

43rd Annual NDSC Convention

# BEYOND ALL LIMITS

June 25-28, 2015



Presented in Phoenix, Arizona  
at the JW Marriott Desert Ridge



Join us this summer for our Giant Family Reunion in Phoenix, where the views are breathtaking and the history is rich. This is your opportunity to reach Beyond All Limits! The NDSC Convention includes inspiring plenary sessions, more than 60 topic-specific workshops, social events, networking, dances, exhibitors, a film festival, sharing sessions, and so much more!

**PARENTS AND PROFESSIONALS:** Learn from the best, as internationally known experts come to Phoenix to share their knowledge and help you envision a world beyond expectations.

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

**SIBLINGS:** Share and learn alongside your peers, going beyond your fears and uncertainties.

**VOLUNTEERS:** Have an experience beyond your imagination by volunteering at our convention.

**Come and enjoy the riches of Down syndrome and look Beyond All Limits!**

# 2015 Convention at a Glance

## Thursday, June 25

- 1:00 p.m. Research Roundtable
- 5:00 p.m. Exhibit Floor Opens
- 6:00 p.m. Registration Opens
- 6:00 p.m. Welcome Party at the Pool
- 7:00 p.m. Adult Sibling Reception
- 7:00 p.m. First-timer Orientation
- 8:00 pm International Reception

## Friday, June 26

- 7:30 am Kids' Camp Session 1
- 8:00 am Pre-Conference Sessions
- 1:30 pm Sharing Sessions
- 1:15 pm Kids' Camp Session 2
- 3:15 pm Y&A and B&S Kick-Off
- 3:30 pm Workshops
- 6:30 pm Opening General Session
- 8:00 pm Opening Reception and Teen/Adult Mixer

## Saturday, June 27

- 7:30 am Kids' Camp Session 3
- 8:00 am Y&A and B&S Conferences
- 8:30 am General Convention
- 1:15 pm Kids' Camp Session 4
- 6:30 pm Reception/Awards Banquet
- 9:00 pm 321 Dance™!

## Sunday, June 28

- 7:30 am Kids' Camp Session 5
- 8:00 am Y&A Talent Show
- 8:00 am B&S Off-Site Trip
- 8:30 am General Convention
- 1:00 pm Convention Closes



## General Convention

The General Convention is designed to educate parents, other family members and caregivers, as well as medical and education professionals. The General Convention programming includes a mix of large plenary sessions with keynote speakers, along with more than sixty breakout workshops. The first plenary session will meet on Friday evening, followed by an opening reception for families and a mixer for our teens and adults with DS and their siblings.

General Convention Attendees will attend breakout workshops over six cycles, beginning

Friday afternoon. With thirteen 90 minute workshops available during each cycle, you'll be able to choose the session that's right for you. To guide you in making selections, a complete workshop list will be available on our website, [ndscenter.org](http://ndscenter.org), on our convention mobile app and within the Souvenir Journal that you'll receive when you arrive onsite. [You'll choose workshops as you go – no need to pre-register for these sessions.]

Most General Convention workshops will be recorded and made available to all general convention attendees a few weeks after the convention. This is a great way to listen to the sessions you are unable to attend in person. After all, you can only be in one place at a time!

## Pre-Conference Sessions

These valuable assemblies, presented by world renowned speakers, offer the first learning opportunity of the weekend. They are designed for those interested in going in-depth on a specific topic. Each session is 4 hours long and takes place on Friday morning at 8:00 am. These sessions are not recorded and do require pre-registration with an additional fee. Check out the 2015 pre-conference line-up later in this brochure and on our website.

## Sharing Sessions

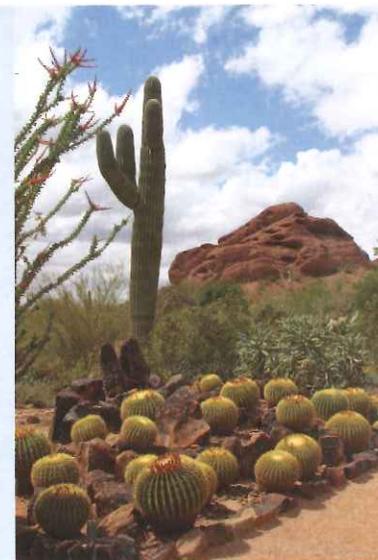
Sharing Sessions take place on Friday afternoon from 1:30 – 2:45 pm and are facilitated by seasoned parents. They encourage participants to connect informally around common age groups and interests, and share similar needs, joys, concerns, resources and strategies. We recommend that parents attend these sessions without their children in order to share their concerns freely.

