

Down Syndrome News

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FIRST QUARTER 2019

NEWSLETTER OF THE



NATIONAL
DOWN SYNDROME
CONGRESS

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Reigning Waste Management Phoenix Open champion Gary Woodland said about Amy's par on 16 "I've been blessed to do a lot of cool things on the golf course, but that is by far the coolest thing I've ever experienced." He went on to also say "I've never rooted so hard for somebody on a golf course."

Announcing the 47th Annual NDSC Convention Main Event Keynote Speaker: Amy Bockerstette

A recent graduate of Sandra Day O'Connor High School in Phoenix, Arizona, Amy Bockerstette was the first person with Down syndrome to play in the Arizona High School Girls Golf Division I State Championship, where she competed as both a Junior and Senior. In 2017, she was honored at the AZCentral.com Sports Awards with the Best Moment of the Year Award for Arizona High School Sports. She was also named by AZCentral.com as one of the "Ten Most Intriguing High School

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Pittsburgh, Pennsylvania
June 27-30, 2019

**Registration
Opens March 25...
Are You Ready?**

All the resources you need
to be ready for the big day.

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Letter From the President



Dear NDSC Family,

Every NDSC Convention that I have had the honor to attend has been an experience to remember. This year though will be the most memorable for me, and my brother Das, as we invite you to join us in my hometown of Pittsburgh, PA. The NDSC's 47th Convention is going to not only be the greatest "family reunion" in the world, but also promises to provide self-advocates, their families, first responders, educators, and medical professionals more resources, workshops, and FUN than ever before. Whether you are a first-time attendee

or a seasoned convention goer, there will be something new for everyone in Pittsburgh.

Recently the Board of Directors and NDSC staff met in Pittsburgh for a convention site visit and to map the strategic plans for the organization's impact and growth over the next 3-5 years. Our priorities contain several exciting initiatives to increase our impact for self-advocates and their families. With funds obtained through a \$500,000 gift from a private donor, we will be expanding the reach of our newest Center. Introduced last year, the Center for Outreach & Education is providing resources, programs, and therapies to underserved areas as well as permitting us to take the Convention's world-renowned Educator Conference on the road to meet the needs of educators across the country who may not be able to make the trip to the host city each year.

If you are interested in further supporting the NDSC mission and vision, and making more of an impact in the Down syndrome community, we would like to hear from you. We are currently accepting applications from

anyone interested in being considered as a candidate for a position on the Board of Directors. Information regarding board member obligations can be found on page 12.

I look forward to seeing everyone in Pittsburgh this June 27th – 30th. As you prepare for convention registration please take a moment to review all of the resources on the NDSC website to assist you with the process. Should you have questions about registration NDSC staff can be contacted by emailing info@ndsccenter.org or calling the National Center at 770-604-9500. Another great way to stay up to date with us is by following us on our social media pages. We're on Facebook, Twitter, and Instagram.

It is indeed an honor and pleasure to serve you and your family. Thank you for your continued support of the NDSC!

Take care,

Kishore



Pittsburgh, Pennsylvania
June 27-30, 2019

Convention Registration Opens March 25th—Are You Ready?

The NDSC General Convention is designed to educate parents, family members and caregivers, as well as medical and educational professionals. From Thursday's Advocacy Boot Camp, Research Roundtable, First Timers Orientation and Connections Receptions, through pre-conference deep-dive sessions, Main Event Opening sessions, the 321 Dance!™, the Evening of Champions Dinner, 6 workshop rotations, Kids' Camp, and Youth & Adult and Brothers and Sisters conferences the weekend has something for everyone. But who in your family will attend which conferences, workshops, and social events? What events require a ticket? Which workshops require an additional registration? Will your children attend Kids' Camp or will they participate in the Youth and Adult conference? Making all of these decisions, in order to get the most from the NDSC Annual Convention, can all be a little overwhelming.

Don't Worry - We've Got Your Back!

The NDSC website has resources, tutorials, tips, and FAQs to help you prepare for registration.

Visit www.ndsccenter.org • from the **Annual Convention** tab dropdown • click **Convention Resources**



Registration
Tutorial Video



Convention
Schedule



Frequently
Asked Questions



Registration Tips



Convention Fees

**We look forward to seeing
you in Pittsburgh!**

Pre-Conference Sessions Take Learning to Another Level

Pre-Conference sessions allow attendees the chance to spend four hours digging deep into one specific topic. Each of the sessions is presented by nationally known speakers, are structured to include content that is research-based, share best practices, and provide proven "how to" strategies. All sessions will include time for Q & A.

Pre-Conferences are not included in General Conference registration. Pre-Conference sessions require an additional \$75 fee to NDSC Convention General Conference attendees if registered by June 4th. After June 4th the cost of pre-conference registration increases to \$100 and is available on-site only. Each attendee may register for ONE pre-conference session as all sessions will be held simultaneously Friday, June 28th from 8:00 a.m. – 12:00 a.m. Space is limited in most sessions, so register early. On-site registration cannot be guaranteed.

Pre-Conference session handouts will be provided to each session attendee, but are only available to those in attendance.

SPEECH/LANGUAGE

Communication Foundations for Children with Down Syndrome

Jennifer Bekins, MS, CCC-SLP, Speech Pathology Coordinator, Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital Medical Center, sister with DS, Cincinnati, OH



INCLUSION

Individual Education Program (IEP) - The Nuts and Bolts for Building and Implementing a Successful IEP

Sean J. Smith, PhD, Associate Professor, Department of Special Education, University of Kansas, NDSC Board of Directors, son with DS, Lawrence, KS



BEHAVIOR

Shake It Off...Effective, Relatable Strategies to Help Improve Behavior at all Ages and Stages

Stacy Taylor, MA, BCBA, President, Advance Behavior & Learning and Advance Learning Academy, daughter with DS, Orlando, FL



MEDICAL

Regression: Understanding Loss of Skills in Children or Young Adults with Down Syndrome

Brian Chicoine, MD, Medical Director, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL



CO-OCCURRING DS & AUTISM

DS-ASD: Recognizing the Signs, Understanding the Diagnostic Process, and Exploring Intervention Approaches

Nancy Raitano Lee, PhD, Licensed Psychologist & Assistant Professor, Director, Accelerated BS/MS and MS Programs, Department of Psychology, Drexel University, Philadelphia, PA



PUBLIC SPEAKING FOR SELF-ADVOCATES

Speak Up! Using Public Speaking to Open Social and Workplace Opportunities for

Self-Advocates

Rob Snow, Founder, Director/Producer, Professional Speaker, Author, Stand Up For Downs, son with DS, Medina, OH



Visit our website for the complete lineup of pre-conference sessions!

