



## 45th Annual NDSC Convention

July 20-23, 2017  
Sacramento, CA



NATIONAL  
DOWN SYNDROME  
CONGRESS

## The General Convention

**The General Convention** is designed to educate parents, family members and caregivers, as well as medical and education professionals. **General Convention** programming includes an opening plenary session **Friday evening** followed by a dessert reception and totally fun dance for the entire family, plus more than seventy breakout workshops throughout the weekend.

**General Convention** attendees will attend breakout workshops over six cycles beginning Friday afternoon. With up to 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, our convention mobile app, and within the Souvenir Journal that you'll receive when you arrive on site. You'll choose as you go - no need to pre-register for these breakout sessions.

Most General Convention workshops will be recorded and made available to general convention attendees shortly after the convention. This is a great way to listen to those 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 sessions, presented by world-renowned speakers, offer the most comprehensive 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 begins on Friday morning at 8:00 a.m. These sessions are **not recorded** and require **pre-registration with an additional fee**. Check out the 2017 pre-conference line-up on pages 4 and 5 of this brochure and on our website.

## Sharing Sessions

Sharing Sessions take place on Thursday evening from 7:15 - 8:30 p.m. and are facilitated by seasoned parents. They encourage participants to connect informally around common age groups and interests while sharing similar needs, joys, concerns, resources and strategies. We recommend that parents attend these sessions without their children in order to share their concerns freely. This is a great way to meet other parents before the convention begins.

## Kids' Camp

The educational playground of the convention, Kids' Camp was created for children ages 6 months to 11 years (up to 14 years with DS) 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 July 20, 2017.**

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 Down syndrome age 15 and up.

The Y&A Conference is planned and presented by self-advocates. The event begins with a kick-off party on Friday afternoon, followed by workshops, sharing sessions, and empowering presentations on Saturday (lunch 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 Board of Directors.

**Registration for the Y&A Conference will close on June 9.** Please note that Y&A Conference registration is not available on site. We encourage interested attendees to register before the deadline so as not to disappoint your self-advocate.

## Brothers and Sisters Conference

**For those entering 4th through 12th grade in 2017-18.**

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.



The B&S Conference begins with a Get Acquainted Session on Friday afternoon. The group meets all day Saturday (including lunch) and will break at day's end concurrent with the General Convention and Y&A Conference. On Sunday, B&S attendees will go offsite to explore a local Sacramento attraction.

## Social Events and Other Activities

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

All attendees are invited to join Friday night's Opening Reception and **321Dance™!** following the Opening Plenary Session, which will feature producer, Jonathan Murray, of Emmy Award Winning "Born This Way"; sibling dynamos, Katie Faith Lingo and Kris Faith; plus local Sacramento self-advocate, Jessica Adler.

Saturday evening's events include our **45th Anniversary Sapphire Celebration** (a ticketed event), followed by another dance for all attendees (no ticket required).

We will also host a vendor **Exhibit Area** featuring the latest books, toys, teaching aids, apparel, software and more.

Our **Film Festival** showcases the best films, clips and documentaries featuring the Down syndrome community. Screenings take place during the workshop cycles Friday through Sunday.



## 2017 Convention at a Glance

**MUST READ - We revamped the convention schedule this year!**

### Thursday, July 20

- 4:00 pm .....Registration Opens
- 4:00 pm .....Exhibit Hall Opens
- 5:00 pm.....Welcome Reception
- 6:00 pm .....First Timer Orientation
- 7:15 pm .....Sharing Sessions
- 7:30 pm.....Affiliate Leader Reception

### Friday, July 21

- 7:30 am.....Kids' Camp Session 1
- 8:00 am .....Pre-Conference Sessions
- 1:15 pm .....Kids' Camp Session 2
- 1:15 pm .....Y&A and B&S Kick Off
- 1:30 pm .....Workshops
- 6:30 pm .....Opening Plenary Session
- 8:00 pm .....Opening Reception and 321 Dance!

### Saturday, July 22

- 9:00 am .....Kids' Camp Session 3
- 9:00 am .....Y&A and B&S Conferences (lunch included)
- 9:30 am.....Workshops
- 2:30 pm.....Kids' Camp Session 4
- 3:30 pm .....Workshops
- 5:00 pm.....Exhibit Hall Closes for 2017 (No hours on Sunday)
- 6:30 pm.....Sapphire Celebration
- 8:00 pm .....Dance

### Sunday, July 23

- 8:00 am.....Kids' Camp Session 5
- 8:15 am.....Y&A Talent Show
- 8:15 am.....B&S Off-Site Trip
- 8:30 am.....Workshops
- 12:00 pm.....Convention Closes

# Specialized Workshop Tracks

## Adult Siblings

The role of 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.

