

KEYNOTE SPEAKERS

Friday, July 31 – 6:30 – 7:45 pm
Opening General Session



***We're More Alike Than Different: Self Advocates
Speak to the Nation***

Sue Joe, NDSC Resource Specialist
Carlene Mattson, NDSC 2nd Vice President
Lee Jones, Self Advocate
Karen Gaffney, Self Advocate
Meredith Martin, Self Advocate

Saturday, August 1 – 8:30 – 10:00 am
General Session

Claire Pomeroy, M.D., M.B.A.,
Vice Chancellor for Human Health Sciences, University of California Davis, Dean, UC Davis
Medical School, Sacramento, CA

Rosario Marin

Former Treasurer of the United States, author, *Leading Between Two Worlds*, mother of a son
with DS, Huntington Park, CA

Eleanor Bailey

Community Advocate, Student, Portland State University Transition Program, Portland, OR

Saturday, August 1 – 3:30 – 4:45 pm
General Session

Barbara Ransom, J.D., Senior Attorney, Disability Rights California, Sacramento, CA

Wayne Godwin, Executive Council to the President and Immediate Past COO, PBS, father of a
daughter with DS, Alexandria, VA

Christi Hockel, Self Advocate, Courtesy Clerk, Safeway, Walnut Creek, CA

Sunday, August 2 – 8:30 – 9:30 am
Closing General Session

William C. Mobley, M.D., Ph.D., Professor and Chair of Neuroscience, University of California,
San Diego, CA

WORKSHOPS – SATURDAY, AUGUST 1

10:30 am – Noon

**Workshop will be repeated at 1:30pm*

- *#1 What Your Other Children Without DS Are Thinking: Lessons from Brothers & Sisters**
Brian Skotko, M.D., M.P.P., Children's Hospital of Boston, Boston Medical Center, and Susan P. Levine, M.A.C.S.W., Family Resource Associates, Shrewsbury, NJ
- *#2 Math Doesn't Have to be a Drag: Tips & Tricks for Making Math Meaningful and Fun**
Dana L. Halle, J.D., Down Syndrome Foundation of Orange County, Irvine, CA
- *#3 Meaningful Inclusion and Participation in General Education**
Kathy Gee, Ph.D., Professor of Special Education, Sacramento State University, Faculty Member, Center for Excellence in Developmental Disabilities, M.I.N.D. Institute, UC Davis
- *#4 Community Inclusion Empowerment, Assisting People with Disabilities to Control their Housing and Individual Support Funding**
Joe Wykowski, Executive Director, Community Vision and Founder of the Homeownership Empowerment Program, Portland, OR
- *#5 Behavior and Communication: Promoting Positive Behavior Change**
Scott Shepard, Director of Avenues Supported Living Services, Professor CSU Northridge, Cal-TASH Board Member, Valencia, CA
- *#6 Improving Feeding Skills and Speech Clarity Using Oral-Motor Therapy**
Sara Rosenfeld-Johnson, M.S., C.C.C.-S.L.P., Innovative Therapists International, Talk Tools Therapy, Tucson, AZ
- #7 A Land of Opportunity: Increasing Diversity within Your Organization (Repeating on Sunday)**
Carole Guess and Roscoe Scott
- #8 Special Needs Trusts As an Advocacy Tool**
Stephen W Dale, Attorney at Law, Stephen Dale Law Firm, Member of Special Needs Alliance; Uncle of a Niece with DS, Walnut Creek, CA
- #9 Growing Up and Growing Older: Mental and Physical Wellness in Adults with DS**
Dennis McGuire, Ph.D., Director of Psychosocial Services, The Adult Down Syndrome Center of Lutheran General Hospital, Park Ridge, IL
- #10 Planning for Adult Communication Needs and Skills During the School Years**
Libby Kumin, Ph.D., C.C.C.-S.L.P., Founder of the Down Syndrome Speech and Language Center for Excellence at Loyola College, Columbia, MD
- #11 Volunteering and Service: Meaningful Opportunities to Foster Community, Independence and Develop Skills**
Jason Wheeler, Senior Program Manager, UMass Boston/Institute for Community Inclusion, Boston, MA
- #12 Gross Motor Development in Children with DS: Post Walking Skills**
Patricia C Winders, P.T., The Children's Hospital, Denver, CO
- #13 DS Cognition Research: "Unprecedented" Progress and Promising New Therapeutic Strategies and Opportunities**
Michael Harpold, Ph.D., Chief Executive Officer, Down Syndrome Research and Treatment Foundation, Palo Alto, CA
- #14 Dual Diagnosis: Neurobehavioral Disorders In Children**
George Capone, M.D., Kennedy Krieger Institute, Assistant Professor of Pediatrics, Johns Hopkins University School of Medicine, NDSC Board Member, Baltimore, MD
- #15 Making Therapy Work for you and your Child: The Role of Therapy Across the Lifespan**
Jennifer Meyers Bekins, MS, CCC – SLP, Katherine Frank, MHS, OTRL and Stacey Maignan, MPT, Thomas Center for DS, Cincinnati Children's Hospital, Cincinnati, OH
- #16 How Current Congressional Activity and Federal Legislation Affect You**
Susan Goodman, J.D., Director of Governmental Affairs, NDSC & Ricki Sabia, Associate Director, NDSS Policy Center
- #17 A Brave New World? Prenatal Testing & DS**
Mark Leach, J.D., Board Member, Down Syndrome of Louisville, father of a daughter with DS, Louisville, KY
- #18 Soñando en Español por Nuestros Hijos**
Rosario Marín, ex-tesorera de los Estados Unidos
- #19 Film Festival Screening - *Strong Love***