The WHY of behavior is important to the PREVENTION of unwanted behavior

Stacy Taylor, MA, BCBA, President, Advance Behavior & Learning and Advance Learning Academy Orlando, FL.

I remember being pregnant with my first child... all the excitement... all the anticipation and wait.. all the free magazines? Yup! One of the great benefits of being pregnant was reading all the wonderful parenting magazines that I was given by my doctor and my friends. Sure, I had a degree in psychology at that point and plenty of experience working with children, but this was different, I was doing it from a new perspective, and I was understandably excited. My excitement turned to frustration though when I realized how much these magazines got it wrong. I mean, they had some great information about new products for baby, but when it came to discipline and parenting, these magazines only offered parents minimal advice that usually boiled down to a single strategy. So, what was the strategy? Well honestly, that differed depending on the article, but the theme was basically the same. Choose 1 strategy, try to do it well, and do it with everything your child does. There were articles about time out, redirection, ignoring and all of them were leading parents in the wrong direction. That is when it all started making sense to me. Parenting is hard and the advice we receive isn't based on what science actually says works.

That was 18 years ago, my oldest graduates high school this year. I have been spending more and more of my time as a behavior analyst and educator working with parents, teachers, and therapists to help them better understand what science actually says

Continued on page 7...

Behavior can be frustrating, but the good news is that there is a science to learning and behavior that can help parents better address behavioral concerns no matter what age or stage of their child. For a detailed discussion about the science of behavior and to learn about new tools to add to your behavior toolbox register for Pre-Con E: Shake It Off...Effective, Relatable Strategies to Help Improve Behavior at all Ages and Stages, Friday, June 28th from 8:00 a.m.–12:00 p.m.

SELF-ADVOCATE SPOTLIGHT

Grace Wisnewski

Grace Wisnewski is a 15-year-old high school sophomore. She is friendly, outgoing, compassionate, athletic, determined, fun-loving, and entertaining. Grace loves an audience! Grace has fantastic peer role models both typical and differently abled. Grace's parents are grateful for the opportunity that full inclusion has afforded her and appreciate the support and patience of all of Grace's peers. Grace likes that her peers value that she is more alike than different!

When the time came for her to enter high school, Grace told her parents that she wanted to try out for the girls' volleyball and basketball teams. The summer before Grace was to begin high school, with trepidation, her parents reached out to the school's athletic director and requested an introduction. During this first meeting, Grace spoke of her love of sports and her involvement in Special Olympics. Her parents expressed their hope that Grace may become a team manager; telling the AD of their desire for Grace to be as involved as possible during her high school career. Grace and her family left this initial meeting joyful and anxious but thrilled that the athletic director was as excited as they were that Grace wanted to be a part of the sports program.

While a little apprehensive to begin, Grace and her family have been pleasantly surprised at how accepting both the coaches and the players have been. Grace enjoys practices, hanging out with the players, and attending games. While the thought never crossed her parents' minds that Grace would get any game time, they were thrilled when Grace's basketball coach made the call to put Grace into a game. Since then, Grace has played in both volleyball and basketball games and has even scored a few points in basketball! Last fall Grace was awarded the Most Improved Player on her volleyball team and was presented with a trophy at the team banquet!

Grace has often expressed her interest in becoming a singer or actress when she grows up. She has done research for school assignments about each career field and with hopes of gaining real, practical experience, last fall, Grace tried out for her high school's musical production. She landed a part as a dancer in the musical and is enjoying rehearsals twice a week learning what may be required for a career on the stage. She is looking forward to being in the spotlight through the month of March!

Along with volleyball, basketball, and her part in her school's musical, Grace is a member of her high school Best Buddy Chapter, which is the largest chapter in Delaware. With twice as many peers as buddies, the Best Buddy peer connections are strong. Grace hopes these friendships will continue for years to come!



In addition to her high school activities, Grace also plays the piano, rides horses, and is a Senior in Girl Scouts. With the help of her Girl Scout troop, Grace just completed her Silver Award and is currently working on her Gold Award.

Grace recently had one, well two, of her greatest thrills when she was asked by two of her cousins to be a bridesmaid in their weddings. After some conversation with each of the brides-to-be and full disclosure of the no-guarantee clause regarding how Grace would go up the aisle, the final decision was made – Grace would be a part of each cousin's big day. Each bride-to-be knew that "their day" would be all about Grace and the understood that Grace's walk would probably involve dancing as soon as she realized that everyone was looking at her. Last December her family watched anxiously as the first of the weddings began and are happy to report that Grace walked very nicely down the aisle.

When asked about raising a child with Down syndrome, Grace's mother commented "We have all heard the saying; It takes a village. Well, we have the best village! We are lucky to have the great support of our family, friends, our local Down Syndrome Association, and committed educators and school staff." She recalls the words of a geneticist whom they met when Grace was born who told them, "Grace will love you unconditionally and you owe it to her to do the same". An equally profound quote she recalls often is "She will be her own person", and that she definitely is.

Grace is an only child and her personality and the young lady she is becoming are due to all of the opportunities she has been given.



The Importance of Immune System Dysregulation in People with Down Syndrome

How does an extra copy of chromosome 21 drive the developmental and clinical features of down syndrome? This question has been the subject of many investigations since 1958, when Jérôme Lejeune reported the presence of trisomy 21 in cells of people with down syndrome. The answer has remained elusive.

Now, research from the Linda Crnic Institute for Down Syndrome points to dysregulation of the immune system as a mechanism by which the extra chromosome would cause this multiorgan, multi-system condition. The implications of these results are profound, because they not only provide a new conceptual framework for future research, but also illuminate avenues for the development of novel diagnostic and therapeutic opportunities to improve health outcomes in Down syndrome.

Of the more than 20,000 genes encoded in the human genome, chromosome 21 carries fewer than 300, the lowest number of genes on any human chromosome. While consensus among scientists is that Down syndrome is a “polygenic condition,” a condition caused by increased activity of more than one gene, it is also agreed that not all genes on chromosome 21 would contribute equally to the condition. If one were to select a random group of 300 genes, it is recognized that only a few genes would be master regulators of cellular and organismal function. What then are the master regulator genes on chromosome 21 with the greatest impact on human biology? To address this question, scientists at the Crnic Institute employed an approach known as functional genomics, which involves measurements of the activity of thousands of genes across the entire genome, to identify the gene networks most impacted by trisomy 21.

OVERACTIVE IMMUNE SYSTEMS?

