

Down Syndrome News

NEWSLETTER OF THE

Volume 40, Number 1

Spring 2017



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Pioneer of research and friend to the Down syndrome community

We are deeply saddened by the passing of Dr. Michael Harpold, Chief Scientific Officer of LuMind Research Down Syndrome Foundation. "Even if you didn't know him, most of you were touched by his legacy of leadership that steered LuMind RDSF to fund groundbreaking research with unprecedented results. Dr. Harpold was a scientist, an advocate, and most importantly, a friend to individuals with Down syndrome and their families," said Carolyn Cronin, President & CEO of LuMind RDSF. He was an engaging speaker at NDSC's Annual Convention as well as the Down Syndrome Medical Interest Group (DS-MIG) Symposium.

Dr. Harpold recognized that there was an urgency to pursuing Down syndrome research because the community had been overlooked for too long. Under Dr. Harpold's scientific leadership, LuMind RDSF has funded transformative cognition research focused on intellectual disability and Alzheimer's disease in individuals with Down syndrome. We join Carolyn in honoring his tenacity, "His legacy will be celebrated with every advancement in the lab, every clinical trial and every therapy that is realized because of this research."

Dr. Harpold will be sorely missed.

Letter from the President

Dear Families,

Spring has sprung! Thanks to the many of you who responded to our End of the Year Appeal in support of the National Down Syndrome Congress. We are eternally grateful for your support, without which we simply would not be able to accomplish everything we want and need to do.

Over these last few months, the National Down Syndrome Congress Board of Directors met to continue and strengthen our Strategic Plan that will lead us into 2017-2019. Our Centers for Excellence are busy preparing webinars, workshops and other opportunities for our community. Be on the lookout for exciting happenings in the months to come!

NDSC Governmental Affairs have been working on your behalf all year on a variety of important legislation. If you are not on our Governmental Affairs

Newsline and Action Alert subscriber list, I encourage you to sign up to stay abreast of everything happening in Washington, D.C. Susan Goodman, Ricki Sabia and Stephanie Smith Lee are on the ground in D.C. advocating and meeting with constituents to ensure our voice is being heard.

The NDSC Convention Committee has been hard at work since the last convention and are busy preparing for our "Family Reunion" in Sacramento! I am so looking forward to seeing many of you there and catching up on all the exciting things in your lives. We have a wonderful line up of workshops and presenters and they are all looking forward to sharing their expertise with each of you. Convention and hotel registration is now open.

Remember that we are only a phone call away if you have questions or concerns. The National Down Syndrome Congress is committed to



serving you and your families. It is our privilege and honor.

Hope these next months are full of love and laughter!

My best,

A handwritten signature in black ink that reads "Marilyn Tolbert". The signature is written in a cursive, flowing style.

Marilyn

Down Syndrome News

ISSN 0161-0716

Publisher: National Down Syndrome Congress

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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.

Reprints From DSN:

We invite editors of other newsletters to reprint items from *Down Syndrome News*, provided proper credit is given to the source. Please delineate clearly the material you are reprinting and indicate that it comes from *Down Syndrome News*, newsletter of the National Down Syndrome Congress, 30 Mansell Court, Suite 108, Roswell, GA 30076, ndsccenter.org

Please note that for material which the DSN reprinted with permission you must contact the original source.

Board of Directors:

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Call for Board nominations!

The NDSC Board is a collegial group with a family feel. Like any Board of Directors, ours directs policy and has fiduciary oversight. However, unlike many boards, ours is a “working” group that is heavily involved in the successful operation of the organization. We hold two face-to-face meetings each year, one on a weekend in the midwinter and one on Thursday before the convention opens. Typically the mid-winter meeting is held in the upcoming convention city and hotel to familiarize the Board with the locale ahead of time. In addition to attending the board meetings, each board member is expected to serve on one or more committees and/or strategic teams who meet by conference call periodically, most often, but not always, during daytime hours. The committees and teams are very active; some meet monthly, others, such as the convention committee, meet more often. Our strategic plan is very dynamic and is being actualized.

Any member in good standing of the NDSC is eligible for nomination to the Board of Directors. Self-nominations as well as nominations by third parties are accepted (provided the third party has secured the consent of the nominee). Board nominations are being accepted now through May 1st.

Three self-advocates serve on the BOD and each year one self-advocate is elected by his or her peers at the convention's Y&A Conference for a three-year term. All individuals with DS ages 22 and older are eligible to run for the NDSC Board of Directors. Self-advocate nominations must be submitted before the May 26th deadline.

