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2014 Convention

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MANY THANKS to Our Sponsors!

We are very grateful for the support of this year’s convention sponsors (listed below). Together, these sponsors contributed $164,376. Their support underwrote the world-class, multi-disciplinary education offered at this year’s convention. To keep the convention affordable for the families we serve, the registration fees NDSC charges only cover 55% of the convention costs. The money contributed by our sponsors helps us keep the costs down and allows us to offer some scholarships for those who would not otherwise be able to attend. Thank you, Sponsors!
A Celebration of the NDSC Family

At Saturday evening’s Awards Banquet, the NDSC launched the Siegfried M. Pueschel Circle to recognize and honor both the memory of Sig Pueschel and to celebrate the long-term commitment of people who have pledged to support the ongoing work of the NDSC for 5 years. Fourteen people have joined the Sig Circle, agreeing to give $1,000/year or more.

Dr. Pueschel was the second President of the NDSC’s Board of Directors, and a devoted champion of the rights and possibilities of those with Down syndrome. Dr. Pueschel’s daughter, Jeanette Pueschel Larson, attended the banquet, and presented the three awards that have traditionally been given by Sig himself.

Two very generous donor families offered matching gifts totaling $45,000 to match the first $45,000 given at this year’s banquet. With the support of the matching gifts’ donors, those who have joined the Sig Circle and the generous gifts of many more, the banquet raised $110,635 toward the ambitious 2014 budget of the NDSC. This year, the NDSC Board of Directors committed to a budget that requires raising about 20% more in revenue than in 2013 in order to reach some of the goals outlined in the organization’s recent strategic plan. These goals include increasing outreach efforts to underserved populations, providing greater programming for adult siblings (including the newly released Adult Sibling Toolkit), improving constituent communications through a convention mobile app and a re-designed website (coming soon), hiring a volunteer coordinator to assist with the recruitment and coordination of the convention volunteers, and to invest in our ability to raise funds and be more self-sustaining.

The inaugural members of the Siegfried M. Pueschel Circle include:

**OPPORTUNITY MAKERS**
Donating $5,000 (or more)/year for 5 years:
- Sean & Cathleen Fromm
- Bob & Jackie Sauter

**ADVOCATES**
Donating $1,000 (or more)/year for 5 years:
- Elizabeth Asplundh
- Bruce & Merilee Bennett
- Tim & Peggy Bergeron
- Bringing Up Down Syndrome (B.U.D.S.)
- Shawn & Pam Hardister
- Jeanette Pueschel Larson
- Harvey & Judy Martz
- Karen Prewitt
- Mike & Robin Sonnier
- David & Kim Tolleson
- Chandra Evans Torry
- Michelle Whitten

If you did not have an opportunity to make a gift or pledge, you can still contribute by visiting the NDSC website’s donation page: http://www.ndsccenter.org/give/donate/ or by calling or emailing Rebecca Davis, Director of Development at rebecca@ndsccenter.org or 1.800.232.NDSC (6372).

The NDSC is very grateful to our matching gift donors, to those who have joined the Siegfried M. Pueschel Circle and to everyone who made a commitment to support the work of the NDSC at this year’s convention.
2014 CONVENTION FACTS AND FIGURES

3,377 people came from all over the globe to take part in our convention weekend. We counted participants from 48 states, the District of Columbia, Puerto Rico and 15 countries, including: Argentina, Brazil, Canada, Chile, Colombia, Dominican Republic, France, Guatemala, Iceland, Mexico, Nigeria, El Salvador, Panama, Switzerland, and Trinidad and Tobago.

154 super siblings participated in our Brothers and Sisters conference. New this year, the addition of a track for 4th and 5th graders.

Our Youth and Adults Conference continues to be the heart and soul of our convention, and we reached our capacity of 310 participants.

234 kiddos took part in our Kids’ Camp activities, which included magicians, clowns and even some firefighters!

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

More than 60 workshops recorded so you can attend the “Convention from your Couch”! (Visit www.convention.ndsccenter.org to find out how you can order these recordings.)

Hoosier Hospitality was evident with 516 Volunteers who made the convention run seamlessly!