The first set of results from the analysis of cells of people with Down syndrome (Sullivan et al., 2016) revealed that trisomy 21 causes constitutive activation of the gene network known as the Interferon response, a key branch of the immune system responsible for fighting off viral infections. In cells from typical people, the Interferon response was dormant, but cells from people with Down syndrome seemed to be fighting off a viral infection that just wasn't there. These results immediately drove attention to four genes on chromosome 21 known as the Interferon receptors, which are required for cells and

tissues to respond to a viral infection and whose triplication could potentially trigger constant activation of this arm of the immune system.

The second set of results from the analysis of blood samples (Sullivan et al., 2017) revealed signs of chronic autoinflammation in people with Down syndrome. Measurements of approximately 4,000 different proteins in the blood identified about 300 that are differentially abundant between people with and without Down syndrome, with about half of those 300 proteins being involved in the immune system. Importantly, this study revealed signs of both constant activation and exhaustion of different aspects of the immune system, with obvious ties to the Interferon response. It is well established that the Interferon response enhances anti-viral defenses, but too much Interferon activity eventually weakens antibacterial defenses. Indeed, the results of the blood analysis were consistent with a type of immune dysregulation caused by lifelong hyperactivation of the Interferon response.

Noteworthy, both studies revealed, among people with Down syndrome, strong inter-individual variation in the degree of activation of the Interferon response and autoinflammation, which could potentially be linked to the obvious clinical diversity in this population.

GREATER INSIGHTS AND POTENTIAL TREATMENTS

These results have triggered a flurry of activity at the Crnic Institute to answer key follow-up questions: Which of the symptoms of Down syndrome could be explained by the observed immune dysregulation? To what degree is the immune dysregulation caused by triplication of the four Interferon receptors versus other genes on chromosome 21? What would be the diagnostic value of measuring immune dysregulation to predict the risk of the same person developing certain co-occurring diseases or conditions? What would be the therapeutic value of medications that inhibit the Interferon response and accompanying inflammatory process?

SCIENCE SNPs

ISSUES WITH MUSCLE REGENERATION

A new publication from the Linda Crnic Institute for Down Syndrome revealed defects in muscle regeneration after injury in a mouse model of Down syndrome. Using a chemical injury model commonly used to study the capacity of muscles to regenerate, scientists observed a failure of the stem cells of the muscle, known as “satellite cells,” to expand and restore muscle mass after the injury. This impairment of satellite cell function, which was exacerbated as the mice aged, underscores stem cell deficiencies as a potential contributor to Down syndrome-associated co-morbidities. Future research will define the relationship between satellite cell malfunction and the common occurrence of hypotonia in people with Down syndrome.

Pawlikowski, et al. Scientific Reports. 2018; 8(1):4309.

LESSONS FROM ZIKA

While it is well established that trisomy 21 causes immune dysregulation, including chronic activation of the anti-viral interferon response, little is known about how increased interferon signaling could affect embryonic development in the womb. Recently, scientists revealed a key role for the interferon response in the adverse fetal outcomes caused by Zika virus infection. They showed that IFNAR1, a key gene on chromosome 21 required to mount the interferon response, was necessary for the ill effects of Zika infection during embryonic development in mice. Although embryos completely lacking IFNAR1 were more susceptible to Zika infection, they fared better during development. In fact, they showed that the immune response to Zika, not the virus itself, inhibited placental development and impaired maternal-fetal communication. These results reinforce the notions that the exacerbated interferon signaling observed in people with Down syndrome could have negative impacts on development and that strategies to dampen interferon signaling could have therapeutic benefits.

Yockey, et al. Science Immunology. 2018; 3(19):1680.

Linda Crnic Institute for Down Syndrome
scientists Joaquín Espinosa, Ph.D.,
Kelly Sullivan, Ph.D., and Keith Smith



Several key facts are generating much enthusiasm in the pursuit of these answers. First, it is well established that a hyperactive Interferon response has negative effects on human development, as illustrated by type I Interferonopathies, a newly recognized class of genetic conditions caused by gene mutations that lead to activation of the Interferon response and share many symptoms with Down syndrome. Second, the pharmaceutical industry has developed many medications that inhibit the Interferon response, some of which are approved for the treatment of autoimmune conditions, such as rheumatoid arthritis, and are currently being tested for the treatment of autoimmune conditions more prevalent in Down syndrome, such as alopecia areata and vitiligo. Third, pioneer studies in mouse models of Down syndrome completed by Lenny Maroun, Ph.D., currently at the Crnic Institute, demonstrated that reducing the Interferon response improves the development of these mice (Maroun et al., 2000).

Altogether, this body of research justifies a strong investment in the study of the immune system in Down syndrome, with the obvious potential to develop diagnostic and therapeutic strategies to improve the well-being of those living with trisomy 21.

To learn more about research at the Crnic Institute, visit globaldownsyndrome.org/our-story/linda-crnice-institute.

References:

Maroun, L.E., Heffernan, T.N., and Hallam, D.M. Partial IFN-alpha/beta and IFN-gamma receptor knockout trisomy 16 mouse fetuses show improved growth and cultured neuron viability. *Journal of Interferon & Cytokine Research: the Official Journal of the International Society for, Interferon and Cytokine Research*. 2000; 20, 197–203.

Sullivan, K.D., Evans, D., Pandey, A., Hraha, T.H., Smith, K.P., Markham, N., Rachubinski, A.L., Wolter-Warmerdam, K., Hickey, F., Espinosa, J.M., et al. Trisomy 21 causes changes in the circulating proteome indicative of chronic autoinflammation. *Scientific Reports*. 2017; 7, 14,818.

Sullivan, K.D., Lewis, H.C., Hill, A.A., Pandey, A., Jackson, L.P., Cabral, J.M., Smith, K.P., Liggett, L.A., Gomez, E.B., Galbraith, M.D., et al. Trisomy 21 consistently activates the interferon response. 2016; eLife. 5.

This article *The Importance of Immune System Dysregulation in People with Down Syndrome*, was written and published by the award-winning *Down Syndrome World™* magazine, a publication of the Global Down Syndrome Foundation.

The WHY of behavior is important to the PREVENTION of unwanted behavior

Continued from page 3

about behavior and what actually works to improve it. It is not a one-size fits all approach. In fact, even for an individual child, a one consequence fits-all approach will likely not work. What these magazines were suggesting (i.e. time out for everything your child does) is not what the research says is effective.

Here is what we know. Function matters. The “WHY” of behavior is an important factor in knowing what to do to prevent the behavior from happening in the future and when selecting an appropriate consequence. We ALL engage in a variety of behaviors for a variety of reasons. These are referred to as “functions”. The four common functions are to get attention, to escape/avoid something you don’t want, to gain access to something you do want, or for sensory purposes. Once we know the function, which we identify by conducting observations and interviews and collecting data, we can begin to put together a plan of action to help improve the behavior.

