shield over the eye and most patients leave it in place. Glasses and sunglasses can take the place of the shield if your loved one prefers. We ask that the shield stay on for 3 days after surgery. It is not typical for a patient to rub the eye after surgery because it hurts more when touched.

Prepare a semi-dark room for your loved one to rest for 2-3 days after surgery. TVs and iPads may be too bright to tolerate during healing so have music, read-aloud stories, or other activities available that do not require bright lights. Plan for your loved one to stay indoors for the first few days to avoid direct sunlight. After this healing period your loved one should not have persistent eye pain and typically go back to their regular activities within 1 week.



Jennifer Leigh Stone

Jennifer Leigh Stone, or as her family and friends call her, Jenny, lives in Fort Worth, Texas, where she is surrounded by a loving, supportive family. She loves that her entire family lives in this area, especially her three beautiful nieces, who are the light of her life. They are her brother's daughters, and they love their aunt Jenny as much as she loves them. Jenny has just one biological sibling, but her cousin Courtney is like a sister to her. Jenny and Courtney grew up together, spending lots of birthday parties, family celebrations, and vacations together.

Jenny will tell you that Courtney has always been her inspiration, but everyone who knows them knows that Jenny was the reason that Courtney chose to be a special education teacher and now works with children with Down syndrome.

Jenny had a great childhood. She and her brother picked on and bugged each other as siblings do. Jenny attended elementary, middle school, and high school in Saginaw, Texas, where she participated in general education and special education classrooms. As part of her preparation for graduation, Jenny spent time exploring a variety of jobs. She had the opportunity to work in hotels, restaurants, and cafeterias, but when she was sent on an assignment at a preschool, Jenny knew she had found her passion. She learned to be a teacher assistant, and when she graduated from high school, she was offered a part-time position. Post-graduation, Jenny attended a two year junior college and eventually landed her dream job. She has been employed for 18 years as a teacher assistant at KinderFrogs School at Texas Christian University. Working with the children, and helping the teacher with whatever she needs (making snacks, picking up toys, reading) brings Jenny great joy. She says, "The children love me, and I love them so much. It is the best job in the world!"

Jenny takes every opportunity to serve her passion for working

with young children. She has also turned her love for dancing into a chance to work with children as a teacher assistant at Encore School of Dance No Boundaries class. Jenny also loves to listen to music, sing karaoke, go to the movie or bowling, play video games, and hang out with family and friends. She also loves art and loves to show off her artistic talent by designing stickers!

Jenny also likes to travel. She has been to Disney World, Disney Land, Universal Studios, has been on several cruises, and has visited New York, Hawaii, and Las Vegas. But, one of her favorite things to do is to go to the Backstreet Boys concerts! Jenny's travels have also taken her to the NDSC Convention for more than 15 years. Jenny's aunt introduced her to NDSC when she took Jenny to her first NDSC Convention. Jenny attended the Youth & Adults Conference and was hooked! Since then, she has been joined at the convention by her mom, her aunt, cousins, and other family members.



Postsecondary Accreditation Program Standards Announced

The National Coordinating Center Accreditation Workgroup, chaired by NDSC Senior Policy Advisor Stephanie Smith Lee, has revised the Model Accreditation Program Standards for Higher Education Programs for Students with Intellectual Disability (ID). The standards are the culmination of ten years of work by this Congressionally-mandated workgroup that will lead to improved postsecondary opportunities for students with ID as well as program accountability. These program accreditation standards have been created, vetted, and refined through rigorous field-testing and extensive public input. Students with Down syndrome and their families have provided input on the standards through surveys, webinars, and input sessions at NDSC Conventions. To learn more, and read the new standards, see "Assuring Quality in Inclusive Higher Education Program Accreditation Standards" on the Think College website at www.ThinkCollege.net.



Policy & Advocacy in Action

The NDSC Policy & Advocacy Team, based in Washington, D.C, advocates for equal rights and improved opportunities for people with Down syndrome and their families throughout the lifespan in the areas of education (pre-K-12), postsecondary education, health care, Medicaid, employment, financial empowerment and community inclusion and supports. Our Policy Team is comprised of disability policy professionals who are experienced, well-connected, and highly regarded national subject matter policy experts and leaders who engage with policymakers on a bipartisan basis and educate and empower stakeholders to speak up for policies that will improve the lives of individuals with Down syndrome and their families.