For more details, and the nomination forms, visit <http://www.ndsccenter.org/board-nomination-form/>

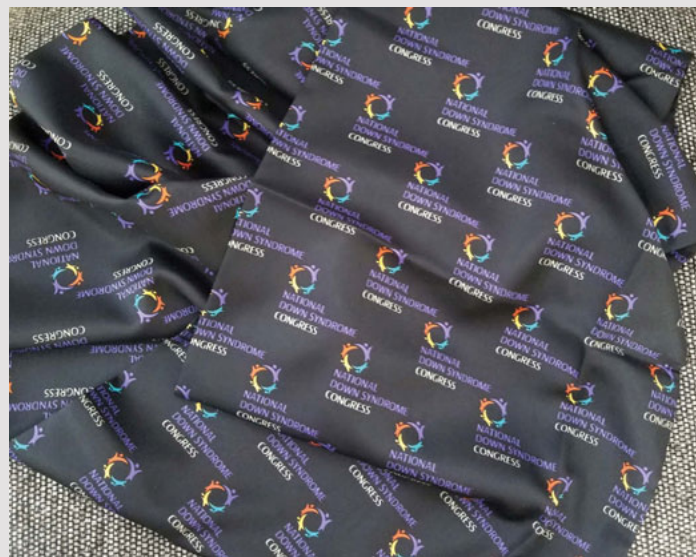


NDSC logo scarf

Our ladies' infinity, poly-blend scarf is versatile to be worn with many colors and shirt styles. 20" x 72" loop. \$25 (includes shipping).

Get yours today!

<http://www.ndsccenter.org/ndsc-scarf-bow-tie/>



When “they” say...

By Kathy Everett

first published in DSN Volume 33, 2010, #2

IEP — Those three little letters instill fear in the hearts of many parents who have a child with a disability. Others have no clue what they mean.

I have attended hundreds of IEP (Individual Education Program) meetings. Some were for my own daughter, Jennifer. Sometimes, I provided a hand to hold or a friendly face in the crowd for other parents who needed it. The process of creating an IEP can be long and confrontational, short and cooperative — or anything in between. The key is for parents to know what to say when “they” say (fill in the blank).

In my journey, I have learned many things that I share with other parents to help them on their journey. When a school member says something you disagree with for your child, your response is key. Here are some of the most common comments said at IEP meetings and what you can say to counter them.

We’ve never done that before.

Well, let’s see how we can figure out how to do it.

She will get more attention in a small group setting.

The average self-contained class has eight students all with significant special needs while the general education classroom has an average of 20 students but statistically only one will have significant special needs.

Your child requires more attention than I can give in my class. I have 20 other students that need my attention.

I understand and it sounds like you do not have enough support in the class to help with all of your students. Then maybe a paraprofessional is necessary.

– Or –

All students need to be challenged and you should not feel like you are the only one who can teach my child. I am sure there are several other children who would love to help out my child. We all know that helping someone else learn reinforces what is being taught. Peer tutoring is a wonderful opportunity for everyone in the class to learn.



It isn’t fair to have a child in the class who is learning have to teach someone else. It isn’t their responsibility.

We all know that kids learn from kids. Kids build competence by teaching someone else because it reinforces the skills they are learning themselves.

He needs to be with other kids that are like him. He will feel always left out and unable to really compete with his peers.

My child needs to be around age-appropriate peers in real life situations to learn how to get along with others in the real world. Research shows that all children benefit from inclusive classrooms.

She really needs adaptive PE (or art or music).

I understand my child has limitations; but she will benefit from access to the general curriculum, just like all of the other students do. And, in a class like PE (or art or music) just learning to follow directions or changing clothes is a skill my daughter needs for life.

They need to be in adaptive PE so they don’t get hurt.

Don’t you have any other children that ever get hurt? My child needs to learn how to play in social environments. What can I do to help you have the supports so that he can safely participate? Let’s work together to plan what supports will help him participate safely.

She is so far below grade level, she cannot even...

I understand my child can’t... _____. That is why we have differentiated instruction. The curriculum needs to be modified so that she can continue to progress and learn.

He is not at the level of the other children.

I know he isn't at the level of the other children. That is why he has an IEP. I don't expect him to be at the same level as his peers, but I do expect us to use a modified curriculum where we can identify the supports that are necessary and helpful for him to learn.

