NEWSLETTER OF THE NATIONAL DOWN SYNDROME CONGRESS

# DOWN SYNDROME

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# **2015 Convention**









"For far too long, limits have been placed on individuals with Down syndrome. This weekend you will be empowered to advocate for people with Down syndrome, and help those around you see beyond those limits."

- Marilyn Tolbert, NDSC President



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Executive Director: David Tolleson

General Correspondence and Memberships: National Down Syndrome Congress 30 Mansell Court, Suite 108 Roswell, GA 30076

phone: 800.232.NDSC fax: 770.604.9898 email: info@ndsccenter.org website: ndsccenter.org

#### Statement of Policy and Disclaimer:

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

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

#### **Reprints From DSN:**

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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.

## MANY THANKS TO OUR SPONSORS!

We depend on the generosity of our convention sponsors to keep the cost of registration as low as possible. With their support, we are also able to offer a limited number of scholarships, provide simultaneous interpretation for our Spanish-speaking attendees, and for the first time this year, we were able to provide digital audio recordings of the workshops to all of our registered attendees.

We hope you will join us in thanking this year's sponsors! If you are interested in learning more about becoming a sponsor (or know of a company or organization that would be interested), please contact our Development Director, Kathy Edwards, at 770-604-9500.



### Self-Advocate Delegation Meets in Phoenix



On Friday, June 26th, this year's **Self-Advocate Delegation** met to learn and share with other selfadvocates and with the NDSC's Self-Advocate Council (SAC). Delegates in attendance represented their local Down syndrome organizations from around the country, and were nominated by leaders of those parent groups.

The SAC, which is made up of the three self-advocates currently serving on the NDSC board and seventeen past board members, meets annually during the convention to brainstorm ideas and set goals for the coming year. By adding the Delegate meeting, we are more effective in spreading information to self-advocates all across the country.

During this one-hour session at the convention, the delegates and council members share what has happened in the past year. Delegates can also share initiatives that are happening in their area.

This year, Jessica Smart from Olive Branch, Mississippi shared a PowerPoint presentation on fundraising. She provided highlights of her work on a fundraising project for the Down Syndrome Association of Memphis and the Mid-South, which was part of their "Get Down & Derby Gala." Jessica chaired the Wine Pull, which involved asking board members to donate bottles of wine, recruiting self-advocate volunteers to paint glassware, and creating the wine display for the gala. Jessie reported that it was a very successful fundraiser!

### **Global Research Roundtable**

On Thursday, June 25th, the Global Down Syndrome Foundation hosted the Research and Medical Care Roundtable with a focus on Down syndrome and Alzheimer's disease. Co-organized with the National Down Syndrome Congress as a free benefit for convention attendees, this Roundtable featured renowned scientists and medical professionals. Topics included a review of promising research, clinical trials, when an adult with Down syndrome should get tested, standards of medical care, and advocacy and support.

Response was overwhelmingly positive for this Roundtable, the quality of the material presented and the caliber of the speakers.



### **DSMIG-USA**

The Down Syndrome Medical Interest Group – USA met in conjunction with our convention again this year. This symposium provides a forum for sharing of knowledge and experiences related to clinical care of children and adults with Down syndrome, clinical research related to Down syndrome, and development of Down syndrome clinics.

DSMIG-USA<sup>®</sup> members and other professionals working in the field of Down syndrome including physicians, research scientists, nurses, Down syndrome clinic coordinators, psychologists, dietitians, occupational and physical therapists, speech-language pathologists, and social workers were in attendance. This year's topics included Neurologic Issues, Alzheimer's Disease, Mental Wellness and Behavioral Health, Regression, and Sexuality Education.

# **Convention Facts and Figures**

Nearly **3400 participants** from all over the globe took part in our convention weekend. We welcomed folks from 45 states, Puerto Rico and 19 countries to the JW Marriott Desert Ridge in Phoenix, Arizona. The facility could not have been more beautiful and the hotel staff was amazing!

Our Youth and Adult attendees exuded the "Beyond All Limits" convention theme all weekend! We reached our capacity of

**315 self-advocate** participants from 41 states, Puerto Rico, Argentina, Canada, Dominican Republic, Guatemala and Nigeria!