## Co-Occurring DS and Autism Spectrum Disorders

The NDSC cares deeply about serving the needs of all families, including those with loved ones with co-occurring DS and autism, autism-like behaviors or complex medical 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.

## About Sacramento

The 1849 Gold Rush brought the world to Sacramento. Now it's your turn to see all that California's capitol offers. From its walkable downtown to the cobblestoned streets of 'Old Sacramento', this great city will delight your family!



Better yet, there are even more treasures just a short drive away. You can reach Napa Valley in under an hour; San Francisco, Lake Tahoe and Muir Woods in under two hours; and Monterey, Reno, and Yosemite National Park in under three. Where else can you find so many natural and cultural treasures within easy reach?

Start planning now to give your family the trip of a lifetime – all with the NDSC Convention included!

# 2017 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 world-renowned speakers. While eight 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 **research-based** content. All sessions will include time for Q & A, and coffee and pastries will be provided. Separate registration is required. Session handouts will only be issued to the person registered for that session. Space is limited in some sessions, so register early. On-site registration cannot be guaranteed. Read complete session descriptions and speaker bios on our website.

## PRE-CON A

### Impact of Oral Motor Impairment on Eating and Speech

Debra Beckman, MS, CCC-SLP  
Beckman & Associates, Inc.

When should assessment and treatment of hypotonia of the facial muscles begin and what outcomes should be expected? Must the individual follow commands to make improvement? How can I help stop drooling, tongue thrust and tooth grinding? How can I make tooth brushing easier? How can I help the picky eater in my family? Find answers to these questions and more in this presentation with handouts, case studies and videos.



## PRE-CON B

### Ditching the Diapers – How to Move Forward With Toilet Training for Children with DS and Co-Occurring DS & ASD

Terry Katz, PsyD  
New England Neurodevelopment, LLC

Toilet training is often a difficult and frustrating process for families of individuals with special needs. During the workshop, we will address sensory, communication, physical, and behavioral issues that make toilet training challenging and discuss strategies and tools that are helpful for individuals of any age. Workshop members will have the opportunity to talk about specific toilet training problems, and we will work together to develop plans and next steps.



## PRE-CON C

### Behavior & Down Syndrome: The Respond but Don't React Method

David Stein, PsyD  
New England Neurodevelopment, LLC

Behavior problems impact approximately 30% of children with DS. Left untreated, these same children often exhibit behavior problems as adults, limiting work and independent living opportunities. In order to address behavior problems effectively, one must understand the brain-based reasons for these challenges and direct treatment appropriately. This workshop will present the basic neuroscience of DS and how this informs effective behavior management, with practical strategies provided for use in the home and school settings.



## PRE-CON D

### Let's Talk Inclusion: The What, Why, & How

Richard Villa, EdD  
Bayridge Consortium, Inc.

Participants will become familiar with the characteristics of inclusionary schools, rationales for change, organizational and instructional strategies to support inclusionary schooling, and successful examples from elementary, middle and high school. Approaches to differentiating the content students learn, the process through which they learn it, and how they demonstrate what they have learned will be examined. Additionally, participants will explore ways in which students can collaborate with adults to meet the needs of a diverse student body.



## PRE-CON E

### Beyond Employment to Economic Stability

Abby Cooper, MA, Consultant  
Kennedy Douglas Consulting

Millions of people with disabilities are trapped in a life of poverty. The last thirty years of focusing exclusively on employment policy has not resulted in individuals with disabilities being part of the financial mainstream, financially stable or gainfully employed. With only 32.8% of working age people with disabilities actually in the workforce, it's time to make a change. This session will address strategies parents, school systems and service agencies can take to stop disability from being interlocked with poverty, as well as how the new requirements within the

Workforce Innovation and Opportunity Act can be part of the solution.



