



Presents

THE UP OF DOWN: AN INSIGHT INTO THE WORLD OF DOWN SYNDROME

A panel of experts in various fields, self-advocates, and family members touched by Down syndrome



Cecilia Barry
ACDS



Carolyn Cronin
DSRTF



Dr. James Dolan, Jr.
Alexander's Angels



Dr. Kathleen Feeley,
LIU Post, DSAF



Mike Hoffman
DSAF



Michael Kelly, Esq.
DSAF



Tania Laterza
Self Advocate



Anthony Providenti
DSRTF



Vinnie Santo
ACDS



Patricia White, M.D.
RDS

Monday, February 4, 2013

Briarcliffe College, Bethpage Campus

11:40 - 1:00 PM, Great Room (1 NH)

1055 Stewart Avenue, Bethpage 11714

Speakers: Barry, Baumer, Burke, Dolan, Hoffman

Moderator: Gómez-Nieto



Kristy Baumer
Self-Advocate

Thursday, February 7, 2013

St. Joseph College, Patchogue, Long Island

12:40 to 1:30 p.m., Shea Conference Room, O'Connor Building (1st Fl)

155 West Roe Blvd., Patchogue, NY 11772

Speakers: Dean, Erickson, Gómez-Nieto



Chris Burke
Actor, Self-Advocate

Wednesday, February 13, 2013

Briarcliffe College, Patchogue Campus

11:40 AM - 1:00 PM, Room 223

225 W. Main Street, Patchogue, NY 11772

Speakers: Gómez-Nieto, Laterza, Kelly, Providenti, Santo



Jack Dean
RDS

Wednesday, February 20, 2013

Briarcliffe College, Queens Campus

11:40 to 1:00 PM, Room Q4

30-30 Thomson Avenue, Long Island City, NY 11101

Speakers: Erickson, Gómez-Nieto, Hoffman, White



Kyle Erickson,
Self-Advocate

Monday, February 25, 2013

Long Island University — LIU Post

12:00 to 1:30 PM, Top of the Commons, Hillwood Commons

720 Northern Blvd, Brookville, NY 11548

Speakers: Burke, Cronin, Erickson, Feeley, Gómez-Nieto



Esther Gomez-Nieto
Alexander's Angels

Bios of panelists on back of flyer

Cecilia Barry, M.S., P.D., SBL/SDL has been at the **Association for Children with Down Syndrome (ACDS)** since 1984 in the capacity of School Psychologist, Director of Intake and Evaluation, and now Principal of ACDS. She received her Master of Science Degree and Professional Diploma in School Psychology from St. John's University and received her certificate in Educational Leadership from St. Rose College. Cecilia's professional training and experience have concentrated on early intervention and preschool special education. She also serves as a consultant to various school districts on Long Island providing curriculum, behavioral, resource and inclusionary modifications for children with special needs. Cecilia is a member of professional organizations and panels that advocate for children with developmental disabilities and their families.

Kristy Baumer, Self-Advocate. Kristy is a young woman with Down syndrome who is a graduate of Calhoun H.S. She is employed by ACDS, both in their preschool and daycare programs, as well as working in an administrative support role at the Center for Family Supports in Westbury. Her computer skills and use of her cell phone parallel her chronological age mates! She is an amazing young woman.

Chris Burke, Actor, Self-Advocate. When Chris was born with Down syndrome in New York City in August of 1965, the doctors advised his parents to put him in an institution. Not only they ignored that advice but treated Chris the same as his older brother and two sisters, a decision that led to a remarkable life and talent! Chris attended private school because of the lack of public education for children with Down syndrome and spent his summers in Long Island at a camp for children with disabilities. "Life Goes On" was created after Burke landed the role of a boy with Down syndrome on the ABC-TV movie, "Desperate". His work so impressed the network executives that the show's producer was asked to write a show with Chris in mind. The drama series "Life Goes On," aired on ABC from 1989-1993, earned Burke a **Golden Globe** nomination.