We are concerned about her life and/or job skills.

That is why she needs to be in this class.

I really appreciate your concern. There are many things I can replicate at home and I can teach my child. But I cannot recreate a high/middle/elementary school environment. My child needs to experience that just like any other child. I will teach my child life skills. I can take my child to the grocery store. I need her to learn how to be around other people.

In communication, one of the most important things to remember is to keep the conversation focused on your child and his needs. It's what he needs, not what you want for him. It sounds simple, but the key is semantics. Always think about how you phrase a question or statement to encourage the response you want. I never ask if something can be done. I ask how it is going to happen. It is important to be knowledgeable and realistic about what your child can and cannot do. Know the law — but use it sparingly. Honestly, you and the educators want the same thing: for your child to learn in a healthy, caring environment. Sometimes, we just have differing philosophies of how to accomplish that. Good luck and remember an IEP is not carved in stone. It can be changed.

Editor's note: Kathy Everett is a certified teacher in both general education and special education who directs her own consulting business, Kathy Everett Consulting, to assist parents in navigating school systems. She also has a daughter with Down syndrome.



Find us on Facebook:

National Down Syndrome Congress

“I never ask if something can be done. I ask how it is going to happen.”



NATIONAL DOWN SYNDROME CONGRESS



July 20 - 23, 2017

SACRAMENTO, CA

New Convention Schedule

Thursday

- 4:00 p.m. - 9:00 p.m. Registration Open
- 4:00 p.m. - 9:00 p.m. Exhibit Hall Open
- 5:00 p.m. - 7:00 p.m. Welcome Reception in Exhibit Hall
- 6:00 p.m. - 7:00 p.m. First Timer Orientation
- 7:15 p.m. - 8:30 p.m. Sharing Sessions
- 7:30 p.m. - 9:00 p.m. Affiliate Leader Reception

Friday

- 7:00 a.m. - 5:00 p.m. Registration Open
- 7:30 a.m. - 12:30 p.m. Kids' Camp Session 1
- 8:00 a.m. - 12:00 p.m. Pre-Conference Sessions
- 9:00 a.m. - 5:00 p.m. Exhibits Open
- 12:00 p.m. - 1:15 p.m. Lunch on own (Concessions available in Exhibit Hall)
- 12:00 p.m. - 1:15 p.m. African American Lunch and Learn
- 1:15 p.m. - 5:15 p.m. Kids' Camp Session 2
- 1:15 p.m. - 3:15 p.m. Y&A/B&S Kick Off Parties
- 1:30 p.m. - 3:00 p.m. Workshop Cycle 1
- 3:30 p.m. - 4:00 p.m. Membership Meeting
- 3:30 p.m. - 6:30 p.m. Dinner on your own
- 4:30 p.m. - 6:15 p.m. Award Winner Dinner
- 6:30 p.m. - 7:45 p.m. Opening Plenary Session
- 8:00 p.m. - 10:00 p.m. Reception and 321Dance!™

Saturday

- 9:00 a.m. - 1:15 p.m. Kids' Camp Session 3
- 9:00 a.m. - 5:00 p.m. Exhibit Hall Open
- 9:00 a.m. - 5:15 p.m. Y&A and B&S (lunch included)
- 9:30 a.m. - 11:00 a.m. Workshop Cycle 2
- 11:30 a.m. - 1:00 p.m. Workshop Cycle 3
- 1:00 p.m. - 3:00 p.m. Exhibit Hall Open with Lunch Kiosks
- 2:30 p.m. - 6:00 p.m. Kids' Camp Session 4
- 3:30 p.m. - 5:00 p.m. Workshop Cycle 4
- 6:30 p.m. - 8:00 p.m. Sapphire Celebration
- 8:00 p.m. - 10:00 p.m. Dance

Sunday

- 8:00 a.m. - 12:30 p.m. Kids' Camp Session 5
- 8:15 a.m. - 12:15 p.m. Y&A / B&S
- 8:30 a.m. - 10:00 a.m. Workshop Cycle 5
- 10:30 a.m. - 12:00 p.m. Workshop Cycle 6
- 12:30 p.m. Convention Closes

**Convention Registration Opens:
April 2017**

www.ndsccenter.org/the-convention

2017 NDSC CONVENTION HOTELS

Which one is best for my family?