## **PRE-CON F**

### **Careers in Entertainment and Media**

**Gail Williamson, Talent Agent, Kazarian, Measus, Ruskin & Associates Talent Agency and Brian Donovan, Producer, Mighty Me Productions, Inc.**

For many people, a career in entertainment and media is a dream. However, for more and more actors with Down syndrome and other disabilities, that dream is becoming a reality! This session's speakers are professionals in the industry and will explore what it takes to break into the business, what tools are available to support success, and where to go to pursue your child's dreams of being a star. This workshop will bring in presenters who have been on the front lines advocating for individuals with Down syndrome in the media for up to 20 years. Whether you're interested in films, television or advertising, join us to be enlightened. Self-advocates, parents, siblings and grandparents are encouraged to attend.



## **PRE-CON G**

### **Brothers and Sisters of People with Down Syndrome: Unique Concerns, Unique Opportunities**

**Don Meyer, Director of the Sibling Support Project, brother with DS, Seattle, WA**

Brothers and sisters will likely be in the lives of family members with Down syndrome longer than anyone. Siblings will be there after parents are gone and special education services are a distant memory. Yet, if they are provided with support and information, they can help their siblings live dignified lives from childhood to their senior years. Throughout their lives, brothers and sisters will share many, if not most, of the same concerns that parents experience, as well as issues that are uniquely theirs. During this lively, interactive session, participants will talk about sibs' issues across the lifespan—the good stuff, the not-so-good stuff, and everything in between. In addition, a sibling panel will share their expertise with participants. Finally, Mr. Meyer will discuss what parents and service providers can do to minimize sibs' concerns and maximize their opportunities.



## **PRE-CON H**

### **Understanding the Who, What, Where, When & Why of Down Syndrome to Help You and Your Community**

**Kate Dougherty, NDSC board member; Tamara Pursley, Communications Director, NDSC; and several amazing self-advocates**

Were you overwhelmed when faced with navigating the various organizations, resources and medical issues related to DS? If you were lucky, there was an individual or organization that guided you. This session provides information about various DS organizations as well as current issues impacting the DS community. It will also highlight how to talk about DS with clarity and confidence in healthcare settings, schools, communities, and families. Participants will leave with not only important tools, but also a better understanding of the DS landscape to help enhance their knowledge and serve as a resource for others. Whether you are a parent, caregiver, and/or affiliate organization leader, help us create a culture-shift in the way DS is viewed, from prenatal diagnosis to adulthood.



## **PRE-CON I**

### **Estrategias prácticas para enseñar sobre sexualidad y afectividad**

**Macarena Lizama, MD, Directora Ejecutiva, Centro UC síndrome de Down, Pontificia Universidad Católica de Chile**

La falta de educación en sexualidad a las personas con discapacidad está principalmente determinada porque los profesionales que participan en su desarrollo no cuentan con herramientas para realizar educación en esta temática, más bien actúan en reacción a problemas o situaciones incómodas que aparecen como consecuencia de la falta de educación sexual de los jóvenes. Si bien expresar y experimentar la sexualidad en plenitud y libertad es un derecho, hoy en día existen obstáculos para que las personas con síndrome de Down puedan vivir su sexualidad en forma saludable. Muchos de estos obstáculos han sido construidos sobre mitos, que son principalmente derivados de la falta de educación. Este workshop está dirigido a entregar a padres y profesionales estrategias prácticas sobre sexualidad y afectividad.

## **Educator Conference:**

### **Effective Practice for Students with Down Syndrome: Tools for Today's Classroom**

**Friday, July 21, 8:00 am - 3:00 pm. CEU's Provided.**



# Registration Information

## Register Online

Visit [www.NDSCCenter.org](http://www.NDSCCenter.org); click "Annual Convention"; and select "Register". **Registration will open April 10 at 9 AM eastern time.**

## 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.

## Ground Transportation

The Sacramento Convention Center is approximately 15 minutes from the Sacramento International Airport. It is also approximately 90 miles from the San Francisco and Oakland Airports. None of the convention venues provide an airport shuttle.

**Avis Rental Car** is pleased to provide a convention discount to NDSC families. The AWD code is **J944711**, call **(800) 331-1600** or book online at [avis.com](http://avis.com).

## Hotel & Travel

### Convention Headquarters:

**Sacramento Convention Center**  
1400 J Street • Sacramento, CA 95814

### NDSC Convention Hotels:

**Hyatt Regency Sacramento**  
1209 L Street • Sacramento, CA 95814

**Sheraton Grand Sacramento**  
1230 J Street • Sacramento, CA 95814

**Residence Inn Downtown Sacramento at Capitol Park**  
1121 15th Street • Sacramento, CA 95814

NDSC Convention rate is \$153 plus tax, per night. Rate is only valid July 17 - 27 based on hotel availability. **NDSC policy:** all attendees must register for the convention before reserving a hotel room in the NDSC Convention block. Check our website for details on how to reserve a room in the NDSC convention block.