“Thank you all for every type of assistance you offer to our family and daughter with Down syndrome. It means so, so much to us as parents. We don’t know where we would be without NDSC’s existence starting at the birth of our child.”
Scenes from Indianapolis
Convención NDSC 2014
¡Nuestra Gran Reunión Familiar!

La 42a Convención Anual del NDSC definitivamente será inolvidable para los 3.377 asistentes que se dieron cita en Indianápolis.

¡Escrucha las grabaciones de las conferencias desde la comodidad de tu hogar!
Adquiere las grabaciones de la Convención del NDSC 2014 desde el siguiente enlace
http://www.conferencemedia.net/store/stores/ndsc/
Costo $70USD. Cada grabación incluye audio y diapositivas.

“Durante la Convención del NDSC aprendimos nuevas cosas, recordamos detalles importantes que fuimos olvidando y lo más importante, volvemos a Buenos Aires rápido a preparar el viaje a Phoenix!”

— Familia Tuliano
Los Conferencistas
A nuestros conferencistas, muchas gracias por compartir sus experiencias, conocimientos y por su gran contribución al fortalecimiento de nuestra comunidad. Contamos con la participación de 86 expertos en síndrome de Down de Chile, EE.UU., México y República Dominicana.

Este año contamos con una maravillosa Exposición de Arte de los talentosos jóvenes de la Fundación Puertorriqueña Síndrome Down.

Durante nuestra Gran Reunión Familiar se reunieron personas de todos los rincones del mundo. Fue una oportunidad maravillosa para aprender juntos, conocer nuevos amigos y convivir con otras familias, así como intercambiar experiencias.

Queridos voluntarios y voluntarias:
Nunca será suficiente, pero de corazón ¡Muchas gracias!
Agradecemos a todos nuestros voluntarios por su dedicación y su gran corazón; ya que gracias a ellos la Convención del NDSC fue todo un éxito. Es simplemente imposible llevar a cabo un evento de esta magnitud sin la ayuda de nuestro pequeño ejército de voluntarios. Los voluntarios fueron amigables, atentos, cordiales, serviciales en fin, no hay suficientes adjetivos para describirlos. ¡Muchísimas gracias a cada uno de ellos! La Asociación Down Syndrome Indiana fue un apoyo sólido y constante para el NDSC. Gracias a DS Indiana y gracias a cada uno de los voluntarios que participaron.

Algunos de los voluntarios bilingües dijeron:
“Comenzaremos a ahorrar desde ahora para poder asistir de nuevo a la Convención del NDSC en Phoenix, quedarnos encantados”.

Down Syndrome Indiana™
Directors Elected to NDSC Board in Indianapolis

Bret Bowerman and his wife, Courtney, live with their three children in Larchmont, New York. Their daughter, Ellie, has Down syndrome. Bret is an investment professional at Irving Place Capital and has an MBA from the University of Pennsylvania’s Wharton School. He chairs NDSC’s Development Committee. This is his second term.

Kate Dougherty is the President and Founder of Down Country, a rural awareness and education non-profit initiative in Illinois, Iowa and Missouri. Kate and her husband, Tony, are the proud parents of four amazing children. Their son, Elliot, has Down syndrome. Kate holds a B.A. in History & Political Science and a lifetime teaching certification for Secondary Education in Communication Arts, Social Science & Speech/Theater. This is her first term.

Dana Halle, of Costa Mesa, California, is the Co-Founder and Executive Director of Down Syndrome Foundation of Orange County and the Vice President of Education and Outreach for Down Syndrome Education USA. She is also the developer and lead trainer for The Learning Program™ — a multi-faceted education-based intervention implemented by 19 Down syndrome organizations across the nation. Dana practiced law as a business litigator for ten years before taking time off to parent her three children, the youngest of whom, Nick, has Down syndrome. This is her first term.

Shawn Hardister is a Certified Public Accountant with extensive experience in audits and taxation of not-for-profit organizations. He currently serves as NDSC’s Treasurer and chairs the Finance Committee. Shawn and his wife, Pam, live in Dunwoody, Georgia, with their three children, the oldest of whom, Matthew, has Down syndrome. Shawn has served on a number of non-profit boards, including that of the Down Syndrome Association of Atlanta. This is his third term.