Carolyn Cronin (DSRTF) As the Executive Director of the **Down Syndrome Research and Treatment Foundation (DSRTF)**, Ms Cronin provides vision, leadership, strategic direction and administrative oversight to this organization dedicated to finding a treatment to improve cognition including learning, memory and speech for individuals with Down syndrome. Before coming to DSRTF, Cronin was President of the National Multiple Sclerosis Society (NMSS) for New York City – Southern New chapter, President and CEO of Accelerated Cure Project for MS, Executive Director at the Cystic Fibrosis Foundation, Greater Illinois Chapter. She also served in leadership positions at other non-profit organizations including Blindness America and the American Cancer Society. A native of Peru, Indiana, Ms. Cronin attended Ball State University. She completed the Fundraising Management Program at the Indiana University Center on Philanthropy and most recently was awarded a scholarship to participate in the Strategic Perspectives in Nonprofit Management Program at Harvard Business School.

Jack Dean, Executive VP with Re-Tron Technologies in Ridgefield, NJ and a **Research Down Syndrome (RDS)** Foundation Ambassador, is responsible for organizing many RDS fundraising activities in the NY/NJ area, and is also the father of an adult son with Down syndrome. His presentation describes the general makeup of the DS community, his experience with raising a DS child and the breakthrough research that will change their lives. He goes through his journey from his son's birth to where he is today and what his family has had to go through to adjust to his life.

James Dolan, Jr., Alexander's Angels Vice Treasurer. James R. Dolan, Jr. is a doctor of social work with over thirty years of experience in delivering and overseeing the provision of care to those with mental health concerns, chemical dependency disorders and developmental disabilities. In addition, he worked a number of years with child protective services, and was an adjunct professor at the Adelphi University School of Social Work. He is currently the Director of the Nassau County Department of Mental Health, Chemical Dependency and Developmental Disabilities Services, and he continues to function as a practitioner in his private psychotherapy practice. Dr. Dolan has a daughter with Down syndrome.

Kyle Erickson, Self Advocate, is an alumnus of the North Shore Schools. He was the first student in his school district to be fully included in regular education with a one-to-one aide and a modified curriculum. Kyle graduated in 2008 with an IEP diploma earning the yearbook attribute "The Most Spirited" from his classmates as well as the *Peer Achievement Award* from the National Honor Society. Following graduation, Kyle began an internship with AXA Equitable in their corporate mail room with the support of a job coach. In January of 2010, Kyle's dream came true and he was hired by AXA and currently works independently three days a week. Kyle is extremely proud of his corporate position and is fortunate to work with a wonderful group of people. Last year Kyle became involved with Alexander's Angels as a panelist for the presentation "The Up of Down: An Insight into the World of Down Syndrome." He enjoys participating as a self-advocate as well as advocating for others with Down syndrome and other disabilities. In Kyle's spare time, Kyle has enjoyed acting in numerous musical theater productions and singing in the church choir. He loves to swim and has participated in Special Olympics.

Dr. Kathleen M. Feeley, PhD is an Associate Professor at LIU Post and the founding director of the Center for Community Inclusion (whose mission is to enhance inclusive opportunities for individuals with disabilities in schools, communities, places of leisure and residence, and the work place). Dr. Feeley has published several studies on the use of behavior analytic interventions to address early developing communication skills in children with autism and children with Down syndrome and she currently provides technical assistance to several school districts as they provide inclusive services to children with Down syndrome. Dr. Feeley is also the Director of the NYS funded Long Island Parent Center and has recently established, with her Colleague Dr. Evelyn Castro from LIU Brooklyn, the NYC Parent Academy. Dr. Feeley is also a member of the **Down Syndrome Advocacy Foundation (DSAF)**.

Esther Gómez-Nieto, Alexander's Angels President. Eleven year-old Alexander who has Down syndrome is one of Esther's ten grandchildren. Upon her retirement in 2006, Esther was instrumental in the establishment of Alexander's Angels, Inc, a 501(c)(3) all-volunteer organization responsible for organizing a Buddy Walk® in L.I; establishing the symposium *The Up of Down: An Insight Into the World of Down Syndrome*; as well as DOWNrightART, exhibits of the works of artists with Down syndrome. All of Alexander's Angels projects aim to raise awareness of the contributions of individuals with Down syndrome to society. With a BA from SUNY College at Old Westbury and an MS from LIU Post, Esther returned to her Old Westbury Alma Mater as a Visiting Instructor where she taught for fourteen years.

