

**The Faculty of Medicine of Harvard University  
Curriculum Vitae**

**Date Prepared:** April 9, 2025  
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**Place of Birth:** Cleveland, OH

**Education**

2001	B.S. summa cum laude	Biological Anthropology and Anatomy	Duke University
2006	M.D.	Medicine	Harvard Medical School
2006	M.P.P.	Public Policy	Harvard Kennedy School

**Postdoctoral Training**

07/06-06/07	Internship	Pediatrics	Boston Combined Residency Program in Pediatrics (Children's Hospital Boston & Boston Medical Center)
07/07-06/09	Residency	Pediatrics	Boston Combined Residency Program in Pediatrics (Children's Hospital Boston & Boston Medical Center)
07/09-06/12	Fellowship	Medical Genetics	Harvard Medical School American Board of Medical Genetics Training Program, Genetics (Children's Hospital Boston, Massachusetts General Hospital, Brigham & Women's Hospital, Dana Farber Cancer Institute)

### **Faculty Academic Appointments**

2011-2013	Instructor	Pediatrics	Harvard Medical School
2013-2017	Assistant Professor	Pediatrics	Harvard Medical School
2018-2024	Associate Professor	Pediatrics	Harvard Medical School
2024-	Professor	Pediatrics	Harvard Medical School

### **Appointments at Hospitals/Affiliated Institutions**

07/06-06/09	Clinical Fellow	Pediatrics	Children's Hospital Boston
07/06-06/09	Teaching Fellow	Pediatrics	Boston University School of Medicine
07/09-06/12	Clinical Fellow	Genetics	Children's Hospital Boston, Brigham & Women's Hospital, Massachusetts General Hospital, Dana Farber Cancer Institute
07/12-12/16	Assistant in Pediatrics	Pediatrics	Massachusetts General Hospital
12/16-	Assistant Pediatrician	Pediatrics	Massachusetts General Hospital
04/13-	Affiliate Faculty Member	Center for Genomic Medicine	Massachusetts General Hospital
10/13-	Member	Leukemia Program	Dana-Farber/Harvard Cancer Center
08/16-12/24	Associate Member	Ariadne Labs	Harvard Medical School/Brigham & Women's Hospital
10/18-	Emma Campbell Endowed Chair on Down Syndrome	Pediatrics	Massachusetts General Hospital

### **Other Professional Positions**

2003-2006	Program Coordinator, More to Life Than Genes	Harvard Medical School	
2005-2007	Clinical Director, Health Promotion	Massachusetts Special Olympics	
2007-2017	Board of Directors	Band of Angels Foundation	
2010-2011	Medical Advisor, Board of Directors	Lettercase	
2009-	Council Member	Gerson Lehrman Group	~4 hours per year
2017-	Expert legal witness	Various legal cases about Down syndrome	~20 hours per year

### Major Administrative Leadership Positions

#### Local

2012-2017	Clinical Co-Director, Down Syndrome Program	Massachusetts General Hospital
2018-	Clinical Director, Down Syndrome Program	Massachusetts General Hospital

#### National

2004-2007	National Board of Governors	American Red Cross
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### Committee Service

#### Local

2007-2009	Advocacy in Clinical Training (ACT) Committee	Children's Hospital Boston
2012-	T32 Steering Committee	Harvard Medical School American Board of Medical Genetics Training Program
2018	Pilot Feasibility Studies Selection Committee	Massachusetts General Hospital <i>for</i> Children
2023-	Research Council	Massachusetts General Hospital
2024-	Promotions, Reappointments, and Appointments Committee	Harvard Medical School

**Regional**

2001-2011	Board of Directors Chair (2009-2011)	Massachusetts Down Syndrome Congress
2011-	Honorary Board of Directors	Massachusetts Down Syndrome Congress
2011-	Chair, Medical and Science Advisory Council	Massachusetts Down Syndrome Congress
2001-2008	Board of Directors	Massachusetts Developmental Disabilities Council

**National**

1999-2004	Disability Task Force National Chair	American Red Cross
2007-2013	Professional Advisory Council	National Down Syndrome Congress
2007-2012	Board of Directors Secretary (2007-2012) Chair, Clinical Advisory Board (2007- 2012)	National Down Syndrome Society

**Professional Societies**

2006-2009	American Academy of Pediatrics	Member
2009-	American College of Medical Genetics and Genomics (ACMG)	Member
	2012 and 2016	Member, Working Group for ACMG Consensus statement on Noninvasive Prenatal Screening
2009-	American Society of Human Genetics (ASHG)	Member
2012-	Down Syndrome Medical Interest Group	Member
2015-	Society for Pediatric Research	Member
2015-	T21 Research Society	Member
	2017-	Member, Down Syndrome Developmental Clinical Committee
	2022-	

		Chair, Down Syndrome Developmental Clinical Committee
2020-		Member, Conference Program Committee
2022-		Member, Executive Committee
2017-2020	Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART)	Council Member, Down Syndrome and Alzheimer's Disease Professional Interest Area

### Grant Review Activities

2020	Dissemination & Implementation Grant Committee	Patient Centered Outcomes Research Institute (PCORI)
2020		Ad-hoc Member

### Editorial Activities

#### Ad hoc Reviewer

*Advances in Therapy*  
*AIMS Public Health*  
*Alzheimer's & Dementia: The Journal of the Alzheimer's Association*  
*Alzheimer's & Dementia: Translational Research & Clinical Interventions*  
*American Journal of Bioethics – Primary Research*  
*American Journal on Intellectual and Developmental Disabilities*  
*American Journal of Medical Genetics, Part A*  
*American Journal of Medical Genetics, Part B*  
*American Journal of Medical Genetics, Part C*  
*American Journal of Obstetrics and Gynecology*  
*American Journal of Sexuality Education*  
*Annals of Neurology*  
*Annals of Clinical and Translational Neurology*  
*Archives of Diseases in Childhood*  
*BMC Health Services Research*  
*Brain Behavior and Immunity*  
*Brain Sciences*  
*British Journal of Obstetrics & Gynecology*  
*Child: Care, Health & Development*  
*CNS Drugs*  
*European Journal of Human Genetics*  
*Frontiers Pediatrics—Pediatric Nephrology*  
*Frontiers Psychiatry*  
*Genetics in Medicine*

*Heliyon*  
*Human Genetics*  
*International Journal of Environmental Research and Public Health*  
*JAMA Otolaryngology—Head & Neck Surgery*  
*JBI Evidence Synthesis*  
*Journal of Alzheimer’s Disease*  
*Journal of Genetic Counseling*  
*Journal of Intellectual Disabilities*  
*Journal of Intellectual Disability Research*  
*Journal of Perinatology*  
*Journal of Psychology and Psychotherapy*  
*Journal on Developmental Disabilities*  
*Medicine*  
*Neuropsychiatric Disease and Treatment*  
*New England Journal of Medicine*  
*Obstetrics & Gynecology*  
*Pediatrics*  
*Pediatric Drugs*  
*Pediatric Pulmonology*  
*Pediatric Quality and Safety*  
*Perspectives in Biology and Medicine*  
*PLOS ONE*  
*Prenatal Diagnosis*  
*Research in Developmental Disabilities*  
*The CRISPR Journal*  
*The Journal of Pediatrics*  
*The Lancet Psychiatry*  
*The New Bioethics*  
*Therapeutics and Clinical Risk Management*  
*Universal Access in the Information Society*  
*Vaccine*

**Honors and Prizes**

1997-2001	Angier B. Duke Memorial Scholarship	Duke University	Merit scholarship for top students
1999	Lord Rothermere Scholarship	Duke University/Oxford University	Merit scholarship for international study
2001	All American Academic First Team	USA Today	Top college students in nation
2001	Faculty Scholar	Duke University	Top merit award to graduating seniors
2004-2005	Jack Kent Cooke Scholarship	Jack Kent Cooke Foundation	Top merit award to graduating seniors

2004	Knowles Fellow	Harvard University	Top merit award
2004	Margaret Schneider Austin Scholarship	Harvard Kennedy School	Top merit award
2006	Presidential Scholars Public Service Initiative Award	Harvard Medical School	Recognizing impressive public service
2008	Dean's Community Service Award	Harvard Medical School	Recognizing leadership through service
2010-2014	NIH Pediatric Loan Repayment Award	National Institutes of Health	Pediatric research
2012	Good Catch Award	Children's Hospital Boston	Excellence in clinical safety
2015	William K. Bowes Jr. Award in Medical Genetics	Partners Healthcare Personalized Medicine	Recognizing an outstanding physician who has recently completed training in medical genetics

## **Report of Funded and Unfunded Projects**

### **Funding Information**

#### **Past**

1997-2006	Literacy Research in Children with Rett Syndrome Duke University institutional grant Co-P.I. (\$5,000) Investigated the communicative use of storybooks in children with Rett syndrome
1997-2008	Memory Formation in Amnesic Patient, H.M. American Foundation of Aging Research P.I. (\$8,000) Studied the preoperative and postoperative semantic memories in amnesic patient, H.M.
1999-2001	Neuroanatomical Research on the Mammalian Tongue Howard Hughes Research Fellowship P.I. Analyzed the neuromuscular development of the mammalian tongue, using mouse models for Down syndrome
2001-2005	Prenatal and Postnatal Support Services for Mothers of Children with Down Syndrome in

- Spain  
Mental Health & Disability Scholarship, Children's Hospital Boston; Rosemary F. Dybwad International Fellowship  
P.I.  
Investigated maternal perceptions of receiving a prenatal or postnatal diagnosis of Down syndrome in Spain
- 2001-2005 Prenatal and Postnatal Support Services for Mothers of Children with Down Syndrome in U.S.  
Tim White Foundation, Children's Hospital Boston  
P.I. (\$15,000)  
Investigated maternal perceptions of receiving a prenatal or postnatal diagnosis of Down syndrome in U.S.
- 2006-2009 Family Attitudes Toward Persons with Down Syndrome  
Fred Lovejoy Housestaff Research and Education Fund, Joel and Barbara Alpert Scholarship, Tim White Foundation  
P.I. (\$51,000)  
Surveyed mothers, fathers, siblings, and people with Down syndrome across the country about family life when someone has Down syndrome
- 2010-2012 Predicting Obstructive Sleep Apnea in Down Syndrome  
NIH/T32; Sircar/Dynan Fund, Division of Genetics, Children's Hospital Boston  
P.I. (\$85,000)  
Developing a screening tool that could be used by physicians to predict obstructive sleep apnea in Down syndrome
- 2011-2013 Predicting Obstructive Sleep Apnea in Down Syndrome  
NICHD/F32 HD068101-01A1  
P.I. (\$117,432)  
Developing a screening tool that could be used by physicians to predict obstructive sleep apnea in Down syndrome
- 2013-2014 A Screening Protocol to Assess Adult and Adolescent Individuals with Down syndrome for Eligibility to Participate in an Upcoming Study to Evaluate the efficacy, safety and tolerability of RG1662 (Study BP27832)  
F. Hoffmann-La Roche Ltd., NCT01920633  
Site P.I. (\$36,844)  
Industry-initiated Screening Protocol for Phase 2 clinical drug trial on a pharmaceutical that might enhance cognition, memory, and language in adults with Down syndrome
- 2013-2015 A 4-Week Randomized, Double-Blind, Placebo-Controlled, Phase 2a Safety and Pharmacokinetic Study of Oral ELND005 in Young Adults With Down Syndrome Without Dementia  
Transitions Therapeutics, NCT01791725  
Site P.I. (\$201,455)

- Industry-initiated Phase 2a clinical drug trial on a pharmaceutical that might enhance cognition, memory, and language in adults with Down syndrome and stave off Alzheimer's disease related dementia
- 2015-2016 A Randomized, Double-blind, Placebo-controlled, Parallel Group 26-week Dose- Investigating Study to Explore the Pharmacokinetics, Pharmacodynamic Effects, Efficacy, Safety and Tolerability of RO5186582 in Children with Down Syndrome Aged 6-11 Years (Study WP28760)  
F. Hoffmann-La Roche Ltd., NCT02484703  
Site P.I. (\$150,282)  
Industry-initiated Phase 2 clinical drug trial on a pharmaceutical that might enhance cognition, memory, and language in children with Down syndrome
- 2015-2016 A Multicenter, Longitudinal, Non-drug Study to Assess the Suitability of Neurocognitive Tests and Functioning Scales for the Measurement of Cognitive and Functioning Changes in Children with Down Syndrome (Study BP29589)  
F. Hoffmann-La Roche Ltd., NCT02451657  
Site P.I. (\$169,011)  
Industry-initiated Phase 2 clinical drug trial looking at appropriate neurocognitive measures in children with Down syndrome
- 2014-2016 A Multi-Center, Randomized, Double-Blind, Placebo-Controlled Phase 2 Study of the Efficacy, Safety and Tolerability of RG1662 in Adults and Adolescents with Down Syndrome (Study BP27832)  
F. Hoffmann-La Roche Ltd., NCT02024789  
Site P.I. (\$789,910)  
Industry-initiated Phase 2 clinical drug trial on a pharmaceutical that might enhance cognition, memory, and language in adults with Down syndrome
- 2012-2016 Predicting Obstructive Sleep Apnea in Down Syndrome  
HRSA/R40MC25322-01-00  
P.I. (\$935,540)  
Developing a screening tool that could be used by physicians to predict obstructive sleep apnea in Down syndrome
- 2016-2020 Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome Patient-Centered Outcomes Research Institute (PCORI)/AD-1507-31567, NCT04227197  
P.I. (\$2,100,000)  
Through an investigator-initiated randomized-control national trial, we created and tested a direct-to-public, always-available, online service yielding comprehensive yet personalized recommendations for patients with Down syndrome who don't have access to specialty care. The online platform was proven to be efficacious and well-received by primary care providers and caregivers.
- 2017-2021 A Phase 1b Multi-Center, Double-Blind, Randomized, Placebo-Controlled Dose Escalation Study of the Safety, Tolerability, and Immunogenicity of ACI-24 in Adults with Down Syndrome  
NIH/1R01AG047922-01, NCT02738450

Site P.I. (\$132,654); Overall PI: William Mobley  
NIH-funded Phase 1b clinical drug trial on a vaccine that might prevent Alzheimer's disease in patients with Down syndrome.