On Thursday evening, attendees could choose one of

**several kick-off events,** including a welcome party at the pool, a reception for International Attendees, one for Adult Siblings and a First Timer Orientation. Led by 10 experienced college-age sibs,

162 siblings

took part in our Brothers and Sisters conference, in one of three age groups: 4th and 5th graders, middle schoolers and high schoolers.

## More than 100

people participated in our second Minority Families "Lunch and Learn" on Friday, sponsored by HSC Foundation.

*"I would like to congratulate you and the entire NDSC staff for an amazing convention. It was truly phenomenal and life-changing, literally."* 



# 244 kiddos

joined the fun in our Kids' Camp activities, which included magicians, clowns, animals, puppet shows (and more!) over five different sessions.

## 93 Exhibit Booths attracted our

attendees to products, services and inspirational messages.



In celebration of achievements in the Down syndrome community, our Awards Banquet was enjoyed by

more than 1,100 people.

Our Convention Mobile App engaged over **1,000 active users!** 

**98 speakers** selflessly gave their time to provide our attendees with a world class experience!



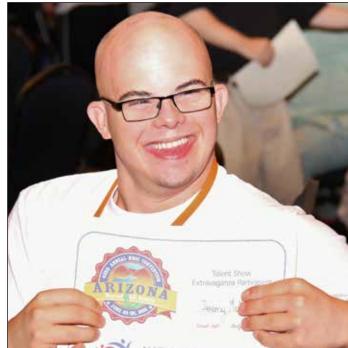
"My husband and I attended for the first time and it was absolutely wonderful. We have 3 boys (ages 11, 10, 7) and a daughter (age 4 with DS)... we will definitely be attending sometime in the future and bringing the whole family! It was a truly awesome experience – tears to my eyes many, many, many times. I can totally see why so many people go to this EVERY YEAR!!!"



### **Convention Recordings**

For the first time, we were able to provide registered attendees with access to digital audio recordings of the workshops and plenary sessions as part of their registration fees! There's nothing like being in the room, but this is the next best option!

If you did not attend the convention, you can get the complete set of recordings for \$70.00. Visit http://www.conferencemedia.net/stores/ndsc/ for a complete listing of recorded workshops.





ADVOCACY ★ OPPORTUNITIES ★ INCLUSION

# **Directors Elected to NDSC Board in Phoenix**

The NDSC's Board of Directors is composed of 23 individuals from across the United States. Three are self-advocates (elected by their peers), and two are representatives from our Partnership Alliance, our affiliate advisory body. Each board member is elected to serve a three year term. Elections were held at our Membership Meeting on June 27th, 2015. Read below to learn more about our newly elected members.

#### Carole Janine Guess, of

Indianapolis, Indiana, is the mother of ten-year-old Evan, who has Down syndrome. Carole has an undergraduate degree in developmental psychology, as well as master's degrees in business administration and accounting. She is also a certified information systems auditor. Carole founded the Minority Families Down Syndrome Network and has served on several committees with Down Syndrome Indiana, including Buddy Walk<sup>®</sup>, Family Assistance and Diversity. Carole, who is an IT audit program manager at Indiana University Health, was instrumental in establishing NDSC's IT policies and has been active in the organization's diversity outreach initiatives. This is Carole's third term on our board. She also serves as Vice President on our Executive Committee.



SEAN SMITH, CAROLE JANINE GUESS, JESSICA SMART, RAYMOND JANCSO, JR., MITCHEL ROTHHOLZ, NADINE MAES. NOT PICTURED: JEANNIE VISOOTSAK

Raymond Jancso, Jr. and his wife, Cari, live in Olive Branch, Mississippi, along with their two children. Their ten-year-old son, Tyler, has Down syndrome. Ray has worked for FedEx Express for twenty-seven years, the last eleven as a Flight Operations manager. In that role, he currently oversees the Crew Travel Services department. This year he is completing his service as President of the Board of Directors of the Down Syndrome Association of Memphis & the Mid-South. Ray has also been an active volunteer with Down Syndrome Affiliates in Action, chairing their Exhibitor Committee for the 2014 DSAIA Leadership Conference. This is Ray's first term.