No matter the function, any good plan must begin with good teaching. Always start teaching before you start reducing problem behaviors. Think about what skills is this person missing? You can never go wrong when you teach. Replacing problem behaviors with alternative appropriate behaviors is essential and using positive approaches is an important key to success. Think about simple solutions first. Consider prevention, but remember that this alone is not a solution. A good plan has prevention, strong teaching, and consequences that consider the function of the behavior. If the behavior is for attention, then the consequence should be to minimize attention so as to not reinforce the problem behavior. If the behavior is to escape or avoid something negative, then the consequence should be to keep the “demand” present so the person learns that problem behaviors do not “get them out” of anything. Understanding the function will help you develop an appropriate intervention plan and get better outcomes. Now, if only I could convince those parenting magazines!

No matter the function, any good plan must begin with good teaching. Always start teaching before you start reducing problem behaviors.



He has a dream; and I am on his team.

I wish you could see him as I do.
He is happy. He is fun.

How he dances and sings all day.
Before he sleeps, he kneels and pray.

I wanted him to ride a bike,
and he did, with hard effort...
like any other kid.

I wish you could see how he reads...
with a smile on his face. For him,
everything has grace.

He has no limits.
He kicks like Ronaldo.
And bounces like Durant.
I am on his team,
would you join the dream?

It's 2:00 o'clock and I am picking him up,
He notices me from the distance
among all, though the doctor
says his vision is small.

We have a dream.
Let's accept each other with love and
genuine respect.
Are you on the team?

He has taught me to see.
He doesn't have a soft heart like books say.
He gives me a million kisses...
and I have buried some bridges.

Ohh, I haven't told you,
he has Down Syndrome,
But he is still a handsome man
with wisdom.

He loves to fly, airplanes, and the sky.
About love, acceptance, and Madrid we dream.
I have been inviting you, are you on the team?

A poem to my cousin Esteban,
and all the kids with Down
Syndrome (dreaming of
equality) everywhere.
I am on your team.

~ Gabriela

Submitted by NDSC Facebook
follower, William Felix, on
behalf of his niece Gabriela.

NDSC's Dr. Macarena Lizama Recognized as One of Chile's Top 100 Women Leaders of 2018

"Without a doubt, when you receive recognition of this magnitude you feel that what you have been doing has an impact, but I think that the most important is that it is a recognition not only to me but to the entire team I work on," said UC Academic and Executive Director of the UC Down Syndrome Center and NDSC Board of Directors Member, Macarena Lizama.



Dra. Macarena Lizama fue reconocida como una de las 100 mujeres líderes de 2018... página 15

Announcing the 47th Annual NDSC Convention Main Event Keynote Speaker: Amy Bockerstette

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Athletes of 2017." Currently, Amy attends Paradise Valley Community College in Phoenix on a full scholarship to play golf, where she is studying Dance.

As an invited representative of Special Olympics Arizona, Amy played in the LPGA Founders Cup Pro-Am in 2017. For the past two years, she has participated in the PGA Phoenix Open Celebrity Putting Challenge. In addition, she represented Arizona in the Special Olympics North America Golf Invitational in Seattle in 2017.

Most recently, during a practice round at the 2019 Waste Management Phoenix Open, Amy was invited by PGA TOUR professional and 2018 Open Champion Gary Woodland to play the iconic 16th hole with him and playing partner Matt Kuchar. To the delight of both pros and fans, Amy parred the hole.

Amy's passions are not limited to only golf. She is also a Special Olympics athlete in swimming and volleyball and plays Challenger baseball. She also plays the piano and loves to dance.

We are proud and honored to announce that Amy Bockerstette will be the Main Event Opening Session Keynote Speaker at the NDSC 47th Annual Convention in Pittsburgh, PA on June 27, 2019.

In a speech she delivered to her classmates, during her senior year, Amy reminded them of 13 different things she learned in her journey through high school. What great advice from our 2019 Spring edition of *Down Syndrome News* Self-Advocate Spotlight!

- | | |
|---|--|
| 1. Introducing yourself helps you make new friends. | 8. Winning is about more than medals and trophies. |
| 2. Most people say yes when you ask for help. | 9. Joking around and laughing makes life more fun. |
| 3. Dancing is a great way to start the day. | 10. Find what you love and do your best. |
| 4. When something is hard, just breathe and believe. | 11. Our choices make us who we are. |
| 5. Hard work pays off. | 12. Anyone can make a difference. |
| 6. Anyone can be a leader. | 13. We are all different, with our own abilities, gifts, and talents. By coming together, we make our school and the world a better place. |
| 7. Being part of a team is awesome. Going to state together is even more awesome. | |

Do You Want to be the Next Self-Advocate Spotlight?

Self-Advocates are the heart of the NDSC. Do you want us to introduce you to the world? Do you have an interesting story? Have you done something exciting in your community? Let us tell our members all about YOU!

Send your original story or article along with a high-resolution photo to:

Editor, Down Syndrome News
National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30076

Or email your article and photo to info@ndsccenter.org. Don't forget to include your name, age, address, and phone number in case we need to get in touch with you to get more information.

About Pittsburgh

You May Wonder Why the *New York Times* Calls Pittsburgh The "Only City With An Entrance"

As you make the journey to downtown you will travel through a mountain (yes, through, not over the mountain) via the Fort Pitt Tunnel. Be ready to hold your breath through the tunnel. No, it does not smell bad, it's for luck! Native Pittsburghers believe that if you make a wish and hold your breath for the entire duration of the tunnel the wish will come true. Then get ready – watch for it - you won't want to miss the breathtaking view of the spectacular skyline and sparkling rivers as they appear suddenly before you as you leave the tunnel.

Recently named one of the "Best Places to Travel", Pittsburgh offers award-winning restaurants, outstanding family attractions, and a vibrant downtown. When you add friendly people, affordability, and walkability, you have the perfect recipe for a memorable getaway.

From gallery crawls to walking tours showing off the finest architecture in the city, Pittsburgh had much to offer for the art enthusiast. Or take in a day to visit one of the city's many museums, sky observatories or well-known, local attraction. There are plenty of activities to enjoy in Pittsburgh, and many of them are FREE!

Pittsburgh is a FAMILY FUN CITY!

Kennywood - Minutes from Downtown, Kennywood Park is one of Pittsburgh's best-loved historic landmarks. But don't let the history fool you! World-class roller coasters, plenty of thrilling rides, games, food and exciting live shows. Fun the entire family will enjoy. For more information visit www.kennywood.com.