## ABOUT PHOENIX

Things are different in the desert. The sky is bigger. The stars are brighter. The sunsets stop you in your tracks. It's a feeling that can't be conjured, landscaped or kindled with twinkling bulbs. John Ford knew that. So did Frank Lloyd Wright. Come to Greater Phoenix and you'll understand, too. America's sixth-largest city still has real cowboys and rugged mountains and the kind of cactus most people see only in cartoons. Phoenix is the gateway to the Grand Canyon, and its history is a testament to the spirit of puebloans, ranchers, miners and visionaries.

Projected against this rich backdrop is a panorama of urban sophistication: Resorts and spas that drop jaws and soothe souls. Stadiums and arenas worthy of the world's biggest sports spectacles. Restaurants with inspired cuisine and inspiring patio views. Golf courses that beckon players the year round. Shopping centers as stylish and eclectic as the fashions they house.

This is Greater Phoenix – Arizona's urban heart and America's sunniest metropolis. Check out [visitphoenix.com](http://visitphoenix.com) for dozens of area attractions to visit when you are not relaxing on the lazy river at the JW Marriott Desert Ridge Resort and Spa.



## Kids' Camp

The educational playground of the convention, Kids' Camp was created for children ages 6 months – 14 years to participate in activities while their parents are attending workshops. The camp is offered in five separate sessions. All children must be pre-registered. Space is limited, so register early.



## Youth and Adults Conference

*Attendees must be 15 years old by June 26, 2015*

Considered “the heart and soul of the Convention weekend,” the annual Youth and Adults [Y&A] Conference is a fun, empowering, enriching and safe environment for attendees with DS age 15 and up.

The Y&A Conference is planned and presented by self-advocates. The event begins with a Friday afternoon kickoff party, followed by workshops, open mic sessions, empower hour and panel presentations on Saturday (lunch is not included). The Conference closes on Sunday with the popular talent show, but not before attendees elect one of their peers to serve on the NDSC's Board of Directors.

*Registration for the Y&A Conference will close May 15, or earlier if capacity is reached. Please note that Y&A Conference registration is not available on-site. We encourage interested attendees to register early, as we typically reach capacity before the deadline date.*

## Brothers and Sisters Conference



*For those entering 4th through 12th grade in 2015-16*

The sibling connection is most often the longest-lasting family relationship attendees have. As a result, it's important that brothers and sisters feel supported, and know how to advocate for their sibling with DS.

Expanding again this year to include rising 4th and 5th graders, the B&S Conference begins with a Get Acquainted Session Friday afternoon. The group meets all day Saturday (including lunch), and will break concurrently with the General Convention and Y&A Conference. On Sunday, B&S attendees will travel off-site to explore a local Phoenix attraction.

## Social Events and Other Activities

What would an NDSC Convention be without a dance or two?

Following the Opening Session on Friday, teens and adults with DS and siblings will have the opportunity to rock out at their own mixer. At the same time the Opening Reception offers families the opportunity to meet, greet and kick-off an exciting weekend together. Saturday evening's events include our annual Awards Banquet (a ticketed event), followed by our 321 Dance (no ticket required).



NDSC's 321 Dance is an exciting fundraising dance that raises awareness and funds for the NDSC. There is no cost to participate, but those who raise \$100 will receive a free T-shirt. Learn more about NDSC's 321 Dance at our website.

## SPECIALIZED WORKSHOP TRACKS

### Co-Occurring DS and Autism Spectrum Disorders (DS-ASD or DS+Complex Behaviors)

The NDSC cares deeply about serving the needs of all families, including those with loved ones with co-occurring autism, autism-like behaviors, or complex needs. In collaboration with the DS-Autism Connection, the NDSC will again offer a specially-designed workshop track to meet the needs of these families. Experts in the field of DS-ASD will be presenting on important issues and will be available to answer questions and provide much needed support.

### Adult Siblings

The role of a brother or sister changes dramatically as parents age. This track of workshops is designed to give adult siblings the tools they'll need to support their brother or sister. Packed with experts in financial planning, adult transition, employment and mental health, coupled with a few networking opportunities, adult sibs will leave feeling prepared, supported and empowered.