Nadine Maes, of Rio Rancho, New Mexico, is a family resource and information specialist at the University of New Mexico Center for Development and Disabilities. Nadine and her husband, James, have five children, including seventeen-year-old Benjamin, who has Down syndrome. Nadine, who founded the Rio Grande Down Syndrome Network, has also served on her state Interagency Coordinating Council, Governor's Commission on Disability, and **Developmental Planning** Commission. Nadine, who has chaired NDSC's Governmental Affairs Committee, is also involved in the organization's diversity outreach efforts. Nadine will be

serving her third term on the NDSC Board of Directors.

Mitchel Rothholz, of Harleysville, Pennsylvania, is a pharmacist and Chief Strategy Officer of the 62,000 member Washington, D.C.-based American Pharmacists Association. A member of NDSC's Convention Planning Committee, Mitch also serves on the Parent Planning Committee for the Children's Hospital of Philadelphia Buddy Walk<sup>®</sup>. Locally, Mitch has been actively involved with the Montgomery County Down Syndrome Interest Group, T-21 Club of the Delaware Valley, Parent-to-Parent of Pennsylvania and The Arc Alliance. Mitch and his wife, Julie, are the parents of four-year-old Evan, who has Down syndrome. This is his first term.



JESSICA SMART

**Jessica Smart,** from Olive Branch, Mississippi, was elected by her peers at the Youth and Adults Conference.

Jessie is 26 years old and lives in Olive Branch, MS with her grandmother, Mom and Dad. She graduated from Lewisburg High School in 2009 with an occupational diploma and works for the DeSoto County schools as a teacher's assistant in the pre-k program at Lewisburg Primary School.

She has taken classes at Northwest Community College in history and American government, and volunteered at the Olive Branch library for 10 years in the summer reading program.

Jessie sings in the choir at Maples Church and she loves Ole Miss football. She is currently enrolled in an online theology program with Liberty University and hopes to someday become a minister.

In 2010 she was honored to receive the International "Yes I Can" Award for self-advocacy. This award is given by the Council of Exceptional Children to honor students with disabilities. Jessie was submitted for the award by her high school occupational teacher and traveled to Nashville to receive the award.

Jessie just completed her term as a board member of the Down Syndrome Association of Memphis & the Mid-South. She enjoys meeting people and speaking to groups about Down syndrome, and tries to be encouraging to others with disabilities.

Jessica is looking forward to representing her fellow selfadvocates on the NDSC Board, and promises to listen to ideas and suggestions and promote awareness about Down syndrome to the wider community. Sean Smith, Ph.D., lives with his wife and four children in Lawrence, Kansas, where he is a Professor of Special Education at the University of Kansas. Nolan, the Smiths' fourteen-year-old son, has Down syndrome. A frequent speaker at the NDSC Convention and elsewhere, Sean is a leading expert on the integration of technological innovations in the lives of individuals with disabilities. A teacher, teacher educator, researcher, speaker and author, Sean served six years on the Special Education Advisory Committee for the State of Kansas. This is Sean's first term.

#### Jeannie Visootsak, M.D.,

of New York, New York, is a member of the Professional Advisory groups of both NDSC and the American Association for Klinefelter Syndrome Information and Support and is also a member of the Down Syndrome Medical Interest Group – USA. A graduate of UCLA School of Medicine, Jeannie completed several postgraduate trainings, particularly focusing on minority and indigent care, as well as developmental and behavioral pediatrics. For ten years, she served as the Medical Director of the Down Syndrome Clinic at Emory University, where she also developed the Down Syndrome Clinical Trials Unit. Jeannie currently serves as the Translational Medicine Leader, Roche Innovation Center New York. This is Jeannie's first term.

# 2015 Award Recipients

Each year, the NDSC recognizes outstanding contributions to the Down syndrome community. We were proud to present the following awards in Phoenix:

Our **Convention Service Award** went to the entire host committee for their hard work in supporting our 2015 "Beyond All Limits" convention. Three leading Down syndrome parent organizations in Arizona pooled their talent and resources, and provided amazing support—in volunteer recruitment and management, as well as with their hospitality and financial support. These organizations are **Down Syndrome Network, Sharing Down Syndrome Arizona,** and **Southern Arizona Network for Down Syndrome.** 

This year's **National Media Award** was presented to the film, *Where Hope Grows*. Shown at our 2014 convention in Indianapolis before it was released widely, our members already gave it two thumbs up!

