



PRE-CONFERENCE A

Advocacy Boot Camp: Producing Effective Federal, State, and Local Advocates

We all want a better world for people with Down syndrome, but how can we make that happen? This session will prepare attendees to effectively advocate for meaningful change from City Hall to the Halls of Congress. Session leaders will cover how to develop "asks" and what is needed to gain support for those asks. They will identify how to find state-specific policy information and provide case studies of successful statewide coalitions. In addition, attendees will learn how to define roles for self-advocates and prepare them to become effective voices for change.

The session will be lead by NDSC's Governmental Affairs Director, ***Susan Goodman*** and Senior Policy Advisor, ***Ricki Sabia***. They will be joined by national and local advocates, ***Michelle Livingston, Patti Saylor, Joe Meares, Angela Jarvis-Holland, Stephanie Smith Lee, Julie Harmon, J.J. Rico*** as well as self-advocates, ***Daniel Chaplin and Tony Piontek***.

Objectives:

- Participants will learn how to advocate for change at the federal, state, and local level.
- Participants will learn how to be effective advocates, including how to develop "asks" and what is needed to support those requests.
- Participants will learn how to create roles and provide support for self-advocates.
- Participants will learn about models for statewide coalitions.
- Participants will learn how to find state-specific policy information and partners for collaboration.

Agenda:

I. OVERVIEW OF LEGISLATIVE AGENDA AND PRIORITIES

A. Areas in which we are advocating

- 1. Employment and Long Term Support Services: Susan Goodman, National Down Syndrome Congress**
- 2. Education: Ricki Sabia, National Down Syndrome Congress**
- 3. Research: Michelle Livingston, Global Down Syndrome Foundation**

B. Questions

II. SELF-ADVOCATES ROLE IN ADVOCACY

A. Daniel Chaplin, Self-Advocate, Indian Springs, AL

B. Tony Piontek, Self-Advocate, New Liberia, LA

III. CASE STUDIES OF STATEWIDE COALITIONS

A. How each got started/training

B. Collaboration with other state/local organizations

C. How they support the self-advocate role

D. Some accomplishments

- 1. Maryland Down syndrome Advocacy Coalition: Patti Saylor**
- 2. Dads Appreciating Down Syndrome: Joe Meares**
- 3. Northwest Down Syndrome Association: Angela Jarvis-Holland**

IV. EFFECTIVE ADVOCACY: Stephanie Smith Lee

A. Tips for successful advocacy (including social media and developing "Asks")

B. Questions

V. HOW TO FIND STATE SPECIFIC INFORMATION AND PARTNERS

A. National Down Syndrome Congress: Ricki Sabia

B. PEAK Parent Center and Colorado Springs Down Syndrome Association: Julie Harmon

B. Arizona Disability Law Center: J.J. Rico

C. Questions

About the Speakers:



As Director of Governmental Affairs, **Susan Goodman** is the National Down Syndrome Congress representative in Washington, DC where she advocates for individuals with Down syndrome as well as people with all manner of disabilities and their families. Susan earned her Jurist Doctorate from St. Louis University School of Law. She began her advocacy for all children with disabilities in 1975, upon passage of the Individuals with Disabilities Education Act and has authored various articles about disability, advocacy and assistive technology. She is married with three children, one of whom has autism.



Ricki Sabia has worked for over two decades as an advocate on the Federal, state and local levels for individuals with Down syndrome and other disabilities, with an emphasis on education policy. Her son, Steve, was born with Down syndrome in 1992. Currently, Ricki is a Senior Policy Advisor for the National Down Syndrome Congress and the Technical Assistance and Parent Training Specialist for the National Center and State Collaborative (NCSC). NCSC is a collaboration between 24 states and five national centers to develop a new alternate assessment, as well as professional development and curriculum and instructional resources for students with significant cognitive disabilities. Currently, Ricki also serves as a Board member for the Down Syndrome Network of Montgomery County and is a member of the Maryland Down syndrome Advocacy Coalition. Ricki also was the Associate Director of the NDSS Policy Center from 2002-2013 and served as an advisor on numerous federally funded education projects. In addition, she founded the National Universal Design for Learning Task Force, a coalition of 45 general, special and higher education advocacy organizations, as well as chaired that task force for six years.



