



Down Syndrome News

NEWSLETTER OF THE

Volume 39, Number 3

Fall 2016



CONVENTION 2016 Imagine the Possibilities

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"To all of the many, many people involved; for all of the many, many hours of work and preparation, we have benefited from it all and are very grateful!"



Executive Director's Report

NDSC Annual Membership Meeting – July 23, 2016

Each year at NDSC's General Membership Meeting, our Executive Director, David Tolleson, provides a "State of the NDSC" report.

Good afternoon. I'm pleased to report that the NDSC remains strong, stable and focused on improving the world for people with Down syndrome.

Over the winter, our board and staff met twice to discuss, and begin implementation of, our new strategic plan. This weekend you can see some of the results of our work. We've launched the NDSC Center for Educational Excellence, with two programs this weekend, including a CEU-generating session for educators. We've also announced our partnership with the Learning Program Online, which will provide continuing education throughout the year. More opportunities will be announced in the coming months as we provide additional direct educational services for parents and professionals.

As you've seen throughout this weekend, we are increasing our commitment to educating and empowering self-advocates and families of all backgrounds to influence public policy. We've increased our presence in Washington, D.C. by expanding the role of Senior Policy Advisor, attorney, parent and educational policy expert Ricki Sabia. It was Ricki who drafted the improved provisions

for students taking alternative assessments that were included in the Every Student Succeeds Act. Ricki has also developed free resources for families to use for education advocacy in their own states. Stephanie Smith Lee, former head of the federal Department of Education's Office of Special Education Programs – and the nation's top expert on post-secondary programs for students with intellectual disabilities – represents the NDSC, and all of us, on Capitol Hill.

They, of course, are joined by our Governmental Affairs Director Susan Goodman. Susan is now in her 15th year with the NDSC, making her the longest tenured member of our team. Both our organization, and our families, owe Susan a great debt for the work she has done. When others cut workers out of ABLE Act coverage, Susan fought successfully to keep them eligible. She has been a leader in the fight to stop restraint and seclusion in schools and is the only national Down syndrome advocate that I know of who meets regularly with the Administration on ensuring community-integrated living for adults. She represents us on civil rights issues and is a vocal advocate for real jobs for real pay in transition from school to work and adult life.

Legislative advocacy isn't just a nice thing to do – it's essential to keeping and expanding the rights of individuals with Down syndrome and other disabilities. Laws we

Down Syndrome News

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Mission

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

Vision

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

Statement of Policy and Disclaimer:

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

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

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Jeannie Visootsak, M.D.

take for granted, like A.D.A. and I.D.E.A. didn't just happen. NDSC and others made them happen and we're still working every day to protect and defend the rights of your family member with Down syndrome.

We are also determined to increase our presence in the medical community. Of course, anyone who has been to an NDSC Convention knows of our long, positive relationship with the Down Syndrome Medical Interest Group. However, many don't realize that for years we've exhibited at professional conferences, such as the American College of Medical Genetics and Genomics; the American College of Obstetricians and Gynecologists; and,

records, but it wouldn't happen without the support of our board, our affiliate partners, our sponsors and a small army of amazing speakers and volunteers. However, most of all, it wouldn't happen without my wonderful colleagues at the NDSC. I've never seen a group do so much with so little. A group that is so passionate about serving others and making the world a better place. And it's not just during the convention, though we all love it and are justifiably proud of it. These folks are good stewards of your gifts and are working hard on your behalf throughout the year. So, if you get a chance to say "thank you," I hope you'll take it.



Finally, whether we like it or not, this is an election year. One of the things that makes America great, that sets us apart from most of the world, is that every four years — in wartime and peace, in depression or boom — we have a peaceful transition of power. It's also something that makes the NDSC great. For 44 years, we have been an extraordinarily stable presence in the Down syndrome community. While

the National Society of Genetic Counselors, presenting free, accurate, up-to-date prenatal and postnatal information about Down syndrome in contemporary America. This year, we've expanded our reach, adding the Academy of Clinical Physicians and the Society of Developmental and Behavioral Pediatricians conferences to our list.

We continue our work to expand our reach to underserved populations. As an organization that promotes full inclusion of individuals with Down syndrome, it would seem disingenuous if we did anything less. As recent events have reminded us, we're better all together.