For years, "Hollywood" told the filmmakers,

- That they shouldn't make the film
- That no one would care; and they wondered,
- How would they get someone to "play like" they had Down syndrome?

This little film not only showed the great abilities of people with Down syndrome (David Desanctis memorized over 130 lines and delivered a pitch perfect performance), but also a little indie film made \$1.2M in the theaters and has almost 500,000 fans on Facebook! Very few films hit the million dollar threshold. The DVD is available now—if you haven't seen it yet, get the DVD!

In recognition of their work to advance best practices in post-secondary opportunities, our **Education Award** went to **Think College**. Think College, a project of the Institute for Community Inclusion at U. Mass in Boston, is a national source for information, training, and technical assistance on inclusive higher education for students with intellectual disabilities. Their website, www.thinkcollege.net includes a searchable program directory, a resource library, online learning modules and publications. Think College plays a key role in the development of high-quality, inclusive postsecondary opportunities for students with intellectual disabilities.

#### The Exceptional Meritorious Service Award

was awarded to **Dr. Jesus Florez** of Santander Spain. This award recognizes an individual whose service and contributions to persons with Down syndrome and their families have had national or international significance.

Dr. Florez serves as President of Fundación Iberoamericana Canal Down, which marks its 15th anniversary this year. We are happy to acknowledge Dr. Florez' lifetime of sharing his time, talent and expertise with people with Down syndrome, their families and the professionals and organizations who serve them, both in Spain and worldwide. His devotion is extraordinary and deserving of recognition by all of us.

#### Our Employer of the Year was Marriott

**Corporation**. Over the years, Marriott has shown great commitment to providing meaningful employment and training opportunities for people with disabilities. Given their history, it's not surprising that a Marriott branded hotel was chosen by the Arc of Indiana in their new 150-room hotel and hospitality training center in Muncie, Indiana.

In 2015, two deserving parent organizations were winners of our **National Parent Group of the Year. First, Down Syndrome Association of Greater St. Louis**. The DSAGSL began in 1970, as many groups do, when three parents of young children with Down syndrome met to exchange questions and ideas. When they met again, there were seven mothers with children of all ages. These seven mothers founded what would later become the DSAGSL. Today the DSAGSL has six staff members and serves over 1700 families, as well as educators, health professionals, and community members. Their programs are interesting and innovative: from therapeutic play groups to bike camps, and movie nights to Toastmasters, families are well-served in their community.

Second, the **Down Syndrome** Awareness Group of Greater Baton

**Rouge**. Since its founding, DSAG has been bringing significant resources to the families they serve, both educational and social. DSAG was founded in 1983 by an amazingly determined group of parents who wanted not only to improve the lives of their children, but to also create a life of inclusion for them.



GAIL WILLIAMSON, CENTER, IS JOINED BY ACTOR SOFIA SANCHEZ, AS WELL AS DAVID TOLLESON, JEANETTE PUESCHEL AND MARILYN TOLBERT

DSAG organizes several annual events including the Buddy Walk<sup>®</sup>, an annual Down Syndrome Conference, holiday parties, educational workshops, social outings, and much more. The organization also participates in other community events such as the Capital Area Heart Walk, and the Alzheimer's Services of the Capital Area's "Walk to Remember."

The Sig Pueschel NDSC Service Award was given to Gail Williamson, and we were honored to have Jeanette Pueschel join us again in Phoenix to make this presentation. Awarded each year to someone who has served the NDSC and its constituents selflessly, Gail has been an advocate in the media for people with Down syndrome since her son Blair landed his first commercial at age 11. Today Blair is 36, and Gail is a talent agent at one of the largest agencies in Los Angeles (and is the only talent agent in the US who specifically represents actors with diverse disabilities). She was responsible for Lauren Potter being cast in *Glee* and Jamie Brewer in *American Horror Story*, as well as helping many more actors with Down syndrome who have found work in entertainment and advertising. Gail has been a support to the National Down Syndrome Congress conventions for close to 20 years. She has been a workshop presenter, a panelist, a keynote speaker, the banquet emcee, and for the past 12 years, she has produced the NDSC Film Festival.

#### The Christian Pueschel Memorial Citizen

this year was **Brandon Gruber**. Brandon recently graduated from Aptos High School in Aptos, California. While he won many awards and accolades along the way, his journey was not without challenges. Brandon learned to navigate the disappointments of being excluded from certain activities, by advocating to become part of the student body leadership, because he knew they were part of the "in crowd."