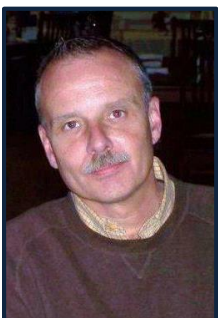
Michelle Livingston is the Director of Operations and Government Affairs at the Global Down Syndrome Foundation. The Foundation is dedicated to significantly improving the lives of people with Down syndrome (DS) through Research, Medical Care, Education, and Advocacy. A primary focus is supporting the Linda Crnic Institute for Down Syndrome, the first academic home for DS in the United States. Michelle started manages the operations and government affair work of the Foundation, and assisted with launching the Foundation's joint initiative with the National Institutes of Health – "Down Syndrome: National Conference on Patient Registries, Research Databases and Biobanks," which has ultimately led NICHD to the establishment of the First National Down syndrome patient registry. She is a member of the NICHD's National Down Syndrome Consortium.



Patti Saylor is the proud mother of three young adult children, Emma, Adam and the late Ethan Saylor. She has been an advocate for most of her life. In 1987, shortly after Ethan was born Patti founded F.R.I.E.N.D.S, The Family Resource Information and Education Network for Down syndrome, a parent support network in Frederick, Maryland which continues today. She went on to become a registered nurse and eventually earned a Master's Degree in Special Education from Johns Hopkins University.

Patti has served on the Maryland Developmental Disabilities Council, co-founded The Parent's Place of Western Maryland and was instrumental in creating inclusive education opportunities for children with Down syndrome in Frederick County. She is also a member of the Maryland Down syndrome Advocacy Coalition (MDAC). Patti is currently the owner of Health Link LLC. Patti and her nurses provide nursing case management and advocacy for adults with disabilities who choose to live in their own homes and self-direct their own services with the support of the significant people in their lives.

Patti and her family were and continue to be tireless advocates for their beloved Ethan. They supported him to follow his dreams and live the life he wanted, a life of love and acceptance. Following his tragic death in January 2013, Patti has dedicated herself to advocate justice for Ethan. In large response to Ethan's senseless death, Governor O'Malley of Maryland issued an executive order establishing the Commission for Effective Community Inclusion of People with Intellectual Disabilities. In addition, Patti collaborated with other members of the advocacy community in Maryland to establish mandatory training for law enforcement regarding interacting with people with Intellectual and Developmental Disabilities. She also worked tirelessly with advocates and legislators in the successful passing of a law establishing The Ethan Saylor Alliance for Self Advocates as Educators. Self Advocates are now recognized by the State of Maryland as significant contributing Co-Trainers in the training of law enforcement and other public sector employees. Patti supports the work of NDSC, serves on the Board of NDSS, the Advisory Board of the IDSC and The Advisory Board of The National Center on Criminal Justice and Disability, a program of The ARC US.



Joe Meares has been married for 25 years and has 4 daughters including Peyton, age 17, who has Down syndrome. Joe is the Founder of Dads Appreciating Down Syndrome (D.A.D.S.), Chair of D.A.D.S. National and past president of Down Syndrome Affiliates in Action. He is also an NDSS Ambassador for the 5th Congressional district in Indiana and a frequent speaker at D.A.D.S. meetings around the US and state/regional and national conferences on advocacy and Down syndrome organization leadership.



Angela Jarvis-Holland, Executive Director, has a Master's in Youth and Community Change and Non-Profit Management and is also a certified nurse specializing in community wellness. She became NWDSA's first executive director in 2008 after seven years of volunteering half-time to build the organization's capacity, leadership, and vision. Angela spearheaded the creation of NWDSA's sister project All Born (In), a cross-disability movement in pursuit of an inclusive civil society and the All Born (In) Conference, now in its 10th year. Angela is also on the board of Disability Rights Oregon. She has worked with them on seclusion and restraint issues and they are taking the lead on the sheltered workshop lawsuit in Oregon. She is past director of Kelly Community House (Lutheran Family Services) and Westminster Youth Service. Angela has two children, one of whom has Down syndrome. During Angela's tenure at NWDSA, our work has been recognized for excellence. In 2005, NWDSA was awarded the OCDD Community Partnership Award for the birth-5 Reciprocal Learning Community and in 2008, the All Born (In) Photo Awareness Campaign received OCDD's Media Award. Angela was a 2008 Person of the Year by the Arc of Clackamas and Multnomah Counties.