**Membership is required for registration. The annual Membership fee is \$50. To determine membership status, see mailing label from the convention brochure with expiration date, or contact the NDSC office at 800-232-6372.**

2017 Registration Fees	By June 9	By June 29	On-Site
<b>General Convention Individual*</b>	\$189	\$249	\$299
<b>General Convention Family*</b> (Up to 3 family members residing in the same household attending the General Convention. One additional adult family member can be added for \$50. After 4 adults a new registration must be completed.)	\$289	\$339	\$399
<b>Pre-Conference</b>	\$75	\$75	\$100
<b>Youth &amp; Adults w/DS Conference</b>	\$99	closed	closed
<b>Brothers &amp; Sisters Conference</b>	\$99	closed	closed
<b>Kids' Camp (per session)</b>	\$40	closed	closed
Options	By June 29	On-Site	Post Conv.
<b>Compendium</b> —flash drive or paper copy (One flash drive compendium is complimentary with an individual or family registration. Paper copies or additional flash drives must be purchased.)	\$20	\$25**	**
<b>Adult Sapphire Celebration Ticket</b>	\$45	N/A	N/A
<b>Child Sapphire Celebration Ticket</b> (12 and under)	\$20	N/A	N/A
<b>Convention T-shirt</b>	\$15	\$18**	N/A
<b>Conference Recording Season Pass</b> (12 months Streaming + Download Offline Access)	\$59	\$59	\$129
<b>Conference Recording USB Works</b> (Season Pass + All files on a USB)	\$99	\$99	\$199

\* One access account to the online conference audio-recordings is complimentary with an individual or family registration!

\*\* Not Guaranteed

# Convención General

La Convención General está diseñada para educar a padres, familiares y cuidadores, así como profesionales médicos y educadores. El programa de la Convención General incluirá una sesión plenaria y más de sesenta talleres que se ofrecerán el fin de semana de la convención. Durante el fin de semana, habrán 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 [www.ndsccenter.org/convencion-del-national-down-syndrome-congress](http://www.ndsccenter.org/convencion-del-national-down-syndrome-congress). También encontrarás la

lista de talleres que se impartirán en español y las que se ofrecerán con interpretación simultánea al español en el programa de la convención y en la aplicación interactiva (no hay necesidad de pre-registrarse para estas sesiones). Además contaremos con equipo de interpretación para los asistentes que requieren el servicio.

La primera Sesión Plenaria será el viernes por la noche, seguido de una recepción de apertura y un divertido baile. Se anima a todos los asistentes y familiares a asistir. La mayoría de los talleres serán grabados, y estarán a disposición de todos, unas semanas después de la convención. Esta es una excelente manera de poder escuchar aquellos talleres a los que no puedes asistir por conflictos de horario.

## Pre-conferencias

El viernes, 21 de julio de 8 a.m. a 12:00 p.m., expertos en síndrome de Down dictarán 8 pre-conferencias sobre un tema específico de interés. Las pre-conferencias tendrán una duración de 4 horas. Como las conferencias serán presentadas simultáneamente, sólo será posible asistir a una. Las pre-conferencias no serán grabadas, tendrán un costo adicional y se requiere inscripción previa. La pre-conferencia **C, "Comportamiento y Síndrome de Down: El método responder pero no reaccionar."** David Stein, Psy.D., Fundador de New England Neurodevelopment, psicólogo pediatra. Autor de Apoyando el comportamiento positivo en niños y adolescentes con síndrome de Down. Sólo una de las pre-conferencias será impartida en español y es la siguiente: **I "Estrategias prácticas para enseñar sobre sexualidad y efectividad"** por Macarena Lizama, Pediatra, Directora ejecutiva del Centro UC Síndrome de Down. Editora y coautora de los manuales de "Educación sexual y afectividad para personas con discapacidad cognitiva".