Marilyn Tolbert is an early childhood professional at Texas Christian University in Fort Worth, Texas. Dr. Tolbert has over 13 years’ experience in the not-for-profit world. In addition to her work as NDSC’s First Vice President and chair of the organization’s Convention Committee, she has also been active in the Down Syndrome Partnership of Tarrant County, having previously served as president. Marilyn, who has an adult niece with Down syndrome, has also served as an NDSC Convention workshop presenter. This is her third term.
George Capone lives with his family in Towson, MD. He serves on the staff at Kennedy Krieger Institute as Director of the Down Syndrome Clinic and as Staff Physician to the Neurobehavioral Disorders Unit and the Brain Rehabilitation Program. George received his medical degree from the University of Connecticut in 1983. He completed a Pediatric Residency at Children’s Hospital in Cincinnati in 1986, a Clinical Fellowship in Neurodevelopmental Pediatrics in 1988, and a Research Fellowship in Neurobiology at Johns Hopkins School of Medicine in 1990. He co-chairs the NDSC Professional Advisory Council and has been active in efforts to reach out to and serve families whose children have complex needs. Dr. Capone was appointed by the board of directors to fill an unexpired term.

Daniel Chaplin

Hi, I am Daniel Chaplin and I am 23 years old. I live with my mom and dad and my dog Bingo. I have an older brother who lives in California and an older sister who lives in Canada.

I have a job at Wiggins, Childs, Pantazis, Fisher & Goldfarb Advocates and Litigators. I pick up and deliver the mail, make copies, scan legal documents, send faxes, and I pick up and put away the dishes.

Outside of work I am a church lector at Prince of Peace in Hoover, Alabama; also I sing in the church choir. I enjoy Ballroom dancing and have competed in the past 2 years. I like to go bowling, participate in running races, play softball and basketball with the Exceptional Foundation in Homewood, Alabama. Also I am a big fan of Major League Baseball where my favorite team is the St. Louis Cardinals, and football fans of the St. Louis Rams and the Missouri Tigers. I also like to ride bikes and go swimming when I find enough time; and I like to go to Six Flags.

Finally, I want to say that I am a fun, loving, caring family member, and will work hard on being on the Board of Directors for the National Down Syndrome Congress. I will do everything I can to make sure that we really are More Alike Than Different.

Board of directors executive committee for 2014-15

Pictured left to right: Bret Bowerman, Vice President, Larchmont, NY; Lori McKee, Vice President, Dallas, TX; Marilyn Tolbert, President, Ft. Worth, TX; Shawn Hardister, Treasurer, Dunwoody, GA; Andy Bean, Vice President, Mentor, OH; Carole Guess, Vice President, Indianapolis, IN; Julie Harmon, Secretary, Colorado Springs, CO.
2014 Award Winners

Each year, the NDSC recognizes outstanding contributions to the Down syndrome community. We were proud to present the following awards in Indianapolis. ESPN’s Holly Rowe (pictured at right) was our enthusiastic Master of Ceremonies.

Down Syndrome Indiana was given our **Convention Service Award** for their hard work in supporting our 2014 “Setting the Pace” convention. It’s important that we also recognize the work they do in their community all year long as they connect families through active support groups, host recreational, social and fundraising events, and support the work of national Down syndrome organizations. Down Syndrome Indiana is dedicated to enhancing the lives of individuals from infancy through adulthood.

This year’s **National Media Award** was presented to HBO for their remarkable film, *The Crash Reel*. *The Crash Reel* follows champion snowboarder Kevin Pearce and the escalating rivalry between Kevin and his nemesis Shaun White in the run-up to the 2010 Olympics. While Shaun ended up on top of the Olympic podium, Kevin was left in a coma following a training accident in Park City, Utah. Kevin’s tight-knit Vermont family helps him rebuild his life as a brain injury survivor. Kevin’s close family relationship, which includes his brother David, who has Down syndrome, is a story that has touched us all.

Our **Education Award** went to Jen Greenstreet, CEO, Just Like You Films, Kansas City, Missouri. Since its debut, the film *Just Like You — Down Syndrome* has been a wonderful educational tool to educate and promote acceptance and inclusion of individuals with Down syndrome in the school community.