After becoming Homecoming King in the fall, Brandon focused his attention on helping others realize their dreams. He started his own Foundation, "321 Life + 1," and raised money by selling his art cards. Between December 2014 and April 2015, he raised enough money to help 67 individuals, without financial resources, go to prom and purchase yearbooks. He even

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#### 2015 Award Recipients

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provided scholarships for three students who are the first in their families to go to college.

Brandon's core belief is "follow your dreams and never say never." His future goals include college, modeling, acting, art, and helping others through his 321 Life + 1 Project.

The Pueschel-Tjossem Research Award was presented to the Down Syndrome Consortium. Founded in 2011, the Down Syndrome Consortium is composed of the seven NIH Institutes and Centers with a strong interest in Down syndrome research, and 13 national and international Down syndrome organizations. The Down Syndrome Consortium has supported the development of the NIH-funded "DS-Connect<sup>®</sup>: The Down Syndrome Registry," an online, secure, confidential database with demographic and health information from individuals with Down syndrome designed to facilitate research. If you have not yet joined the registry, we encourage you to do so today!

NDSC President Marilyn Tolbert presented two **President's Awards** this year.

Catherine Beck accepted her late husband **Steve Beck's** award, in recognition of his dedication to advocacy for people with Down syndrome. Steve was unwavering in his work to right the inequities in the ability of parents to invest in the futures of their children with Down syndrome. He became involved in the Down Syndrome Society of Northern Virginia (DSANV) as an enthusiastic participant in the annual Buddy Walk, a board member and vice-chairman. He also participated with the Down Syndrome Affiliates in Action from its birth in 2005 and most recently served as Vice Chairman of the National Down Syndrome Society.

His tireless advocacy led to the passage of the ABLE Act, and in January 2015, President Barack Obama



CATHERINE BECK (CENTER) ACCEPTED A PRESIDENT'S AWARD ON BEHALF OF HER LATE HUSBAND, STEVE BECK.

signed the "Stephen E. Beck, Jr. Achieving a Better Life Experience" bill into law. The title was amended to add Stephen's name after his sudden passing, in honor of his signature efforts that made the passage of the bill a reality.

#### Puerto Rico Down Syndrome Foundation,

which was founded in 1989, received the second President's Award. The PRDSF was created by a group of mothers and fathers who were unable to find services for their daughters and sons. They began providing parent support, then an early intervention program, then they escalated to a pre-school/day care program, and most recently has become a learning therapeutic center for future professionals of the School of Medicine of the University of Puerto Rico and other undergraduate educational centers.

For more than 25 years, PRDSF has received support from local and federal governments, private foundations, and from the private sector. More than 2500 children and adolescents with Down syndrome have been able to receive services. These services include physical therapy, occupational therapy, speech therapy, day care services, arts (music, dancing, and painting), sports (Karate, others), workshops for parents, speech-language tutorials, living skills workshops and employment, among others. **Board Service Awards** were presented to retiring board members George Capone, John T. Farley, Tonia Ferguson and Lori McKee, in grateful appreciation for their years of service to the NDSC.

**George Capone** has served a full term and then some more. Since 1990, he has been on the medical staff at the Kennedy Krieger Institute, and currently serves as Director of the Down Syndrome Clinic & Research Center. We are grateful for his many years of service to the NDSC, but more importantly, to people with Down syndrome everywhere.

John T. Farley ran for a self-advocate position on the NDSC Board for five years before being elected. During his three years of service he also completed the TigerLIFE program and graduated from the University of Memphis. He will continue working with the University of Memphis Baseball Team as an assistant manager. John T has been dancing and performing for 24 years, including his Multi Media Elvis presentation last year at the Youth and Adults Conference. John T is also active at home with basketball, power lifting, and a book club. We will miss his presence at NDSC Board Meetings, where he has little patience for wasting time, and encourages his fellow board members to get straight to the point.

**Tonia Ferguson** is a parent of a child with Down syndrome and Autism Spectrum Disorder, and she has trained families and advocates on special education and family support issues during her career. Ms. Ferguson is currently the Vice President of External Affairs at the Autism Society and was a Joseph P. Kennedy Foundation Fellow working for Senator Christopher Dodd on Capitol Hill on the issues of early childhood issues and education. Tonia has served on the NDSC Board for nine years.