We know how important finding the right hotel can be for your overall convention experience so we hope these details will help you decide. The NDSC has a convention block at the following hotels. Each property has its own flavor and style as well as their own amenities. All three are within walking distance to the Sacramento Convention Center, which will hold 95% of the convention meeting space. The only convention programming not at the Sacramento Convention Center is the Brothers and Sisters Conference, which is meeting at the Hyatt Regency. Please check out the map to the right and the information about each hotel below before you decide which hotel to book. Rooms will be offered on a first-come, first-served basis. The system will only allow you to book one room per convention registration.

Should you need additional rooms to accommodate your family, or have specific requests, please email coleen@ndsccenter.org.



Hyatt Regency Sacramento

1209 L Street, Sacramento

Convention Rate: \$153 plus tax

Parking: Overnight Guests

(in/out privileges)

- Self-Parking | \$20.00
- Valet Parking | \$29.00

Hotel Features:

- Outdoor Pool
- Fitness Center (outside of the hotel)
- Spa (outside of the hotel)
- Business Center
- Pet Friendly
- Free Wifi
- Club Lounge (not available with convention rate)

Dining Options:

- Vines Cafe
- Dawson's Steakhouse
- Amourath 1819 (Lobby Bar)
- Starbucks (outside of the hotel)

Brothers & Sisters Conference Meeting Site

Sheraton Grande Sacramento

1230 J Street, Sacramento

Convention Rate: \$148 plus tax

Parking: Overnight Guests

(in/out privileges)

- Self-Parking | \$20.00
- Valet Parking | \$32.00

Hotel Features:

- Outdoor Pool
- Fitness Center
- Business Center
- Wifi \$9.95 per day/ Free to SPG Members
- Club Lounge (not available with convention rate)

Dining Options:

- Lobby Coffee
- Morgan's Restaurant
- Public Market

DSMIG Symposium Meeting Site

Residence Inn Sacramento

Downtown at Capitol Park

1121 15th Street, Sacramento

Convention Rate: \$149 plus tax

Parking: Overnight Guests

(in/out privileges)

- Self-Parking | \$20.00

Hotel Features:

- Outdoor Pool
- Fitness Center
- Pet Friendly
- Free Wifi
- Free Breakfast
- Kitchenette

Dining Options:

- 3 Fires Lounge (lunch and dinner)

No NDSC Convention Programming at this site

The 2017 Convention headquarters will be the Sacramento Convention Center.
All General Convention programming will be held at Sacramento Convention Center.
All Youth & Adults Conference programming will be held at the Sacramento Convention Center.
All Brothers & Sister Conference programming will be held at the Hyatt Regency Sacramento.
All Kids' Camp programming will be held at the Sacramento Convention Center.
The DSMIG Symposium will be held at the Sheraton Grande Sacramento Hotel.

Souvenir Journal messages available now!

The NDSC invites exhibitors, speakers, vendors, families and others to place a message in the convention program, the Souvenir Journal. The inclusion of your message shows your support for the work of the NDSC and assists us to better serve persons with Down syndrome.

Messages may provide information, recognition, good wishes or may memorialize an individual. Business logos and photos may be included. More than 3,500 people are expected to attend. Each attendee will receive a copy of the Souvenir Journal.

The National Down Syndrome Congress is a non-profit organization registered with the IRS to accept tax deductible contributions. All funds received will be used to offset the cost to produce the Souvenir Journal for the 2017 convention. The NDSC reserves the right to accept or reject any message.

Prices start at \$75 for a 1/8 page black & white message.

<http://www.ndsccenter.org/wp-content/uploads/CH-SJ-Message-App17-2B.pdf>



For more information, including availability, pricing and specifications, contact Coleen Popp at coleen@ndsccenter.org.

The deadline for submitting your artwork and payment is June 16.



Self-Advocate Book Project

This project began in 2003 when self-advocate Tracy Hile introduced the idea of self-advocates presenting books on Down syndrome to the NDSC convention host community. Self-advocates and friends donate money for books that positively portray individuals with Down syndrome. They present these books to libraries in the NDSC Convention host city.

How can you help?

During on-line convention registration, check the box to have \$1 or more added to your registration fee to be donated to the Self-Advocate Book Project. For a donation of \$100, you will receive a "bundle" of all the books listed below (to take back to your local community).

- **ABC Building Blocks for Growing Up With Down Syndrome**, by self-advocate Meredith Martin — Nicely outlines some of the key components that lead her to independent living.
- **Donovan and the Big Hole**, by Nancy Lambert Davenport — This delightful, fictional Texas adventure is

narrated by fourteen-year-old Donovan, who happens to have Down syndrome. He and his neighborhood friends don't ask for trouble, but manage to find it!