The **Exceptional Meritorious Service Award** was awarded to Bernie Veldman of South Bend, Indiana. His SureStep SMO system has revolutionized orthotic management for children with hypotonia, and has become the standard of care for children worldwide, including children with Down syndrome.

Our **Employer of the Year** is Walgreen’s Company, Deerfield, Illinois. Walgreens is responsible for exploring, designing and applying new systems to train staff, supervisors and upper management for inclusion of employees with disabilities. Their new goal is to fill more than 20% of its workforce with people with disabilities.

The **National Parent Group of the Year** is the Down Syndrome Association of Jacksonville. The DSA of Jacksonville is celebrating their 25th anniversary of serving individuals with Down syndrome and their families in a five-county area in and around Jacksonville, Florida. They make a real difference in their community year round, with social events, financial assistance for therapies; medical outreach; new parent outreach; and wellness and fitness programs, partnering with Weight Watchers, Inc. and local sports teams. The DSAJ also supports the On Campus Transition Program at the University of North Florida, where people with intellectual disabilities attend college and live in campus housing.

The **Sig Pueschel Service Award** (re-named this year to honor the late Sig Pueschel), was awarded to Jay Silverman, of Owings Mills, Maryland. Jay is the co-founder and past president of the Chesapeake Down Syndrome Parent Group, where he continues to serve on their Board of Directors, and is currently the treasurer. Jay has been a member of the National Down Syndrome Congress for 32 years,
since the birth of his daughter Melissa. He was a
member of the NDSC Board of Directors from 2000
to 2009, during which time he served as the Board’s
treasurer and vice president. Jay has been the “official”
photographer at the NDSC Convention for more years
than we can count. We are deeply grateful for the
countless volunteer hours Jay has devoted to the NDSC.

The Christian Pueschel Memorial Citizen this
year is Megan Layton of St. Louis, Missouri. Megan
works as a hostess at Massa’s Italian Restaurant, where
she gets to be herself: “friendly, nice and polite.” She
lives independently, and volunteers at the DSA of
Greater St. Louis. Megan loves to write, work on the
computer, and be creative through arts and crafts. She
loves music and dancing, having fun, and hanging out
with her family and friends.

The Pueschel-Tjossem
Research Award was
presented this year to
Dr. Marilyn Bull,
Indianapolis, Indiana.
Dr. Bull has served on the
faculty at the Indiana
University Medical Center
since 1976, where she
currently is the Morris
Green Professor of
Pediatrics at Riley Hospital for Children at IU Health.
Dr. Bull represents the American Academy of Pediatrics
on the NIH Down Syndrome Consortium and the
Board of Directors of the Down Syndrome Medical
Interest Group. Dr. Bull most recently led the way
through research and clinical work to develop and
publicize guidelines for the healthcare for individuals
with Down syndrome.

NDSC President Jim Faber presented two
President’s Awards this year.

Yvonne Maddox (pictured above, second from left)
of Bethesda, Maryland deserves this honor for her
tireless work advocating for the health needs of
underserved populations. Dr. Maddox’s work gave birth
to the National Institutes of Health Down Syndrome
Consortium, as well as DS Connect: The Down
Syndrome Registry for our families. Dr. Maddox is the
Acting Director of the National Institute on Minority
Health and Health Disparities (NIMHD).

She has also served as the Acting Deputy Director of
the NIH and the Deputy Director of the Eunice
Kennedy Shriver National Institute of Child Health and
Human Development (NICHD).

Patti Saylor (pictured, third from left), New Market,
Maryland, has been an advocate for most of her life,
and continues to advocate tirelessly on behalf of her
late son, Ethan. Following his tragic death eighteen
months ago, Patti has dedicated herself to advocate
“Justice for Ethan.” Patti continues to fight fearlessly at
the federal, state and local levels of government to
ensure what happened to Ethan never happens to
another member of the Down syndrome or disability community
again. In large response to Ethan’s senseless death, the governor of
Maryland established the Commission for Effective
Community Inclusion of People
with Intellectual Disabilities. In
addition, Patti along with other
dedicated advocates in the state of
Maryland are spearheading an
effort to pass “Ethan’s Law” which they hope to have
introduced in this fall’s legislative session in Annapolis.