Since the COVID-19 pandemic began, NDSC has been working to protect the rights of individuals with disabilities and to obtain funding and resources to support them across many areas. During COVID-19, NDSC has been advocating to:

- **Increase funding and resources for Medicaid Home and Community-based Services (HCBS) providers who are faltering and collapsing due to COVID-related closures. HCBS are vital to individuals with disabilities to help them maintain their independence and access to the community.**
- **Secure resources for Direct Support Professionals (DSPs) and provider agencies, and designate DSPs as essential workers, so they have access to personal protective equipment when assisting people with disabilities.**
- **Increase funding for implementation of the Individuals with Disabilities Education Act (IDEA) in schools to support students with disabilities during virtual learning and protect their IDEA rights;**
- **Prevent COVID-related medical rationing that discriminates against people with disabilities and to change hospital visitation policies so that people with disabilities can have a support person with them;**
- **Expand paid leave to caregivers of people with disabilities who need to stay home due to COVID; and**
- **Expand payment of COVID stimulus checks (dependent credit of \$500) to taxpayers who claim dependents over age 18 with disabilities.**

To advocate for this agenda, the NDSC Policy Team relies heavily on our National Down Syndrome Advocacy Coalition members, which we refer to as NDAC. NDAC is a grassroots advocacy service designed to educate individuals with Down syndrome, their family members, and other allies about policy issues and provide the advocacy tools and techniques they need to engage with their legislators to effectively advocate for change. With this program, we bring together advocates of all abilities and levels of experience from across the country who have a passion for the Down syndrome community. Through NDAC's education, training opportunities, and engagement on social media, we have cultivated a broad coalition of advocates who will effectively engage with lawmakers, agencies, and other key decision-makers to promote policy change.

We currently have over 450 individual NDAC members and 45 group NDAC members who represent 48 states. If you are interested in joining NDAC, please submit a simple application online on the NDSC website. We welcome advocates of all levels and abilities to join NDAC.

The Policy Team has been busy hosting various webinars, providing training, and sharing resources. Presentations included:

- **the 3rd annual Advocacy Training Boot Camp during our Convention From Your Couch virtual convention**
- **the Your Voice, Your Vote- What to Know Before Your Cast Your Ballot webinar that was part of NDSC's voter engagement campaign**
- **Back to School or Not? Understanding Your Options**
- **No Discrimination in Health Care Rationing**
- **Take a Deep Breath: IDEA Implementation During COVID-19**
- **NDAC Briefings on COVID-19**

If you missed any of these webinars, links to recordings of these presentations are available on the NDSC website.



Caption: (L to R) Heather Sachs, NDSC Policy & Advocacy Director, Ricki Sabia, NDSC Senior Education Policy Advisor, Stephanie Smith Lee, NDSC Senior Policy Advisor.

Accepting Nominations for NDSC Board of Directors



BOD Nominations

The NDSC Board is made up of individuals of various backgrounds and connections to the Down syndrome community. Our members elect NDSC board members each year at the annual General Membership meeting. Those elected serve a three-year term with a limit of three consecutive terms for a possible total of nine years. Self-advocate board members are elected by their peers and serve only one 3-year term but are lifetime members of the NDSC Self-Advocate Council (SAC).

Expectations of Board members include:

- **an annual gift to the NDSC**
- **attendance at two meetings per year. Ideally, both meetings are held in the upcoming convention host city, with the winter meeting in January and the other held the week of the convention**
- **service on one or more committees and/or strategic teams who meet by conference call periodically**
- **active commitment to the overall mission of the NDSC**
- **participation in NDSC events, fundraisers, and overall messaging of NDSC priorities**

If you are interested in making a difference in the Down syndrome community and would like to be considered by the Nominating Committee for a Board position, please visit www.ndscenter.org and search Board to access our online nomination form.



NDSC's Involvement with the National Technical Assistance Center on Inclusive Practices and Policies (TIES)

TIES Center is the federally funded center on inclusive practices and policies for students with significant cognitive



disabilities. NDSC Senior Education Policy Advisor, Ricki Sabia, is the parent liaison for this center. In that role, Ricki co-authors parent briefs that can be found under the parent tab on the TIES Center website. She also reviews and provides feedback on the many other resources developed by TIES, including materials for educators to use directly with their students and materials to create systems change at the state and district level. Recognizing that inclusion during the COVID-19 pandemic means meaningful participation in the general education curriculum that is being offered remotely in many places, TIES is creating unique distance learning resources to support students with significant cognitive disabilities. All of the resources discussed above can be found via links on the TIES Center website's landing page at tiescenter.org.

Reminder—Down Syndrome News is Going Digital in 2021

This is the last edition of the Down Syndrome News that will be mailed. *Down Syndrome News* was created as a benefit of paid membership. The NDSC Board of Directors decided last year that we would no longer charge for membership. We made this decision so to eliminate all barriers to membership. We wanted to ensure that no one feels excluded from our family for any reason, including finances. Eliminating annual membership fees also meant eliminating the hard copy of *Down Syndrome News*. **No need to worry, though—all future publications and archived editions can be found on the NDSC website at ndscenter.org under the News & Events tab at the top of the home page.**





Accepting 2021 Award Nominations

Each year we honor the individuals and organizations whose achievements, service, and contributions to the Down syndrome community are exemplary. If you know of an individual or organization that you feel is deserving of consideration for one of the 2021 NDSC awards, please nominate them through our online nomination form found on the NDSC website.