Nothing exemplifies that more than our annual convention. Some people think it's all we do, which can be a bit frustrating the other 51 weeks of the year. But, if what we're best known for is a weekend that brings together people from every inhabited continent to learn and laugh and dance and celebrate, I'll take it.

Once again, our convention has broken attendance

other organizations have come and gone, or seen abrupt leadership changes — as in, "has anyone heard from 'so-and-so' lately, 'cuz it seems like he's just disappeared" — the NDSC has been a calm, consistent, reliable force in the community.

No, we're not really flashy. We prefer substance over style. When we advocate for policy, we're looking for real, meaningful change, not just a "win" we can promote. While we're working to increase public knowledge of our work, whether it's in Washington, or at medical conferences, or one-on-one with families, that hasn't historically been part of our culture. What we want — what we've always wanted — is to be a force for good and to make the world a better place for people with Down syndrome.

So, as we begin our 45th year, I want to thank you for your support and to tell you with complete certainty that the best days of the NDSC — in fact the best days for the entire Down syndrome community — lie ahead.

Thank you.

Sincere Appreciation

to our 2016 Convention Sponsors



NATIONAL
DOWN SYNDROME
CONGRESS

DIAMOND – \$40,000



Genentech
A Member of the Roche Group

GOLD – \$15,000



ds·connex
Empowering Down Syndrome Communities

SILVER – \$10,000



INTERNATIONAL
QUALITY WITH THE
STRENGTH OF STEEL



BRONZE – \$5,000



PATRON – \$2,500



DOWN SYNDROME
AFFILIATES IN ACTION



Down Syndrome Association of Minnesota



Why we love being an NDSC Convention Sponsor

By the founders of ds-connex

Ds-connex was proud to be a Gold Sponsor of the 2016 NDSC Convention. For those readers who aren't familiar with us, we are a company who provides team fundraising software and social media support exclusively to the Down syndrome community. Our inspiration to create ds-connex was our nephew with Down syndrome and a desire to give the community a bigger voice. We work with Down syndrome organizations all across the country to engage their community for local walk and 5k events.

Being a supporter of the NDSC Convention goes far beyond just sponsorship. The convention is truly a coming together of the Down syndrome community. It's not just the individual with Down syndrome and their family in attendance. You see aunts and uncles, grandmas and grandpas, longtime friends, and even employers come out to celebrate someone they know with Down syndrome. The convention is an opportunity to make connections with new people, reunite with familiar faces, learn from experts across multiple fields of study, and of course, dance. That last one is a fan favorite of the convention; and there's plenty of opportunities for those of all ages to partake!

Our team flew to Orlando this year to provide social media support and visit with our current partners. While our founder has attended past conventions, it was the first time attending the convention for several of our team members. That first night (Thursday), we were so amazed at how the packed the crowd was at registration. You could feel the excitement, anticipation, and enthusiasm in the air. It was so evident the attendees knew they were in for a weekend they would never forget.

Right before registration started, we bumped into two moms sitting together on the floor. It turns out the one mother had a baby with Down syndrome and the woman she was speaking with had an adult son with Down syndrome. She was sharing with her all of the things her son COULD do and how proud she was of all of his accomplishments. It was such an inspiring feeling to see this unfold and to witness their two paths cross. And that was just the first night!

Over the next few days, we interfaced with families from all across the country, and several of our ds-connex partners! We chatted with attendees as they excitedly

waited in line to meet the cast of A&E's hit series "Born This Way" (the line formed right next to our booth), we talked with self-advocates as they shared their interests and goals with us, and we met other sponsors who are just as sold as we are on the valuable work and contribution NDSC is making in the Down syndrome community.

One mom we met at our table traveled from Cleveland, Ohio to attend the convention with her daughter. She owns a bakery and funded their trip to the convention by selling cakes. Wow! Her daughter even had custom Down syndrome awareness shirts made for each day of the convention. We could just feel their excitement in talking with them; they were so thrilled to be a part of the convention. This was a striking moment for us as a sponsor and member of the community. You know an event has a powerful impact when individuals will fundraise through all means necessary to be there.

When we look back on the 2016 NDSC Convention, we are grateful to have had the opportunity to be a part of it. The theme of this year's event was "Imagine The Possibilities." As the book closes on the 2016 event, we'd like to make one change to this statement as we look towards 2017: "Imagining the Possibilities if...." What we mean by this is imagine what could happen for someone you know with Down syndrome if you attended next year or invited others to attend, or if you volunteered your time in Kids' Camp, or asked your company if they'd like to sponsor the event, etc. The possibilities are endless!