In grateful appreciation for their years of service to the
NDSC, Board Service Awards were presented to
retiring board members, Jose Florez of Boston,
Massachusetts, Martine Hobson of Germantown,
Tennessee, Brooks Robinson, Jr. of Pittsburgh,
Pennsylvania, and Tony Piontek of New Iberia,
Louisiana. It’s always hard to say good bye to our Self
Advocate Board Members, but the good news is they
become lifetime members of our Self Advocate
Council. Tony’s service on the board can be summed
up by his ‘big ideas’. Tony is never shy in sharing his
passion or his vision—it has been a pleasure for this
board to feel his influence.
Call For Convention Speakers

While we’d love to keep celebrating the great time we had in Indianapolis, we are already hard at work planning for next summer’s convention in Phoenix. We’ll be heading Beyond All Limits June 25th through the 28th at the JW Marriott Desert Ridge. We are accepting speaker proposals now!

**GENERAL CONVENTION**

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

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

Workshop proposals are being accepted on our convention website at http://convention.ndscenter.org/, so please pass this information along to everyone you know that might be interested.

**YOUTH AND ADULTS PROGRAM**

Our self advocate attendees enjoy interactive workshops that get people moving, thinking, learning, and having fun. If you are a self advocate (or you know a self advocate) who is knowledgeable on a topic that others will find interesting, this is the place to share what you know with your peers in a workshop or panel presentation.

Successful speakers in the past have presented on topics such as acting, cooking, swing dancing, blogging, finances and pretty much everything in between. Are you an artist or photographer? Share your creativity! Do you volunteer in your community? Tell your friends how they can get involved in their hometowns. An expert at cake decorating? Share your skills! You can find more ideas on our convention website: http://convention.ndscenter.org/.

Discuss your ideas with someone you like to work with. Friends, parents, siblings, coaches and teachers all make good partners. Then just fill out the easy-to-complete speaker proposal form on our website. If you have questions, contact Jean Beck at Jean@ndscenter.org.
Self Advocate Delegation Meets in Indy

On Friday, July 11, 2014, this year’s “Self Advocate Delegation” met to learn and share with other self advocates and with the NDSC’s Self Advocate Council (SAC.) The Delegation was formed to better connect members of our SAC with delegates from local Down Syndrome Associations around the country.

The SAC, which is made up of the three self advocates currently serving on the NDSC board and sixteen past board members, meets annually during the convention to brainstorm ideas and set goals for the coming year. By adding the delegate meeting, we have created a way to spread information to self advocates everywhere. Each DSA is allowed to nominate two self advocates from their area to represent them at the delegate meeting. This year, delegates were asked to introduce themselves and then place a star on their home state on a map of the United States.

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

For example, Tony Piontek from New Iberia, Louisiana, shared that he has been working on getting a Down syndrome stamp approved by the United States Postal Service. He is pursuing the possibility of creating a custom stamp that would be available for purchase at next year’s convention! We invite self advocates to submit their original designs to the NDSC so that one can be selected. Please send your design or design ideas to:

National Down Syndrome Congress
30 Mansell Court, Suite 108
Roswell, GA 30338

Or by email to info@ndsccenter.org

Also at this year’s delegate meeting, Jessica Smart and Laurie Hobson from the Down Syndrome Association of Memphis and the Mid-South presented a power point about their organization’s new self-advocate project.

NDSC’s Director of Development, Rebecca Davis, talked about the “321 Dance” and how to bring one to your community. If you have questions about 321 Dance, please contact Rebecca at 800-232-6372.
With your help, this year’s 321 Dance!™ at the Indianapolis convention raised $37,617 (150% of our goal of $25,000)! The dance itself was a blast with Radio Disney leading the fun.

Congratulations to our top individual fundraiser Bruce Bennett, whose “Make Me Dance” campaign raised over $17,500! Each time Bruce’s fundraising campaign reached a new milestone, he posted a video on YouTube of his own unique dance style. Many of his friends made requests “How about the Hokey Pokey?” or the “Bunny Hop?” they would ask. Over the course of several weeks, he did the Twist, the Moonwalk, and the Funky Chicken (among others).