WORKSHOPS – SATURDAY, AUGUST 1

1:30 – 3:00 pm

- #20 We're An Important Two and We're Important Too!: Nourishing Your Relationship While Parenting a Child with Special Needs**
Renee Schulz, LMFT, Westhampton, MA
- #21 Gross Motor Development in Children with DS: Birth through Walking**
Patricia C Winders, P.T., The Children's Hospital, Denver, CO
- #22 Free From Gluten: Full of Flavor (and Choices!)**
Joan Medlen, RD, LD, author of the Down Syndrome Nutrition Handbook, Mother of a Son with DS, Portland, OR
- #23 Open Your Gifts: Sharing the Riches of Parenting A Child with DS**
Kathryn Lynard Soper, Editor and Contributing Author, Gifts, Mother of a Son with DS, Salt Lake City, UT
- #24 Sing, Play and Learn! Handwriting Development for Early Learning Success**
Diane Eldridge, RN, COTA, Handwriting Without Tears, Manassas, VA
- #25 Employment for All: What You Need to Know About Supported and Customized Employment**
Robert A. Lawhead, Executive Director, Employment Link and Director of Colorado's SEARCH Initiative, Boulder, CO
- #26 Dual Diagnosis: Neurobehavioral Disorders In Adolescents & Adults**
George Capone, M.D., Kennedy Krieger Institute, Assistant Professor of Pediatrics, Johns Hopkins University School of Medicine, NDSC Board Member, Baltimore, MD
- #27 Building Inclusive Friendships**
Jenni Newbury, Josh Stein, Jason Toff, Co-founders, CampPals, and Jason Newbury, Self Advocate and Camper
- #28 Reading Made Easy for Learners with DS**
Natalie Hale, President and Founder, Special Reads for Special Needs, Los Gatos, CA
- #29 Universal Design for Learning: Meaningful Access to the Curriculum for All Students**
Ricki Sabia, Associate Director, NDSS Policy Center
- #30 Down Syndrome - A Global Perspective**
Frank Buckley, Chief Executive, Down Syndrome Education International, CEO/President, Down Syndrome Education USA
- #31 Support Networks for African American Families including: Ministry, Child Care & School Services**
Pastors Melvin and Victoria William, Temple of Faith New Testament Church; George and Alyce Taylor, God's Little People Child Care; Deborah Abraham and Teri Kendle, DSIA; Tonia Ferguson, J.D. and Viviana Fernandez, NDSC Board Members
- #32 Film Festival Screening**
Down in Number 5 (Rated R for language and subject matter.)
Elmont
Jeftown