The NDSC Convention is such a powerful, inspiring, motivational, and influential experience. We hope to see you in Sacramento next year!

Learn more about
ds-connex at ds-connex.org

Orlando Convention Fun Facts



More than 3500 people

participated in our Giant Family Reunion in Orlando!

With 102 speakers, and attendee representation from 45 states, Puerto Rico and 16 countries, the NDSC Convention truly is where the Down syndrome world comes together!



The Down Syndrome Medical Interest Group (DSMIG-USA) reported

134 medical professionals

from around the world took part in their two day symposium.

406 people volunteered during the weekend to make it all possible!



Digital audio recordings

of 70 workshops and the plenary sessions are available at conferencemedia.net. (Registered attendees can access these at no charge.)

With our experienced Sibling Leadership Team guiding the way, **166 siblings** participated with their peers in late elementary, middle-school, and high school age groups.



"This experience for our son without DS was invaluable. The time he spent hearing from other kids his age about their concerns and challenges at home changed his perspective towards his older brother immediately."

It was our largest Youth and Adults Conference ever, with **330 teens and adults**, ages 15 and up, learning, sharing and having an all-around awesome time together.

"My son, who is 23, had immense personal growth during this conference."



247 of our youngest attendees had a super great time in our Kids' Camps — this year with even more activities for every age group!

Ninety exhibitors showed off their stuff, including 20 self-advocate exhibitors!

Election of NDSC Board of Directors

Andrew Bean and his wife, Laura, live with their three children in Mentor, OH. Their son, Chris, has Down syndrome. Andy has been a member of the NDSC for sixteen years and has attended every NDSC convention during that time. He has been a volunteer coordinator of our Youth & Adults Conference since 2002, and supports our Self-Advocate Council members all year long. Andy was elected to his third term, and will continue to serve as First Vice President on our Executive Committee.

Bruce Bennett lives with his wife, Merilee, in Napa, CA. They are the parents of two adult children, including Christopher, who has Down syndrome. Bruce is President of a health care management and consulting business, and has held various leadership positions with the American College of Health Care Administrators. Additionally, Bruce serves as a Director of Provident Bank and has volunteered in a variety of civic and municipal roles. Bruce was elected to his second term and will continue to work with our strategic

team to develop self-advocate leaders.

Kathleen Forney and her husband, David, live in Minneapolis, MN. They have two children and two grandchildren. Her son, David-Michael, has Down syndrome. Since 1999, Kathleen has served as Executive Director of the Down Syndrome Association of Minnesota, where she has been instrumental in developing support programs for grandparents, educators and self-advocates. Kathleen

serves on NDSC's Partnership Alliance and is on the board of Down Syndrome Affiliates in Action. She was elected to her third term.

Elected to her third term, **Julie Harmon** lives in Colorado Springs, CO, with her husband Dave and their two sons, who both have Down syndrome. The oldest, Nick, is a graduate of the University of Colorado, Colorado Springs. Younger son Noah is now in tenth grade and enjoys all that life brings him. Julie is the Director of Parent Services for PEAK Parent Center and a Board Member of the Colorado Springs Down Syndrome Association. She serves on NDSC's Partnership Alliance.

Katie Kremer of Las Vegas, Nevada, was elected by her peers to serve as the newest self-advocate member of our Board of Directors. Katie is 33, the oldest of four girls. She was raised in Nome, Alaska, but recently moved to Las Vegas.

Katie received her high school diploma in 2003, then took classes at the University of Alaska, Northwest campus. She was accepted into a statewide cultural exchange program for young adults with disabilities from Alaska and Hawaii and participated in local cultural activities, including learning the hula in Hawaii.

Katie has been a Special Olympics athlete for many years, participating in alpine and cross country skiing, bowling, equestrian, figure skating, gymnastics, and track and field events. She was on TEAM USA at the 2001 World Winter Games, where she participated in closing ceremonies and met and spoke with Eunice Kennedy Shriver and Arnold Schwarzenegger.

Katie has long been a self-advocate — whenever she travels, she enjoys meeting new people, visiting with them, and forming a friendly connection. She is always glad to see when others realize "We're More Alike Than Different."