- **The Little King and His Marshmallow Kingdom**, by Louis Rotella III — This beautiful book encourages children to be themselves with confidence, and challenge pressures to conform.
- **Sam's Top Secret Journal (3 Book Series)**, by Sean Adelman — This is a set of three short novels about the adventures of Sam, a middle school girl with Down syndrome. They solve mysteries, have adventures, and deal with the world and its conflicts.
- **Stealing First: the Teddy Kremer Story**, by T Kremer with D Lang & M Buchanan — "Nothing — can top that night — I was batboy for the Cincinnati Reds!"
- **Why Are You Looking At Me?**, by Lisa Tompkins — A child with Down syndrome only wants to be a friend and have friends. She wants them to learn she "is more alike than different!"

Recommended Reading

Meet Lucy

Lucy has Down syndrome and may need a little extra help at times, but she's also curious, funny, and always at-the-ready for adventure. Follow Lucy as she grows and learns along with her family and friends through make-believe magic, scavenger hunts, temper tantrums, and wild animal encounters. You know – totally normal kid stuff.

Enhanced read-aloud e-books with music and narration, the My Sister Lucy book series is for all preschoolers/young readers of any ability to enjoy. They are about acceptance, inclusion and real friends just exploring and enjoying the world together. Although the first book introduces Lucy and encourages the conversation about Down syndrome, it is not the focus of all of the books. Lucy is a main character like any other main character – she experiences the same fabulous adventures as any other curious child her age! And she's super cute ta boot...

The author has generously offered to donate 20% of the proceeds to NDSC, and other DS organizations, to further our goal to enhance available resources, information and advocacy for people with Down syndrome. You can order them now at mysisterlucy.com.



About the Author – Sue Workman, PT, MA is the author and illustrator of *My Sister Lucy*, *Lucy at the Zoo* and *Lucy's Halloween Treasure Hunt*. Sue is both a practicing physical therapist who works with children of all ages and a professional photographer whose passion for photography started while living in New York City. She loves being behind the camera to capture the simplest moments of life to tell a story. After receiving her Bachelors of Science in Physical Therapy from Ithaca College in 1991 and a Masters of Arts in Applied Physiology from Columbia University in 1995, Sue, along with her husband Michael, started professionaltherapies.com and bamboobrace.com.



RapidSOS and National Down Syndrome Congress partner to provide mobile safety to the Down syndrome community

RapidSOS is an advanced emergency technology start-up, revolutionizing personal safety and connectivity. RapidSOS will offer the Haven smartphone app for free to NDSC families, providing enhanced access to emergency services for individuals with Down syndrome. Haven represents a transformation in access to

- Type of emergency
- Relevant medical and demographic data

When setting up the app, users can enter medical conditions, allergies, and medications, so that lifesaving information is communicated directly to 9-1-1 when an alert is triggered.

Congress,” said RapidSOS co-founder and CEO Michael Martin. “Through this partnership, families will be able to stay connected and at the same time individuals with Down syndrome will feel safe and independent.”

The Haven app also includes access to RapidSOS’ Family Connect feature. For the first time, people can call 9-1-1 on behalf of a loved one, transmitting their loved one’s location and relevant data directly to the dispatch center closest to them. Additionally, Family Connect allows users to share their location with loved ones, see family members’ real-time locations without the distraction of a phone call or text, and easily ask family and friends for help.

“This partnership means a lot to our community,” said David Tolleson, Executive Director of National Down Syndrome Congress. “By

allowing for the transmission of key medical information during an emergency, first responders will respond with better awareness and individuals with Down syndrome will be able to get appropriate care.”

RapidSOS is offering free access to Haven for one year to those associated with NDSC if they sign up for Haven here: rapidsos.com/ndsc. The Haven app is available for iPhone and Android devices and works anywhere across the contiguous U.S. and Hawaii, with one touch emergency calling in over 250 countries and jurisdictional territories.



emergency services — from a phone call solely dependent on voice to a robust data connection for voice, text, medical/demographic data.