- 2021-2021 MGH Down Syndrome Clinic to You (DSC2U) Continuation  
MassGeneral Brigham Innovation Discovery Grant  
PI (\$69,565)  
Selected by Chris Coburn, Chief Innovation Officer, and Dr. Ravi Thadani, Chief Academic Officer, at MassGeneral Brigham to receive this award which further improves the clinical innovation, Down Syndrome Clinic to You (DSC2U: [dsc2u.org](http://dsc2u.org))
- 2020-2022 PTN Task Order # 6-Clinical Pharmacokinetics and Safety Trials in Down Syndrome  
NIH / HHSN-275201800003I  
Co-I (\$6,491)  
Through this project, the Pediatric Trials Network in partnership with the NIH INLCUDE initiative aspires to create a platform upon which on- and off- patent therapeutics can be studied to address the knowledge gap related to drug dosing in children with Down syndrome. The mechanisms to accomplish this will include site education through participation in the Pharmacokinetics, Pharmacodynamics, and Safety of Understudied Drugs Administered to Children per Standard of Care (POPS) study, and also through the conduction of a population-specific, multisite, pharmacokinetic, safety, and efficacy study. In order to achieve this, we need strong collaboration with experts in this field to determine an area of therapeutic need specific to this population. Then, through a collaborative process with these expert thought leaders, we will develop the detailed study protocol to be implemented at up to 10 academic medical centers.
- 2020-2022 Engaging underserved families in the United States with Down Syndrome Clinic to You (DSC2U)  
Patient-Centered Outcomes Research Institute (PCORI)/ 19659-MGH  
PI (\$177,360)  
We seek to identify what barriers prevented engagement with our online platform, DSC2U, with minority populations. We intend to establish culturally appropriate ways to communicate with Spanish-speaking and/or African American caregivers in partnership with our Diversity Outreach Specialist so that we could create partnerships with caregivers who have strong networks within the minority Down syndrome communities.
- 2016-2022 Making Activity and Nutritional Goals Obtainable (MANGO)  
Internal award, Massachusetts General Hospital & Research Grant from Google, Inc.  
P.I. (\$95,000)  
Through use of focus groups and design workshops, we are creating of a mobile app for patients with Down syndrome so that they can improve their nutrition and exercise habits.
- 2023-2024 International Mosaic Down Syndrome Association Community-Empowered Research and Retreat Weekend: Increasing Partnerships, Cohorts, and Diversity for Research Related to Down Syndrome  
NIH/R13 HD112166  
Significant Contributor

Under the direction of Colleen Jackson-Cook (PI), who received \$37,100 grant, I spoke and participated in this research symposium about mosaic Down syndrome.

- 2018-2024 Longitudinal Investigation For the Enhancement of Down Syndrome Research (LIFE-DSR)  
LuMind IDSC Foundation  
PI (\$264,620, to date, with accumulate revenue per patient visit)  
The LIFE-DSR study is an observational investigation with the goal to better understand the cognitive and behavioral changes along with the health issues found in adults with Down syndrome as they progress toward Alzheimer's disease.
- 2020-2024 Comparative Effectiveness and Implementation of Best Practices to Prevent COVID-19 in Staff and People with Serious Mental Illness and Developmental Disabilities in Congregate Living Settings  
Patient-Centered Outcomes Research Institute (PCORI)/ PCORI 20-10803  
co-PI (\$4,972,283); other co-PI: Steve Bartels  
A randomized control trial/comparative effectiveness of different types and intensities of preventive interventions in reducing rates of COVID-19 and related hospitalization and mortality in staff and adult residents with serious mental illness and intellectual disabilities/developmental disabilities in congregate care settings.
- 2020-2024 Transcranial Photobiomodulation with Near-Infrared Light for Down Syndrome Language (TransPhoM-DS Language)  
Down Syndrome Resource Foundation  
Co-I (\$415,420)  
Under the direction of Dr. Casano (P.I.) at MGH, we are examining the safety, tolerability, and effectiveness of transcranial photobiomodulation (tPBM) on improving language, memory and attention in adults with Down syndrome (ages 18-30 years). The study consists of 1 screening visit, approximately 3 study visits and 18 treatment sessions (3/week for 6 weeks). Study visits include neuropsychological testing, EEG testing, and MRI scans.

## **Current**

- 2020-2026 Effects of Hypoglossal Nerve Stimulation on Cognition & Language in Down Syndrome  
NIH/ 1 U01 DC019279-01  
MPI (\$3,956,176); other MPI: Christopher Hartnick  
Assessing the impact of the hypoglossal nerve stimulator, primarily used to treat obstructive sleep apnea, on cognition and expressive language in patients with Down syndrome.
- 2021-2025 Down Syndrome: Toward Optimal Trajectories and Health Equity using Medicaid Analytic eXtract (DS-TO-THE-MAX)  
NIH/ 1 R01AG073179-01  
Co-I (\$67,122)

Under the direction of Dr. Rubenstein (P.I.) at Boston University, the research team will use Medicaid Analytic Extract data to perform a 10-year retrospective cohort of > 100,000 adults with and >4,000,000 adults without Down syndrome enrolled in Medicaid. With these data, we will describe epidemiology, identify risks and social determinants, and use machine learning to identify factors that may predict occurrence of resilience of obstructive sleep apnea, dementia, and mortality in a diverse sample of orders of magnitude larger than previous studies.

- 2023-2028 A phase 1b/2, multicenter, adaptive, double-blind, randomized, placebo-controlled study to assess the safety, tolerability, immunogenicity, and pharmacodynamic effects of ACI-24.060 in subjects with prodromal Alzheimer’s disease and in adults with Down syndrome (ABATE)  
AC Immune, NCT05462106  
Site PI (\$116,593, estimated, to be reimbursed on enrollment)  
This industry-initiated study is assessing the safety, tolerability, immunogenicity and pharmacodynamic effects of ACI-24.060 in adults with Down syndrome who do not have clinical signs of dementia.
- 2023-2028 Development and Validation of the Down Syndrome Regression Rating Scales  
NIH / 1R01 HD113711-01  
Co-I (\$141,045)  
Under the direction of Ruth Brown (PI) at Virginia Commonwealth University, we will develop a Down Syndrome Regression Rating Scale (DSRRS) through an iterative process of focus groups, pre-testing, and item reduction. We will validate the newly created scale against well-validated assessments of symptoms associated with Down Syndrome Regression Disorder (DSRD), examine the test-retest reliability, and examine sensitivity and specificity to optimize recommended cutoff scores. These tools will lay the groundwork for vital research for years to come aimed at identifying the prevalence and etiologies, the gene-brain-behavior connections underlying DSRD, a devastating condition associated with a subacute decline in cognitive and adaptive functioning, mood, and catatonia, with the highest risk period between 10 and 30 years old for people with Down syndrome.
- 2023-2027 An Online Platform to Promote Evidence-Based Care for Underserved Patients with Neurofibromatosis 1  
Patient Centered Outcomes Research Institute / AD-2022C2-24790  
Co-I (\$49,999.45)  
Under the direction of Dr. Plotkin and Dr. Merker (mPIs) at MGH, we are modifying “Down Syndrome Clinic to You” to provide personalized healthcare recommendations for neurofibromatosis 1 (NF1) patients with limited access to specialty care, and testing the efficacy of this new platform in a randomized clinical trial. Aim 1: To test whether a customizable Patient/Caregiver Plan and Primary Care Provider Letter will increase patient and caregiver-reported, provider-driven health actions consistent with national guidelines compared to generic reminder notices. Aim 2: To identify implementation factors related to user satisfaction and platform effectiveness to inform future replications of the platform to additional rare diseases.

## **Training Grants and Mentored Trainee Grants**

- 2025-2026 Somatic mutations and neurodegeneration insights from Down syndrome brains  
NIH/ 5T32GM007748-33  
Mentor to Dr. William Choi  
The primary goal is to define how somatic mutations affect neurodegenerative progression in Down syndrome, with the aim of translating this knowledge into biomarkers and personalized therapies to address age-related cognitive decline.
- 2020-2025 Developing a Down Syndrome Health Instrument  
NIH / 1K23HD100568-01A1  
Mentor to Dr. Stephanie Santoro  
The major goal is to develop a validated survey instrument that can assess overall health status of adults with Down syndrome. Such a survey tool will be welcomed and crucial component of future clinical trials.
- 2021-2026 Non-invasive biometric screening for cerebrovascular disorders in persons with Down syndrome  
NIH / 1K23HL155898-01  
Mentor to Dr. Jonathan Santoro  
The major goal is to develop a clinical screening mechanism to detect cerebrovascular disorders (such as moya moya disease) in people with Down syndrome before they become symptomatic. Such a clinical screen has the potential to reduce mortality and morbidity associated with these co-occurring cerebrovascular disorders.
- 2012- Training Grant in Genetics  
NIH / T32 GM007748  
Faculty  
The major goal is to train and mentor fellows in the Harvard Medical School American Board of Medical Genetics Training Program. To date, I have helped train and mentor more than 35 fellows.

## **Report of Local Teaching and Training**

### **Teaching of Students in Courses**

- |           |   |   |
|-----------|---|---|
| 2012-     | Outpatient Care of Patients with Down Syndrome for Med Students<br>3 <sup>rd</sup> and 4 <sup>th</sup> year MD students | Harvard Medical School<br><br>Instructor in this month-long clinical elective on the care of patients with Down syndrome across the age spectrum; typically providing clinical supervision and instruction to about 4-5 students per year |
| 2015-2016 | Human Genetics Course<br><br>1 <sup>st</sup> year MD and PhD students in Health, Sciences, & Technology Program         | Harvard Medical School and Massachusetts Institutes of Technology<br>Presented 90-minute lecture on prenatal testing for Down syndrome and how best to  |

		deliver prenatal diagnoses to expectant parents
2015-	PhD Program in Biological and Biomedical Sciences: Genetics in Medicine 1 <sup>st</sup> year PhD students	Harvard Medical School  Organized and presented 3-hour course on Down syndrome
2018	AISC-Human Genetics course 1 <sup>st</sup> year MD students	Harvard Medical School Preceptor 2 students of 5 hours precepting
2019-2023	The Developing Physician, The Practice of Medicine 1 <sup>st</sup> year MD students	Harvard Medical School  Course instructor 11 sessions of 90 minutes each

**Formal Teaching of Residents, Clinical Fellows and Research Fellows (post-docs)**

2009-2021	Introduction to Metabolic Disorders  1 <sup>st</sup> year medical genetics fellows	Children’s Hospital Boston, Massachusetts General Hospital, Brigham & Women’s Hospital, Dana Farber Cancer Institute One-hour lecture
2009	A Challenging Dynamic: Presenting a Diagnosis of Down Syndrome to New and Expectant Parents Med-Peds Residency Program	Massachusetts General Hospital  One-hour lecture
2013	Healthcare Updates for Patients with Down Syndrome Pediatrics residents (all years)	Massachusetts General Hospital  One-hour lecture
2014	Newborn Care for Patients with Down Syndrome Pediatrics residents (all years)	Massachusetts General Hospital  One-hour lecture
2016	A Challenging Dynamic: Presenting a Diagnosis of Down Syndrome to New and Expectant Parents Obstetric Residents and Fellows	Brigham & Women’s Hospital  One-hour lecture
2019	Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates	Massachusetts General Hospital Institutes of Healthcare Professions

	for the Healthcare Professional Genetic counseling graduate students	One-hour lecture
2020	Supporting Sexual Development in Patients with Down Syndrome Pediatric residents (first year)	Massachusetts General Hospital  One-hour lecture
2024	Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional Maternal-fetal medicine fellows	Brigham & Women's Hospital  One-hour lecture

### **Clinical and Supervisory Training Responsibilities**

2012-current	Down Syndrome Program Clinic Preceptor / Massachusetts General Hospital	4 hours per week
2012-current	Medical Genetics Clinic Preceptor / Massachusetts General Hospital	4 hours per week
2012-current	Medical Genetics and Metabolism Inpatient Services Consultation Supervising Attending / Massachusetts General Hospital	2 hours/day for one week every 2 months

### **Research Supervisory and Training Responsibilities**

2012-current	Supervision of Research Assistant and Clinical Research Coordinator for the MassGeneral Hospital Down Syndrome Program (average 2 per year)	Massachusetts General Hospital 5-10 hours/week supervision, which resulted in authorship on scholarly works
2016-current	Supervision of Program Manager for the MassGeneral Hospital Down Syndrome Research Program	Massachusetts General Hospital 5 hours/week supervision, which resulted in authorship on scholarly works
2015-2017	Supervision of postdoctoral research fellow in the MassGeneral Hospital Down Syndrome Program	Massachusetts General Hospital ~2 hours/week including 1 hour for 1:1 meetings

### **Mentored Trainees and Faculty**

2011-2012	Laura Kline / Genetic Counseling Student, Brandeis University Thesis approved; abstract presentation at National Society of Genetic Counselors
2011-2013	Timothy Ridge / Clinical Psychology, Massachusetts Professional School of Psychology

- Thesis approved
- 2014-2015 Devon Haynes / Genetic Counseling Student, University of South Carolina School of Medicine  
Thesis approved
- 2015-2016 Alex Ilacqua / Genetic Counseling Student, The Ohio State University  
Thesis approved
- 2015-2017 Alexandra Garza-Flores, M.D. / Medical Genetics Resident, Harvard Medical School  
American Board of Medical Genetics Training Program  
NIH F32 submitted; oversaw the implementation of her clinical research project. Now a practicing medical geneticist at Cook's Childrens Hospital in Texas
- 2016; 2017 (summer) Sierra Weiss / Undergraduate student, Emory University  
Created multiple patient and family handouts for our Massachusetts General Hospital Down Syndrome Program
- 2016-2017 Ibrahim Elsharkawi, MB, BCH / Research Fellow, Massachusetts General Hospital  
Co-author on multiple research manuscripts and now a practicing geneticist and metabolism specialist at Mt. Sinai Medical Center, New York
- 2016-2018 Maggie Salinger / MPP Candidate at Harvard Kennedy School and MD Candidate at Emory University School of Medicine  
Developing business analysis of the financial sustainability for our Massachusetts General Hospital Down Syndrome Program
- 2017 (summer) Sophia Campbell / Undergraduate student, Harvard University  
Created multiple patient and family handouts for our Massachusetts General Hospital Down Syndrome Program
- 2017 (summer) Elaina Ramos / MD Candidate at Boston University Medical Center  
Created multiple patient and family handouts for our Massachusetts General Hospital Down Syndrome Program
- 2018 Courtney Verscaj / MD Candidate at Boston University Medical Center  
Helped to create an online CME-course through Harvard Medical School for primary care physicians to learn about medical care for patients with Down syndrome
- 2018-2024 Daniel Kats / MD Candidate at Case Western University School of Medicine  
Developed a survey tool to measure human rights for people with Down syndrome across the world; also conducted structured phone interviews with families whose children have Down syndrome and infantile spasms  
Co-author on multiple scholarly manuscripts; now a pediatric fellow at Boston Children's Hospital
- 2019-2025 Stephanie Santoro, MD / Assistant Professor, Harvard Medical School and medical geneticist at Massachusetts General Hospital

Secured a K23 award to develop a validated assess to measure overall health of people with Down syndrome, a needed tool for clinical trials and translational research  
 Co-author on multiple scholarly manuscripts; now the Director of Quality Improvement Research at Massachusetts General Hospital Down Syndrome Program