Nominations may be submitted by any person or organization. All nominations will be reviewed by the NDSC Board of Directors. Consideration will not necessarily be restricted to those programs or individuals but may consider reports of outstanding achievement from other sources and may, on its own initiative, select award recipients. Nomination forms and supporting materials should be submitted by mail, email, or fax to the NDSC Center by January 15, 2021. Awards winners will be notified prior to the 2021 NDSC Convention with awards being presented at the 49th Annual NDSC Convention.

Award Categories

Exceptional Meritorious Service Award

This award recognizes an individual whose service and contributions to people with Down syndrome and their families have had local, state and national significance.

Employer of the Year Award

This award recognizes an employer for efforts in creating employment opportunities for people with Down syndrome.

Christian Pueschel Memorial Citizen Award

This award recognizes an individual with Down syndrome whose achievements, service and contributions have enhanced the value and dignity of people with Down syndrome and their families.

Sig Pueschel NDSC Service Award

This award recognizes an individual or organization for outstanding contributions to the NDSC.

National Parent Group Award

This award recognizes an affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with Down syndrome 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

This award recognizes research, which has contributed to greater knowledge and understanding of Down syndrome and has improved the lives of people with Down syndrome or their families.

AWARD GUIDELINES

- Does the program, publication, or individual promote a positive image of people with Down syndrome?
- Does it accentuate abilities, not disability?
- Does it focus on people, not on the condition of Down syndrome?
- Does it celebrate diversity?
- Does it use people-first language?
- Does it enhance the dignity of people with Down syndrome?
- Does it avoid stereotyping?
- Does it present accurate information?
- Does it recognize the value of the person with Down syndrome?

National Media Award

This award honors outstanding national media efforts, which create better understanding of Down syndrome and people with Down syndrome. The award recognizes programs on television, documentaries, feature films, national publications, serials, syndicated columns and social media. National Media Awards may be presented for the categories of film, print and online. The media efforts must have been broadcast or published within the last calendar year.

Education Award

This award recognizes outstanding performance on behalf of students with Down syndrome. Nominees will be judged by their demonstrated leadership and innovation in creating or advancing best educational practices for students with Down syndrome.

Strategies for Adapting to COVID-19

Dennis McGuire Ph.D.

COVID-19 stay-at-home orders and lockdowns, which limit social contact with family, friends, peers, as well as school and work activities, have created challenges for sons and daughters with Down syndrome.

Families are concerned about a loss of expressive language, particularly as there are far fewer opportunities to talk to others outside the home. They report that their children (of any age) talk far less and use single words if they talk at all. Many parents wonder if this is an indication of a mental illness or a major regression in skills. But it's important to remember that verbal speech is not easy or safe for people with Down syndrome, even in the best of circumstances. They want to please and to say things right, but talking is fraught with many hazards. We call this reluctance to talk "Taking the fifth" because they often want to avoid being wrong.

To encourage expressiveness, remember that individuals with Down syndrome are far more comfortable with mediums that are concrete and visual. This may include drawing, painting, or coloring. The written word is still visual, so note-writing in journals can absolutely work. The expression "a picture is worth a thousand words" is especially true for people with Down syndrome. Therefore, encouraging them to take pictures with phones or iPads may allow them to more easily express a need, thought, or feeling when verbal expression is difficult. It may also be advantageous to try acting out a need or concern through role play. People with Down syndrome are incurable hams; they love drama. Use it to help them communicate. Listen carefully to the self-talk they express in their own bedroom or private space, as it may allow them to speak or act out what they cannot verbalize to you.

With COVID-19, there has also been a noted increase in less productive 'grooves' or "OCD-type" behaviors. Minor examples include sitting in the same seat at dinner or not allowing different foods to touch on their plate. But grooves/compulsions can be a problem if they interfere with essential activities. Someone with Down syndrome may get stuck arranging things over and over, such as items on their desk or in a closet, to the detriment of any other activities. At the very least, these grooves may keep people from attending beneficial activities such as an online dance, family gathering, or a painting class. At worst, a compulsive groove may keep people from doing essential activities, resulting in a regression in skills.

Should parents "disrupt" the rigid positioning of things, the rigid schedules, or compulsive behaviors? Remember, OCD-groove-like-behaviors are a key way to express (and even



manage) stress. Assess if the repetitious behavior is a real problem or truly interferes in essential activities. If it does **not**, then you may need to be tolerant (even if it drives you a little crazy). If it **does** interfere or **prevents** needed flexibility, try starting with the stuck pattern or behavior and gently moving it to something more productive. We found that trying to stop groove/compulsive behavior is like trying to stop a river. It's much better to go with the flow and then redirect through the use of visual cues, to which people with Down syndrome are very responsive. For example, instead of spending a morning playing video games or arranging items compulsively, give them a picture and/or word checklist of beneficial (but also fun and entertaining) activities, with a small but effective reward as an incentive. The visual picture or image may be a powerful incentive in-and-of-itself. Calendars are also a very useful means for changing routines. People can see and plan activities in a format that is a strength (concrete and visual) over the period of a day, week, or month depending on the calendar. It is best if these schedules or calendars are created with or by the person with Down syndrome, so they can make it their own.