With one tap on Haven, the app connects the user with the nearest dispatch center anywhere in the contiguous U.S., enabling a voice connection and a data pipeline to 9-1-1 to transmit:

- Text messages: Haven speaks the text message if the dispatch center does not have the capability to receive texts. Currently works one-way (user to 9-1-1); two-way coming in future
- Precise location

Haven’s “Can’t Speak” function allows users to notify 9-1-1 that they cannot speak and/or have difficulty hearing. When a user taps “Can’t Speak,” their location and relevant information is automatically transmitted to the dispatcher, without the need for a verbal back-and-forth. The user can then send text messages to 9-1-1 to further explain their emergency. While currently, only about 15% of dispatch centers have the technology to receive text messages, Haven enables universal texting by speaking (text-to-speech) the text message.

“We are thrilled to be partnering with National Down Syndrome

Research Studies

National Child Feeding Study

What is involved in this study?

We are conducting a feeding study on children 1 – 4 years old, including children with a diagnosis of Down syndrome or an Autism Spectrum Disorder. Participation in the study will involve recording video of your child eating different food products at home.



How long will this study last?

This study will be conducted over the course of several months during 2017. Individual participation will take 1 week to complete and will involve video recording child-feeding sessions at home for 6 days in a row.

What will I get for participating in this study?

For filling out our questionnaire regarding the eating habits of your child, you will be entered in a drawing for the chance to win a \$500 gift card. If you and your child are selected to participate in the study, and complete all child-feeding sessions, you will receive a \$125 gift card.

Please contact us to let us know that you're interested!

Contact: Ben Bernhard

Email: charles.bernhard@wsu.edu

This study has been reviewed and approved for human subject participation by the Washington State University Institutional Review Board.



Family and Individual Needs for Disability Supports (FINDS) Survey



For people with intellectual and developmental disabilities

The Arc is in need of your help. They are inviting people to participate in the 2017 FINDS survey. The goal of the survey is to learn more about the experiences of parents and family members who provide support to a family member with an intellectual or developmental disability.

To participate, the caregiver must be 18 years or older and provide primary paid/unpaid and frequent support to a family member or friend with an intellectual or developmental disability living in the United States (and U.S. territories). This survey is not for direct support professionals – we need the perspective of family caregivers, paid or unpaid.

To connect to the survey, please follow the link:

<http://www.thearc.org/FINDS>

Are You Ready to Be in the Spotlight of Our Self-Advocate Corner?

We love to share stories and articles written about and by people with Down syndrome. If you, or someone you know, has something to share with our members, please send it our way. People all over the country will read it!

Send your original story or article, or article that we can reprint to:

Editor, Down Syndrome News
National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30076
or tamara@ndsccenter.org

Don't forget to send your name, age, address, phone number and a photo of yourself to go with your article.



NUEVO HORARIO DE LA CONVENCION

JUEVES

- 4:00 pm – 9:00 pm Inscripción
- 4:00 pm – 9:00 pm Sala de Expositores
- 5:00 pm – 7:00 pm Recepción de bienvenida en la Sala de Expositores
- 6:00 pm – 7:00 pm Orientación para familias que Asisten por primera vez
- 7:15 pm – 8:30 pm Encuentros familiares
- 7:30 pm – 9:00 pm Recepción para afiliados

VIERNES

- 7:00 am – 5:00 pm Inscripción
- 7:30 am – 12:30 pm Sesión #1 Campamento de niños
- 8:00 am – 12:00 pm Preconferencias
- 9:00 am – 5:00 pm Sala de Expositores
- 12:00 pm – 1:15 pm Tiempo libre *
- 1:15 pm – 5:15 pm Sesión #2 Campamento de niños
- 1:15 pm - 3:15 pm Inauguración programas: Jóvenes/Adultos y Hermanos
- 1:30 am - 3:00 pm Bloque #1 Talleres
- 3:30 pm - 4:00 pm Reunión de miembros del NDSC
- 3:30 pm – 6:30 pm Tiempo libre
- 4:30 pm - 6:15 pm Cena de premios (Invitación)
- 6:30 pm - 7:45 pm Acto inaugural
- 8:00 pm - 10:00 pm Recepción y Baile 321

SÁBADO

- 9:00 am – 1:15 pm Sesión #3 Campamento de niños
- 9:00 am - 5:00 pm Sala de Expositores
- 9:00 am - 5:15 pm Programas: Jóvenes/Adultos y Hermanos (almuerzo Incluido)
- 9:30 am - 11:00 am Bloque #2 Talleres
- 11:30 am - 1:00 pm Bloque #3 Talleres
- 1:00 pm - 3:00 pm Sala de Expositores *
- 2:30 pm - 6:00 pm Sesión 4 Campamento de niños
- 3:30 pm - 5:00 pm Bloque #4 Talleres
- 6:30 pm - 8:00 pm Celebración 45 años del NDSC (Boleto requerido)
- 8:00 pm - 10:00 pm Baile