- 2020- Jonathan Santoro, MD / Neurology Fellow at Massachusetts General Hospital and now Assistant Professor, Keck School of Medicine of University of Southern California  
 Secured a K23 to develop a clinical screening mechanism to detect cerebrovascular disorders (such as moyo moyo disease) in people with Down syndrome before they become symptomatic. Such a clinical screen has the potential to reduce mortality and morbidity associated with these co-occurring cerebrovascular disorders. Co-author on multiple scholarly manuscripts; now Medical Director, Neuroimmunology and Demyelinating Disorders Program at Children’s Hospital Los Angeles
- 2020-2022 Ronita Samuels, PhD, MS, MPH / Post-doctoral fellow at Massachusetts General Hospital Mongan Institute  
 Funded through my PCORI grant (20-10803), Dr. Samuels is focused on measuring the impact on COVID-19 on minority and underserved populations living in congregate living environments

**Formal Teaching of Peers (e.g., CME and other continuing education courses)**

No presentations below were sponsored by 3<sup>rd</sup> parties/outside entities

2010- current	Down Syndrome: Healthcare Updates for the Primary Care Pediatrician Harvard Medical School	Single presentation  Online CME course
2013-2019	Prenatal Diagnoses of Down Syndrome: Delivering Results in Our New Age of Genetic Testing Massachusetts General Hospital Academy	Single presentation  Online CME course
2013-2016	Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician Harvard Medical School 35 <sup>th</sup> Annual Primary Care Pediatrics Conference	Single presentation Boston, MA  CME course
2015	Prenatal Diagnoses of Down Syndrome: Delivering Results in Our New Age of Genetic Testing Harvard Center for Bioethics Conference: Families Matter Ethically, Legally, and Clinically	Two presentations Boston, MA  CME course
2020	Massachusetts Initiative to Improve Transition to Adult Healthcare for Individuals with Neurodevelopmental Disabilities Course Boston Children’s Hospital	One co-presentation Boston, MA  CME course

## Local Invited Presentations

No presentations below were sponsored by 3<sup>rd</sup> parties/ outside entities

- 2007 Prenatal and Postnatal Medical Support: Capturing the Sentiments of Parents Who Have Children with Down Syndrome / Lecture  
Division of Genetics, Massachusetts General Hospital
- 2008 A Challenging Dynamic: Delivering and Prenatal and Postnatal Diagnosis of Down Syndrome to New and Expectant Parents / Lecture  
Department of Newborn Medicine, Children's Hospital Boston
- 2009 Prenatal Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Lecture  
Division of Genetics, Massachusetts General Hospital
- 2009 Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters / Lecture  
Department of Pediatrics, Children's Hospital Boston
- 2009 Multiple Options on a Changing Menu / Walk Rounds  
Division of Genetics, Children's Hospital Boston
- 2009 A Dip in Time / Walk Rounds  
Division of Genetics, Children's Hospital Boston
- 2009 A Challenging Dynamic: Presenting a Diagnosis of Down Syndrome to New and Expectant Parents / Lunchtime Talk  
Pediatric Advanced Care Team, Children's Hospital Boston
- 2009 Sharing the Diagnosis of Neurofibromatosis / Seminar  
Harvard Medical School Center for Neurofibromatosis and Allied Disorders
- 2009 Prenatal Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Grand Rounds  
Department of OB/GYN, Mount Auburn Hospital, Cambridge, MA
- 2010 Making a Diagnosis of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of OB/GYN, Massachusetts General Hospital
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, Beth Israel Deaconess Medical Center
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of Pediatrics, Mt. Auburn Hospital, Cambridge, MA

- 2010 A Second Look: Jacobsen syndrome / Walk Rounds  
Division of Genetics, Children's Hospital Boston
- 2010 Down Syndrome / Lecture  
Partners Healthcare Center for Personalized Genetic Medicine
- 2010 What your other children without Down syndrome are thinking: Sibling Issues for Parents / Allen C. Crocker Lecture Series  
Division of Developmental and Behavioral Pediatrics, Children's Hospital Boston
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, Cambridge Hospital
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Children's Hospital Boston Community Outreach Conference
- 2011 Down Syndrome Healthcare Updates for Older Children / Lecture  
Division of Developmental and Behavioral Pediatrics, Children's Hospital Boston
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of Neonatology, Children's Hospital Boston
- 2011 Down syndrome / Lecture  
Partners Healthcare Center for Personalized Genetic Medicine
- 2011 Community Partnerships / Panel Discussion  
Harvard Medical School Center for Neurofibromatosis and Allied Disorders
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy / Lecture  
Division of Nutrition, Children's Hospital Boston
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of Maternal Fetal Medicine, Brigham and Women's Hospital
- 2011 Predicting Obstructive Sleep Apnea in Down Syndrome / Lecture  
Division of Genetics, Children's Hospital Boston
- 2012 Predicting Obstructive Sleep Apnea in Down Syndrome / Lecture  
Division of Genetics, Massachusetts General Hospital
- 2012 Predicting Obstructive Sleep Apnea in Down Syndrome / Lecture  
Division of Sleep Medicine, Children's Hospital Boston
- 2012 Down Syndrome / Lecture

Partners Healthcare Center for Personalized Genetic Medicine

- 2012 Behavioral Concerns in Children and Adolescents with Down Syndrome: A comprehensive approach / Lecture  
MassGeneral Hospital Psychology Assessment Center
- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Updates that Healthcare Professionals Need to Know / Grand Rounds  
Department of Pediatrics, Massachusetts General Hospital
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of Pediatrics, Newton-Wellesley Hospital
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of Perinatal Services / Massachusetts General Hospital
- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Updates that Healthcare Professionals Need to Know / Grand Rounds  
Department of Audiology / Massachusetts Eye and Ear Infirmary
- 2013 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Pediatrics Department, Cambridge Hospital, Cambridge, MA
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician / Grand Rounds  
Division of Genetics, Massachusetts General Hospital, Boston, MA
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician / Grand Rounds  
North Shore Medical Center, Salem, MA
- 2015 Representations of Down Syndrome in Art / Grand Rounds  
Division of Genetics, Massachusetts General Hospital, Boston, MA
- 2015 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Division of Newborn Medicine, Brigham & Women's Hospital, Boston, MA
- 2015 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Division of Neurology, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician / Grand Rounds

Division of Endocrinology, Department of Pediatrics, Massachusetts General Hospital, Boston, MA

- 2016 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Division of Neurology, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2017 Creating a Fulfilling Career in Academic Medicine: Four Decision Points / Lecture  
Pediatric Intensive Care Unit, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2017 Sharing a diagnosis: An initial discussion of strategies and lessons learned / Grand Rounds  
Division of Medical Genetics, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2018 Down Syndrome Across the Lifespan / Grand Rounds, co-presented with Clo Cottrell  
Department of Social Work, Massachusetts General Hospital, Boston, MA
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician / Grand Rounds  
Division of Endocrinology, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Ariadne Labs, Brigham & Women's Hospital, Boston, MA
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture, MGHfC Research Day  
Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2019 Strategic Planning for the Future  
Cystic Fibrosis Program, Department of Pediatric Pulmonology, Massachusetts General Hospital, Boston, MA
- 2020 MGH Down Syndrome Program in the Virtual World / Grand Rounds  
Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2020 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Women's and Gender Studies, Massachusetts Institutes of Technology, Boston, MA
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Mongan Institute, Massachusetts General Hospital, Boston, MA
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for

- Caregivers and Primary Care Providers / Lecture  
Department of Neurology, Massachusetts General Hospital, Boston, MA
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Department of Anesthesiology, Massachusetts General Hospital, Boston, MA
- 2020 Down Syndrome Across the Lifespan: Addressing Medical and Psychosocial Needs in the Healthcare Setting/ Lecture  
The Maxwell & Eleanor Blum Patient and Family Learning Center, Massachusetts General Hospital, Boston, MA
- 2021 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Women's and Gender Studies, Massachusetts Institutes of Technology, Boston, MA
- 2021 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Division of Medical Genetics and Metabolism, Massachusetts General Hospital, Boston, MA
- 2021 Down Syndrome Across the Lifespan: Addressing Medical and Psychosocial Needs in the Healthcare Setting/ co-Lecture  
The Maxwell & Eleanor Blum Patient and Family Learning Center, Massachusetts General Hospital, Boston, MA
- 2022 Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, of mixed race, or come from primarily Spanish-speaking homes / Grand Rounds (co-presentation with Albert Pless)  
Division of Medical Genetics and Metabolism, Massachusetts General Hospital, Boston, MA
- 2022 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Center for Genomic Medicine, Massachusetts General Hospital, Boston, MA
- 2022 Harnessing the Power of Universal Design to Achieve Diversity, Equity, and Inclusion in Research / Panel Discussion  
Achieving Research Equity & Inclusion Conference, Massachusetts General Hospital, Boston, MA (virtual)
- 2023 In This Together Project: Best Practices to Prevent COVID-19 Illness in Staff and People with Serious Mental Illness and Intellectual & Developmental Disabilities in Congregate Living Settings / Grand Rounds (co-presentation with Dr. Steve Bartels)  
Division of Medical Genetics and Metabolism, Massachusetts General Hospital, Boston, MA
- 2023 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates

for the Healthcare Professional / Perinatal Grand Rounds  
Division of Maternal Fetal Medicine, Massachusetts General Hospital, Boston, MA

- 2023 Keeping Children and Adolescents with Down Syndrome Healthy: Medical Updates for the Primary Care Physician / Lecture  
Massachusetts General Hospital for Children (MGHfC) Pediatric Primary Care Conference, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
- 2025 Latest and Greatest Research on Down Syndrome / Lecture  
Division of General Academic Pediatrics, Department of Pediatrics, Massachusetts General Hospital, Boston, MA

## **Report of Regional, National and International Invited Teaching and Presentations**

Those presentations below sponsored by 3rd parties/outside entities are so noted and the sponsor is identified.

### **Invited Presentations and Courses**

#### **Regional**

- 2007 Prenatal and Postnatal Medical Support: Capturing the Sentiments of Parents Who Have Children with Down Syndrome / Grand Rounds  
Department of OB/GYN, Boston University Medical Center, Boston, MA
- 2008 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Grand Rounds  
Hartford Hospital & University of Connecticut Medical Center, Hartford, CT
- 2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Grand Rounds  
Hasbro Children's Hospital, Providence, RI
- 2009 Brothers and Sisters Who Have Siblings with Down Syndrome: Questions and Answers / Lecture  
Department of Pediatrics, Boston University Medical Center, Boston, MA
- 2009 A Challenging Dynamic: Delivering and Prenatal and Postnatal Diagnosis of Down Syndrome to New and Expectant Parents / Grand Rounds  
Department of OB/GYN, South Shore Hospital, South Weymouth, MA
- 2009 Prenatal Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Grand Rounds  
Department of Pediatrics, Tufts Medical Center, Boston, MA
- 2010 Best Practices in Healthcare Communication and Relationships / Lecture  
Department of Pediatrics, Tufts Medical Center, Boston, MA

- 2010 New Prenatal Tests for Down Syndrome: Everything You Need to Know and Should be Doing / Grand Rounds  
Department of Family Medicine and Community Health, UMass Memorial, Boston, MA
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of Genetic Counseling, Boston Medical Center, Boston, MA
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Genetic Counseling Department, Brandeis University, Boston, MA
- 2010 New Prenatal Testing for Down Syndrome: Everything You Need to Know and Should be Doing / Grand Rounds  
Department of OB/GYN, Tufts Medical Center, Boston, MA
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, Boston University Medical Center, Boston, MA
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates / Lecture  
Brown University, Providence, RI
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Women and Infant's Hospital, Providence, RI
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, South Shore Hospital, South Weymouth, MA
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of OB/GYN, Winchester Hospital, Winchester, MA.
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Division of Genetic Counseling, Brandeis University, Waltham, MA
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates / Lecture  
Boston College, Boston, MA
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Department of Pediatrics, BayState Health, Springfield, MA

- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of Pediatrics, BayState Health, Springfield, MA
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
OB/GYN Department, Lowell General Hospital, Lowell, MA
- 2012 Best Practices in Healthcare Communication and Relationships / Lecture  
Tufts Medical School, Boston, MA
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
University of New England College of Osteopathic Medicine, Biddeford, ME
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2013 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN & Pediatrics Departments, MetroWest Medical Center, Framingham, MA
- 2013 Prenatal Diagnoses of Down Syndrome, Delivering Results in our New Age of Genetic Testing / Lecture  
Center for Biotechnology and Biomedical Sciences, Merrimack College, North Andover, MA
- 2014 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2014 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
South Shore Hospital, South Weymouth, MA
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Bridgewater State University, Bridgewater, MA
- 2015 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA

- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Tufts University Medical Center, Boston, MA
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Clinicians Need to Know  
Boston Medical Center Primary Care Conference, Boston, MA
- 2015 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Pediatrics Department, Boston Medical Center, Boston, MA
- 2015 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, South Shore Hospital, South Weymouth, MA
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Tufts University Dental School, Boston, MA
- 2016 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2017 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Tufts University Dental School, Boston, MA
- 2017 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Edmund Ervin Pediatric Center, MaineGeneral Medical Center, Waterville, ME
- 2017 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows  
Edmund Ervin Pediatric Center, MaineGeneral Medical Center, Waterville, ME
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Bridgewater State University, Bridgewater, MA

- 2018 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2018 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
OB/GYN Department, St. Elizabeth's Medical Center, Brighton, MA
- 2018 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Tufts University Dental School, Boston, MA
- 2019 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Franciscan Children's Hospital, Brighton, MA
- 2019 Down Syndrome Clinic to You (DSC2U): A New Virtual Clinic for All Families  
Massachusetts Institutes of Technology, Boston, MA
- 2021 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2021 5 Decision Points: Building a Meaningful Career in Academic Medicine / Lecture  
Premedical Society, University of Massachusetts, Worcester, MA (virtual)
- 2022 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA
- 2022 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Grand Rounds  
University of Massachusetts Medical School, Worcester, MA (virtual)
- 2022 Creating a Fulfilling Career in Academic Medicine  
Caring for Pediatric Patients with Complex Medical Needs course, University of Massachusetts Medical School, Worcester, MA (virtual)
- 2023 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture

Tufts University Dental School, Boston, MA (virtual)

2023 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University School of Medicine, Boston, MA

2023 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Division of OB/GYN, St. Elizabeth's Medical Center, Boston, MA

2024 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of OB/GYN, South Shore Hospital, Weymouth, MA (virtual)

2024 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Boston University Medical School, Boston, MA

**National**

2008 Compassionate Delivery of a New Diagnosis to New and Expectant Parents of Children with Down Syndrome / Lecture  
Vanderbilt Kennedy Center & Vanderbilt Medical School, Nashville, TN

2008 Brothers and Sisters Who Have Siblings with Down Syndrome: Questions and Answers / Lecture  
Department of Pediatrics, Vanderbilt Medical Center, Nashville, TN

2008 Prenatal and Postnatal Medical Support: Capturing the Sentiments of Parents Who Have Children with Down Syndrome / Grand Rounds  
Department of Obstetrics and Gynecology, Vanderbilt Medical Center, Nashville, TN