### Research & Medical Care Roundtable – A Free Benefit for Attendees Registered for the NDSC Convention.

#### Alzheimer's Disease and Down Syndrome – What parents and caregivers should know

On Thursday, June 25, 2015 from 1 pm to 4 pm the GDSF will be hosting the Research & Medical Care Roundtable with a focus on DS and Alzheimer's disease.

Co-organized with the NDSC at the JW Marriott Desert Ridge in Phoenix, this roundtable will feature renowned scientists and medical professionals. Topics will include a review of promising research including clinical trials, when a child or adult with DS should get tested, standards of medical care, advocacy, and support.

Gift Bags & Seating is limited! Register to reserve your spot.

# 2015 PRE-CONFERENCE SESSIONS

Our Pre-Conference sessions take your learning to another level! These 4-hour sessions enable you to dig deeper into one specific topic with nationally-known speakers. While ten sessions are offered, you'll choose just one, and spend the entire morning focusing on the single subject of interest to you.

The sessions are structured to share best practices and proven "how to" strategies, while providing evidence-based content. All sessions will include time for Q&A, and coffee will be provided. Separate registration is required. Session handouts will be issued only to the person registered for that session. Space is limited in some sessions, so register early. On-site registration cannot be guaranteed. Read the complete session descriptions and speaker bios on our website.



## **PRE-CON A:** **Advocacy Boot Camp: Producing Effective Federal, State, and Local Advocates**

*Susan Goodman, JD, Governmental Affairs Director, NDSC, son with Autism, Olney, MD, and Ricki Sabia, JD, Education Policy Advisor, NDSC, son with DS, Silver Spring, MD*



We all want a better world for people with DS, but how can we make that happen? This session will prepare attendees to effectively advocate for meaningful change from City

Hall to the Halls of Congress. Session leaders will cover how to develop "asks" and what is needed to gain support for those asks. They will identify how to find state-specific policy information and provide case studies of successful statewide coalitions. In addition, attendees will learn how to define roles for self-advocates and prepare them to become effective voices for change.



## **PRE-CON B:** **E.I., E.I., OH! - Adventures in Early Intervention**

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

Families who have infants and toddlers with DS are eager to begin teaching, but are often confused about how to best promote early learning and development at home. What can you do with a baby and toddler? What can you expect? Lots! Come and learn the science and strategies that early interventionists use so you can help give your little one a great start.



## **PRE-CON C:** **Setting the Stage for Effective Education**

*Dana L. Halle, JD, Executive Director, Down Syndrome Foundation of Orange County, Vice President, Education and Outreach, Down Syndrome Education USA, NDSC Board Member, son with DS, Orange County, CA*

Every child deserves an effective education, yet obtaining one can be challenging. In this session, we will share how to make changes to curriculum, environment, instruction, and assessment to improve educational outcomes. We will also discuss how to create and implement an effective educational plan.



## **PRE-CON D:** **Targeting Speech Intelligibility Difficulties in Children and Adults with DS**

**Disponible con interpretación simultánea al español**

*Libby Kumin, PhD, CCC-SLP, Professor of Speech-Language Pathology and Author, Loyola University, Baltimore, MD*

There are many factors that affect speech intelligibility in children and adults with DS, but the occurrence and combination of factors are different for each person. Dr. Kumin will present a framework that can be used for identifying, analyzing, and treating the factors that affect speech intelligibility, e.g. rate, articulation, oral motor skills, and apraxia of speech. Attendees will learn how to write IEP goals that target factors affecting speech intelligibility, how to develop a home-school communication plan, and home activities to practice speech skills that are effective through adulthood.



## **PRE-CON E:** **Technology Today & Tomorrow: Tools For Home and Classroom**

*Sean Smith, PhD, Associate Professor, Department of Special Education, University of Kansas, son with DS, Lawrence, KS*

This session provides interactive, innovative, and practical technology-based solutions for the student with DS. Participants will engage in activities to further expand their understanding of apps, technology-based solutions, and innovative tools applicable to challenges in the areas of academic, functional, and social growth and development. Parents and educators will walk away with practical tips for students and children of all ages.