Pittsburgh Zoo - Enjoy a family experience that fosters understanding, respect, and appreciation of wildlife with a visit to the Pittsburgh Zoo & PPG Aquarium. Discover the giant anteater, and the world's largest rat, the capybara, and the pygmy hippo. Take in the scenic bird's-eye view of the African Savanna before heading to the PPG Aquarium and Water's Edge, home of the impressive polar bear and playful sea otter.

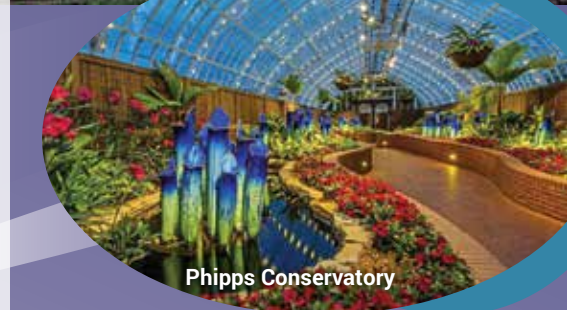
Phipps Conservatory and Botanical Gardens - Explore the beauty and wonders of nature at Phipps Conservatory and Botanical Gardens, encompassing 15 acres including the historic 14-room glasshouse and 23 distinct gardens. Park. Learn more at phipps.conservatory.org.

Gateway Clipper Fleet – Take a tour and see Pittsburgh from a new point of view. Head down the river on a dining or sightseeing cruise and make a memory out on the water! Located on the southern shores of the Monongahela River in Historic Station Square.

Duquesne Incline - Enjoy a spectacular panorama of Pittsburgh and its three rivers. Ride to the incline's Observation Deck in the 140-year-old Incline car to see what USA Today Weekend Magazine calls one of the "10 most beautiful views in America". Historical exhibits in the waiting room entertain between rides.

The Allegheny Observatory - One of the major astronomical research institutions of the world.

Carnegie Science Center - Four floors filled with hundreds of hands-on interactive experiences for every age. Experience what it's like to work on a space station in SpacePlace or play basketball against a robot in roboworld™, the world's largest permanent robotics exhibit.



Phipps Conservatory



Carnegie Science Center



Kennywood Park



Pittsburgh Zoo & PPG Aquarium



Be a Social Champion for the NDSC

Everyone needs a Champion, and we are hoping to gain thousands in 2019! One of the easiest ways to support the National Down Syndrome Congress is to use your Social Media skills to host an online Facebook fundraiser on our behalf. Each month we will have a different Social Champion Gift, and when you raise \$321.00 or more in your fundraiser, that gift is yours! Ask your friends to donate for your birthday, your anniversary, or just pick a date and go for it! If you need help setting up your fundraiser, simply contact our Community Engagement and Event Manager, Rhonda Rice, at Rhonda@ndsccenter.org.

NDSC Social Champion Monthly Gifts

- March – NDSC Tumbler Set
- April – NDSC Umbrella
- May – NDSC Beach Towel
- June – NDSC Cooler
- July – NDSC Tank Top
- August – NDSC Padfolio
- September – NDSC Stadium Chair
- October – NDSC Chocolates
- November – NDSC Hot Cocoa Mug
- December – NDSC Hat & Scarf Set



NATIONAL DOWN SYNDROME CONGRESS ALL KINDS OF HEROES GOLF CLASSIC

Fireballs

\$10 EACH
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CLICK SUPPORT – GOLF TOURNAMENT

NATIONAL
DOWN SYNDROME
CONGRESS

From the Center for Outreach & Education

The next NDSC Rural Outreach Program is March 16 in Fort Wayne, IN

Do you live within driving distance of Fort Wayne? Join us for the one-day conference. Workshop topics will include:

**Inclusion | Advocacy | Behavior
Health & Medical | Adult Siblings
Special Needs Law**

Please visit the NDSC website for details and registration information - www.ndsccenter.org/outreach-education/down-syndrome-summit

Upcoming Webinars:

March 7 - Grab a Parachute: Transitioning to Adulthood Without Falling Off a Cliff

In this webinar, Dr. Alyssa Siegel, Medical Director of the Children's Hospital of Philadelphia's Transition to Adulthood Comprehensive Care, will address the common challenges that families face during this exciting but daunting time.

March 12 – NDSC Convention 101

Just in time to help you get ready for our 47th Annual Convention! Learn about all things NDSC Convention and make registration a breeze! Presented by NDSC staff members, we cover how to register, what the experience is all about, and what to do when you get to Pittsburgh.

April 10 - When Autism and Down Syndrome Co-Occur - Presented by NDSC and the Autism Society of America

May 14 – Decline in Skills - Brian Chicoine, MD

**For details on individual webinars
and to visit [www.ndsccenter.org/
outreach-education/parent-webinars/](http://www.ndsccenter.org/outreach-education/parent-webinars/)**

Join us for **World Down Syndrome Day 2019** on March 21, as we stream on Facebook Live the 2nd Annual Fireball Drop from the NDSC All Kinds of Heroes Golf Classic at Legacy Golf Course at Lake Lanier. You can watch as we hoist the Fireballs up the aerial ladder of a firetruck then drop them to the 10th green below. The ball that lands in the hole first, or closest to the hole, wins 50% of the worldwide sales of Fireballs!

To purchase your Fireballs, register to play, for sponsor information, or just support the NDSC visit:
NDSCCenter.org • Click the Support, Join, Be Involved tab at the top of the page • Drop down to Golf Tournament

Advocacy in Action

The NDSC Policy Team Will be Busy This Spring—See Where We Are Headed!

The NDSC Policy & Advocacy Team is second to none in Washington, D.C., but they are also busy working across the country and the world! Our incredible team is working for you and representing the NDSC in creating a world with equal rights and opportunities for people with Down syndrome. If you are near an area where they will be speaking we would love to have you join them.



March 21 – 1:00 p.m.

National Down Syndrome Advocacy Coalition Quarterly Webinar – Online – Join NDAC to get your invitation

The NDSC Policy Team will host the First Quarter NDAC Update Call. If you haven't joined NDAC yet now is a great time to join so you can be a part of this member-only call! Fill out the simple application to become an NDAC member today (you must be an NDAC member to join the call).

To join NDSC visit <https://www.ndsccenter.org/political-advocacy/national-down-syndrome-advocacy-coalition/>

March 22 through 25

World Down Syndrome Day Conference in Trinidad

Stephanie Smith Lee will speak on "Inclusive Education: the Foundation for Lifelong Inclusion" in a TV appearance and workshop with a joint partnership with the US Embassy, Public Affairs Unit, stakeholder engagement Government, NGO's at the US Embassy of Public Affairs Offices.