2008 Prenatal and Postnatal Medical Support: Capturing the Sentiments of Parents Who Have Children with Down Syndrome / Lecture  
Riley Hospital for Children, Indianapolis, IN

2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Grand Rounds  
Children's Mercy Hospital, Kansas City, MO

2009 Brothers and sisters who have siblings with Down syndrome: Questions and Answers / Lecture  
Children's Mercy Hospital, Kansas City, MO

2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Lecture  
St. Louis University Hospital, St. Louis, MO

- 2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Lecture  
St. John's Mercy Hospital, St. Louis, MO
- 2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Grand Rounds  
Department of Pediatrics, Christiana Hospital, Wilmington, DE
- 2009 What the Other Children Without Down Syndrome are Thinking: Sibling Issues for the Pediatrician / Lecture  
Al DuPont Hospital, Wilmington, DE
- 2009 Making a Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Lecture  
OB/GYN Department, University Hospitals, Cleveland, OH
- 2009 Making a Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Lecture  
Pediatrics Department, University Hospitals, Cleveland, OH
- 2009 Accessing Quality Healthcare for your Brother or Sister: New Advances and Updates / Lecture  
The Ohio State University, Columbus, OH
- 2009 Prenatal and Postnatal Diagnoses of Down Syndrome / Lecture  
U.S. Congress, Washington, D.C.
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Gerber Center for Infant Development and Nutrition at Helen DeVos Children's Hospital, Grand Rapids, MI
- 2010 Making a Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Grand Rounds  
Pediatrics Department, Helen DeVos Children's Hospital, Grand Rounds, MI
- 2010 Delivering a Sensitive Diagnosis / Lecture  
Helen DeVos Children's Hospital, Grand Rapids, MI
- 2010 Making a Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Grand Rounds  
Texas Children's Hospital, Houston, TX
- 2010 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of Pediatrics, Children's Hospital of Wisconsin, Milwaukee, WI

- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: All of the Things that Residents Need to Know / Lecture  
The Children's Hospital, Oklahoma University Medical Center, Oklahoma City, OK
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of OB/GYN, Holy Cross Hospital, Silver Spring, MD
- 2011 What Your Other Children Without Down Syndrome are Thinking: Sibling Issues / Lecture  
The Children's Hospital of Philadelphia, Philadelphia, PA
- 2011 Celebrating Life with Down Syndrome / Keynote  
The Children's Hospital of Philadelphia, Philadelphia, PA
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All of the Medical Updates that Parents Need to Know / Lecture  
The Children's Hospital of Philadelphia, Philadelphia, PA
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Bergan Mercy Hospital, Omaha, NE
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Methodist Women's Hospital, Omaha, NE
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Division of Genetics, Duke University Medical Center, Durham, NC
- 2011 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of Pediatrics, Children's Hospital of Los Angeles, Los Angeles, CA
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Bergan Mercy Medical Center, Omaha, NE
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Children's Hospital & Medical Center, Omaha, NE
- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Cold Spring Harbor Laboratory, Cold Spring Harbor, NY

- 2012      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
United Nations, New York, NY
- 2012      Genetics and Obstetrics: New Down Syndrome Testing / Lecture  
Nurse Practitioners in Women's Health conference, Orlando, FL
- 2012      Does NextGen sequencing diminish the value of individuals with Down syndrome? / Oral platform  
National Society of Genetic Counseling, Boston, MA
- 2012      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
East Tennessee Children's Hospital, Knoxville, TN
- 2013      Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Carolinas Medical Center, Charlotte, NC
- 2013      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians and Parents Need to Know / Lecture  
University of Arkansas for Medical Sciences, Little Rock, AR
- 2013      Celebrating Life with Down Syndrome / Keynote  
University of Arkansas for Medical Sciences, Little Rock, AR
- 2013      Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Lecture  
Duke University, Durham, NC
- 2014      Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Grand Rounds  
Department of Pediatrics, Medical University of South Carolina (MUSC), Charleston, SC
- 2014      Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Lecture  
College of Charleston, Charleston, SC
- 2014      Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Department of OB/GYN, Medical College of Wisconsin, Milwaukee, WI
- 2014      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Department of Neonatology, Novant Health Presbyterian Medical Center, Charlotte, NC
- 2014      Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds

Department of Pediatrics, University of Wisconsin School of Medicine and Public Health,  
Madison, WI

- 2015 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Gundersen Healthcare, La Crosse, WI
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Gundersen Healthcare, La Crosse, WI
- 2015 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Marshfield Clinic, Marshfield, WI
- 2015 Launching a New Clinical Program / Concurrent Session  
American College of Medical Genetics and Genomics Annual Conference, Salt Lake City, UT
- 2015 Down syndrome: Caring for Patients Across a Lifespan / Concurrent Session  
American College of Medical Genetics and Genomics Annual Conference, Salt Lake City, UT
- 2015 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN Department, University of Nebraska Medical Center, Omaha, NE
- 2015 Medical Work-up for Regression in Patients with Down Syndrome  
Down Syndrome Medical Interest Group National Meeting, Phoenix, AZ
- 2015 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN Department, Bellin Health Care, Green Bay, WI
- 2015 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Division of Medical Genetics, Baylor Medical Center, Houston, TX
- 2016 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN Department, Christiana Healthcare, Wilmington, DE
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Family Medicine Department, St. Francis Healthcare, Wilmington, DE
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture

Department of Pediatrics, Nemours, Wilmington, DE

- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Family Medicine Department, Christiana Healthcare, Wilmington, DE
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Grand Rounds  
Department of Pediatrics, Christiana Healthcare, Wilmington, DE
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Grand Rounds  
Department of Pediatrics, East Tennessee Children's Hospital, Knoxville, TN
- 2016 Building a National Down Syndrome Biobank  
Down Syndrome Medical Interest Group national meeting, Orlando, FL
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Grand Rounds  
Department of Pediatrics, Maimonides Medical Center, Brooklyn, NY
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Cumberland Pediatric Foundation, Nashville, TN
- 2017 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN Department, Vanderbilt University Medical Center, Nashville, TN
- 2017 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
OB/GYN Department, University of Rochester Medical Center, Rochester, NY
- 2017 Urinary Biomarkers and Obstructive Sleep Apnea in Patients with Down Syndrome / Lecture  
Trisomy 21 Research Society, Northwestern Medical Center, Chicago, IL
- 2017 Down Syndrome & Unexplained Regression  
Down Syndrome Medical Interest Group, Sacramento, CA
- 2017 Predicting Obstructive Sleep Apnea in Patients with Down Syndrome  
Down Syndrome Medical Interest Group, Sacramento, CA
- 2017 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Lecture  
St. Luke's Hospital of Kansas City, Kansas City, MO
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical

- Updates that Parents Need to Know / Grand Rounds  
Children's Mercy Hospital, Kansas City, MO
- 2017 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / McBride Lecture  
Simpson College, Indianola, IA
- 2017 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing / Grand Rounds  
Division of Genetics, University Hospitals, Cleveland, OH
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Grand Rounds  
Department of Pediatrics, Cleveland Clinics, Cleveland, OH
- 2017 Delivering a Prenatal Diagnosis of Down Syndrome: Lessons Learned from Evidence-Based Literature / Lecture  
5<sup>th</sup> annual Advances in Prenatal Molecular Diagnostics conference, Boston MA
- 2018 The Latest and Greatest Research on Down Syndrome / Lecture  
Department of Pediatrics, Nationwide Children's Hospital, Columbus, OH
- 2018 The Latest and Greatest Research on Down Syndrome / Lecture  
Quillen College of Medicine, East Tennessee State University, Johnson City, TN
- 2018 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Clinicians Need to Know / Lecture  
Quillen College of Medicine, East Tennessee State University, Johnson City, TN
- 2018 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Grand Rounds  
Department of Pediatrics, Children's Hospitals and Clinics of Minnesota – Minneapolis Campus, Minneapolis, MN
- 2018 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Medical Interest Group Annual Meeting, Dallas, TX
- 2018 Two Years Later: The Implementation of ACMG's NIPS Guidelines / Lecture  
6<sup>th</sup> annual Advances in Prenatal Molecular Diagnostics conference, Boston MA
- 2018 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
Combined Society Meeting of Obstetricians and Pediatricians, Buffalo, NY
- 2018 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Healthcare Professionals Need to Know / Grand Rounds  
Department of Pediatrics, Oishei Children's Hospital, Buffalo, NY

- 2018 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
Jacobs School of Medicine and Biological Sciences, Buffalo, NY
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families  
American College of Medical Genetics and Genomics Annual Clinical Genetics Meeting, Seattle, WA
- 2019 What does it mean to live with Down syndrome?  
AC Immune Key Opinion Leaders meeting, New York City, NY  
[sponsored by AC Immune]
- 2019 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Grand Rounds  
Department of Obstetrics and Gynecology, Medical College of Wisconsin, Milwaukee, WI
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Lecture  
Department of Pediatrics, Mayo Clinic Health System, La Crosse, WI
- 2019 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of Pediatrics, University of Wisconsin Health University Hospital, Madison, WI
- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Waisman Center at University of Wisconsin-Madison, Madison, WI
- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Department of Pediatrics, Gunderson Healthcare, La Crosse, WI
- 2019 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Northwell Health 2019 Perinatal Neonatal Nursing Conference, New Hyde Park, NY
- 2019 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Department of Family Medicine, Saint Joseph Hospital, Ft. Wayne, IN
- 2019 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Central New York Regional Perinatal Program, Crouse Hospital, Syracuse, NY
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers

International Conference on Communication in Healthcare, San Diego, CA

- 2020 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families / Lecture  
American College of Medical Genetics and Genomics Annual Clinical Genetics Meeting, virtual meeting (originally San Antonio, TX)
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families / Lecture  
Down Syndrome Medical Interest Group, virtual meeting (originally New Orleans, LA)
- 2020 Practicing Dignity in Healthcare for People with Intellectual Disabilities: Prenatal Diagnostics / Lecture  
American Academy of Developmental Medicine & Dentistry annual conference, virtual meeting
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families / Lecture  
New York State Genetics Task Force Meeting, virtual meeting (originally New York City, NY)
- 2020 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Remote Grand Rounds  
Division of Medical Genetics and Metabolism, Washington University Medical Center, St. Louis, MO
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families / Online Lecture  
Children's Hospital Wisconsin, Milwaukee, WI
- 2021 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for the Healthcare Professional / Lecture  
Case Western Reserve University, Cleveland, OH (virtual)
- 2021 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Grand Rounds  
Department of Genetics, University of Washington, Seattle WA (virtual)
- 2021 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Grand Rounds  
Department of Pediatrics, Union Hospital, Terre Haute, IN (virtual)
- 2021 Down Syndrome Clinic to You (DSC2U): An Online Automated Clinic for Patients and Families / Online Lecture  
New England Regional Genetics Network conference, New York City, NY (virtual)
- 2021 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Physicians Need to Know / Grand Rounds  
Department of Child Health, University of Missouri, Columbia, MO (virtual)

- 2021 Social Networks of People with Down Syndrome / Lecture  
3<sup>rd</sup> Annual Social Networks in Medicine Symposium, Philadelphia, PA (virtual)
- 2021 5 Decision Points: Building a Meaningful Career in Academic Medicine / Lecture  
Premedical Society, University of Michigan, Ann Arbor, MI (virtual)
- 2021 Incorporating People with Intellectual Disabilities into All Aspects of Your Research /  
Lecture  
Patient-Centered Outcomes Research Institute (PCORI) Annual Meeting, Washington, DC  
(virtual)
- 2022 Guidelines Regarding Prenatal Testing and Educational Materials / Lecture  
Prenatal Disability Education Summit / Joseph P. Kennedy, Jr. Foundation, Baltimore,  
MD
- 2022 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Physicians Need to Know / Grand Rounds  
Department of Pediatrics, University of Pennsylvania Medical Center, Pittsburgh, PA  
(virtual)
- 2022 Healthcare experiences of patients with Down syndrome who are Black, African  
American, of African descent, of mixed race, or come from primarily Spanish-speaking  
homes / Grand Rounds (co-presentation with Albert Pless)  
Department of Pediatrics, UCSF Benioff Children's Hospital, Oakland, CA (virtual)
- 2022 Tongue Pacemaker Reduces Sleep Apnea in Adolescents with Down Syndrome  
National Institute on Deafness and Other Communication Disorders, National Institutes of  
Health, Bethesda, MD (virtual)
- 2022 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates  
for the Healthcare Professional / Lecture  
American College of Osteopathic Obstetricians and Gynecologists national conference,  
Boston, MA
- 2022 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates  
for the Healthcare Professional / Lecture  
Department of Neonatology, Cleveland Clinic, Cleveland, OH (virtual)
- 2022 Tongue Pacemaker Reduces Sleep Apnea in Adolescents with Down Syndrome  
T21 Research Society International Conference, Long Beach, CA
- 2022 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for  
Caregivers and Primary Care Providers  
T21 Research Society International Conference, Long Beach, CA
- 2023 Healthcare experiences of patients with Down syndrome who are Black, African  
American, of African descent, of mixed race, or come from primarily Spanish-speaking

homes / Grand Rounds (co-presentation with Albert Pless)  
Developmental Disabilities Conference, UCSF, Oakland, CA (virtual)

2025 Latest and Greatest Research About Down Syndrome  
University of New England College of Osteopathic Medicine, Biddeford, Maine (virtual)

### **International**

- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Albert Einstein Hospital, Sao Paolo, Brazil
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers  
Japan Society of Human Genetics, Tokyo, Japan
- 2012 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers  
Japan Association for Bioethics, Kyoto, Japan
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers  
KK Women's & Children's Hospital, Singapore
- 2013 Celebrating Life with Down Syndrome  
Karolinska University Hospital, Stockholm, Sweden
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers  
Karolinska University Hospital, Stockholm, Sweden
- 2013 Let's Get Real About Down Syndrome: New Research on Family Attitudes  
Karolinska University Hospital, Stockholm, Sweden
- 2013 What the Other Children Without Down Syndrome are Thinking: Sibling Issues  
Karolinska University Hospital, Stockholm, Sweden
- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Japan Society for Human Genetics, Sendai, Japan
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
St. Luke's International Hospital, Tokyo, Japan
- 2014 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture

Shinshu Univeristy, Matsumoto, Japan

- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: Building the Down Syndrome Program at Massachusetts General Hospital  
Kinki University, Osaka, Japan
- 2015 Predicting Obstructive Sleep Apnea in People with Down Syndrome / Plenary presentation  
Trisomy 21 Research Society, Brain and Spine Institute, Hôpital Pitié Salpêtrière, Paris, France
- 2016 New Prenatal Tests for Down Syndrome: Updates and What This All Means for Professionals and Families / Lecture  
Royal Society of Paediatrics and Child Health, Liverpool, United Kingdom
- 2016 Latest and Greatest Research About Down Syndrome  
Royal Society of Paediatrics and Child Health, Liverpool, United Kingdom
- 2016 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Healthcare Professionals Need to Know / Lecture  
Department of Pediatrics and Adolescent Medicine, Queen Mary Hospital, The University of Hong Kong, China
- 2016 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
Department of Pediatrics, Ospedale Bambino Gesù, Rome, Italy
- 2017 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
Aga Khan University Hospital, Karachi, Pakistan
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Healthcare Professionals Need to Know / Lecture  
59th Annual Meeting of Japanese Society of Child Neurology, Osaka, Japan
- 2017 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Konan University, Kobe, Japan
- 2018 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Healthcare Providers / Lecture  
Onaizah Association for Human Services, Onaizah, Saudi Arabia
- 2018 Latest and Greatest Research About Down Syndrome  
Onaizah Association for Human Services, Onaizah, Saudi Arabia
- 2018 Adult Brothers and Sisters Who Have Siblings with Down Syndrome  
Onaizah Association for Human Services, Onaizah, Saudi Arabia

- 2019 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today’s Healthcare Providers / Lecture  
Indus Health Network, Karachi, Pakistan (virtual)
- 2020 The latest and greatest research on Down syndrome  
5<sup>th</sup> Sabará International Child Health Conference, Sao Paolo, Brazil (virtual)
- 2021 Preparing for a Fulfilling Life in Adulthood: All of the Medical Updates about Down Syndrome that Physicians Need to Know  
Department of Genetic Medicine, Osaka Women’s and Children’s Hospital, Osaka, Japan (virtual)
- 2022 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers  
Department of Clinical Medicine, Aarhus University, Aarhus, Denmark (virtual)
- 2023 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Healthcare Professionals Need to Know / Lecture  
Hippocrates Academy, Netherlands [virtual presentation]
- 2024 If you don’t count, you don’t matter: People with Down syndrome around the world / Testimony  
United Nations, New York City, NY
- 2024 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Trisomy 21 Research Society, Rome, Italy
- 2024 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Australia Association of Developmental Disability Medicine, Brisbane, Australia

## **Report of Clinical Activities and Innovations**

### **Current Licensure and Certification**

- 2004 Passed USMLE Step 1
- 2006 Neonatal Resuscitation (NALS) Provider
- 2006 Passed USMLE Step 2
- 2006 Basic Life Support (BLS) for Healthcare Providers
- 2006 Pediatrics Advanced Life Support Program (PALS) Provider
- 2008 Passed USMLE Step 3
- 2008 Massachusetts Registered Physician
- 2011 Design and Implementation of Clinical Trials, Harvard Catalyst
- 2011 American Board of Medical Genetics
- 2017 Basic Life Support (BLS) for Healthcare Providers

## Practice Activities

2012- current	Ambulatory Care	Medical Genetics, Massachusetts General Hospital	2-3 half-day sessions per week (8-12 hours/week)
2012- current	In-patient consultations	Medical Genetics, Massachusetts General Hospital	1 week every 2 months and 1 weekend per month

## Clinical Innovations

Creating a Virtual Down Syndrome Clinic (2016 to current)	As the P.I. on a \$2M PCORI grant, I oversaw a multidisciplinary team of clinicians and caregivers from around the country who transformed the way that healthcare is delivered to the overwhelming majority of patients with Down syndrome who do not have access to a specialty clinic like the one that I direct at MGH. Down Syndrome Clinic to You (DSC2U, <a href="http://www.dsc2u.org">www.dsc2u.org</a> ) automates customized healthcare information about Down syndrome for caregivers and primary care physicians. Our national randomized controlled trial demonstrated that DSC2U is not only effective in improving medical care but was also received with great satisfaction from both caregivers and primary care physicians. After the grant, I helped launch DSC2U as a first-of-its-kind commercial entity from MassGeneral Hospital, now available in English and Spanish to families all around the world.
Creation of multidisciplinary Down Syndrome Program at Massachusetts General Hospital (2012 to current)	As the Director of the MGH Down Syndrome Program, I helped create a now internationally renowned program of clinical excellence. Each year, my team of about 20 healthcare professionals see ~700 patients with Down syndrome, of all ages, during carefully coordinates multidisciplinary evaluations. Our MGH Down Syndrome Program offers the most robust services in the world for people with Down syndrome, and physicians and community leaders from around the globe, including Japan, Sweden, Canada, and the United Arab Emirates, have come to visit our Program in an effort to replicate our programming. I have also now permanently endowed the MGH Down Syndrome Program, having secured \$10.1M in philanthropic donations to support the operating salaries of the multidisciplinary team of clinicians, who are not otherwise reimbursed in full or in part from insurance reimbursement.
Creation of an International Down Syndrome Patient Database (2012 to current)	I oversee a multi-institutional Patient Database, collecting and tracking clinical data on patients with Down syndrome seen in specialty clinics around the world. Under my leadership, we have published research papers in top-tier medical journals, and I have presented on the Patient Database in international conferences. Ultimately, by closely tracking

longitudinal prospective clinical data on patients with Down syndrome, we will be able to develop more evidence-based guidelines to improve their overall outcomes.

Creating a New Screening Tool for Obstructive Sleep Apnea in Patients with Down Syndrome (2010-2023)

As the P.I. on grants from the NIH and HRSA, I oversaw a team of researchers who investigated a novel assessment for the presence of significant sleep apnea in patients with Down syndrome. This work has been published.

Creating a Mobile App for Nutrition and Exercise Goals for Patients with Down Syndrome (2015 to current)

As the P.I. on an institutional award, I oversaw a multidisciplinary team of clinicians and software engineers to design a mobile app which empowers patients with Down syndrome, and their caregivers, to address obesity and its co-morbidities. We have engaged a team of patients with Down syndrome and caregivers in focus group and design workshops to help create this first-of-its-kind application for a population with intellectual disabilities. This work has been published, and the mobile app is currently available through the Apple store.

Creation of Electronic intake form at Down Syndrome Program at Massachusetts General Hospital (2014 to current)

This first-ever HIPAA-compliant electronic intake form allows families and caregivers to input clinically relevant information in advance of clinical appointments at the MGH Down Syndrome Program. This resulted in more efficient and effective care and higher satisfaction levels from our patients. The data collected through these intake forms have also been used for quality improvement projects. This intake form has also served as a national model, and we have plans to license the form to other healthcare systems.

Creation of Registry of Patients in Medical Genetics Division at Massachusetts General Hospital (2013 to 2017)

I created an online, secure registry, using REDCap software, for our Division to track all of the patients seen in our general genetics and metabolism out-patient clinics. This clinical advancement has allowed our Division to perform quality improvement projects and link families whose members have similar diagnoses.

Creation of multidisciplinary Down Syndrome Program at Boston Children's Hospital (2009-2012)

As an Instructor, I expanded the Down Syndrome Program at Boston Children's Hospital to offer, for the first time, multidisciplinary services to patients with Down syndrome between the ages of 3 to 18. Our team of 8 healthcare professional saw about 300 patients with Down syndrome each year. During this time, I also helped oversee an online series of ~25 one-hour Webinars for caregivers and families on a diversity of topics related to their children's needs (e.g., celiac disease, toilet training).

## **Report of Education of Patients and Service to the Community**

### **Activities**

No activities or materials below were sponsored by 3rd parties/outside entities.

- 2006 Celebrating Life with Down Syndrome / Lecture  
YMCA of Wykoff, NJ
- 2007 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings  
with Down Syndrome / Seminar  
Massachusetts Down Syndrome Congress, Worcester, MA
- 2007 What Your Other Children are Thinking / Lecture  
Down Syndrome Association of Middle Tennessee, Nashville, TN
- 2008 Brothers and Sisters Who Have Siblings with Down Syndrome: Questions and  
Answers / Lecture  
Affiliates In Action Conference, Scottsdale, AZ (national)
- 2008 Compassionate Delivery of a New Diagnosis to New and Expectant Parents of  
Children with Down Syndrome/ Lecture  
Affiliates In Action Conference, Scottsdale, AZ (national)
- 2008 Prenatal and Postnatal Medical Support: Capturing the Sentiments of Parents Who  
Have Children with Down Syndrome / Keynote  
National Down Syndrome Congress, Boston, MA (national)
- 2008 What Your Other Children Are Thinking/ Keynote  
National Down Syndrome Congress, Boston, MA
- 2008 Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY
- 2008 What Your Other Children Are Thinking / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY
- 2008 What Your Other Children are Thinking / Lecture  
Fundación Síndrome de Down de Nuevo León, Monterrey, Mexico (international)
- 2008 Brothers and Sisters: Lifelong Teachers/ Lecture  
Fundación Síndrome de Down de Nuevo León, Monterrey, Mexico (international)
- 2008 What Your Other Children Are Thinking / Lecture  
Down Syndrome Association of Central Florida, Orlando, FL
- 2008 Giving the Diagnosis of Down Syndrome: The 'How To' Guide / Lecture  
Down Syndrome Association of Central Florida, Orlando, FL
- 2008 Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Network of West Virginia, Charleston, WV

- 2008      What Your Other Children Without Down Syndrome Are Thinking: Sibling  
Issues / Lecture  
Down Syndrome Association of Atlanta, Atlanta, GA
- 2008      Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Association of Atlanta, Atlanta, GA
- 2008      Compassionate Delivery of a New Diagnosis to New and Expectant Parents of  
Children with Down Syndrome / Lecture  
Down Syndrome Association of Atlanta, Atlanta, GA
- 2009      What Your Other Children Without Down Syndrome Are Thinking: Sibling  
Issues / Lecture  
Down Syndrome Guild of Greater Kansas City, Kansas City, MO
- 2009      What your other children without Down syndrome are thinking: Sibling issues /  
Lecture  
Down Syndrome Association of Peterborough, Ontario, Canada (international)
- 2009      What your other children without Down syndrome are thinking: Sibling issues /  
Lecture  
Down Syndrome Affiliates in Action, Washington, D.C. (national)
- 2009      Prenatal and postnatal medical support: How your group can make a difference/  
Lecture  
Down Syndrome Affiliates in Action, Washington, D.C. (national)
- 2009      Celebrating Life with Down Syndrome / Lecture  
The Down Syndrome Association of Greater St. Louis, St. Louis, MO
- 2009      What your other children without Down syndrome are thinking: Sibling issues /  
Lecture  
National Down Syndrome Congress, Sacramento, CA (national)
- 2009      What your other children without Down syndrome are thinking: Sibling issues /  
Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA
- 2009      What your other children without Down syndrome are thinking: Sibling issues /  
Lecture  
Down Syndrome Association of Memphis & the Mid-South, Memphis, TN
- 2009      Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Association of Memphis & the Mid-South, Memphis, TN
- 2009      Down Syndrome / Lecture  
Loveland, Inc., Lincoln, MA

- 2009 A Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and Expectant Parents / Lecture  
Kennedy Willis Center on Down Syndrome, Cooperstown, NY
- 2009 Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Association of Northern Virginia, Fairfax, VA
- 2009 What your other children without Down syndrome are thinking: Sibling issues / Lecture  
Down Syndrome Association of Northern Virginia, Fairfax, VA
- 2009 What your other children without Down syndrome are thinking: Sibling issues / Lecture  
Down Syndrome Association of Delaware, Wilmington, DE
- 2009 What your other children without Down syndrome are thinking: Sibling issues / Lecture  
Down Syndrome Association of Central Ohio, Columbus, OH
- 2009 What your other children without Down syndrome are thinking: Sibling issues / Lecture  
Down Syndrome Information Alliance, Sacramento, CA
- 2010 Making a Diagnosis of Down Syndrome: New Advances and Updates for Healthcare Professionals / Lecture  
Down Syndrome Network of Montgomery County, Bethesda, MD
- 2010 Down Syndrome Prenatal Testing: Everything Your Group Should Know and Should Be Doing / Lecture  
National Down Syndrome Society, New York City, NY (national)
- 2010 Celebrating Life with Down Syndrome / Lecture  
Greater Clear Lake Families Exploring Down Syndrome, Houston, TX
- 2010 What your other children without Down syndrome are thinking: Sibling issues / Lecture  
Greater Clear Lake Families Exploring Down Syndrome, Houston, TX
- 2010 Celebrating Life with Down Syndrome / Lecture  
Canadian Down Syndrome Society, Regina, Saskatchewan, Canada (international)
- 2010 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues/ Lecture  
Canadian Down Syndrome Society, Regina, Saskatchewan, Canada (international)
- 2010 Down Syndrome Prenatal Testing: Everything Your Group Should Know and Should Be Doing / Lecture  
Down Syndrome Affiliates in Action, Kansas City, MO

- 2010 Sibling Issues: What Your Organization Can Do to Support Brothers and Sisters/  
Lecture  
Down Syndrome Affiliates in Action, Kansas City, MO
- 2010 What Your Other Children without Down Syndrome are Thinking / Lecture  
GRAAL, Krakow, Poland (international)
- 2010 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know/ Lecture  
GRAAL, Krakow, Poland (international)
- 2010 Therapies for Children and Adolescents with Down Syndrome/ Lecture  
GRAAL, Krakow, Poland (international)
- 2010 What Your Other Children Without Down Syndrome Are Thinking: Sibling  
Issues / Lecture  
Down Syndrome Association of Roanoke, Roanoke, VA
- 2010 Challenging Dynamic: Delivering a Diagnosis of Down Syndrome to New and  
Expectant Parents / Lecture  
Down Syndrome Association of Roanoke, Roanoke, VA
- 2010 Celebrating Life with Down Syndrome / Lecture  
Down Syndrome Association of Roanoke, Roanoke, VA
- 2010 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
National Down Syndrome Congress, Orlando, FL
- 2010 New Prenatal Tests for Down Syndrome: Local Updates, National Strategies, and  
What This All Means for Your Family / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA
- 2010 Celebrating Life with Down Syndrome / Lecture  
Eastern Pennsylvania Down Syndrome Center, Center Valley, PA
- 2010 Crash Course on Down Syndrome for Brothers & Sisters / Lecture  
Eastern Pennsylvania Down Syndrome Center, Center Valley, PA
- 2010 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings  
with Down Syndrome / Lecture  
Down Syndrome Aim High Resource Center, Albany, NY
- 2010 REDCap Registry: A practical solution for the Down Syndrome Program at  
Children's Hospital Boston / Lecture  
National Down Syndrome Society, Washington, D.C. (national)

- 2010 New Prenatal Tests for Down Syndrome: Local Updates, National Strategies, and What This All Means for Your Family / Lecture  
Down Syndrome Guild of Southeast Michigan, Dearborn, MI
- 2010 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Guild of Southeast Michigan, Dearborn, MI
- 2010 Current Research on Prenatal Testing and Parent Responses / Lecture  
Down Syndrome Guild of Greater Kansas City, Kansas City, KS
- 2010 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Guild of Greater Kansas City, Kansas City, KS
- 2010 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Association of West Michigan, Grand Rapids, MI
- 2010 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Wisconsin Upside Down, Milwaukee, WI
- 2010 Crash Course on Down Syndrome for Brothers & Sisters / Lecture  
Down Syndrome Association of Houston, Houston, TX
- 2010 Celebrating Exceptionalities / Keynote  
North Coast Community Homes, Cleveland, OH
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA
- 2011 Celebrating Life with Down Syndrome / Keynote  
Down Syndrome Association of Central Oklahoma, Oklahoma City, OK
- 2011 What Your Other Children Without Down Syndrome are Thinking: Sibling Issues / Lecture  
Down Syndrome Association of Central Oklahoma, Oklahoma City, OK
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All of the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Central Oklahoma, Oklahoma City, OK
- 2011 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Fundación Down Tigre, Buenos Aires, Argentina (international)