During **Lori McKee**'s time on the board, she's been involved with the Affiliate Leader Pre-conferences, served as both Secretary and Treasurer on the Executive Committee, and will continue to serve as a part of the Youth and Adults Support Team. For Lori, the convention has grown from being a resource for herself as a parent, to an annual event for her entire family. She is looking forward to being involved as a board member again with the Down Syndrome Guild of Dallas, and to attending many more NDSC conventions in the future.



RECOGNIZED FOR THEIR OUTSTANDING BOARD SERVICE, TONIA FERGUSON, GEORGE CAPONE, JOHN T. FARLEY AND LORI MCKEE

"Thank you so much for all of the hard work that went into putting this convention together! I had high hopes and expectations, and they were blown out of the water! So thankful that we attended!"

# **Call for Speakers**

While we'd love to keep celebrating the great time we had in Phoenix, we are already hard at work planning for next summer's convention in Orlando, Florida! We'll be heading to the JW Marriott Grande Lakes July 21st through the 24th in 2016, and we are accepting speaker proposals now!

#### **GENERAL CONVENTION**

We are always proud to bring the best speakers to our convention each year. Don't miss this opportunity to be a presenter (or let your favorite speaker know about this awesome event).

NDSC is now accepting proposals for knowledgeable, family-friendly speakers to present 90 minute workshops on topics related to Down syndrome. Be creative! Proposals should be interactive, provide "how to" strategies and evidence-based research as often as possible. Workshops will take place on Friday, July 22 beginning at 3:30 pm, all day Saturday, July 23 and Sunday, July 24 ending at 12:00 pm. Please only submit a proposal if you are available to present on all days! (Speakers participating in the DSMIG Annual Symposium who are selected to present at the NDSC Convention will not be scheduled to present on Friday, July 22.)

We look for experts in topics that cover the lifespan of individuals with Down syndrome, including health and medical concerns, therapies, positive behavior support, education (from pre-school to post-secondary), transition, employment, living options, friendships and social relationships, speech and communication, advocacy and systems change, aging and much more.

Workshop speakers who are selected will be responsible for securing their own travel arrangements at their own expense. Honoraria or speaker fees are not available. This policy has allowed the NDSC to keep registration fees as low as possible. Workshop proposals are being accepted on our convention website at http://convention.ndsccenter.org/, so please pass this information along to everyone you know that might be interested.



#### YOUTH AND ADULTS PROGRAM

Our self-advocate attendees enjoy interactive workshops 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 an interest in a topic that others will find interesting, this is the place to share what you know with your peers in a workshop or panel presentation.

Successful speakers in the past have presented on topics like: staying physically fit; how to dress for success; tips for living independently; Zumba; ballroom dance; cake decorating...and many more! You can find more ideas on our convention website: http://convention.ndsccenter.org/.

Discuss your ideas with someone you like to work with. Friends, parents, siblings, coaches and teachers all make good partners. Then just fill out the easy-to-complete speaker proposal form on our website. Start planning now and submit a proposal so you can share your skills!

If you have questions, contact Jean Beck at Jean@ndsccenter.org.



La 43a Convención Anual del NDSC definitivamente estuvo ¡Sin Límites! y fue una experiencia inolvidable para los 3.400 asistentes que se dieron cita en Phoenix, Arizona. Entre los asistentes se encontraban: personas con síndrome de Down, sus familias y amigos, profesionales y expertos en síndrome de Down.

"La Convención del NDSC causó un impacto positivo en nuestra familia, que siempre llevaremos en nuestra mente y en nuestro corazón; ver a toda esa gran familia reunida y ver el gran desarrollo que pueden alcanzar nuestros hijos con síndrome de Down nos llenó de mucha esperanza. Gracias a todos y nos vemos el próximo año en Orlando!"

- Familia Batista Rodríguez de Panamá



#### Los Ponentes

Durante la convención contamos con la participación de expertos en síndrome de Down de diversos países quienes presentaron más de 60 talleres, 10 preconferencias y 2 sesiones plenarias.