Related to stuck grooves and routines is a concern that those who had a busy schedule before COVID-19 may have difficulty adapting to the re-entry into normal school, work, and social activities. Having established a groove at home, how are they to move back to a more active life? Again, any change is difficult for people with Down syndrome (just as it is for most

Thank You to All Who Attended the NDSC Soiree of Stars Gala

On October 22, we hosted the inaugural NDSC Soiree of Stars Virtual Gala. It was an incredible evening that allowed us to shine a light on the event's honorees; individuals, organizations, and corporations making a difference in the Down syndrome and their own communities. The highlight of the evening was when we honored three self-advocate Everyday Heroes, Todd Fuller, Gracie Eudy, and Christopher Drewniak, for performing essential jobs in their communities during the COVID-19 pandemic.

There were special guest appearances by Clemson Football Head Coach, Dabo Swinney, Ludacris, Dale Murphy, Tim Tebow, and Broadway's Neil Berg and Rita Harvey debuted their latest compilation. NDSC's Daniel Chaplin interviewed Felicia Patti from the Netflix hit show "Away," and Mary Warm interviewed the honoree in the Individual category, Meria Carstarphen. We also caught up with the cast of "Born This Way" in an exclusive interview with the whole gang.

If you could not attend the live event, you can see the recorded show on our YouTube channel.



of us over 25). But it is important to remember that most people with Down syndrome are like anyone else in that most want to be active, social, and successful at home or school. I would then suggest "gradual re-entry" using any aids available such as the visual schedule and calendars or role-play, to reinforce positive behavior. Use of a calendar will often result in your family member with Down syndrome reminding you of an activity and not the other way around. Still, it may take extra time and patience by all involved to return to life as it was pre-COVID-19.

For some, there is also an increase in isolation and solitary play, coupled with a resistance to socialize with family or friends, either virtually or in person. It is important to note here that even before COVID-19, we found people with Down syndrome would tend to "make an appearance" for family gatherings but then leave to go back to their rooms or individual activities. The challenge with staying at home is getting creative with activities so as to virtually socialize in ways that work for the person with Down syndrome. Perhaps it may help to have them set up the Zoom or FaceTime meetings, or even try creative in-person activities, such as picnics or movies outside while maintaining safe distancing and limited numbers of people.

A further concern is that many have made great strides in establishing independence with teachers, employers, and peers pre-COVID-19, only to lose the opportunity to "spread their wings" as parents once again become their primary teachers, friends, and playmates. The problem then is not the type of activities they engage in but the need to branch out of the home to do these activities. Again, this may take some creativity, such as Zoom/FaceTime or safe gatherings with peers, siblings or extended family, and eventually others in the community; once COVID-19 is over. However, as noted above, change is difficult and opportunities are limited. While

COVID-19 still exists, one or two in-person or online Zoom contacts may suffice.

As the restrictions for work, school, and social gatherings continue, many parents have also reported an increase in frustration and anger directed at them from their family member with Down syndrome. This may be particularly problematic when parents are forced back into roles as rule makers and guardians with individuals who have made progress "doing for themselves" and being more independent in the community prior to COVID-19. Wearing masks can become a particular source of this anger and contention with parents, which may put people at risk for the virus when in public. Thus, the very people who care the most (parents and family members) become the villains. What to do? We found that there is often a person or persons with great influence on the individual with Down syndrome and who may be called upon to reduce their animosity. This may be an older sibling that is looked up to, a favorite grandparent or godparent, or a special teacher or supervisor. These are all people who can say things that have an impact when parents influence is "blown." This may be an online or in-person visit with the person of influence who is wearing a mask and discusses how hard this has been for them while emphasizing that they themselves are soldiering on, and so can the person with Down syndrome.

Finally, one of the most valuable resources you may have as a family is support and advice from other families. No one knows the challenges like another family with a family member with Down syndrome. Of course, it may require some effort to reach out to local parent groups or families with who you have been in contact over the years. But we have found that people are very open to Zoom or FaceTime meetings and may just lack the opportunity or invitation to do so. Creating that opportunity yourself might be the extra support you need in these difficult times.

**SAVE
the
DATE**

SUNDAY, MARCH 21, 2021
 NATIONAL DOWN SYNDROME CONGRESS
4th ANNUAL
 ALL KINDS OF HEROES
 GOLF CLASSIC

2021 NDSC All Kinds of Heroes Golf Classic

We are happy to announce that we will be hosting the 2021 NDSC All Kinds of Heroes Golf Classic at the beautiful Bear's Best – Atlanta Golf Course on World Down Syndrome Day, Sunday, March 21.

Look for details and registration to open in early 2021.