- 2011 Prenatal Testing for Down Syndrome: National Updates and What Your Affiliate Can and Should Be Doing Right Now / Lecture  
Down Syndrome Affiliates in Action, Dallas, TX (national)
- 2011 Healthy Students with Down Syndrome: All the Medical Updates that Educators Need to Know / Lecture  
Down Syndrome Network of Montgomery County, Gaithersburg, MD
- 2011 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
National Down Syndrome Society, New York City, NY (national)
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All of the Medical Updates that Parents Need to Know / Lecture  
Family Resources Associates, Inc., Colts Neck, NJ
- 2011 Brothers and Sisters with Rett Syndrome / Lecture  
International Rett Syndrome Foundation, Boston, MA (national)
- 2011 Crash Course on Down Syndrome for Brothers & Sisters / Lecture  
Down Syndrome Information Alliance, Sacramento, CA
- 2011 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Information Alliance, Sacramento, CA
- 2011 Down Syndrome Patient Registry Pilot Project / Lecture  
National Down Syndrome Congress, San Antonio, TX (national)
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
National Down Syndrome Congress, San Antonio, TX (national)
- 2011 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome/ Lecture  
National Down Syndrome Congress, San Antonio, TX (national)
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All of the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Alliance of the Midlands, Omaha, NE
- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All of the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Exeter, NH
- 2011 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Rett Syndrome / Webinar  
International Rett Syndrome Association, Boston, MA (national)

- 2011      What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues  
for Parents / Lecture  
St. Clair County Community Mental Health Authority, Port Huron, MI
- 2011      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know/ Lecture  
St. Clair County Community Mental Health Authority, Port Huron, MI
- 2011      Celebrating Life with Down Syndrome/ Lecture  
St. Clair County Community Mental Health Authority, Port Huron, MI
- 2011      New Prenatal Tests for Down Syndrome: National Updates and What This All  
Means for Your Family/ Lecture  
St. Clair County Community Mental Health Authority, Port Huron, MI
- 2011      Celebrating Life with Down Syndrome / Keynote  
Connecticut Down Syndrome Congress, Westbrook, CT
- 2011      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know/ Keynote  
Connecticut Down Syndrome Congress, Westbrook, CT
- 2011      What Your Other Children Without Down Syndrome are Thinking: Sibling Issues  
for Parents / Lecture  
Connecticut Down Syndrome Congress, Westbrook, CT
- 2012      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Alliance of the Midlands, Omaha, NE
- 2012      What Your Other Children Without Down Syndrome are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Alliance of the Midlands, Omaha, NE
- 2012      Prenatal Tests for Down Syndrome: All of the Updates that Your Group Needs to  
Know / Lecture  
Down Syndrome Affiliates in Action, Washington, D.C. (national)
- 2012      Let's Get Real About Down Syndrome: How You Can Use New Research for  
Families/ Lecture  
Down Syndrome Affiliates in Action, Washington, D.C. (national)
- 2012      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA
- 2012      What your other children without Down syndrome are thinking: Sibling Issues/  
Lecture

Massachusetts Down Syndrome Congress, Worcester, MA

- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
South Carolina Down Syndrome Family Conference, Colombia, SC
- 2012 What your other children without Down syndrome are thinking: Sibling issues/ Lecture  
South Carolina Down Syndrome Family Conference, Colombia, SC
- 2012 Celebrating Life with Down Syndrome / Lecture  
Upper Peninsula Down Syndrome Association, Marquette, MI
- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Upper Peninsula Down Syndrome Association, Marquette, MI
- 2012 New Prenatal Tests for Down Syndrome: National Updates and What This All Means for Your Family / Lecture  
Massachusetts Down Syndrome Congress, Ipswich, MA
- 2012 Down Syndrome Patient Database / Lecture  
Down Syndrome Medical Interest Group, Washington, DC (national)
- 2012 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
National Down Syndrome Congress Convention, Washington, DC (national)
- 2012 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
World Down Syndrome Congress Convention, Cape Town, South Africa (international)
- 2012 New Prenatal Tests for Down Syndrome: National Updates and What This All Means for Your Family / Lecture  
World Down Syndrome Congress Convention, Cape Town, South Africa (international)
- 2012 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
World Down Syndrome Congress Convention, Cape Town, South Africa (international)
- 2012 Celebrating Life with Down Syndrome / Lecture  
World Down Syndrome Congress Convention, Cape Town, South Africa (international)
- 2012 Celebrating Life with Down Syndrome / Keynote  
National Association for Down Syndrome, Chicago, IL (national)

- 2012      What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
National Association for Down Syndrome, Chicago, IL (national)
- 2012      Celebrating Life with Down Syndrome / Keynote  
The Early Childhood Direction Center, Edmeston, NY (national)
- 2012      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
The Early Childhood Direction Center, Edmeston, NY (national)
- 2012      What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
The Early Childhood Direction Center, Edmeston, NY (national)
- 2012      Celebrating Life with Disabilities / Keynote  
The Moore Center, Manchester, NH (national)
- 2012      Celebrating Life with Disabilities / Keynote  
Down Syndrome Awareness Group of East Tennessee (national)
- 2013      What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Association of Greater Charlotte, Charlotte, NC (national)
- 2013      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Singapore, Singapore (international)
- 2013      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Gigi's Playhouse, Rockford, IL (national)
- 2012      Celebrating Life with Disabilities / Keynote  
Gigi's Playhouse, Rockford, IL (national)
- 2012      Celebrating Life with Disabilities / Keynote  
Down Syndrome Association of Acadiana, Lafayette, LA (national)
- 2013      What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Association of Acadiana, Lafayette, LA (national)
- 2013      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Acadiana, Lafayette, LA (national)

- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Educators Need to Know / Lecture  
Down Syndrome Association of Acadiana, Lafayette, LA (national)
- 2013 Let's Get Real About Down Syndrome: How You Can Use New Research on Families / Lecture  
Down Syndrome Association of Acadiana, Lafayette, LA (national)
- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)
- 2013 The Brave New World of Prenatal Testing / Lecture  
The Jack Kent Cooke Foundation (regional)
- 2013 Celebrating Life with Disabilities / Keynote  
Down Syndrome Association of San Diego, San Diego, CA (national)
- 2013 Celebrating Life with Disabilities / Keynote  
Canadian Down Syndrome Society, Winnipeg, Canada (international)
- 2013 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Canadian Down Syndrome Society, Winnipeg, Canada (international)
- 2013- National Center for Prenatal and Postnatal Down Syndrome Diagnoses Resources / Professional Advisory Committee  
Provide guidance to the national organization on accurate, up-to-date, balanced materials for expectant women
- 2013 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Wyoming Down Syndrome Association, Casper, Wyoming (national)
- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Wyoming Down Syndrome Association, Casper, Wyoming (national)
- 2013 Adult Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
National Down Syndrome Congress Convention, Denver, CO (national)
- 2013 Prenatal and Postnatal Diagnoses of Down Syndrome: New Advances and Updates for Today's Physicians / Lecture  
Department of Developmental Services, Boston, MA
- 2013 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Chesapeake Down Syndrome Parents Group (national)

- 2013 Celebrating Life with Disabilities / Lecture  
Trisomy 21 Foundation of Northern New York (national)
- 2013 Celebrating Life with Down syndrome / Lecture  
Svenska Downforeningen, Stockholm, Sweden (international)
- 2013 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Maine Down Syndrome Network, Portland, ME (regional)
- 2013 Celebrating Life with Disabilities / Plenary talk  
Maine Down Syndrome Network, Portland, ME (regional)
- 2013 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Maine Down Syndrome Network, Portland, ME (regional)
- 2013 Crash Course on Down Syndrome for Brothers & Sisters / Workshop  
Maine Down Syndrome Network, Portland, ME (regional)
- 2014 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Father's Joy, Houston, TX (national)
- 2014 Crash Course on Down Syndrome for Brothers & Sisters / Workshop  
Father's Joy, Houston, TX (national)
- 2014 Celebrating Life with Disabilities / Keynote talk  
Down Syndrome Association of Northeast Indiana, Ft. Wayne, IN (regional)
- 2014 Adult Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Association of Northeast Indiana, Ft. Wayne, IN (regional)
- 2014 What is the New Prenatal Testing, and How Can Affiliates Respond? / Webinar  
Lecture  
National Center for Prenatal and Postnatal Down Syndrome Resources (national)
- 2014 Celebrating Life with Disabilities / Keynote talk  
Down Syndrome Parent Group of Western New York, Buffalo, NY (regional)
- 2014 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Parent Group of Western New York, Buffalo, NY (regional)
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Parent Group of Western New York, Buffalo, NY (regional)

- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Family Resource Associates, Inc., Shrewsbury, NJ
- 2014 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
National Down Syndrome Congress Annual Convention, Indianapolis, IN (national)
- 2014 Adult Brothers and Sisters who Have Siblings with Down Syndrome  
National Down Syndrome Congress Annual Convention, Indianapolis, IN (national)
- 2014 What Your Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Down Syndrome Association of Greater Charlotte, Charlotte, NC (national)
- 2014 Celebrating Life with Disabilities / Keynote talk  
Down Syndrome Association of Greater Charlotte, Charlotte, NC (national)
- 2014 Crash Course on Down Syndrome for Brothers & Sisters / Lecture  
Down Syndrome Association of Greater Charlotte, Charlotte, NC (national)
- 2014 Down Syndrome / Lecture  
Wells Fargo, Charlotte, NC (national)
- 2014 Celebrating Life with Disabilities / Keynote talk  
CCARC, New Britain, CT (regional)
- 2014 Celebrating Life with Disabilities / Keynote Remarks  
ACDS, Plainview, NY (national)
- 2014 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Human First, Westbury, NY (national)
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Service Providers Need to Know / Lecture  
Human First, Westbury, NY (national)
- 2014 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
The 21 Club, New Hartford, NY (national)
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
The 21 Club, New Hartford, NY (national)
- 2014 New Prenatal Tests for Down Syndrome: National Updates and What This All Means for Your Family / Lecture

- The 21 Club, New Hartford, NY (national)
- 2014 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2014 New Prenatal Tests for Down Syndrome: National Updates and What This All Means for Your Family / Lecture  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2014 Celebrating Life with Disabilities / Lecture  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2014 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Advocacy Foundation of Long Island, Brookville, NY (national)
- 2014 Adult Brothers and Sisters who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Advocacy Foundation of Long Island, Brookville, NY (national)
- 2014 Keeping Students with Down Syndrome Healthy: All the Medical Updates that Educators Need to Know / Lecture  
Down Syndrome Advocacy Foundation of Long Island, Brookville, NY (national)
- 2015 Celebrating Life with Disabilities / Keynote  
GiGi's Playhouse, Syracuse, NY (national)
- 2015 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Down Syndrome Association of Wisconsin, La Crosse, WI (national)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Wisconsin, Marshfield, WI (national)
- 2015 The Latest and Greatest Research About Down Syndrome / Lecture  
Family Resources Associates, Inc., Shrewsbury, NJ (national)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)
- 2015 The Latest and Greatest Research About Down Syndrome / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)

- 2015 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Down Syndrome Association of Central Ohio, Columbus, OH (national)
- 2015 New Prenatal Tests for Down Syndrome: New Advances in Genetic Testing / Lecture  
Down Syndrome Association of Central Ohio, Columbus, OH (national)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Alliance of the Midlands, Omaha, NE (national)
- 2015 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2015 Crash Course on Down Syndrome for Brothers & Sisters / Workshop  
Down Syndrome Association for Families of Nebraska, Lincoln, NE (national)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 Adult Brothers and Sisters who Have Siblings with Down Syndrome / Lecture  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 Celebrating Life with Down Syndrome / Keynote  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 Weight Management Challenges for People with Down Syndrome / Lecture  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 New Prenatal Tests for Down Syndrome: National Updates and What This All Means  
for Your Family  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows  
World Down Syndrome Congress conference, Chennai, India (international)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Wisconsin, Green Bay, WI (national)
- 2015 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Family Connections of South Carolina, Lexington, SC (national)

- 2015           The Latest and Greatest Research About Down Syndrome / Lecture  
Family Connections of South Carolina, Lexington, SC (national)
- 2016           Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Awareness Group (DSAG) of Baton Rouge, Baton Rouge, LA  
(national)
- 2016           Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Down Syndrome Awareness Group (DSAG) of Baton Rouge, Baton Rouge, LA  
(national)
- 2016           The Latest and Greatest Research About Down Syndrome / Lecture  
Down Syndrome Awareness Group (DSAG) of Baton Rouge, Baton Rouge, LA  
(national)
- 2016           What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Awareness Group (DSAG) of Baton Rouge, Baton Rouge, LA  
(national)
- 2016           Crash Course on Down Syndrome for Brothers & Sisters / Lecture  
Down Syndrome Awareness Group (DSAG) of Baton Rouge, Baton Rouge, LA  
(national)
- 2016           Celebrating Life with Down Syndrome / Keynote  
GiGi's Playhouse Westchester, Tarrytown, NY (national)
- 2016           Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Down Syndrome Awareness Group of East Tennessee, Knoxville, TN (national)
- 2016           Keeping Students with Down Syndrome Healthy: All the Medical  
Updates that Educators Need to Know / Lecture  
Down Syndrome Association of Delaware, Wilmington, DE (national)
- 2016           The Latest and Greatest Research about Down Syndrome / Lecture  
Down Syndrome Association of Delaware, Wilmington, DE (national)
- 2016           Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Canadian Down Syndrome Society, Montreal, Canada (international)
- 2016           The Latest and Greatest Research about Down Syndrome / Lecture  
Canadian Down Syndrome Society, Montreal, Canada (international)
- 2016           What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture

- National Down Syndrome Congress Convention, Orlando, FL (national)
- 2016 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
Chesapeake Down Syndrome Parent Group, Baltimore, MD (national)
- 2016 Brothers and Sisters Workshop  
Chesapeake Down Syndrome Parent Group, Baltimore, MD (national)
- 2016 Prenatal Diagnoses of Down Syndrome: Delivering Results in our New Age of Genetic Testing  
Upside for Down Foundation, De Vervolmaakte Mens, Leiden, Netherlands (international)
- 2016 Common Threads: Celebrating Life with Down Syndrome / Keynote Lecture  
Metrocare Services, Dallas, Texas (national)
- 2016 The Latest and Greatest Research about Down Syndrome / Lecture  
Metrocare Services, Dallas, Texas (national)
- 2016 My Life as a Clinical Geneticist / Lecture  
The Hotchkiss School, Salisbury, Connecticut (regional)
- 2016 Building a Virtual Clinic for Patients with Down Syndrome / Lecture  
Ariadne Labs, Boston, MA (regional)
- 2017 Medical Updates: Keeping Children and Adolescents with Down Syndrome Healthy / Lecture  
Blessed by Downs, Thibodaux, LA (regional)
- 2017 The Latest and Greatest Research about Down Syndrome / Lecture  
Blessed by Downs, Thibodaux, LA (regional)
- 2017 Celebrating Life with Down Syndrome / Keynote  
Blessed by Downs, Thibodaux, LA (regional)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Central Florida, Orlando, FL (regional)
- 2017 The Latest and Greatest Research about Down Syndrome / Lecture  
Down Syndrome Association of Central Florida, Orlando, FL (regional)
- 2017 Common Threads: Celebrating Life with Down Syndrome / Keynote Lecture  
Down Syndrome Association of Central Florida, Orlando, FL (regional)
- 2017 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture

- Down Syndrome Association of Central Florida, Orlando, FL (regional)
- 2017 Adult Brothers and Sisters who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Association of Central Florida, Orlando, FL (regional)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (local)
- 2017 Promising Developments in Alzheimer's Research & Down Syndrome / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (local)
- 2017 Celebrating Life with Down Syndrome / Keynote  
GiGi's Playhouse NYC, New York City, NY (national)
- 2017 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
Down Syndrome Association of Middle Tennessee, Nashville, TN (regional)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Flower City Down Syndrome Network, Rochester, NY (regional)
- 2017 Down Syndrome: Not Just an Extra Chromosome (lecture)  
Yokohama Project, Yokohama, Japan (international)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Yokohama Project, Yokohama, Japan (international)
- 2017 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Lecture  
National Down Syndrome Congress, Sacramento, CA (national)
- 2017 Our New Age of Genetic Testing / Lecture  
Anne Carlsen Center, Medora, ND (national)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Designer Genes of North Dakota, Bismarck, ND (national)
- 2017 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues / Opening Lecture  
Down Syndrome Federation of India, New Delhi, India (international)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Federation of India, New Delhi, India (international)

- 2017 The Latest and Greatest Research about Down Syndrome / Lecture  
Upside of Downs, Cleveland, OH (national)
- 2017 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Deutsches Down-Syndrom InfoCenter, Nuremberg, Germany (international)
- 2017 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Down Syndrome Association of Wisconsin, Milwaukee, WI (national)
- 2017 Crash Course on Down Syndrome for Brothers & Sisters  
Down Syndrome Association of Wisconsin, Milwaukee, WI (national)
- 2018 The Latest and Greatest Research about Down Syndrome / Lecture  
F.R.I.E.N.D.S., Johnson City, TN (national)
- 2018 Celebrating Life with Down Syndrome / Keynote  
F.R.I.E.N.D.S., Johnson City, TN (national)
- 2018 What the Other Children Without Down Syndrome Are Thinking: Sibling Issues /  
Lecture  
Massachusetts Down Syndrome Congress annual conference, Worcester, MA  
(regional)
- 2018 Obstructive Sleep Apnea in People with Down Syndrome / Lecture  
Massachusetts Down Syndrome Congress annual conference, Worcester, MA  
(regional)
- 2018 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings  
with Down Syndrome / Lecture  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018 Adult Brothers and Sisters Who Have Siblings with Down Syndrome  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018 Down Syndrome & Unexplained Regression  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018 Prenatal Diagnoses of Down Syndrome: New Advances and Updates for Today's  
Healthcare Providers / Lecture  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018 Down Syndrome Clinic to You (DSC2U): An Online Personal Care Plan for  
Caregivers and Primary Care Providers  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings

- with Down Syndrome / Lecture  
World Down Syndrome Congress, Glasgow, Scotland (international)
- 2018      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings  
with Down Syndrome / Lecture  
National Down Syndrome Congress Convention, Dallas, TX (national)
- 2018      Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Grand  
Rounds  
Jack's Basket, Minneapolis, MN (national)
- 2018      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings  
with Down Syndrome / Lecture  
Down Syndrome Federation of India, Pune, India (international)
- 2018      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Down Syndrome Federation of India, Pune, India (international)
- 2018      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
Canadian Down Syndrome Society Annual Conference, Hamilton, Canada  
(international)
- 2018      Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Grand  
Rounds  
Canadian Down Syndrome Society Annual Conference, Hamilton, Canada  
(international)
- 2018      Obstructive Sleep Apnea in People with Down Syndrome / Lecture  
LuMind Down Syndrome Research Foundation, Boston MA (regional)
- 2018      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical  
Updates that Parents Need to Know / Lecture  
21 Connect, Buffalo, NY (national)
- 2019      Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for  
Caregivers and Primary Care Providers  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)
- 2019      Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for  
Caregivers and Primary Care Providers  
National Down Syndrome Congress, Pittsburgh, PA (national)
- 2019      Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's  
Disease in Patients with Down Syndrome  
National Down Syndrome Congress, Pittsburgh, PA (national)

- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome Association of Wisconsin, Milwaukee, WI (national)
- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
UP21 Foundation, Covington, LA (national)
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
UP21 Foundation, Covington, LA (national)
- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome Advocacy Foundation, Brookville, NY (national)
- 2019 Down Syndrome: All People Deserve to be Healthy  
Fidelity, Boston MA (regional)
- 2019 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome Association of Minnesota, Minneapolis, MN (national)
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers  
Down Syndrome Association of Minnesota (national)
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers  
Special Needs Initiative, United Healthcare, Minneapolis, MN (national)
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Clinicians Need to Know / Lecture  
Down Syndrome Association of Northeast Indiana, Ft. Wayne, IN (regional)
- 2019 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers  
Down Syndrome Association of Northeast Indiana, Ft. Wayne, IN (regional)
- 2019 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
The 21 Cub of Central New York, Utica, NY (regional)
- 2019 Taking Care of Your Family: Celebrating the Highs and Surviving the Lows / Lecture  
The 21 Cub of Central New York, Utica, NY (regional)
- 2020 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture

Family Resource Associates, Inc., Red Bank, NJ (regional)

- 2020 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
GiGi's Playhouse, El Paso, TX (regional)
- 2020 Two Virtual Toolkits for Down Syndrome Associations: Online Medical Clinic (DSC2U) and Brothers & Sisters Workshops / Lecture  
Down Syndrome Affiliates in Action, Orlando, FL (national)
- 2020 Safety Considerations as the Re-Entry Process Begins for People with Down Syndrome into Their Communities / Webinar  
Massachusetts Down Syndrome Congress, virtual presentation to Boston, MA (regional)
- 2020 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Association of Los Angeles, virtual presentation to Los Angeles, CA (regional)
- 2020 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents and Educators Need to Know / Lecture  
Down Syndrome Association of Wisconsin, virtual presentation to Milwaukee, WI (regional)
- 2020 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Unified Health & Performance, virtual presentation to Boston, MA (local)
- 2020 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
F.R.I.E.N.D.S., virtual presentation to Johnston City, TN (regional)
- 2020 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
F.R.I.E.N.D.S., virtual presentation to Johnston City, TN (regional)
- 2020 Brothers-and-Sisters who have Siblings with Down Syndrome / Workshop  
Down Syndrome Association of Minnesota, virtual co-presentation to Minneapolis, MN (regional)
- 2020 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Down Syndrome Association of Minnesota, virtual presentation to Minneapolis, MN (regional)
- 2020 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture

- Down Syndrome Association of Minnesota, virtual presentation to Minneapolis, MN (regional)
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Association of Minnesota, virtual presentation to Minneapolis, MN (regional)
- 2020 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Yokohama Project, virtual presentation to Yokohama, Japan (international)
- 2020 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Yokohama Project, virtual co-presentation to Yokohama, Japan (international)
- 2021 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Association of Delaware, virtual presentation to Delaware (national)
- 2021 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome Association of Delaware, virtual presentation to Delaware (national)
- 2021 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Association of Central Ohio, virtual presentation to Columbus, OH (national)
- 2021 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Affiliate in Action, virtual presentation (national)
- 2021 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Massachusetts Down Syndrome Congress, virtual presentation (regional)
- 2021 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Project Irmãos, virtual co-presentation to Sao Paolo, Brazil (international)
- 2021 COVID-19 Updates for People with Down Syndrome and their Families / Panel Discussion  
Massachusetts Down Syndrome Congress, virtual co-presentation, Massachusetts (regional)
- 2021 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture

- National Down Syndrome Congress annual conference, virtual presentation (national)
- 2021 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome Association of Central Ohio, virtual presentation (regional)
- 2021 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
Down Syndrome Association of New Zealand, virtual co-presentation to New Zealand (international)
- 2021 COVID-19 Updates for People with Down Syndrome and their Families / Panel Discussion  
Massachusetts Down Syndrome Congress, virtual co-presentation, Massachusetts (regional)
- 2022 Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, of mixed race, or come from primarily Spanish-speaking homes / Lecture (co-presentation with Albert Pless)  
Down Syndrome Affiliates in Action conference, Las Vegas, NV (national)
- 2022 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
European Down Syndrome Association, virtual presentation (international)
- 2022 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
National Down Syndrome Society, virtual presentation (national)
- 2022 Healthcare experiences of patients with Down syndrome who are Black, African American, of African descent, of mixed race, or come from primarily Spanish-speaking homes / Lecture (co-presentation with Albert Pless)  
National Down Syndrome Congress conference, New Orleans, LA (national)
- 2022 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture  
National Down Syndrome Congress conference, New Orleans, LA (national)
- 2022 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
National Down Syndrome Congress conference, New Orleans, LA (national)
- 2022 Down Syndrome Clinic to You (DSC2U): An Online Personalized Care Plan for Caregivers and Primary Care Providers / Lecture  
Down Syndrome Affiliates in Action, virtual presentation (national)
- 2022 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome New South Wales, Australia, virtual presentation (international)

- 2022      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture (co-presentation with Sue Levine)  
New Zealand Down Syndrome Association, virtual presentation (international)
- 2022      Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
21 Club of Central New York, virtual presentation (national)
- 2022      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
21 Club of Central New York, virtual presentation (national)
- 2022      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Down Syndrome New South Wales, Australia, virtual presentation (international)
- 2022      The Latest and Greatest Research on Down Syndrome / Lecture  
Svenska Downföreningen, Stockholm, Sweden (international)
- 2023      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture (co-presentation with Sue Levine)  
Down Syndrome New South Wales, Australia, virtual presentation (international)
- 2023      What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture (co-presentation with Sue Levine)  
Massachusetts Down Syndrome Congress, virtual presentation (local)
- 2023      Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY, virtual presentation (national)
- 2023      Down Syndrome: Not Just an Extra Chromosome / Lecture  
Down Syndrome New South Wales, Australia, virtual presentation (international)
- 2023      Down Syndrome Clinic to You (DSC2U)/ Lecture  
International Mosaic Down Syndrome Association, San Diego, CA, (international)
- 2023      Down Syndrome Clinic to You (DSC2U)/ Lecture  
Down Syndrome Diagnosis Network, virtual presentation (national)
- 2023      Down Syndrome Clinic to You (DSC2U)/ Lecture  
Down Syndrome Association of Northeast Ohio, virtual presentation (national)
- 2023      Down Syndrome Clinic to You (DSC2U)/ Lecture  
New Zealand Down Syndrome Association, virtual presentation (international)

- 2024 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
Down Syndrome New South Wales, Australia, virtual presentation (international)
- 2024 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Georgian Down Syndrome Association, Georgia, virtual presentation (international)
- 2024 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)
- 2024 What Your Other Children Are Thinking: Brothers and Sisters Who Have Siblings with Down Syndrome / Lecture (co-presentation with Sue Levine)  
Down Syndrome New South Wales, New South Wales, Australia, virtual presentation (international)
- 2024 If you don't count, you don't matter: People with Down syndrome around the world / Keynote  
World Down Syndrome Congress, Brisbane, Australia (international)
- 2024 Down Syndrome Clinic to You (DSC2U)/ Lecture  
World Down Syndrome Congress, Brisbane, Australia (international)
- 2024 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
World Down Syndrome Congress, Brisbane, Australia (international)
- 2024 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Health Professionals Need to Know / Lecture  
World Down Syndrome Congress, Brisbane, Australia (international)
- 2024 Down Syndrome Clinic to You (DSC2U)/ Lecture  
Lettercase National Center for Prenatal and Postnatal Resources, Human Development Institute - University Center for Excellence in Developmental Disabilities, University of Kentucky, Lexington, KY, virtual presentation (national)
- 2024 Brain Train: SMART Actions that Might Boost Cognition and Prevent Alzheimer's Disease in Patients with Down Syndrome / Lecture  
New Zealand Down Syndrome Association, virtual presentation (international)
- 2024 Down Syndrome Clinic to You (DSC2U)/ Lecture  
New Zealand Down Syndrome Association, virtual presentation (international)
- 2024 Down Syndrome Clinic to You (DSC2U)/ Lecture  
Down Syndrome Connections Las Vegas, Las Vegas NV (national)
- 2024 Celebrating Life with Down Syndrome / Keynote

- Down Syndrome Connections Las Vegas, Las Vegas NV (national)
- 2024 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY, virtual presentation (national)
- 2025 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Massachusetts Down Syndrome Congress, Worcester, MA (regional)
- 2025 Brian Train: Socialize / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY, virtual presentation (national)
- 2025 Brian Train: Move / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY, virtual presentation (national)
- 2025 Brian Train: Activate the Brain / Lecture  
Down Syndrome Advocacy Foundation, Long Island, NY, virtual presentation (national)
- 2025 Lived experiences of parents who have received a prenatal diagnosis of Down syndrome / Lecture (co-presented with Marsha Michie, PhD)  
Down Syndrome Education International, United Kingdom, virtual presentation (international)
- 2025 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know / Lecture  
Instituto Mano Down, Sao Paulo, Brazil, virtual presentation (international)

### **Educational Material for Patients and the Lay Community**

No educational materials below were sponsored by outside entities.