**PRE-CON F:**

**Tapping into Hidden Human Capital: Global Journey of Successful Employment of Persons with DS**

*Debra Ruh, Global Disability Inclusion Strategist, G3ict Employability & Technology Chair, Ruh Global Communications, daughter with DS, Rockville, VA*

The session will cover best practices in the employment of persons with DS, including accommodations, accessibility, and market opportunities from the viewpoint of employing persons with disabilities to helping employers understand the value of inclusion. Attendees will explore ways corporations have employed and empowered individuals with DS in their workforce. This session will also look at programs in the U.S. that are models for other countries. Findings from Ruh's book, "Uncovering Hidden Human Capital: How Leading Corporations Leverage Multiple Abilities in Their Workforce" will also be presented.



**PRE-CON G:**

**Doing the Detective Work to Create Positive Behavior Change**

*Scott Shepard, Director of Avenues Supported Living Services, Professor at CSU Northridge, Cal-TASH Board Member, Valencia, CA*

In this session, participants will receive an overview of functional behavior assessment and positive behavior support, learn how to identify behavioral motivations, learn how to identify and teach replacement behavior and skills as an alternative to challenging behavior, and acquire a variety of "tools" to assist in identifying why behaviors are occurring. These principles can be applied with children and adults of all ages and abilities.



**PRE-CON H:**

**When DS and Autism Intersect: Gaining a Better Understanding of DS-ASD**

*Margaret Froehlke, RN, BSN; Sarah Hartway, RN, MS; and Robin Zaborek, all representatives of the Down Syndrome-Autism Connection, including two seasoned parents of children with DS-ASD, Denver, CO*



Could it be more than DS? This presentation will provide an overview of DS-ASD for family members who suspect that a person in their life may have autism, or for those who have already received an autism diagnosis. This presentation is also valuable for professionals who want to learn more about the co-occurrence and how to understand and help the families in their care. Come and



learn about the following: research findings, recognizing autism behaviors, barriers to receiving a proper evaluation and diagnosis, parents' emotional journey, and finding support and inspiration for the journey.



**PRE-CON I:**

**Mi hijo se está haciendo adulto. ¿Qué hacemos ahora?**

*Jesús Flórez, MD, PhD, Presidente de la Fundación Iberoamericana Down21, España*

La llegada de nuestro hijo con síndrome de Down a la edad adulta, es una realidad gozosa, pero al mismo tiempo, nos supone a él y a nosotros nuevos retos. En esta pre-conferencia, abordaremos los más importantes, los cuales versarán sobre: la salud, la educación, la vida activa y bien ocupada, la búsqueda de empleo, la utilización del tiempo libre, el desarrollo de actividades comunitarias, el envejecimiento precoz [¿Alzheimer, sí o no?...] Pero habrá que insistir en dos premisas previas indispensables: 1) cada persona y su entorno, son únicos y distintos 2) la vida del adulto se prepara desde la niñez y la adolescencia.



**PRE-CON J:**

**Solidifying a Healthy Foundation for DS Affiliate Organizations**

*Jim Hudson, MA, CFRE, Executive Director, Down Syndrome Association of Greater Cincinnati, Cincinnati, OH*

Building a healthy affiliate means managing many moving parts. This session will touch on a variety of topics such as managing a healthy staff team, raising the resources to fuel your mission, creating an engaged board and volunteer culture, as well as the primacy of being mission-focused. Although there are hundreds of DS affiliates of many different sizes and geographical settings, we will explore some common themes that will hopefully apply across these lines. Much of the content will be principle-driven as principles are statements not just about who we are, but also about who we want to be, with the hope that what we do will flow out of healthy principles. Additionally, there will be many practical tips aligned with the four core topics you can take home and apply to your affiliate within the next year.



# REGISTER NOW!

## Register Online

Visit [www.NDSCCenter.org](http://www.NDSCCenter.org); click "Annual Convention"; and select "Register"

## Register by Mail

Access downloadable forms at [www.NDSCCenter.org](http://www.NDSCCenter.org), or contact us at [800] 232-6372 or [info@ndsccenter.org](mailto:info@ndsccenter.org) to request hard copy registration forms. These forms can be completed and returned [with payment] by mail to the address listed on the back cover.



## Convention Headquarters & Hotel

**JW Marriott Desert Ridge Resort & Spa**  
 5350 East Marriott Drive  
 Phoenix, AZ 85054  
 [480] 293-5000  
[jwdesertridgeresort.com](http://jwdesertridgeresort.com)

NDSC Convention rate is \$145 plus tax per night; Rate is only valid until June 18 or when capacity is reached. One night deposit is required at time of booking.