**Conferencistas internacionales:** Dr. Jesús Flórez Beledo, Santander, España. Dra. Teresa Aguilasocho Montoya, Monterrey, México. Dra. Macarena Lizama y la Fonoaudióloga Fabiana Sevilla, Santiago, Chile. El taller para hermanos fue impartido por Georgina y Edgardo Pezzettoni de Buenos Aires, Argentina.



Los encuentros para familias latinas brindaron la oportunidad de reunirse para compartir las experiencias de tener un hijo o un familiar con síndrome de Down. Fueron encuentros muy enriquecedores que ayudaron en el intercambio de vivencias, opiniones y propuestas. Los encuentros fueron divididos por temas.

- Rosa Mary Rodríguez Buñols de República Dominicana. Tema: Atención Temprana
- Dra. Teresa Aguilasocho Montoya de México Tema: Salud y Conducta
- Isabel Tejada de Springmuhl de Guatemala Tema: Educación
- Dr. José Raúl Ayala Cuervos de Puerto Rico Tema: Vida Adulta

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## Durante la cena de gala se entregaron diversos reconocimientos, dos de los cuales fueron entregados al Dr. Jesús Flórez y a la Fundación Puertorriqueña Síndrome Down.



El Premio *"Exceptional Meritorious Service Award"* fue otorgado al Dr. Jesús Flórez Beledo, Presidente de la Fundación Iberoamericana Canal Down 21, por su distinguida trayectoria y dedicación



a las personas con síndrome de Down a nivel mundial.

Y, el Premio **"President's Award"** a la Fundación Puertorriqueña Síndrome Down, quienes a lo largo de 25 años han proporcionado un



Durante la Gran Reunión Familiar del NDSC

**2015** contamos con la participación de familias y profesionales de 19 países. La convención ofreció un sinfín de sesiones para padres, adolescentes y adultos con síndrome de Down, para los hermanos, así como un campamento de niños y varios eventos sociales.





"La Convención del NDSC nos abrió nuestros ojos al mundo, descubrimos que no estamos solos y que podemos lograr avances si nos disponemos, aprendemos y tenemos fe en Dios y en nuestros hijos, nos vemos en la próxima convención." – Familia Mosso Quintana de Chile

síndrome de Down y a sus familias. ¡Muchas felicidades y gracias por su valioso legado!

valioso apoyo incondicional a las personas con







#### ¡Escucha las grabaciones de las conferencias desde la comodidad de tu hogar!

Adquiere las grabaciones de la Convención del NDSC 2015 desde el siguiente enlace http://www.conferencemedia.net/stores/ndsc/ Costo \$70USD. Cada grabación incluye audio y diapositivas. Informes: (770) 604-9500 o envía un correo a: info@ndsccenter.org



Este año contamos con 93 stands en la sala de expositores donde se encontró lo más novedoso y reciente en libros, materiales didácticos, juguetes educativos, moda, joyería y más.

"Un pequeño grupo de gente, en lugares pequeños, haciendo cosas pequeñas, puede cambiar el mundo."





Estamos llenos de gratitud y admiración con los más de **400 voluntarios** quienes con su gran corazón y dedicación hicieron de nuestra convención todo un éxito. Es simplemente imposible llevar a cabo un evento de esta magnitud sin la ayuda de nuestro pequeño ejército de voluntarios. Los voluntarios fueron amigables, atentos, cordiales, serviciales en todo momento y no existen suficientes adjetivos para describirlos. ¡Muchísimas gracias de corazón a cada uno de ustedes!

Mi experiencia como voluntaria en la Convención del NDSC:

"Ser voluntaria durante la Convención del NDSC ha sido una de las más bellas experiencias en mi vida. Más que regalar mi tiempo sin ninguna ganancia monetaria, es dar un poco de mí a cambio de algo que no tiene precio. Ese algo es la sonrisa y los abrazos que he recibido de los jóvenes y adultos con síndrome de Down y sus familias. Y eso no se puede comprar."

– Korina Mancillas

¡Te esperamos en la Convención del NDSC 2016! Del 21 al 24 de julio en el hotel JW Marriott Grande Lakes en la ciudad de Orlando, Florida. *Down Syndrome News* is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndsccenter.org or call 1-800-232-NDSC (6372).



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# DOWN SYNØROME

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# Save the Date for the 2016 Convention in Orlando, Florida!

## July 21-24, 2016

JW Marriott Grande Lakes