 **NATIONAL
DOWN SYNDROME
CONGRESS**

Town Hall Meeting on
Race Relations:

**CONTINUING
THE
CONVERSATION**

Continuing the Conversation

We are planning our next Town Hall on Race Relations for early 2021, as we continue the conversation with affiliate leaders from around the country. We know we can all do better and that we are all better together.



NDSC's Center for Outreach & Education Expands to Better Serve YOU!

Ages & Stages is here to support your family across the lifespan. Whether you are a new or expectant parent, preparing for your next IEP meeting, finding your way through the teenage years and beyond, or a self-advocate we've got you covered.

We have been busy at work, reorganizing and adding to the accurate and up-to-date information we have always provided for families and the professionals who serve the Down syndrome community. You will find Ages & Stages our website when you visit the "Programs & Resources" tab. In addition to our "COVID-19" and "Race Relations" resource libraries, we have arranged documents and articles by each age or stage you are navigating through or towards. If you can't find what you are looking for, you can call the Center and we will help!

Next, we will be bringing you Ages & Stages webinars, as well as opportunities to share and network with your peers.

Our Ages & Stages icons will help guide you to what you are looking for:



Birth - 2



3-5



Elementary



Tweens & Teens



Transition



40 Plus



DS-ASD



Self-Advocate

Concienciación del Queratocono en la comunidad del síndrome de Down

Cada año, aproximadamente 6,000 bebés nacen con síndrome de Down y se informa de alguna forma de enfermedad ocular en más del 50 por ciento de la comunidad. Afortunadamente, estos problemas de la visión a menudo pueden ser tratados si se detectan a tiempo. Por este motivo, se recomienda que las personas con síndrome de Down, aunque no presenten síntomas, consulten a un oftalmólogo cada uno o dos años, a veces incluso con mayor frecuencia.

Problemas de visión en personas con necesidades

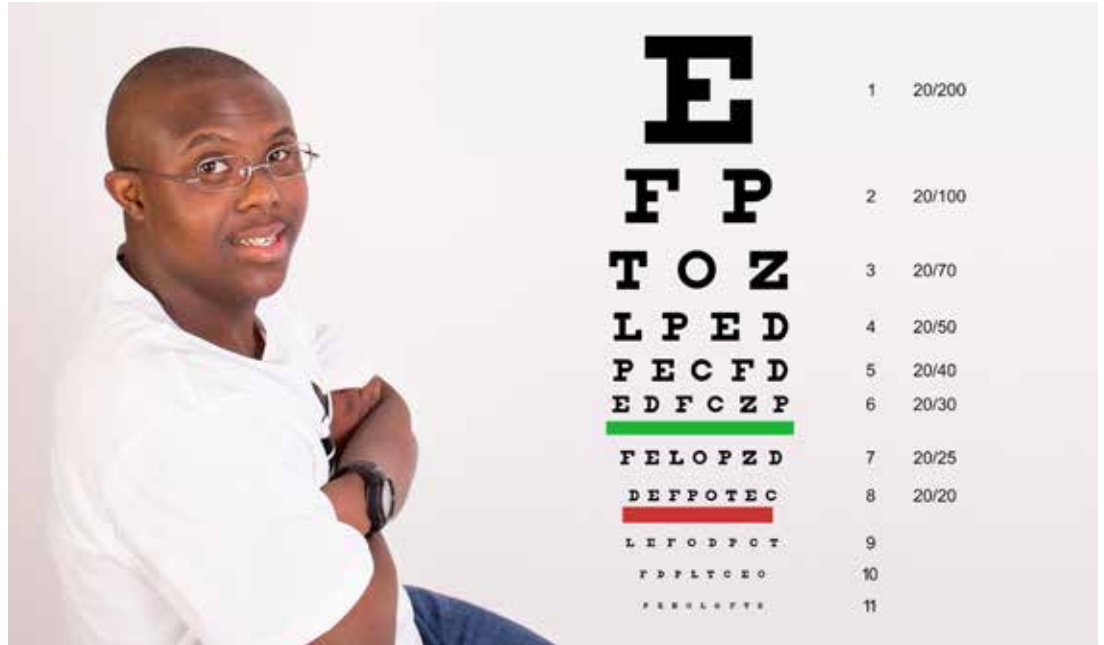
Experimentar cambios visuales, como la visión borrosa o distorsionada, puede ser una experiencia inquietante para cualquiera. Si bien cada persona procesa los cambios en su salud de manera diferente, las personas con necesidades especiales, en particular con el síndrome de Down, pueden tener dificultades para comunicarse con los cuidadores y es menos probable que informen sobre los cambios en la visión. Aunque un ser querido no se queje de problemas de visión, hay señales pequeñas que pueden indicar un problema.

Cualquier cambio de comportamiento notable - sostener objetos y pantallas más cerca de la cara o entrecerrar más los ojos - puede ser una señal de que están teniendo algún problema con su visión. Es importante ponerse en contacto con un médico para ver si hay otros posibles problemas o cambios en la visión que deberían detectar o controlar.