Jenny’s Jubilant Dancers — Jenny Stone and her aunt, Marilyn Tolbert — were the winners of the 4 one-day Park Hopper passes to Walt Disney World. Everyone who raised $250 or more was entered into a drawing for the Disney tickets, graciously donated by Disney.

If you missed the chance to participate in Indianapolis, there will be several more opportunities, including a 321 Dance!™ at next year’s convention in Phoenix!

Many Thanks to our 321 Dance!™ Sponsors!

On August 23rd, the NDSC partnered with Camp Glisson in Dahlonega, GA, to host a 321 Dance!™ For more than 42 years, Camp Glisson has been the home to a special needs camping program that each year serves many Self Advocates with Down syndrome. NDSC and Camp Glisson are very grateful for the Dahlonega dance sponsors:
New Book Based on Self Advocate’s Life

by Meredith Martin

Attending the annual NDSC conventions each summer is a highlight of my year. This year’s conference in Indianapolis was no different. However, thanks to the idea and energy of a special friend from my hometown, Indianapolis held a little extra excitement for me.

A little over a year ago, I was asked to share my journey of establishing my independent living experience with the Down Syndrome Association for Families in Lincoln, Nebraska. In order to create a more effective PowerPoint to go with my presentation, we called on a friend and local media specialist. Gloria Christiansen stepped up to the task. Gloria, a master of big dreams, suggested we have the information put into a book so that more people could know my story. She took it from there and used her knowledge and connections to accomplish the dream. After obtaining permission for printing pictures and some editing and more careful wording on some of the script, the book was published the week before our trip to Indianapolis.

My *ABC Building Blocks for Growing Up with Down Syndrome* is the story of my independent living “building project.” It is my hope that my story will inspire and motivate self-advocates and their families to dream big and set their sights on reaching as much independence as possible. In the book I have highlighted the joys and challenges of achieving independent living. My objective is to spark ideas, help you dream, establish a blueprint and anticipate success for the future. There are ideas for starting at a young age or even if the self-advocate is older.

Anyone who is interested in copies or information may send inquiries to Gloria Christiansen at airolg508@gmail.com. Please include *ABC Booklet for Down Syndrome* in the subject line. Or, you can contact her by mail at 602 “N” Street, Neligh, NE 68756.

One of the biggest lessons we have learned from this publishing experience is that others in the community are there for us, too. I have had many dreams and goals that I have accomplished. Publishing a book was a huge surprise and one that probably would not have been accomplished without the help of my friend, Gloria.

Watch our Convention Video on YouTube!

Even after you read all about our convention, it can be hard to imagine what it's really like, until you've experienced it in person. Now, you can visit our YouTube Channel and get a true picture of the joy and camaraderie experienced each year!

As one attendee wrote, “Beyond the family connections and incredible seminars are the lifelong friendships of our DS community. This conference is like no other...and I’m so thankful for every second that all of those dedicate to the tireless work to make it simply the best!!” We hope you'll get to join us at our next “giant family reunion”!

https://www.youtube.com/NDSCCENTER
Down Syndrome News is a benefit of your annual membership in the National Down Syndrome Congress. To renew or join today, visit ndsccenter.org or call 1-800-232-NDSC (6372).

43rd Annual NDSC Convention
June 25–28, 2015 • Phoenix, Arizona

Join us next summer for our Giant Family Reunion in Phoenix, the Gateway to the Grand Canyon! This spectacular location provides a unique opportunity to combine learning with a breath-taking vacation.

The NDSC Convention is: more than 60 topic-specific workshops, inspiring plenary sessions, social events, networking, dances, exhibitors, a film festival, sharing sessions, and so much more!

Visit www.convention.ndsccenter.org often to view our growing schedule of activities.

Our block of rooms at the JW Marriott Desert Ridge will also open in March, 2015.

CONTACT:
800-232-6372 / 770-604-9500
info@ndsccenter.org
www.convention.ndsccenter.org

www.NDSCCenter.org