Mike Hoffman, DSAF's President. Mike Hoffman is a parent of four boys, one of whom has Down syndrome. Mike is a founding member of the **Down Syndrome Advocacy Foundation**, a not-for-profit organization that assists families and individuals with Down syndrome in accessing inclusive environments. Mike is a graduate of Partners in Policy Making and has had a profound effect on services for children with Down syndrome on Long Island.

Michael Kelly, Esq. DSAF. Mr. Kelly is the Principal of Kelly Development Corp. focusing on the development of subdivisions and consulting on various real estate issues. The developer for "The Riverwalk" in the Village of Patchogue, prior to forming his own businesses, Mike was Vice President of Land Acquisitions for Pulte Homes of Long Island a Fortune 500 Company. Mike has over 20 years of diversified real estate industry experience, was the President for the Long Island Builders Institute; a former member of Energia, Long Island's regional leadership program within Molloy College; and has been the recipient of the Paul S. Miller "With Liberty and Justice for All" award by Touro Law School 2006 and The Good Neighbor of the Year from The Central Islip Civic Association in 2008. He is a member of the New York State Bar has been appointed for his second term to the Suffolk County Planning Commission as the Commissions' Town of Brookhaven representative; and is a member of the Business Improvement District for the Village of Patchogue. Mike serves on the Board of Directors of the **Down Syndrome Advocacy Foundation (DSAF)** and lives in Stony Brook with his wife and 4 children, including Owen who has Down syndrome. Mr. Kelly has advocated for inclusive preschool and elementary school placements for Owen who is a middle schooler at Murphy Junior High currently playing basketball and eager about his performance in the school play.

Tania Laterza, Self-Advocate. Tania Laterza is a 40 year old woman with Down syndrome. She has been living in ACDS' first IRA since 2000. Tania has been an aide in a classroom at ACDS for many years, helping out with the children. She also works in a doctor's office for the last 15 years as a file clerk. She was even just featured in their newsletter for her hard work and dedication to the job. Tania has been advocating for herself for many years and has even had the honor of speaking at other agency functions in her role as a self-advocate. She is perfect example of what can be accomplished when you try.

Anthony Providenti, DSRTF Board Secretary. Mr. Providenti is Vice President - Corporate Business Development and Special Counsel at Henry Schein, Inc., a Fortune 500 healthcare company. At Henry Schein, Anthony is responsible for mergers and acquisitions and other strategic transactions that drive growth and profitability. Anthony previously served as a senior attorney in Henry Schein's legal department. Prior to joining Henry Schein, Anthony was a senior corporate and transactional attorney with the New York office of Gibson, Dunn & Crutcher LLP, an international law firm. Anthony received a J.D. from Fordham University School of Law where he was a Notes and Articles Editor of the Fordham Law Review, and a B.S. from the College of Business and Economics at Lehigh University. Anthony and his wife have three children, including a son who has Down syndrome.

Vinnie Santo has been Director of Development and Corporate Relations at the **Association of Children with Down Syndrome (ACDS)** since January 2010. He joined ACDS in May 2005 as Chief Financial Officer and served in that capacity until October 2008, when he assumed additional responsibilities as Chief Administrative Officer. Prior to joining ACDS, Vinnie spent most of his career at American Express in a variety of financial management roles, including Assistant Controller. He also was an Assistant Professor of accounting and finance at St. Joseph's College from 2002 through 2005. Vinnie is a member of the Association of Fundraising Professionals and a CPA; he received his BS from Bucknell University and an MBA from Duke University.

Patricia White, M.D., is a board certified Internist and Fellow of the American Academy of Physicians. She received her M.D. from the State University of New York, Downstate Medical Center. She joined the Department of Internal Medicine at New York Medical College, where she was actively involved in medical student education and residency training, was an investigator in several clinical trials, and served as the Director of the outpatient medical clinic at Westchester County Medical Center and Director of the Medical Research Associates Headache Center. She retired in 2001 as an Assistant Professor of Medicine. Patricia and her husband have five children, including a son who has Down syndrome. In addition to her involvement with numerous local and national advocacy activities, Patricia has been leading participant in the Down syndrome cognitive research effort and participates in numerous local and national support and advocacy activities on behalf of those with Down syndrome. Dr. White is a Director on the Board of the **Research Down Syndrome (RDS)** Foundation.