El Queratocono y el síndrome de Down

El queratocono, a menudo llamado "KC", es una condición ocular en la que la córnea se debilita y se adelgaza con el tiempo, causando el desarrollo de un abultamiento en forma de cono y una irregularidad óptica de la córnea. El queratocono puede resultar en una pérdida visual significativa y puede llevar a un trasplante de córnea en casos severos.

Lo que mucha gente no sabe es que las investigaciones muestran que entre el 5 y el 15% de las personas con síndrome de Down están afectadas por el queratocono. Con las mejoras en las herramientas de diagnóstico y el aumento de la conciencia de queratocono, más personas están siendo diagnosticadas más temprano y con mayor precisión. Muchos padres y cuidadores no están conscientes del queratocono, y eso, combinado con una persona que es menos probable que reporte cambios en la visión, crea una combinación a menudo difícil. En última instancia, el queratocono puede impactar la habilidad de un individuo para funcionar a su nivel más alto, especialmente porque es una condición progresiva y puede continuar afectando la visión de una persona con el tiempo.



Pruebas de visión estándar para personas con síndrome de Down

Para diagnosticar los problemas de visión lo antes posible, los cuidadores de niños con necesidades especiales deben programar exámenes oculares anuales (o bianuales) desde la infancia para controlar cualquier cambio en la visión. Al revisar la visión de un ser querido anualmente, los profesionales de la visión podrán notar cualquier anomalía o cambio y tomar medidas proactivas para tratarlos.

Con una mayor prevalencia de queratocono en personas con síndrome de Down, es importante hablar con un oftalmólogo sobre el queratocono y solicitar que las pruebas de detección formen parte de los exámenes anuales, especialmente en la adolescencia y en los primeros años de la edad adulta. Si bien el queratocono puede ser una condición difícil de diagnosticar y tratar, se puede controlar con los pasos adecuados. La detección temprana del queratocono ofrece a las personas un mayor número de opciones de tratamiento, incluida la posibilidad de retrasar o detener la progresión de la enfermedad.

Desafíos de diagnóstico y tratamiento

Muchos de los cuidadores de personas con síndrome de Down no son conscientes de la prevalencia del queratocono y de cómo puede afectar a la capacidad de un individuo para funcionar a su nivel más alto. A menudo, el queratocono no se diagnostica o incluso se diagnostica mal, lo que resulta en una etapa más avanzada de la condición. Como resultado,

encontrar lentes correctivos puede ser un desafío.

Si se diagnostica un queratocono progresivo, un oculista puede tener dificultades para determinar la mejor opción de tratamiento disponible. Históricamente, los tratamientos invasivos - como un trasplante de córnea o el injerto de una córnea - se utilizaban. Sin embargo, las personas pueden querer frotarse los ojos después de la cirugía, lo que puede poner en riesgo el trasplante y el ojo. En la actualidad, existen opciones menos invasivas, como el reticulado corneal aprobado por la FDA.

Opciones de tratamiento disponibles

Si bien el queratocono puede ser una condición difícil, puede ser manejado eficazmente cuando se detecta a tiempo. Se pueden usar lentes de contacto o gafas para ayudar a corregir la visión, mientras que el reticulado corneal aprobado por la FDA es un tratamiento no invasivo para desacelerar o detener el queratocono que es progresivo. Cuando el queratocono progresivo se diagnostica tarde, se puede requerir un trasplante de córnea más invasivo, que a menudo resulta en un tiempo de recuperación prolongado y la necesidad de rehabilitación.

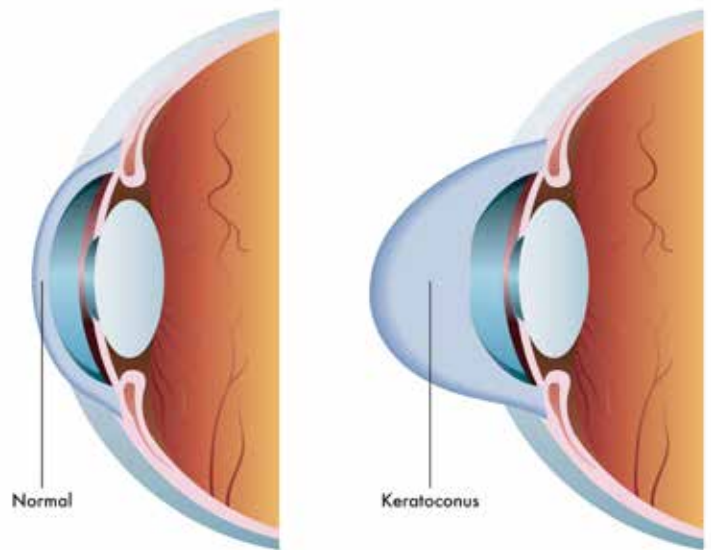
Escuche de un experto

La Dra. Erin Stahl, oftalmóloga pediátrica del Children's Mercy Hospital de Kansas City, habla de las consideraciones únicas para las familias con niños que tienen necesidades especiales y queratocono, específicamente cómo determinar las mejores opciones de tratamiento y el proceso de recuperación.