DOMINGO

- 8:00 am – 12:30 pm Sesión #5 Campamento de niños
- 8:15 am - 12:15 pm Programas: Jóvenes/Adultos y Hermanos
- 8:30 am - 10:00 pm Bloque #5 Talleres
- 10:30 am – 12:00 pm Bloque #6 Talleres
- 12:30 pm Cierre de la Convención del NDSC

* Puntos de venta de comida en la Sala de Expositores

Inscripciones comienzan el 10 de abril de 2017

La 45 Convención Anual de NDSC, se llevará a cabo del 20 al 23 de julio de 2017 en Sacramento, CA. La inscripción en línea y la reserva del hotel comienza el 10 de abril de 2017 a las 12 del medio día.

Puede hacer un solo registro para personas o familias que viven en la misma dirección para el registro familiar. Personas que no vivan en la misma residencia deben realizar su inscripción por separado. Se requiere ser miembro del NDSC para poder hacer la inscripción a la Convención. Los niños pequeños no necesitan ser registrados a menos que estén atendiendo específicamente los campamentos para jóvenes y adultos, para hermanos o el campamento para niños. Un adulto se debe inscribir en la convención para poder inscribir a los niños en el campamento de niños.

Para registrarse, debe crear una cuenta (nombre de usuario y contraseña) dentro de nuestro sistema de registro para convenciones. Esto no es lo mismo que completar un formulario para ser miembro del NDSC. Si no ha asistido anteriormente a la convención, debe hacer clic en Nuevo usuario. Registrarse aquí En la página de inicio de sesión para establecer primero su cuenta.

Al crear la cuenta, le permitirá al usuario abandonar el proceso de registro antes de realizar el pago y

regresar en un momento posterior para completarlo, si es necesario. Sólo se necesita un titular de cuenta por inscripción individual o familiar. El titular de la cuenta no necesariamente tiene que registrarse para la convención, pero es responsable del pago. Usted puede desconectarse en cualquier momento, y el sistema guardará sus selecciones actuales. Puede retomar la sesión más adelante, para realizar cambios y completar su registro con el pago.

La inscripción por línea requiere que el pago se haga con tarjeta de crédito. Si desea utilizar otra forma de pago, complete su registro por internet hasta el momento en que debe ingresar una tarjeta de crédito. Luego, cierre la sesión y póngase en contacto con la oficina de NDSC para obtener más instrucciones.

Después de realizar el pago, su registro estará completo y ya NO podrá realizar cambios, pero podrá ver la opción de pago seleccionada para su registro en cualquier momento. Política de reembolso de NDSC: Las cuotas de inscripción no son reembolsables después del 29 de junio. Se deducirá un cargo de \$50 por procesamiento de cada solicitud de reembolso, por los derechos de registro antes de la fecha límite.



Cuando “ellos” dicen...

By Kathy Everett

Publicado anteriormente en la edición de DSN volumen 33, 2010, #2

IEP — Estas tres letras infunden miedo en los corazones de muchos de los padres que tienen un hijo con alguna discapacidad. Otros no saben lo que significan.

He asistido a cientos de reuniones del IEP (Plan de Educación Individualizado). A algunas de estas reuniones fui por mi hija Jennifer y a otras para echar una mano a aquellos padres que la necesitaban o simplemente para poner una cara sonriente en tre la multitud.

El proceso de creación de un IEP puede ser largo y controvertido, corto y cooperativo, o algo intermedio. La clave para los padres es saber qué decir cuando “ellos” dicen _____ (rellene el espacio en blanco). Comparto con otros padres todo lo que he aprendido de mi experiencia para que les sirva de ayuda. Si un miembro de la escuela dice algo con lo que usted no está de acuerdo, su respuesta es muy importante.

Aquí tiene algunos de los comentarios más comunes en las reuniones del IEP y qué puede decir para contra argumentarlos.

Nunca lo hemos hecho.

Bueno, vamos a ver si encontramos la manera de hacerlo.

Pondrá más atención en un grupo pequeño.

Una clase de educación especial tiene una media de ocho alumnos, todos ellos con necesidades especiales significativas, mientras que una clase de enseñanza general tiene unos 20 alumnos, pero estadísticamente sólo uno tendrá necesidades especiales significativas.