During her term on the board, she hopes to use her enthusiasm for meeting people and getting to know them to promote

Katie Kremer



independent living skills and involvement in community activities, as well as involvement in organizations that assist people with Down syndrome.

Macarena Lizama of Santiago, Chile, is an Assistant Professor of Pediatrics in the School of Medicine at Pontificia Universidad Católica de Chile, where she earned her medical degree. In her clinical work, Dr. Lizama provides primary care to children with Down syndrome and other disabilities. She has spoken at numerous conferences around the world, including the NDSC Convention. This is her first term on our board of directors.

Elected to her first term, **Shauntel Neal-Howe** lives in Marietta, GA, with her husband and their ten-year-old daughter, Zoe, who has Down syndrome. Shauntel, who works in both finance and project management, earned her undergraduate degree in Technology and Information Systems from Purdue and her MBA in Finance from the University of St. Thomas. She has been active with Down Syndrome Indiana and with the Down Syndrome Minority Family Network.

Chandra Torry of Fayetteville, NC, received her Doctor of Pharmacy degree from Campbell University, and currently works as a Pharmacy Manager for Wal-Mart. She has five siblings, the youngest of whom has Down syndrome. Chandra previously served on the Board of Directors of the Down Syndrome Association of Memphis and the Mid-South and serves on NDSC's Adult Sibling Task Force. Chandra was elected to her third term.



Executive Committee Members Shawn Hardister, Kate Dougherty, Kishore Vellody, Marilyn Tolbert, Andy Bean and Carole Guess

Kishore Vellody, who lives with his family in Seven Fields, PA, is an Associate Professor of Pediatrics and the Medical Director of the Down Syndrome Center of Western Pennsylvania. He earned his medical degree at the University of Illinois, Chicago. Dr. Vellody, who has a brother with Down syndrome, is an active member of Down Syndrome Medical Interest Group – USA, leads NDSC's Professional Advisory Council, and serves as second Vice President on our Executive Council. This will be his second term.



Newly elected board members Bruce Bennett, Shantel Neal-Howe, Chandra Torry, Kishore Vellody, Andy Bean (back row) with Katie Kremer and NDSC President, Marilyn Tolbert

2016 Award Winners

Each year, we are proud to recognize outstanding contributions in the Down syndrome community across a broad span of categories. Our Awards Committee and Board of Directors ask the following questions when evaluating the nominations:

- 1) Does the program, publication, or individual promote a positive image of people with Down syndrome?
- 2) Does it accentuate abilities, not disability?
- 3) Does it focus on people, not on the condition of Down syndrome?
- 4) Does it celebrate diversity?
- 5) Does it use people first language?
- 6) Does it enhance the dignity of people with Down syndrome?
- 7) Does it avoid stereotyping?
- 8) Does it present accurate information?
- 9) Does it recognize the value of persons with Down syndrome?

With that in mind, please help us celebrate the following award recipients!

We received amazing support from not one, but from ELEVEN strong affiliate groups as our **Convention Hosts**. They are, in alphabetical order: Broward Gold Coast Down Syndrome Organization; Down Syndrome Association of Central Florida; Down Syndrome Association of Jacksonville; Down Syndrome Association of Panama City; Down Syndrome Association of Polk County; Down Syndrome Association of Tallahassee; Families Exploring Down Syndrome of Brevard; Fun Coast Down Syndrome Association; Gold

Coast Down Syndrome Organization; Manasota BUDS; and Treasure Coast Down Syndrome Awareness Group.

NDSC's **Education Award** recognizes outstanding performance on behalf of students with DS. Professor Sue Buckley is Director of Research for Down Syndrome Education International and Emeritus Professor of Developmental Disability, Department of Psychology, University of Portsmouth UK. She was the first person to publish research (in 1985) showing that children with Down syndrome could learn to read, at a time when expert opinion was that our children were ineducable. She continues to work to improve education worldwide and has just published an online course on effective education for children with Down syndrome with DSE.

The **Exceptional Meritorious Service Award** recognizes an individual whose service and contributions to people with Down syndrome and their families have had local, state and national significance. Florida Senate President Andy Gardiner was this year's recipient, whose legacy in the state includes championing the ABLE Act; the creation and then the expansion of "personal learning scholarship accounts," providing about \$10,000 a year to enhance services and education for children with disabilities; and his focus on providing post-secondary opportunities for students with intellectual disabilities.