More info at <https://www.facebook.com/events/320458938579245/>

March 27- Presentation at the Northern Virginia Down Syndrome Association

Heather Sachs, NDSC Policy Advisory and Lauren Camp, NDSC Policy Associate will be speaking with parents about how to get started in advocacy and provide updates on the most current policy topics.

For more info visit <https://www.dsanhv.org>

April 6- All Born in Conference - Portland Airport Holiday Inn

Stephanie Smith Lee, along with Debra Hart of Think College, will present a postsecondary education session entitled "So your Child/Student with Intellectual Disability is Thinking About College - What's Next What's Possible."

The All Born (in) Conference is an annual educational inclusion conference in its 13th year serving Oregon, Washington, and surrounding communities. It's an exciting day for parents, caregivers, and professionals working to end segregation in schools and the community. It's a day of celebrating community and learning how to use Universal Design for Learning and Best Practices.

More information can be found at www.abicomunity.org

April 8 and 9

Disability Policy Seminar – Renaissance Hotel, Washington, D.C. - Get informed, connected, and ready to protect the things that matter most

NDSC will serve as a promotional partner for the 2019 Disability Policy Seminar. The challenges and realities facing the disability community demand our focus and diligent advocacy – now more than ever! Join your NDSC Policy & Advocacy Director and fellow advocates for the 2019 Disability Policy Seminar, where you will strengthen grassroots advocacy skills and connect with your representatives on the issue that matter most to you. The event is packed with informative sessions from experts in the field, and opportunities to discuss key issues with others from your state.

Heather Sachs, NDSC Policy Director, will be speaking on a panel about proposed changes to the Achieving a Better Life Experience (ABLE) Act.

Visit <https://disabilitypolicyseminar.org> to sign up!

April 16 and 17- Southeast Postsecondary Education Alliance (SEPSEA) Capacity Building Institute Conference - hosted by the REACH Program at the College of Charleston, Charleston, South Carolina

Stephanie Smith Lee will present: How to Build Relationships and Advocate with Policy Makers and Inclusive Postsecondary Education and Education: Current Policy Challenges and Opportunities.

For more information visit <https://www.sepsea.org>

June 27 - Advocacy Training Bootcamp – Pittsburgh, PA

Making your travel plans for the convention? Be sure to come in on Wednesday so you can join us Thursday for the Advocacy Training Boot Camp! This training is free for convention attendees and is designed as an Advocacy 101 mini-course. Learn about advocacy, basic government processes, how to effectively engage with legislators and hear from a panel of advocates as they share their tips and experiences. Date: Thursday, June 27, 8 a.m. -12 p.m. Registration opens March 25th

Book Review

Broccoli Boot Camp

Authors: Keith E. Williams & Laura Seiverling

Just the name and cover alone will send you into a laughing, hysterical fit. I mean, who in their right mind would think you could ever get a child to eat broccoli, let alone one of our children with food aversions? But as I dig deeper into this reading gem, I am pleasantly surprised at the recommended approach to overcoming the hardship of a picky eater.

After what feels like hundreds of thousands of miles driven to countless therapy appointments, I wish I had been given this "handbook" years ago. The authors take years of research with real-life picky eater case studies and compiled a simple, yet scientific approach to getting our children to eat. Start small.

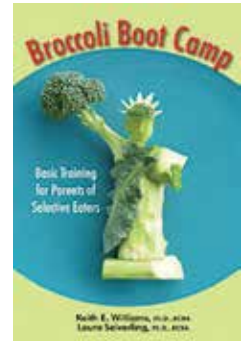
This book not only teaches parents the exact, step-by-step process of these interventions, but speaks directly about the reasons behind the issue from mealtime behavior, oral anatomy, sensory issues, environment, genetics, GERD, constipation... the list goes on and on. The authors not only name these reasons but also give you details regarding the rationality of each of these concerns. Don't beat yourself up

parents. It is NOT what we as Mom or Dad do during mealtime that causes the aversion. It is a multitude of factors.

It was alarming to me as I read that "40 percent of children who were irregular eaters at five years of age, continued to be irregular eaters at fourteen years of age", suggesting that this is in fact a chronic problem we must face as a parent or caregiver to a child with food issues.

Broccoli Boot Camp discusses in detail interventions to follow and guides you from start to finish in successfully introducing new foods. Through the case studies you will read about within these pages, you find yourself having ah-ha moments and realizing you are not alone and that you now have help. When modeling might work for one child or reinforcers for another, this book will direct you in five different intervention plans in order for you to have complete success.

Review written by Andrea Holmes | Parent to Gavin | BSN, RN, CMSRN | NDSC Board of Directors



Nominations Are Now Being Accepted for the NDSC Board of Directors

The National Down Syndrome Congress is looking for people who are interested in making a bigger impact in the Down syndrome community by serving on the NDSC Board of Directors. The National Down Syndrome Congress Board of Directors is composed of twenty-three parents, family members of individuals with Down syndrome, self-advocates, and other individuals involved with people with Down syndrome. The Board of Directors is responsible for carrying out and shaping NDSC policy as well as overseeing the fiduciary responsibility of the organization.

The Board Director elections will be held at the NDSC's General Membership Meeting, Friday, June 28, 2019, during the 47th Annual NDSC Convention in Pittsburgh, PA. NDSC Board Directors are elected by the membership of the NDSC to a three-year term. Elected Executive Officers are elected to serve one-year terms. Any NDSC member in good standing is eligible for nomination to the Board of Directors. Individuals may self nominate or may be nominated by a third party individual or organization also in good standing.

Elected members are expected to attend bi-annual Board/Staff meetings. Meetings are generally held in the Convention host city. One of the two meetings has historically been held the Thursday prior to the Convention, and a mid-year meeting is held in January. Board members comprise the committees and strategic teams who carry out the work of the NDSC. Members will sit on one or more of these working groups and are expected to attend the work group's meetings usually conducted via conference call or webinar.



Each year one self-advocate is elected to the Board of Directors. All individuals with Down syndrome, age 22 and older, are eligible to run for the NDSC Board of Directors. Elections are held during the Y&A Conference at the Annual Convention. The new self-advocate Director will be voted in by their peers to serve a three-year term.

Nominations Deadlines

Director nominations will be accepted through April 15, 2019. Nominations for Self-Advocate Directors must be submitted before May 1, 2019.

For more details, and nomination forms visit the NDSC website at www.ndsccenter.org

- Click the About NDSC tab at the top of the page
- From the dropdown menu click Board of Directors.