**Hotel Cancellation Policy** – Reservations can be cancelled without a penalty until June 10. Cancellations after June 10 will result in the loss of your deposit.

Please visit the NDSC Website for complete details on accessing the convention room block.

## Ground Transportation

**Avis** is pleased to provide a convention discount to NDSC families. The AWD code is **J944711** – call [800] 331-1600 or book online at <http://www.avis.com>.



## Meal Plan

Attendees can register for an optional meal plan that will provide four meals throughout the weekend – dinner Friday evening, breakfast and lunch Saturday, and breakfast Sunday. Menus have been pre-selected [gluten-free is available], and can be viewed on our website. The cost is \$70 per person for the four-meal package (meals cannot be ordered separately), and may not be available to purchase on-site. If you are interested, please order during registration to ensure availability.

## 2015 Registration Fees

Membership is required for registration. The annual membership fee is \$35 [\$45 for international addresses]. To determine membership status, see the expiration date on the mailing label from the convention brochure or contact the NDSC office at 800-232-6372.

	By May 15	By June 10	On-Site
General Convention Individual*	\$170	\$220	\$270
General Convention Family* (up to 3 people - one additional adult can be added for \$50)	\$260	\$310	\$360
Pre-Conference	\$75	\$75	\$100
Youth & Adults w/DS Conference	\$85	closed	closed
Brothers & Sisters Conference	\$85	closed	closed
Kids' Camp	\$30 per session	closed	closed
Options	By June 10	On-Site	Post-Convention
Extra compendium	\$20	not guaranteed	not guaranteed
Adult Banquet Ticket	\$45	not guaranteed	N/A
Child Banquet Ticket (12 and under)	\$19	not guaranteed	N/A
Meal Plan (4 meals)	\$70	closed	N/A
Convention T-Shirt	\$12	\$15	N/A

\* Your General Convention Registration Fee Includes Access To The 2015 Convention Recordings For Two Years!

## Convención General

El programa de la convención general incluirá dos sesiones plenarias y más de sesenta talleres que se ofrecerán el fin de semana de la convención. Durante el viernes y el domingo, habrá seis bloques de talleres de noventa minutos cada uno. Cada bloque incluirá dos talleres, uno con interpretación simultánea al español y el otro, impartido en español. La lista completa de talleres estará disponible varias semanas antes de la convención y agrupada por edades en nuestra página web <http://convention.ndsccenter.org/en-espanol/> Además contaremos con equipo de interpretación para los asistentes que requieren el servicio.



## Pre-conferencias

El viernes, 26 de junio de 8 a.m. a 12:30 p.m., expertos en síndrome de Down dictarán 10 pre-conferencias sobre un tema específico de interés. Las pre-conferencias tendrán una duración de 4 horas y media cada una. Como las conferencias serán presentadas simultáneamente, sólo será posible asistir a una. Las pre-conferencias tendrán un costo adicional y se requiere inscripción previa. La pre-conferencia letra D, **“Enfoque en las dificultades de la inteligibilidad del habla en niños y en adultos con síndrome de Down” por Libby Kumin, Ph.D., CCC, SLP** contará con servicio de interpretación simultánea al español. Sólo una de las pre-conferencias será impartida en español y será la letra I, **“Mi hijo se está haciendo adulto. ¿Qué hacemos ahora?, por Jesús Flórez, M.D., Ph.D, Presidente de la Fundación Iberoamericana Down21, España.**



## Encuentros para familias de habla hispana

Estos encuentros se llevarán a cabo el viernes 26 de junio de 1:30 p.m. a 2:45 p.m. y serán para padres desde recién nacidos hasta de hijos adultos. Los encuentros serán divididos en distintos temas. El objetivo principal de ellos será brindarles a las familias la oportunidad de conocer a otras familias y de intercambiar experiencias.