The **Employer of the Year Award** recognizes an employer for efforts in creating employment opportunities for people with Down syndrome. This year's recipient is Clara LeBlanc from Clara's Tidbits in Jacksonville, Florida.



Sports Columnist Paul Daugherty served as Awards Banquet Emcee

NDSC member Frank Harmon has been on staff since October 2014, and Clara knows how to make Frank a valued employee. It is an extremely busy and fast-paced environment where natural supports help him be successful. Because Clara believes in Frank's abilities, he has been given the opportunity to live his best life.

National media efforts create better understanding of DS and people with DS. The award recognizes programs on television and radio, national publications, serials and syndicated columns.

This year's **Media Print Award** was presented to Paul Daugherty. Best known as a sports columnist, since 1979 Paul has covered Super Bowls, Summer Olympics, World Series, Masters Golf Tournaments and NBA Final Fours. In 2013, he was named the best newspaper sports columnist and sports feature writer in America, by the Associated Press Sports Editors. He has also written four books and is in the midst of a fifth. His most recent work, *An Uncomplicated Life*, details the first 25 years of his daughter, Jillian the Magnificent's life, from the time she was diagnosed with Down syndrome, until her marriage just one year ago.

Our **Media Broadcast Award** was given to A&E Network and Bunim/Murray Productions for their Emmy nominated show, *Born This Way*. For many viewers, *Born This Way* is their introduction to someone who has Down syndrome. Thankfully, the introduction provided by this program is accurate and respectful — as well as enjoyable to watch. We are grateful for, and applaud, their work.

The **Sig Pueschel NDSC Service Award** is presented each year to an individual or organization for outstanding contributions to the NDSC. This year's award was presented to the Kurt Asplundh

Special Education at Peabody College of Vanderbilt University and a member of the Vanderbilt Kennedy Center. His research focuses on improving academic outcomes for children and adolescents with intellectual, developmental, and learning disabilities.

The **Christian Pueschel Memorial Citizen Award** goes to an outstanding self-advocate and is named in honor of the late Christian Pueschel. This year's recipient is Ashley DeRamus. In February 2012, Ashley, along with her mother, Connie, established The Ashley DeRamus Foundation, which works to increase awareness of Down

that country's ratification of the United Nations Convention on the Rights of People with Disabilities — has been outstanding.

For the past four years, Rhode Island-based photographer Laura Kilgus, has been offering free photography sessions to children with Down syndrome and their families. Laura's photography has been featured on *The Today Show*, *Good Morning America*, *ABC National News*, *The Huffington Post*, *Women's Day Magazine*, *Red Book Magazine* and other news outlets.

Since its inception, UCF Go Baby Go has built and distributed 30 modified ride on cars and offered educational opportunities for therapists from throughout Florida. Through partnerships such as those established with the Down Syndrome Association of Central Florida, UCF Go Baby Go and other chapters can continue to collaborate to provide innovative solutions to provide mobility to children and adults.

The Dominican Down Syndrome Association (ADOSID) is a foundation created in 1992, dedicated to developing the potential of children and young people with Down syndrome. ADOSID was the first Dominican organization dedicated to the guidance and support of families who had members with Down syndrome. Since it was founded, they have helped over two thousand children and young people with Down syndrome and their families.

We thank the following **Board Members** for their combined 27 years of service to the NDSC: Christopher Bennett, Napa, CA; Regina Britt of Columbus, OH; Jim Faber of Monument, CO and Viviana Fernandez of Johns Creek, GA.



The Kurt Asplundh Family was honored with this year's Sig Pueschel NDSC Service Award, presented by Jeanette Pueschel Larson.

Family. The NDSC is grateful for the Asplundhs' long-term support, especially around the meaningful inclusion of self-advocates on our Board of Directors; public awareness about Down syndrome; and most recently in outreach to adult siblings.

The **Pueschel-Tjossem Research Award** recognizes an individual whose research contributes to the understanding of DS or whose research improves the lives of people with DS or their families. Presented this year to Christopher J. Lemons, Ph.D., an Assistant Professor of

syndrome and enlighten others about the positive contributions those with Down syndrome make to society.