¿Cómo puedo preparar mejor al miembro de mi familia con necesidades especiales para que se haga las pruebas oculares necesarias para determinar si está viviendo con queratocono?

Como oftalmólogo pediátrico, me siento muy cómodo trabajando con pacientes pediátricos de todas las habilidades y niveles de miedo que rodean a las visitas médicas. Hay algunos pasos necesarios para lograr un buen examen de la vista. El primero es usar una de las muchas técnicas para revisar la visión. Esto va desde seguir un juguete iluminado hasta revisar la visión en una tabla de ojos. El siguiente paso importante es dilatar la pupila con gotas para los ojos. Después de que las pupilas se han dilatado (lo que toma unos 30 minutos, así que traiga algo para entretener a su ser querido) utilizamos luces especiales y el "reflejo rojo" del reflejo en la parte posterior del ojo para determinar la graduación de los anteojos, y para obtener una muy buena visión de cualquier irregularidad de la córnea, incluyendo el queratocono temprano y tardío.

Si a su ser querido le ha ido bien con estas pruebas que se hacen con linternas a un pie de distancia del paciente, podemos pasar a más mediciones. Usando un microscopio llamado lámpara de hendidura podemos obtener una vista cercana de la córnea y buscar cicatrices y cambios sutiles en la córnea, así como signos de alergia. Si su ser querido se siente cómodo con todas estas pruebas, entonces tratamos de obtener mediciones de la córnea incluyendo un mapa



topográfico (topografía corneal) y mediciones del grosor de la córnea. Estas pruebas utilizan máquinas que no tocan al paciente y no le hacen daño.

En algunos casos, obtenemos más información de cada visita ya que el paciente tiene menos miedo con los exámenes posteriores.

La mejor manera de preparar a su ser querido para estas pruebas es diciéndole que le pondrán gotas en los ojos que le harán la visión borrosa. Puede decirles que esperen varias linternas diferentes pero nada doloroso. A muchos pacientes jóvenes les preocupa que les pongan inyecciones o que les hagan pruebas dolorosas en el médico. Como oftalmólogo pediátrico, tengo muchos juguetes de distracción - juguetes iluminados, películas, animales en movimiento y calcomanías. Muchos piensan que un viaje al oftalmólogo es muy divertido!

Mi ser querido tiene síndrome de Down y queratocono. ¿Qué tenemos que tener en cuenta al considerar las opciones de tratamiento?

Los oftalmólogos pediátricos tienen mucha experiencia en el trabajo con todos los niños y adolescentes. También hay oftalmólogos de adultos que trabajan a menudo con estos grupos de edad. Los niños y adolescentes con necesidades especiales deben ser atendidos por alguien que se sienta cómodo examinando a los pacientes jóvenes y que tenga las herramientas en su consultorio para que el examen sea divertido y fácil.

Uno de los factores más limitantes a la hora de elegir una opción de tratamiento es la disponibilidad de diferentes niveles de sedación durante el tratamiento. La mayoría de los pacientes con necesidades especiales necesitarán sedación para el tratamiento de reticulación corneal. El procedimiento dura aproximadamente una hora, por lo que la sedación puede ser necesaria para asegurar que el paciente esté tranquilo y no tenga dolor o molestias durante el procedimiento. La anestesia para el procedimiento puede variar desde gotas anestésicas tópicas hasta anestesia general. La anestesia pediátrica es más segura cuando la realizan anesthesiólogos

Concienciación del Queratocono en la comunidad del síndrome de Down

pediátricos en un entorno controlado. Estas decisiones se toman con su familia dependiendo de las necesidades de su ser querido.

¿Cuál es la mejor manera de ayudar a mi ser querido con necesidades especiales a prepararse y recuperarse del procedimiento de cross-linking?

El reticulado de la córnea, aprobado para pacientes de 14 a 65 años de edad, puede causar sensibilidad a la luz y molestias postoperatorias. Hay muchos pasos que podemos tomar para reducir estos síntomas. En pacientes más cooperativos, se colocará y retirará un lente de contacto en la clínica 3 días después de la cirugía. Este lente actúa como un vendaje y reduce el dolor. En pacientes más temerosos, un lente de contacto disoluble puede ser colocado en el ojo y no necesita ser removido después de la cirugía.

Se pueden aplicar bolsas de hielo de gel en el párpado después del procedimiento para reducir el dolor y pueden ser muy eficaces para reducir el dolor si su ser querido permite la colocación. El Tylenol y el ibuprofeno también pueden ser útiles para reducir las molestias.

Mientras el ojo se cura después del procedimiento, es importante

que su ser querido no se frote el ojo. Ponemos un protector transparente sobre el ojo y la mayoría de los pacientes lo dejan en su lugar. Los anteojos y las gafas de sol pueden reemplazar al protector si su ser querido lo prefiere. Pedimos que el escudo permanezca puesto durante 3 días después de la cirugía. No es típico que un paciente se frote el ojo después de la cirugía porque le duele más al tocarlo.