WORKSHOPS – SUNDAY, AUGUST 2

10:00 – 11:30 am

**Workshop will be repeated at 12:00pm*

- *#33 Teaching Children with DS to Read: From Research to Practice across the Age Range**
Sue Buckley, O.B.E., Director of Science and Research/Chief Scientist, Down Syndrome Educational International, UK
- *#34 Music Therapy for Children with DS**
Bessie Barth, MT-BC, NMT, Music to Grow On, Sacramento, CA
- *#35 Why Not College? Start Planning Now**
Eric Latham, Executive Director, Pathway, UCLA Extension, Wilbert Francis, MBA, Director, Open the Doors to College, Tarjan Center, UCLA and Ricki Sabia, Associate Director, NDSS Policy Center
- *#36 Comprehensive Special Needs Planning – Life, Resource, Financial and Legal**
Hal Wright, CFP, Colorado Financial Partners, LLC, Father of a son with DS, Greenwood Village, CO
- #37 Issues and Concerns During Pubescence**
Terri Couwenhoven, M.S., AASECT, Sexuality Educator and Consultant, Clinic Coordinator, CHW – Down Syndrome Clinic of Wisconsin, Milwaukee, WI
- #38 School Behavior: Medication, Communication and IEP's**
Philip Mattheis, M.D., Jennifer Meyers Bekins, M.S., CCC – SLP, Gretchen Carroll, Education Consultant, Thomas Center for DS, Cincinnati Children's Hospital, Cincinnati, OH
- #39 The Importance of Optimal Sensory Functions with Focus on Vision and Hearing in Persons with DS**
Siegfried Pueschel, M.D., Ph.D., J.D., M.P.H., Professor of Pediatrics
- #40 Setting them Free to Live Healthfully: Crafting Strategies for Healthful Eating for Teens and Adults with DS**
Joan Guthrie Medlen, R.D., L.D., author of the Down Syndrome Nutrition Handbook, Portland, OR
- #41 Prenatal Screening: The Canadian Experience**
Krista J. Flint, Executive Director, Canadian Down Syndrome Society
- #42 Creating a Collaborative Environment**
Kathy Everett, M.A., Education Consultant, Mother of a Daughter with DS, Atlanta, GA
- #43 Genetic Counseling for DS — Meeting the Informational Needs of Parents**
Katie Sheets, M.S., Genetic Counselor, University of South Carolina, Columbia, SC
- #44 Speech & Language Skills: Birth to Three-Word Phrases**
Libby Kumin, Ph.D., C.C.C.-S.L.P., Founder of the Down Syndrome Speech and Language Center for Excellence at Loyola College, Columbia, MD
- #45 Behavioral Restraint and Seclusion: Overview and Current National Reform Initiatives**
Leslie Morrison, MS, RN, JD, and Ricardo Jauregui, Sr. Investigator, both from Disability Rights California
- #46 5 Secrets of Effective Parents**
Scott Hammond, CEO, Become a Better Father.com and father of a son with DS and Autism, McKinleyville, CA
- #47 How to Help Adolescents and Adults with DS Achieve New Gross Motor Skills**
Helen Milligan, MPT, Children's Hospital of Philadelphia, mother of a son with DS, Philadelphia, PA
- #48 Keeping Your Child's Emotional Tank Full**
Nina Fuller, Director, SMILE on Down Syndrome, author, Special Strengths for Special Parents
- #49 Supporting Higher Math: Songs, Stories, Games and More**
Linda Chan Rapp, M.A. and Eden Rapp, Self Advocate, Torrance, CA
- #50 Film Festival Screening – Spanish Language Films**

La vida con síndrome de Down

Yo puedo (empleo con apoyo)

Paco de La Fuente

Sé que puedo, tú puedes?

WORKSHOPS – SUNDAY, AUGUST 2

12:00 – 1:30 pm

- #51 Fathers Only – Fun, Inspirational and Motivating Strategies to Becoming a Better Father**
Scott Hammond, CEO, Become a Better Father.com and father of a son with DS and Autism, McKinleyville, CA
- #52 A Land of Opportunity: Increasing Diversity within Your Organization**
Carole Guess and Roscoe Scott
- #53 Next Chapter Book Club: A Model Adult Literacy & Community Inclusion Program**
Tom Fish, Ph.D., Director of Social Work & Family Support Services, Ohio State University Nisonger Center on Disabilities, Columbus, OH
- #54 Chronic Breathing-Related Issues and Obstructive Sleep Apnea in DS**
Sanjay Jhawar, M.D., Associate Professor, Pediatric Pulmonary Division, UC Davis Medical Center, Sacramento, CA
- #55 Fitness Fun for EVERYone! Use the Joy Fitstix to Shake Up your Workout**
Karen Joy Allen, ACE and AFAA Certified Group Fitness Instructor/Personal Trainer, Applegate, CA
- #56 Personal Safety Skills, Self Determination and Abuse Awareness**
Stacey Hoffman and Susan Whaley, Directors, Safe Life Coalition, Sacramento, CA
- #57 Visual Tools and Strategies**
Patti McVay, M Ed, Special Education Director, Larkspur & Ross School Districts, Larkspur, CA
- #58 Cognitive and Brain Development in Down syndrome: What do we know?**
Susan Rivera, PhD, Associate Professor of Psychology, Center for Mind and Brain and the M.I.N.D. Institute, UC Davis, CA
- #59 Intercambio Latino**
Zoila Martínez, Coordinadora, NDSC
- #60 Strategies for Teaching and Supporting Healthy Sexuality**
Terri Couwenhoven, M.S., AASECT, Sexuality Educator and Consultant, Clinic Coordinator, CHW – Down Syndrome Clinic of Wisconsin, Milwaukee, WI
- #61 New Technology for Detecting DS: What Does the New Test Really Mean?**
Panelists:
*Susan Gammon, PhD, MBA, Director of Scientific Affairs, Prenatal Diagnostics for Sequenom, Inc.,
Frank Chervenak, MD, Professor, Chairman & Director of Maternal Fetal Medicine of the Dept of OBGYN at New York Presbyterian Hospital, Weill Medical College of Cornell University, New York, NY
George Capone, M.D., Kennedy Krieger Institute, Assistant Professor of Pediatrics, Johns Hopkins University School of Medicine, NDSC Board Member, Baltimore, MD
Laura Cifra-Bean, M.D., Pediatrician, NDSC Board Member
Campbell K. Brasington, MS, CGC, Board Certified Genetic Counselor, Levine Children's Hospital at Carolinas Medical Center, Dept Pediatrics, Clinical Genetics, Charlotte, NC*
Moderator:
David Tolleson, Executive Director, NDSC
- #62 Film Festival Screening - All these films are Rated R**
A Possible Dream: The Andrea Friedman Story
Reunion; Thirteen Worth Remembering

Workshop Schedule is Subject to Change!