NDSC President Marilyn Tolbert presented four **President's Awards:**

Down Syndrome Family Network: In five short years, the DSFN has done amazing work in promoting acceptance, inclusion and awareness of individuals with Down syndrome in Trinidad and Tobago. In addition to providing conferences, workshops and classes, their outreach to government officials — resulting in

Call for Speakers



Pre-conference and General Convention
Speaker George Tilson shares his
expertise on employment.

GENERAL CONVENTION

Are you an expert in inclusion, speech pathology, technology, employment (or another topic across the lifespan) for people with Down syndrome? Are you engaging and motivating with solid presentation skills? Do you have proven strategies that will bridge the gap between parents and professionals in the Down syndrome community? If so, then the NDSC wants to hear from you! Proposals for 90 minute workshops for the 45th Annual NDSC Convention are currently being accepted.

The NDSC Convention is the largest event of its kind attracting more than 3,500 participants worldwide. It will take place July 20 – 23, 2017 at the Sacramento Convention Center in Sacramento, CA. Workshops will take place Friday, July 21, Saturday, July 22 and Sunday, July 23. Only speakers who are available to present on all three days should apply. Special consideration will be given to professionals attending the DSMIG Annual Symposium on Friday, July 21.

Visit our website <http://www.ndsccenter.org/the-convention/> for all the details regarding submissions, including:

- Submission guidelines
- List of requested topics
- Selection criteria
- Tips for getting selected
- Review process
- Important dates and deadlines

YOUTH & ADULTS PROGRAM

Our self-advocate attendees enjoy interactive workshops and presentations that get people moving, thinking, learning, and having fun. If you are a self-advocate (or you know one) who likes presenting to a live audience and has expertise in a topic that others will find interesting, this is the place to share what you know with your peers.

There are several types of presentations needed. We are looking for self-advocates to give 4-5 minute presentations on their life experiences. We are looking for self-advocates to lead smaller groups in interactive workshops. We are looking for self-advocates to lead large groups in a craft, activity or game. You can find topic ideas and more details about presenting, including the presenter proposal form on our convention website, <http://www.ndsccenter.org/the-convention/>.



Collin Clarke presented to both the Youth & Adults
Program and in the General Convention on his success
in bodybuilding.

Join LP Online™ to Improve Reading, Comprehension and Math Skills

The NDSC Center for Educational Excellence has partnered with the Down Syndrome Foundation of Orange County, and we invite you to participate in LP Online™ 2016-2017!

LP Online™ is an online learning community based on The Learning Program™ and serves as a platform for sharing strategies, resources and activities to improve academic outcomes for students with Down syndrome.

We are so excited to bring you this amazing educational opportunity! Participants are able to join live sessions in real time or view recorded learning sessions at their convenience. LP Online™ works to replicate the very successful face to face program currently serving families all across the country through Learning Program Partners.

In a nutshell, LP Online™ consists of ten sessions of The Learning Program's™ face to face program (LP Onsite™) offered via webinars in both live and recorded formats. These sessions support the development of reading, comprehension and math skills, and address general topics related to accessing curriculum, fostering independence

and memory. Sessions are geared towards supporting parents in the educational process, but administrators, teachers and therapists are welcome to join.

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

- Level 1 is appropriate for students in preschool through 1st grade (ages 3-5)
- Level 2 is appropriate for students in 2nd or 3rd grade (ages 6-8)
- Level 3 is appropriate for students in 4th through 6th grade (ages 9-12)

If you have a question about which level to choose or have any other questions about the program, contact info@dsfoc.org or tamara@ndsccenter.org.



Recommended reading and viewing

Supporting Positive Behavior in Children and Teens with Down Syndrome

David Stein, Psy.D.

David Stein is a pediatric psychologist, and is co-director of the Down Syndrome Program at Boston Children's Hospital. As a presenter, Dr. Stein is so popular at our convention that people not only ask for him to come back each year, they even want him to expand from his 90 minute workshop to a four hour pre-conference. His new book, *Supporting Positive Behavior in Children and Teens with Down Syndrome*, is another way to access his



Respond but Don't React Method. At just 140 pages, this book will guide you in responding to common behavior issues seen in children with Down syndrome. "Bad" behavior means a person has unmet needs and challenges! This book will help you with tools to be consistent and to be proactive instead of reactive. You are not alone!