Jueves, 27 de junio

- 8:00 a.m. Campamento de defender derechos
- 1:00 p.m. Mesa redonda de investigación
- 4:00 p.m. Se abre el registro
- 4:00 p.m. Sala de expositores
- 6:00 p.m. Orientación para los asistentes por primera vez
- 7:00 p.m. Encuentros para familias de habla hispana

Viernes, 28 de junio

- 7:30 a.m. Campamento para niños Sesión 1
- 8:00 a.m. Pre-conferencias
- 8:00 a.m. Conferencia de educadores
- 1:15 p.m. Campamento para niños Sesión 2
- 1:15 p.m. El inicio de las Conferencia Jóvenes y Adultos y Conferencia de Hermanos y Hermanas
- 1:30 p.m. Talleres
- 3:00 p.m. Feria Universitaria
- 6:30 p.m. Sesión Plenaria
- 8:00 p.m. Baile 321

Sábado, June 29

- 7:00 a.m. Desayuno de investigación
- 9:00 a.m. Campamento para niños Sesión 3
- 9:00 a.m. Conferencia Jóvenes y Adultos y Conferencia de Hermanos y Hermanas (almuerzo incluido)
- 9:30 a.m. Talleres
- 2:30 p.m. Campamento para niños Sesión 4
- 3:30 p.m. Talleres
- 6:00 p.m. Sala de expositors cierra
- 6:30 p.m. Tarde de campeones (se requiere boleto de entrada)
- 8:00 p.m. Baile

Domingo, 30 de junio

- 7:30 a.m. Campamento para niños Sesión 1
- 8:15 a.m. Talleres y Show de Talentos de la Conferencia Jóvenes y Adultos
- 8:15 a.m. Viaje fuera del sitio para la conferencia de Hermanos y Hermanas
- 8:30 a.m. Talleres
- 12:00 p.m. Fin de la convencion

Anunciando la pre-conferencia

El viernes, 28 de junio de 8 a.m. a 12 p.m., expertos en síndrome de Down dictarán 8 pre-conferencias sobre un tema específico de interés. Las pre-conferencias tendrán una duración de 4 horas.

Como las conferencias serán presentadas simultáneamente, sólo será posible asistir a una. Las pre-conferencias no serán grabadas, tendrán un

costo adicional y se requiere inscripción previa. La pre-conferencia que presentaremos en español es Neurodesarrollo, Transición y Comportamiento. La transición son los pasos de una etapa a otra, en el momento en la que la persona pasa en estos cambios, hay una serie de procesos que es importante cubrir para lograr el éxito de la siguiente etapa. En estas transiciones, pueden surgir conductas, comportamientos y reacciones emocionales disfuncionales que se presentan en las personas con síndrome de Down y sus familias. Los padres necesitan aprender a ver y observar las transiciones, informándose en acciones y actitudes que los lleven a ser eficaces en el manejo y momento de establecerlas, esto siempre a la par de conductas y comportamientos adaptativos que estén relacionados con los hábitos y reacciones emocionales favorables que los lleven a una transición funcional y exitosa. Esta pre conferencia nos dará una visión integral sobre las áreas de neurodesarrollo y sus transiciones que son claves en la formación de la conducta y comportamiento adaptativo adaptativa presentes en todas las etapas de las personas con síndrome de Down. Conocer, observar y detectar cómo los padres reaccionan en estas transiciones de sus hijos, es clave para el éxito de este proceso que es determinante en su vida, desarrollo personal y social.



Dra. Teresa Aguilasoch,

Médico Ginecologa, Lic. en Psicología, Tanatologa Familia, Salud y Desarrollo en Síndrome de Down A.C.



Silvia Maravilla Ávila y

José Alberto Alonso García

Lic. en Psicología y Terapia Familiar API, Centro de Asesoría Psicologica Integral

Nuestro Director del Programa Multicultural viajó a McAllen, Texas, para presentar nuestra "Guía para hermanos mayores". Los hermanos adultos que quieran estar presentes en la vida de su hermano o hermana pero no estén familiarizados con todos los datos relacionados pueden utilizar este manual para hablar con sus padres y saber cómo ser un buen defensor, amigo y, tal vez, cuidador de su hermano cuando sus padres ya no puedan. ¿Interesado en traer esta presentación a su área? Envíe un correo electrónico a Mateo Fernández a matthew@ndsccenter.org.



Guía para hermanos mayores™

La importancia del sistema inmune en las personas con síndrome de Down

El 8 de noviembre de 2018 | De Down SyndromeWorld caso 3 2018

La interrogante de cómo una copia extra del cromosoma 21 conduce a las características clínicas y del desarrollo del síndrome de Down ha sido objeto de muchas investigaciones desde el año 1958. En este año Jérôme Lejeune observó la presencia de una trisomía en el cromosoma 21 en las personas con síndrome de Down. Sin embargo, todavía no existe respuesta.

Los estudios del Instituto Linda Crnic para el estudio del síndrome de Down señalan que la desregulación del sistema inmune es el mecanismo por el cual el cromosoma extra causa esta condición multiorgánica y multisistémica. La importancia de este descubrimiento es fundamental, ya que no solo aporta una nueva concepción que servirá para futuras investigaciones, sino que también abre nuevas vías para el desarrollo de un nuevo diagnóstico y una mejora de las medidas terapéuticas para las personas con síndrome de Down. De los más de 20 000 genes codificados en el genoma humano, el cromosoma 21 posee menos de 300; el número más bajo de todos los cromosomas del ser humano. Aunque los científicos están de acuerdo que el síndrome de Down es una «condición poligénica», es decir, que está causado por el incremento de actividad de varios genes (no solo de uno), también coinciden en que no todos los genes del cromosoma 21 contribuyen de igual forma a la condición. Si cogemos un grupo de 300 genes aleatorios podemos observar que solo algunos de ellos son genes maestros reguladores de la función celular y orgánica. Para conocer cuáles de los genes reguladores maestros tienen mayor impacto en la biología humana, los científicos del Instituto Crnic utilizaron el llamado enfoque de la genómica funcional, el cual mide la actividad de miles de genes de todo el genoma para identificar las redes genéticas que reciben mayor impacto debido a la trisomía 21.

Hiperactividad del sistema inmune

Los primeros resultados del análisis de células de personas con síndrome de Down (Sullivan et al., 2016) revelan que la trisomía 21 activa la red genética conocida como la respuesta del interferón, el cual compone una rama clave del sistema inmunitario encargada de combatir las infecciones virales. Mientras que en las células de las personas que no padecen el síndrome no se generaba ninguna respuesta por parte del interferón, las células de las personas con síndrome de Down parecían estar luchando contra una infección que no existía. Estos resultados señalaron inmediatamente cuatro genes concretos presentes en el cromosoma 21, los receptores del interferón. Dichos receptores están presentes en las células y tejidos para responder a una infección vírica. Su triplicación podría producir la activación constante de esta rama del sistema inmune.