## Encuentros para familias de habla hispana

Estos encuentros se llevarán a cabo el jueves de 7:15 a 8:30 p.m. y serán impartidos para padres de acuerdo a la edad de sus hijos. 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. **Se recomienda que los padres asistan a estas sesiones sin sus hijos con el fin de compartir sus inquietudes libremente.**

## Campamento para niños

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

## Programa para jóvenes y adultos con síndrome de Down

*Los participantes deberán tener mínimo 15 años de edad, cumplidos para el 20 de julio del 2017.*

Este evento es en sí el corazón y el alma de la Convención del NDSC y su objetivo será el de brindarle 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. Incluye almuerzo. Durante el domingo, los jóvenes participarán en el popular festival de talentos el cual talentos. No se incluye el almuerzo para este día. Los participantes contarán con equipo de interpretación, el apoyo del NDSC y de un



## Eventos Sociales y Otras Actividades

**¿Qué sería de la Convención del NDSC sin una fiesta o dos?** Todos los participantes están invitados a participar de la recepción el viernes en la noche y el 321Dance! después de la Sesión Plenaria de Apertura donde tendremos como invitados especiales a Jonathan Murray, ganador del premio Emmy por "Somos Así" (Born this Way), los hermanos Katie Faith Lingo y Kris Faith, y Jessica Adler, autogestora de Sacramento.

El sábado en la tarde celebraremos nuestro 45 aniversario (se requiere boleto de entrada), luego tendrá lugar el tradicional baile juvenil en donde todos podrán bailar y divertirse en 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 de 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 de Cine se llevará a cabo durante los bloques de los talleres del viernes hasta el domingo.

## Mesa Redonda de Investigación y Atención Médica

Organizada por Global Down Syndrome Foundation y el NDSC

Jueves 20 de julio de 1:00 pm a 4 pm

Un beneficio gratuito para los asistentes inscritos para asistir a la Convención del NDSC.

**Cuidado y Medicina con un enfoque en síndrome de Down y la enfermedad de Alzheimer. Todo lo que los padres y cuidadores deberían saber**

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

**Página web de la convención:** <http://www.ndsccenter.org/convencion-del-national-down-syndrome-congress/>

**Teléfono:** (770) 604-9500

## Acerca de Sacramento

La fiebre del oro de 1849 llevó el mundo a Sacramento. Ahora es tu turno de ver todo lo que ofrece la capital de California. Desde su centro con andenes a las calles con adoquines del histórico "Sacramento Antiguo". Será un placer conocer Sacramento en familia!

Mejor aún, hay más tesoros en un corto trayecto en auto. Puedes ir a Napa Valley en menos de una hora; A San Francisco, Lake Tahoe y Muir Woods en menos de tres. ¿Dónde más puedes encontrar tantos tesoros naturales y culturales a tu alcance?

¡Comienza a planear ahora para dar a tu familia el viaje de su vida - todo con la Convención del NDSC incluida!



# NATIONAL DOWN SYNDROME CONGRESS

## NDSC 45th ANNUAL CONVENTION

**July 20–23, 2017**

30 Mansell Court, Suite 108  
Roswell, GA 30076  
Toll Free: (800) 232-NDSC (6372)  
Local: (770) 604-9500  
Fax: (770) 604-9898  
E-Mail: info@ndsccenter.org  
[www.NDSCcenter.org](http://www.NDSCcenter.org)



### Registration Deadlines

**June 9** - Best Value Rates, Y&A, B&S

**June 9 or when capacity is reached** -  
Kids' Camp

**June 29** - General Convention

After June 29, registration for the general convention and pre-cons will be available on-site  
**ONLY if space allows.**



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



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



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



## Special Thanks

The National Down Syndrome Congress would like to thank the 2017 Host Committee for their assistance in providing local support and coordination of the 45th Annual Convention.

Down Syndrome Connection of the Bay Area  
Down Syndrome Information Alliance  
Club Twenty-One



### GLOBAL DOWN SYNDROME FOUNDATION RESEARCH & MEDICAL CARE ROUNDTABLE: *What parents, self-advocates & caregivers should know*

**"This was fantastic to get to hear the research as a parent. Thanks to Global for being such an awesome advocate. You are changing lives forever!"**

Jenny, IL  
2016 Global Roundtable Attendee



**Thursday, July 20, 2017 • 1:00pm-5:00pm  
Sacramento Convention Center, California**

**Lunch and seating are limited.  
Sign up for free with your NDSC registration!**

Co-organized with the NDSC, the Global Roundtable is a free benefit and features renowned scientists and medical professionals.

To learn more, call 303-621-6277 or visit [GlobalDownSyndrome.org](http://GlobalDownSyndrome.org)