## Programa para jóvenes y adultos con síndrome de Down

*Los participantes deberán tener mínimo 15 años de edad, cumplidos para el 26 de junio del 2015.*

Este evento es en sí el corazón y el alma de la Convención del NDSC y su objetivo será el de brindarles

a los participantes un fin de semana divertido y lleno de aprendizaje. Este programa comenzará el viernes por la tarde con una divertida reunión. El sábado, los asistentes participarán en talleres, sesiones generales y presentaciones de panel. No incluye almuerzo. Durante el domingo, los jóvenes participarán en el popular festival de talentos el cual incluirá almuerzo para los asistentes. Los participantes contarán con el apoyo del NDSC y de un maravilloso equipo de voluntarios bilingües. Los espacios son limitados y la inscripción cierra el 15 de mayo. Cada participante deberá proveer la documentación y autorización de los padres para participar. La documentación nos permitirá conocer a cada uno de los participantes y entender sus necesidades para así brindarles el mejor apoyo posible.

## Reunión de hermanos de personas con síndrome de Down

*Requisito: cursar desde cuarto año de primaria al 12vo de preparatoria o bachillerato*

Durante este evento, los participantes tendrán la oportunidad de aprender y de aclarar dudas acerca del síndrome de Down. También será una oportunidad para compartir experiencias y hacer nuevos amigos. Las actividades comenzarán el viernes con una divertida reunión para conocerse. El sábado se reunirán durante todo el día [almuerzo incluido] y ese será el fin del encuentro. El domingo habrá un divertido paseo a una atracción turística en la ciudad de Phoenix.

## EVENTOS SOCIALES Y OTRAS ACTIVIDADES

**Cóctel de bienvenida.** Jueves 25 de junio de las 8:00 p.m. – 9:30 p.m. Durante este cóctel daremos la bienvenida oficial a las familias internacionales que asistirán este año a nuestra gran reunión familiar. Se requiere reservación previa online al momento de inscribirse a la Convención General.

## Cena de gala y premiaciones

[se requiere boleto en la entrada]

El sábado por la noche será la cena de gala del NDSC y la entrega de premios. Durante este evento habrá interpretación simultánea al español. Luego tendrá lugar el tradicional baile **¡321 a Bailar!** en donde podrán bailar y divertirse a lo grande.

**Sala de expositores.** En este espacio encontrarán lo más novedoso y reciente en libros, materiales didácticos, juguetes educativos y programas de computación, entre otras cosas más.

**Festival del cine.** Asistir al festival de cine es una magnífica oportunidad para disfrutar de los mejores cortometrajes, filmes y documentales en los que los protagonistas son personas con síndrome de Down. El Festival del Cine se llevará a cabo durante los bloques de los talleres.

**Kids Camp** es un campamento para niños desde los 6 meses de edad hasta los 14 años. El campamento provee un ambiente seguro, estructurado y divertido. Consiste de cinco sesiones separadas. Habrá actividades tales como arte, manualidades y juegos educativos. Se requiere inscripción y pago adicional. Los espacios son limitados.

**Plan de comidas.** Este plan es opcional e incluye cuatro comidas: cena del viernes por la noche, desayuno y almuerzo del sábado y desayuno del domingo. Costo \$70 USD por persona.

Informes:

[info@ndsccenter.org](mailto:info@ndsccenter.org)

Página web:

[convention.ndsccenter.org/en-espanol/](http://convention.ndsccenter.org/en-espanol/)



# NATIONAL DOWN SYNDROME CONGRESS

30 Mansell Court, Suite 108  
Roswell, GA 30076

## NDSC 43rd Annual Convention June 25 – 28, 2015

Toll Free: [800] 232-NDSC [6372]  
Local: [770] 604-9500  
Fax: [770] 604-9898  
Email: [info@ndscenter.org](mailto:info@ndscenter.org)  
[www.NDSCcenter.org](http://www.NDSCcenter.org)



### Important Registration Deadlines:

**May 15** – Best Value Rates

**May 15 or When Capacity is Reached** –  
Y&A, B&S and Kids' Camp

**June 10** – General Convention and Pre-Conferences

After June 10, registration for the general convention and precons will be available on-site **ONLY if space allows.**



[twitter.com/NDSC](http://twitter.com/NDSC)



[facebook.com/thendsc](http://facebook.com/thendsc)



[youtube.com/NDSCCENTER](http://youtube.com/NDSCCENTER)



## SPECIAL THANKS

The National Down Syndrome Congress would like to thank our 2015 Host Committee Partners for their assistance in providing local support and coordination of the 43rd Annual Convention.



# 321 dance



June 27, 2015

Fundraising Goal: \$25,000



Register Today:

[www.ndsc.donordrive.com/](http://www.ndsc.donordrive.com/)

Free T-Shirt for everyone  
who raises \$100 or more!