Los segundos resultados de los análisis de muestras de sangre (Sullivan et al., 2016) revelan signos de autoinflamación crónica en personas con síndrome de Down. De entre aproximadamente 4000 proteínas en la sangre, se han identificado unas 300 que varía su cantidad dependiendo de si se trata de una persona con síndrome de Down o no. Esto señala la constante activación y agotamiento de partes diferentes del sistema inmune, lo cual está ligado a la respuesta de los interferones. Se sabe que la respuesta de los estos desencadena las defensas antivirales pero la hiperactividad del interferón conlleva un posterior debilitamiento de las defensas antibacterianas. Además, los resultados de los análisis muestran un tipo de desregulación inmune específico que está causado por la hiperactividad a largo plazo de los interferones.

Es importante señalar que ambos estudios revelan que existe una gran variación individual en cuanto al grado de activación de los interferones y la autoinflamación. Seguramente ligado a la clara diversidad que existe dentro de este grupo.

Un mayor entendimiento y tratamientos potenciales

Estos resultados han movilizado el Instituto Crnic que busca la respuesta a las cuestiones clave siguientes: ¿Qué síntomas del síndrome de Down pueden explicarse mediante la desregulación inmune? ¿Cuánto influye la triplicación de los receptores del interferón a la desregulación inmune en contraposición a otros genes del cromosoma 21? ¿Cuál es el valor del diagnóstico de medirla desregulación inmune para predecir el riesgo de desarrollar de ciertas enfermedades o condiciones en una misma persona? ¿Cuál es el valor terapéutico de medicamentos que inhiben la respuesta de los interferones y se asocian con el proceso inflamatorio?

Existen varios factores que están generando mucho entusiasmo en la búsqueda de respuesta a estas preguntas. En primer lugar, se sabe que la hiperactividad de la respuesta de los Interferones tiene efectos negativos en el desarrollo humano, como se muestra en el IFN tipo I, un tipo de condición genética que está causado por mutaciones del gen, las cuales propician la activación de los interferones. Comparte muchos síntomas con el síndrome de Down. En segundo lugar, la industria farmacéutica ha desarrollado varios medicamentos que inhiben la respuesta de los interferones, algunos tratan condiciones autoinflamatorias como la artritis reumatoide. Y que actualmente se están probando para tratar las condiciones autoinmunes prevalentes en el síndrome de Down como la alopecia y el vitiligo. Por último, el estudio con ratones con el síndrome por parte de Lenny Maroun, doctorado en el Instituto Crnic, ha demostrado que la reducir la respuesta dada por los interferones mejora el desarrollo.

En conclusión, el conjunto de estos estudios muestra un gran interés en el estudio del sistema inmune en las personas con síndrome de Down, lo cual conlleva un desarrollo potencial en el diagnóstico y los tratamientos terapéuticos para mejorar el bienestar de las personas con trisomía 21.

Para saber más sobre las investigaciones del Instituto Crnic, visita globaldownsyndrome.org/our-story/linda-cnic-institute.

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Este artículo La importancia del sistema inmune en las personas con síndrome de Down, fue escrito y publicado por la galardonada revista *Down Syndrome World™*, una publicación de la Fundación Mundial del síndrome de Down. Traducción al español dentro del proyecto PerMundo para la traducción gratuita de páginas web y documentos para ONG y asociaciones sin ánimo de lucro. Proyecto dirigido por Mondo Agit. Traductora: Candela Gómez Sancecilio. Revisora: Gema García Crespo.



PERMONDO
Translations for non-profit

Dra. Macarena Lizama fue reconocida como una de las 100 mujeres líderes de 2018



En la decimoséptima versión del premio, se recibieron sobre 600 postulaciones, donde personas naturales, agrupaciones e instituciones pudieron postular a sus candidatas. Ser figuras de liderazgo en sus áreas, con labor destacada y potencial como modelo a seguir, fueron los principales atributos que evaluó el jurado en cada una de las participantes, de las que salieron las 100 Mujeres Líderes 2018.

Una de las premiadas fue la pediatra Macarena Lizama, académica UC y directora ejecutiva del Centro UC Síndrome de Down: "Sin duda cuando uno recibe un reconocimiento de esta envergadura siente que lo que ha ido haciendo tiene un impacto, pero yo creo que lo más importante es que es un reconocimiento no solo a mí sino que a todo el equipo en el que trabajo", comentó la doctora.

"Las personas con Síndrome de Down tienen muchas necesidades y muchas de ellas no están resueltas, y en ese sentido creo que de a poco hemos podido ir viendo esas necesidades y trabajando por ir resolviéndolas de la mejor forma, pero sin duda queda mucho camino por recorrer", agregó la especialista UC.

Su pasión por el área nació mientras era becada de pediatría y le tocó atender a una paciente con Síndrome de Down, una joven de 15 años, que tenía una cardiopatía congénita que no había sido operada. La doctora cuenta que en la época en que debiera haberse operado, hace unos 30 años, la cirugía

cardíaca no estaba dentro de las oportunidades habituales de personas con Síndrome de Down, ya que se privilegiaba a aquellos que tenían mejor pronóstico de vida.

"Cuando la conocí ya estaba muy complicada, estaba teniendo efectos muy adversos entorno a su cardiopatía y falleció. En ese momento comencé a cuestionarme la falta de equidad en las oportunidades de personas con Síndrome de Down. Ella fue uno de mis primeros pacientes y después de poco más de 15 años es mi principal área de trabajo", comentó la Dra. Lizama.

Los futuros proyectos 2019 son ampliar el apoyo del Centro UC Síndrome de Down hacia la etapa más adulta y vida independiente, y poder llevar a cabo el proyecto Centro Sobre Ruedas, que consiste en recorrer distintas regiones de Chile e ir capacitando a equipos que trabajan con personas con Síndrome de Down, con el fin de disminuir las brechas en regiones por desconocimiento.

Las 100 Mujeres Líderes 2018 recibirán su reconocimiento en una ceremonia que se realizará el martes 27 de noviembre, y durante el primer semestre de 2019 estarán convocadas a un encuentro en Las Majadas de Pirque, encuentro donde podrán conversar y plantear sus preocupaciones y propuestas en relación a la equidad de género.

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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Down Syndrome News

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To renew or join, visit ndsccenter.org.

To update your contact information, call 800-232-6372 or email 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

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