Stephanie Smith Lee has over thirty years of experience in public policy, including serving in senior Congressional staff positions and as a nationally recognized disability expert. Since her daughter, Laura, was born with Down syndrome in 1982, she has led many successful disability advocacy efforts at the local, state, and Federal levels and served as Vice President of the National Down Syndrome Congress in the mid-1990s. As the Director of the Office of Special Education Programs (OSEP) in the US Department of Education, from 2002 through March 2005, Ms. Lee was responsible for the implementation of IDEA, the Federal special education law. As Senior Policy Advisor for the National Down Syndrome Society's Policy Center from 2005 through 2012, she developed and trained an effective grassroots, advocated with Congress, and directed the Riggio Postsecondary Education and Transition Project. Ms. Lee was directly involved in developing postsecondary projects for students with intellectual disabilities in various states and led a successful effort to obtain financial aid for these students. She offers technical assistance to parents, educators, and institutions of higher education on how to develop and implement high quality inclusive opportunities for students with intellectual disabilities and speaks frequently at state and national conferences. She is chair of the Think College Accreditation Workgroup that is developing model accreditation standards for these programs and Chair of the Working Group on Postsecondary Education and Students with Intellectual Disabilities.



Julie Harmon lives in Colorado Springs and is the proud parent of two sons with Down syndrome. Julie is the Director of Parent Services for PEAK Parent Center and a Board Member for the Colorado Springs Down Syndrome Association and the National Down Syndrome Congress. Her oldest son, Nick, attended college at the University of Colorado, Colorado Springs and is now a co-teacher for the Intro to Special Education course for General Education teachers. Julie's youngest son, Noah, is in middle school and enjoys all that life brings for him. Julie advocates for inclusion for people with disabilities in all aspects of life to someday realize a world with equal rights and opportunities for everyone.



J.J. Rico is the Executive Director at the Arizona Center for Disability Law which is the protection and advocacy agency in Arizona, providing free legal services to people with disabilities. J.J. joined the Center following his graduation from the University of Arizona College of Law. Prior to becoming the Executive Director, J.J. worked as ACDL's Litigation Director and as a staff attorney. His legal work primarily focused on the employment and access provisions of the Americans with Disabilities Act. J.J. has represented individuals with disabilities before both State and Federal Courts and administrative agencies such as the Equal Employment Opportunity Commission and the Arizona Attorney General's Civil Rights Division. He provides numerous presentations to people with disabilities and advocacy groups about the Americans with Disabilities Act and how its titles applies to their lives and to promote self advocacy.



Tony Piontek has been a public speaker, since graduating from high school, on the many interesting experiences and achievements in his life. As an Eagle Scout and an Assistant Scoutmaster in a Troop, he teaches at the University of Scouting and presents at workshops. He has represented Louisiana Special Olympics at press conferences and at the International World Games as an athlete and as an Official in Aquatics. He is currently a Global Messenger for Special Olympics. In his role as a strong self-advocate, Tony speaks on these topics: Not Giving Up, Volunteerism, Attitudes, Education and Independence. Tony has recently been selected to sit on the Global Down Syndrome Foundation Adults with Down Syndrome Task Force and looks forward to being a voice for advocacy there. Tony has been employed by Lowe's Home Improvement for four years. He is also following his dream by volunteering in a fine restaurant, under the watchful eye of a great Cajun Chef, to gain culinary skills.



Daniel Chaplin is 24 years old and lives with his dog Bingo, and with his parents. He is currently working at Wiggins, Childs, Pantazis, Fisher and Goldfarb Advocates and Litigators law firm as the mailman. Also, he picks up and puts away the dishes, completes copy jobs, scans paperwork and faxes. He enjoys playing basketball, competing in running races, playing softball, bowling, going to movies, and hanging out at night. He has a brother who lives in Los Angeles, and a sister who lives in Canada. His brother recently became a father to Daniel's niece, whose name is June. Finally, he really enjoys being on the NDSC Self-Advocate Council and on the NDSC Board of Directors.