Woodbine House, paperback, 140 pages, July 5, 2016

Stealing First

Stealing First is a wonderful memoir written by self-advocate Teddy Kremer, with assistance from authors Diane Lang and Mike Buchanan. If you met Teddy in our exhibit hall in Orlando, you know he is as charming as they come.

"Nothing — not the state championship, Disney World, President Obama waving at



me, or getting my own baseball card — can top the night of April 18, 2013. On that night, I was at the Great American Ball Park as batboy for the Cincinnati Reds. It was the second time I was the Reds' batboy. The

year before, I was an honorary batboy for the Reds because my parents won a bid at a silent auction. When I walked on the field in that first game and met the players, it was so exciting! That night the Reds hit seven home runs and Manager Dusty Baker said, "Seems you're our good luck charm, Teddy." I guess that's why they invited me back."

Deeds Publishing, paperback, 231 Pages, April 13, 2016

Convención NDSC 2016

¡Imaginamos las posibilidades

y este año fuimos 4000! Seguimos creciendo no solo en número, pero también en talento y conocimiento. A nuestra gran reunión familiar asistieron personas de 19 diferentes países todos con la conciencia de que juntos es posible crear un presente donde la inclusión es la protagonista.



Testimonio Maria isabel Aguilera y Jorge Rojas

Es la primera vez que asistimos al congreso y fue una experiencia maravillosa! Nos llevamos grandes aprendizajes, motivación y alegría por ver que nuestros niños SI pueden! Solo hay que apoyarlos y guiarlos. Un abrazo desde Panamá.



Testimonio Trinidad Gutierrez, Chile

Para mi como madre de Felipe Belmar fué una tremenda oportunidad de compartir con padres y familias latinoamericanas, y participar de actividades con tantas personas felices con síndrome de Down. Para Felipe una gran experiencia de darse a conocer y relacionarse con tantos jovenes como él ¡Muchas Gracias!



Testimonio Rosario Nicaso

Agradezco de todo corazón a los organizadores de la 44ª Convención Anual del NDSC, por el premio a ADOSID y por la extraordinaria oportunidad de asistir junto a mi familia a un encuentro sin fronteras. Felicidades!!!



En la cena de Gala del sábado en la noche

se entregó el Premio "President's Award" a la Asociación Dominicana de síndrome de Down ADOSID por la labor realizada durante 24 años en este país. El premio fue recibido por Rosario Nicasio de Frigati y Lourdes Rodriguez de Lima.



Testimonio Familia Moreno Campuzano

Para mi esposo y para mí fue la mejor de las experiencias, teniendo nuestros tres hijos con síndrome de Down nos dimos la oportunidad de asistir para conocer e informarnos más en la materia. Ser padres de tres niños es un reto todos los días, pero afortunadamente existen las conferencias de ayuda y a nosotros nos ayudan muchísimo. Muy felices de haber participado, aprendimos de todo un poco para llevarlo a cabo en nuestra vida cotidiana. Esperamos que no sea la primera participación de nuestra familia, sino seguir asistiendo a este tipo de eventos que tanta falta nos hace para ayudar a nuestros hijos. Gracias por todo!!



Testimonio Familia Figueroa Cardenas

Fue la primera vez que participamos en el Congreso, una experiencia espectacular e inimaginable. Sentimos que estábamos en casa y que las 4000 personas eran nuestra familia, todos de diferentes países, culturas, edades, etc pero todos con un solo objetivo: Seguir formándonos, aprendiendo y fortaleciéndonos para mejorar como Personas y como Padres, para guiar, educar, formar, corregir y seguir el mejor camino de vida para nuestros hijos por el gran amor que les tenemos y con mucha FE en DIOS.



Una foto del primer día que llegamos y nos encontramos con amigos peruanos Pablo Gomez y familia (Presidente de la Sociedad de Síndrome de Down de Perú) y nosotros Pavel Figueroa y Familia.

Los Ponentes

Durante tres días en seis ciclos de 13 talleres cada uno expertos en medicina, en terapia del lenguaje, fonoaudiólogos, genetistas, profesores, psicólogos y otros profesionales compartieron los últimos descubrimientos de la ciencia en el tema, sus conocimientos, y sus propias experiencias. Gracias a todos ellos por su gran contribución.



Down Syndrome News

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When we **empower** individuals
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by the National Down Syndrome Congress



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Share your love of the NDSC and our mission by wearing
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