Su hija requiere una mayor atención de la que yo puedo darle en mi clase. Tengo 20 alumnos más a los que atender.

Lo entiendo. Al parecer usted no tiene suficiente apoyo en clase para atender a todos los alumnos. Por lo que quizás necesite un profesor auxiliar.

– O –

Usted no debería sentirse como la única persona que puede enseñar a mi hija y, además, todos los alumnos necesitan nuevos retos. Estoy segura de que a otros niños les encantaría poder ayudarlo. Todos sabemos que ayudar a otras personas a aprender refuerza lo que se le está enseñando. Enseñar unos a otros es una oportunidad magnífica de aprender.



No es justo que un niño de la clase que está aprendiendo tenga que enseñar a otro. No es su responsabilidad.

Como todos sabemos, los niños aprenden de otros niños. Al enseñar a los demás adquieren capacidades porque esto refuerza las aptitudes que están desarrollando.

Necesita estar con otros niños que son como ella. Siempre se sentirá excluida e incapaz de competir realmente con sus compañeros.

Mi hija necesita estar rodeada de compañeros de su misma edad en situaciones reales para aprender a cómo llevarse bien con el resto del mundo. Los estudios demuestran que las clases inclusivas benefician a todos los niños.

Necesita una educación física adaptada (arte o música).

Sé que mi hija tiene sus limitaciones, pero le beneficiará entrar en el plan general de estudios, al igual que el resto de alumnos. Además, en clases como la de educación física, arte o música, el simple hecho de aprender a seguir instrucciones o cambiarse de ropa son habilidades que ella va a necesitar en la vida.

Tienen que ir a una clase de educación física adaptada para que no se hagan daño.

¿No ha tenido a ningún otro niño que se haya hecho daño? Mi hija tiene que aprender a jugar en entornos sociales. ¿Qué puedo hacer para garantizar que pueda participar de una forma segura? Podemos trabajar juntos para planificar el tipo de asistencia que necesitaría para participar de un modo más seguro.



Está muy por debajo del nivel del curso, ni siquiera puede...

Entiendo que mi hija no pueda... Por esa razón existen instrucciones diferenciadas. Se tiene que modificar el plan de estudios para que ella pueda seguir avanzando y aprendiendo.

No tiene el mismo nivel que los otros niños.

Sé que no tiene el mismo nivel que los otros niños. Por este motivo está dentro del IEP. No espero que esté al nivel de sus compañeros, sino que se utilice un plan de estudios modificado en el que podamos identificar el tipo de atención que necesita y que le ayudará a aprender.

Nos preocupamos por su vida y/o sus aptitudes para el trabajo. Por ello, necesita estar en esta clase.

Aprecio su preocupación. Hay muchas cosas que puedo reproducir en casa y que puedo enseñar a mi hija. Pero no puedo recrear los entornos de la escuela primaria, media o secundaria, de manera que lo tiene que experimentar ella misma como cualquier otro niño. Le enseñaré las destrezas básicas de la vida. Puedo llevarla al supermercado, ya que necesito que aprenda a estar rodeada de otras personas.

En la comunicación, una de las cosas más importantes a tener en cuenta es que hay que mantener la conversación enfocada en su hijo y en sus necesidades. Qué es lo que necesita, y no qué es lo que usted quiere para él. Parece sencillo, pero la clave es la semántica. Ha de pensar siempre en cómo formular la pregunta o la afirmación para conseguir la respuesta que quiere. *No pregunte si se puede hacer algo, si no pregunte cómo se hará.* Es importante tener el conocimiento y ser realista respecto a lo que su hijo puede y no puede hacer. Conozca

las reglas, pero úselas con moderación. Francamente, usted y los educadores quieren lo mismo para su hijo: que aprenda en un entorno sano y solidario, aunque a veces tengamos filosofías diferentes sobre cómo conseguirlo. Buena suerte y recuerde que un IEP no es algo definitivo, se puede cambiar.

Nota del editor: Kathy Everett es una profesora certificada en educación general y especial que dirige su propia consultoría, Kathy Everett Consulting, para ayudar a los padres en su experiencia con el Sistema escolar. También tiene una hija con síndrome de Down.

Traducción realizada para el National Down Syndrome Congress por Verónica Juárez Arterodentro del marco de la iniciativa PerMundo y con el apoyo de la empresa de traducción Mondo Agit.



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