Prepare una habitación semioscura para que su ser querido descanse durante 2 o 3 días después de la cirugía. Los televisores y iPads pueden ser demasiado brillantes para tolerar durante la recuperación, así que tenga a mano música, historias de lectura en voz alta u otras actividades que no requieran luces brillantes. Planifique que su ser querido permanezca en el interior durante los primeros días para evitar la luz solar directa. Después de este período de curación, su ser querido no debe tener dolor persistente en los ojos y normalmente vuelve a sus actividades regulares en una semana.

Para más información sobre el queratocono, o para encontrar un médico cerca de usted, visite LivingwithKeratoconus.com.

Mensaje del Presidente

Queridas familias del NDSC,

A medida que nos acercamos a finales de 2020, creo que todos podemos estar de acuerdo en que este año ha sido uno como ningún otro que ninguno de nosotros haya visto nunca. Aunque este año nos ha traído muchos desafíos, también ha traído muchos triunfos. No podría estar más orgullosa de formar parte de una organización que hace tanto por las personas que cuentan con nosotros. Desde el pivote inmediato a nuestra primera convención virtual hasta la rápida respuesta y la creación de seminarios web para ayudar a los padres con la difícil adaptación al aprendizaje digital, nuestro equipo de personal y miembros voluntarios de la junta se unieron para atender las necesidades de nuestras familias miembros. No sólo trabajamos en equipo dentro de nuestra organización, sino que también trabajamos con otras organizaciones nacionales para proporcionar las "Preguntas y Respuestas sobre COVID y el síndrome de Down", un recurso esencial para la comunidad del síndrome de Down. Actuamos con rapidez para reunir a un grupo de líderes comunitarios para proporcionar una plataforma de comunicación abierta en torno al racismo, ya que esta cuestión nacional recibió mucha atención este año. Nuestro impacto en Washington, D.C., aseguró que los derechos de las personas con síndrome de Down y otras discapacidades fueran protegidos y que fueran atendidos adecuadamente. Este año ha traído tantos desafíos a tantas familias, pero estos desafíos nos permitieron dar un paso adelante para nuestros miembros como nunca antes. Ahora, más que nunca, entendemos que nuestro trabajo no sólo es importante, sino que es esencial.

El personal del NDSC y el comité de la Convención están trabajando duro planificando y preparando la 49 Convención Anual del NDSC que se celebrará del 8 al 11 de julio en Phoenix, AZ. Estamos siguiendo de cerca la última información sobre COVID-19 y tomaremos decisiones basadas en lo que sea más conveniente para nuestros miembros. Gracias a todos los que completaron la primera encuesta de la convención. Sus aportaciones nos ayudan en nuestra planificación. Estén atentos a una segunda encuesta después del primer del año. Esperamos que se tomen un momento para dar su opinión para que podamos planear sus necesidades en 2021.

Aunque se nos conoce mejor por nuestra "Reunión Familiar Gigante" anual, por favor sepan que estamos aquí para ustedes los 365 días del año para proporcionarles recursos y apoyo. No importa lo que venga, sepan que el NDSC continuará trabajando con ustedes y para ustedes para promover los intereses de las personas con síndrome de Down.

¡Le deseo a usted y a su familia unas muy felices fiestas y un próspero y saludable año nuevo! Espero verlos en el 2021. Es un placer y un privilegio servirle a usted y a su familia.

Shauntel Neal-Howe



Nominaciones para la Junta Directiva

La Junta Directiva de NDSC esta compuesta por individuos de diferentes origines y conexiones con la comunidad del síndrome de Down. Los miembros de la organización eligen a los miembros de la junta del NDSC cada año en la reunión anual de miembros generales. Los elegidos sirven por un período de tres años con un límite de tres períodos consecutivos para un posible total de nueve años. Los miembros del Consejo de Auto-Abogacía son elegidos por sus compañeros y sirven sólo por un período de 3 años, pero son miembros vitalicios del Consejo de Auto-Abogacía del NDSC.

Las expectativas de la Junta de cada miembro incluyen:

- **Un regalo anual para el NDSC**
- **asistencia a dos reuniones por año. Lo ideal sería que ambas reuniones se celebraran en la ciudad anfitriona de la próxima convención, con la reunión de mitad de año en enero y la otra celebrada la semana de la convención**
- **servicio en uno o más comités y/o equipos estratégicos que se reúnen periódicamente por teleconferencia**
- **compromiso activo con la misión general del NDSC**
- **participation in NDSC events, fundraisers, and overall messaging of NDSC priorities**

Si está interesado en marcar la diferencia en la comunidad del síndrome de Down y le gustaría ser considerado por el Comité de Nominaciones para un puesto en la Junta, por favor visite www.ndsccenter.org y busque Junta para acceder a nuestro formulario de nominación en línea.



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.

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



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