#### **Books, monographs, articles**

- |      |  |           |  |
|------|--|-----------|--|
| 2001 | <i>Common Threads: Celebrating Life with Down Syndrome</i> | Co-author | Award-winning book for families about success stories about people with Down syndrome (Band of Angels Press) |
| 2009 | “Driving Forward”  | Author    | Chapter in <i>Thicker than Water: Essays by Adult Siblings of People with Disabilities</i> (Woodbine House)  |

2009	<i>Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters</i>	Co-author	Book for brothers and sisters who have siblings with Down syndrome (Woodbine House)
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**Presentations in other media**

2001-current	<i>New York Times, The Wall Street Journal, Boston Globe, Boston Herald, L.A. Times, and others</i>	Print Appearances	Numerous quoted interviews in national publications each year.
2005	ABCNews, Boston, MA	Television Appearance	“Study: Down Syndrome Diagnosis Talk Should Change”
2005	ABC’s Good Morning America (national)	Television Appearance	“Mothers: Doctors Too Negative When Diagnosing Down Syndrome”
2005	WBUR’s “On Point” (NPR)	Radio Appearance	“Down Syndrome & Doctors”
2006	PBS’s Religion and Ethics Newsweekly (national)	Television Appearance	“Down Syndrome”
2008	CNN (national)	Television Appearance	“Down syndrome decision”
2008	NPR (national)	Radio Appearance	“Prenatal Down Syndrome Screening”
2008	NPR’s Brian Lehrer Show (national)	Radio Appearance	“Down syndrome”
2008	CNN’s House Call with Dr. Sanjay Gupta (national)	Television Appearance	“Couples Faced with the News That Their Child May Have Down Syndrome”
2009	NPR (WPBS)	Radio Appearance	“A San Diego Company Develops a Test for Down's”
2009	The Parents’ Journal with Bobbi Conner	Radio Appearance	“Guidance for Kids Who Have a Sibling with Down Syndrome”

2009	NPR (WBUR)	Radio Appearance	“Living with a Sibling with Down Syndrome”
2009	FOXNews, Boston	Television Appearance	“Down syndrome and siblings”
2009	FOXNews, Boston	Television Appearance	“Down Syndrome Research”
2009	CNN	Television Appearance	“Una leccion para todos”
2009	ABCNews NOW	Television Appearance	“Special Needs Kids and Their Siblings”
2010	ABC World News with Diane Sawyer (national)	Television Appearance	“The R Word”
2011	WBUR (NPR), Boston	Radio Appearance	“Down Syndrome Test Raises Questions for Future Moms”
2011	WBUR (NPR), Boston	Radio Appearance	“New, Safer Test for Down Syndrome Sparks Ethical Concern”
2011	WGBH, Boston	Television Appearance	"A New Down Syndrome Test Raises Ethical Issues”
2011	WPCC (NPR), South Carolina	Radio Appearance	“How much do you want to know--and should you know--about your unborn baby?”
2011	FOX News, Boston	Television Appearance	“GQ controversy: Down Syndrome Comment”
2011	MSNBC, New York (national)	Television Appearance	"Down Syndrome's Rewards Touted as New Test Looms”
2011	ABCNews with Diane Sawyer (national)	Television Appearance	“Safer Down Syndrome Test Hits Market Monday”
2012	WNPR (NPR), Connecticut	Radio Appearance	“Prenatal Genetic Testing”
2012	CBS’s “This Morning,” New York City (national)	Television Appearance	“Early prenatal test raises ethical questions”

2012	“Think Out Loud,” Oregon Public Broadcasting	Radio Appearance	“Living with Down Syndrome”
2012	“Chronicle,” ABC News, Boston	Television Appearance	“Down Syndrome”
2012	NBC News, Knoxville	Television Appearance	“Down Syndrome”
2013	FOX News, Boston	Television Appearance	“Doctors finding it easier to diagnose Down syndrome”
2013	ABC News, Boston	Television Appearance	“UMass Researchers block Down syndrome chromosome”
2013	“The Takeaway,” NPR	Radio Appearance	“New Genetic Therapy Provides Breakthrough for Down Syndrome”
2013	“Here and Now,” NPR	Radio Appearance	“New Genetic Therapy Could Erase Down Syndrome”
2013	“Chronicle,” ABC News, Boston	Television Appearance	“Potential End to Down Syndrome Leaves Parents Torn”
2013	WGN Radio (Chicago)	Radio Appearance	“Major Breakthroughs in Down Syndrome Treatment”
2013	KKSF Radio (San Francisco)	Radio Appearance	Down Syndrome Research
2013	Today Show, NBC News	Television Appearance	“How Down Syndrome Might Help Unravel the Alzheimer’s Puzzle”
2014	NPR	Radio Appearance	“Blood Test Provides More Accurate Prenatal Testing For Down Syndrome”
2014	WCVB, ABCNews Boston	Television Appearance	“Why lower rates of breast cancer in women with Down syndrome?”
2015	WCVB, ABCNews, Boston	Television Appearance	“Man hoping cutting edge genetic technology can identify disability”

2017	“The Pulse,” NPR	Radio Appearance	“People with Down syndrome living longer, but at higher risk for Alzheimer’s”
2017	WCVB, ABCNews, Boston	Television Appearance	“New study examines medical cost of caring for a Down syndrome child”
2017	“Brains On!,” NPR	Radio appearance	“What is Down Syndrome?”
2018	WCVB, ABCNews, Boston	Television Appearance	“Clinical Trial Could Give Answers to Potential Link Between Down Syndrome, Alzheimer’s”
2018	WBZ, CBSNews, Boston	Television Appearance	“Vaccine Being Tested to Prevent Dementia in People with Down Syndrome”
2018	“Dateline,” NBC	Television Appearance	“Meet Jamie Foxx’s Superstar Sister.”
2019	FOX25 News, Boston	Television Appearance	“Report: Labs not following all guidelines for noninvasive prenatal screening”
2019	“The Source,” Texas Public Radio	Radio Appearance	“1 In Every 700 Babies Is Born With Down Syndrome In The U.S.”
2020	WCVB, ABCNews, Boston	Television Appearance	“Online health care platform offers medical expertise to Down syndrome patients”
2020	CHNL Kamloops, Canada	Radio Appearance	Down Syndrome Clinic to You (DSC2U)
2022	WCVB, ABCNews, Boston	Television Appearance	COVID-19 and Patients with Down Syndrome
2023	Sirius XM – Canada Now	Radio Appearance	Down syndrome

## Patient educational material

2012-current	Numerous handouts about co-occurring conditions with Down syndrome	Co-author	Patient education handouts on <a href="http://www.massgeneral.org/downsyndrome">www.massgeneral.org/downsyndrome</a>
2020-current	Down Syndrome Brain Train	Creator	An online educational video series for caregivers of patients with Down syndrome, using evidence-based research to propose practical actions which might boost cognition and reduce the chances of Alzheimer's disease for people with Down syndrome. <a href="http://downsyndromebraintrain.com">downsyndromebraintrain.com</a>

## Recognition

2002	National Media Award	National Down Syndrome Congress
2003	National Book Award	TASH
2003	Diversity Ambassador Award	American Red Cross
2005	Down Syndrome Community Service Award	National Down Syndrome Society
2006	President's Award	National Down Syndrome Society
2008	Christian Pueschel Memorial Research Award	National Down Syndrome Congress
2011	Gunnar Dybwad Leadership Award	MA Department of Developmental Services, Executive Office of Health & Human Services
2012	Allen C. Crocker Award of Excellence	Massachusetts Down Syndrome Congress
2012	Allen Crocker, M.D., Health Services Award	MA Department of Developmental Services, Executive Office of Health & Human Services
2013	Down Syndrome Association Star Award	Down Syndrome Association of San Diego
2014	ACDS Inspirational Service Award	ACDS

## **Report of Scholarship**

ORCID ID: 0000-0002-5232-9882

### **Peer reviewed publications in print or other media**

#### **Research Investigations**

1. Koppenhaver, D., Erickson, K., **Skotko, B.** (2001). Supporting communication of girls with Rett syndrome and their mothers in storybook reading. *International Journal of Disability, Development, and Education*, 48: 395-410.
2. Koppenhaver, D., Erickson, K., Harris, B., McLellan, J., **Skotko, B.**, & Newton, R. (2001). Storybook-based communication intervention for girls with Rett syndrome and their mothers. *Disability and Rehabilitation*, 23: 149-159.
3. **Skotko, B.**, & Canal, R. (2004). Apoyo postnatal para madres de niños con síndrome de Down. (Postnatal Support for Mothers of Children with Down Syndrome in Spain). *Revista Síndrome de Down*, 21: 54-71.
4. **Skotko, B.**, Koppenhaver, D., & Erickson, K. (2004). Parent reading behaviors and communication outcomes in girls with Rett syndrome. *Exceptional Children*, 70(2): 145-66.
5. **Skotko, B.** (2005). Communicating the postnatal diagnosis of Down syndrome: An international call for change. *Italian Journal of Pediatrics*, 31: 237-243.
6. **Skotko, B.**, & Canal, R. (2005). Postnatal support for mothers of children with Down syndrome. *Mental Retardation*, 43: 196-212.
7. **Skotko, B.** (2005). Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers. *American Journal of Obstetrics & Gynecology*, 192: 670-77.
8. **Skotko, B.** (2005). Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics*. 115: 64-77.
9. Rosen, D., Lombardo, A., **Skotko, B.**, & Davidson, EJ (2011). Parental perceptions of sleep disturbances and sleep-disordered breathing in children with Down syndrome. *Clinical Pediatrics*, 50: 121-125.

10. **Skotko, B.G.**, Levine, S.P., Goldstein, R. (2011). Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers. *American Journal of Medical Genetics Part A* 155:2335-2347.
11. **Skotko, B.G.**, Levine, S.P., Goldstein, R. (2011). Having a Brother or Sister with Down Syndrome: Perspectives from Siblings. *American Journal of Medical Genetics Part A*: 155:2348-2359.
12. **Skotko, B.G.**, Levine, S.P., Goldstein, R. (2011). Self-perceptions from People with Down Syndrome. *American Journal of Medical Genetics, Part A*: 155:2360-2369.
13. **Skotko, B.G.**, Davidson, E.J., Weintraub, G.S. (2013). Contributions of a specialty clinic for children with Down syndrome. *American Journal of Medical Genetics, Part A*: 161(3): 430-437.
14. Grieco, J., Pulsifer, M., Seligsohn, K., **Skotko, B.**, Schwartz, A. (2015). Down Syndrome: Cognitive and Behavioral Functioning Across the Lifespan. *American Journal of Medical Genetics, Part C* 169C:135-149.
15. de Graaf, G., Buckley, F., **Skotko, B.G.** (2015). Estimates of the live births, natural losses, and elective terminations with Down syndrome in the United States. *American Journal of Medical Genetics, Part A*: 167A:756-767.
16. Lavigne, J., Sharr, C., Ozonoff, A., Prock, L.A., Baumer, N., Brasington, C., Cannon, S., Crissman, B., Davidson, E., Florez, J.C., Kishnani, P., Lombardo, A., Lysterly, J., McCannon, J.B., McDonough, M.E., Schwartz, A., Berrier, K.L., Sparks, S., Stock-Guild, K., Toler, T.L., Vellody, K., Voelz, L., **Skotko, B.G.** (2015). National Down syndrome patient database: Insights from the development of a multi-center registry study. *American Journal of Medical Genetics Part A* 167A:2520-2526.
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19. Sharr C, Lavigne J, Elsharkawi IMA, Ozonoff A, Baumer N, Brasington C, Cannon S, Crissman B, Davidson E, Florez JC, Kishnani P, Lombardo A, Lysterly J, McDonough ME, Schwartz A, Berrier KL, Sparks S, Stock-Guild K, Toler TL, Vellody K, Voelz L, **Skotko BG.** (2016). Detecting celiac disease in patients with Down syndrome. *American Journal of Medical Genetics, Part A* 170A:3098-3105.
20. Allareddy V, Ching N, Macklin E, Voelz L, Weintraub, G, Davidson E, Albers Prock L, Rosen D, Bruun R, **Skotko BG.** (2016). Craniofacial features as assessed by lateral cephalometric measurements in children with Down syndrome. *Progress in Orthodontics* 17:35-47.

21. Kageleiry A, Samuelson D, Duh MS, Lefebvre P, Campbell J, **Skotko BG**. (2017). Out-of-pocket medical costs and third-party healthcare costs for children with Down syndrome. *American Journal of Medical Genetics Part A* 173(6):627-637.
22. de Graaf G, Buckley F, **Skotko BG**. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine*. 19(4):439-447.
23. **Skotko BG**, Macklin EA, Muselli M, Voelz L, McDonough ME, Davidson E, Allareddy V, Jayaratne YSN, Bruun R, Ching N, Weintraub G, Gozal D, Rosen D. (2017). A predictive model for obstructive sleep apnea and Down syndrome. *American Journal of Medical Genetics Part A*. Apr;173(4):889-896.
24. Elsharkawi I, Gozal D, Macklin EA, Voelz L, Weintraub G, **Skotko BG**. (2017). Urinary biomarkers and obstructive sleep apnea in patients with Down syndrome. *Sleep Medicine*. 34:84-89.
25. Rafii MS, **Skotko BG**, McDonough ME, Pulsifer M, Evans C, Doran E, Muranevicib G, Kessler P, Abushakrah S for the ELND005-DS Study Group (2017). A Randomized, Double-Blind, Placebo-Controlled, Phase II Study of Oral ELND005 (scyllo-Inositol) in Young Adults with Down Syndrome without Dementia. *Journal of Alzheimer's Disease*, 58: 401-411.
26. Lavigne J, Sharr C, Elsharkawi I, Ozonoff A, Baumer N, Brasington C, Cannon S, Crissman B, Davidson E, Florez JC, Kishnani P, Lombardo A, Lyerly J, McDonough ME, Schwartz A, Berrier K, Sparks S, Stock-Guild K, Toler T, Vellody K, Voelz L, **Skotko BG**. (2017). Thyroid dysfunction in patients with Down syndrome: Results from a multi-institutional registry study. *American Journal of Medical Genetics Part A*, 173(6):1539-1545.
27. De Graaf G, Buckley F, Dever J, **Skotko BG** (2017). Estimation of live birth and population prevalence of Down syndrome in nine U.S. states. *American Journal of Medical Genetics Part A*, 173(10):2710-2719.
28. Jayaratne YSN, Elsharkawi I, Macklin EA, Voelz L, Weintraub G, Rosen D, **Skotko BG** (2017). The facial morphology in Down syndrome: A 3D comparison of patients with and without obstructive sleep apnea. *American Journal of Medical Genetics Part A*, 73(11):3013-3021.
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38. Hart SJ, Zimmerman K, Linardic CM, Cannon S, Pastore A, Patsiogiannis V, Rossi P, Santoro SL, **Skotko BG**, Torres A, Valentini D, Vellody K, Worley G, Kishnani PS (2020). Detection of iron deficiency in children with Down syndrome. *Genetics in Medicine*, 22(2):317-325.
39. Ilacqua A, Benedict J, Shoben A, **Skotko BG**, Matthews T, Benson B, Allain DC (2020). Alzheimer's disease development in adults with Down syndrome: Caregivers' perspectives. *Am J Med Genet Part A*, 182(1):104-114.
40. Tarui T, Im K, Madan N, Madankumar R, **Skotko BG**, Schwartz A, Sharr C, Ralston SJ, Kitano R, Akiyama S, Yun HJ, Grant E, Bianchi DW (2020). Quantitative MRI Analyses of Regional Brain Growth in Living Fetuses with Down Syndrome. *Cerebral Cortex*, 30(1):382-390.

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47. Kats DJ, Patsiogiannis V, **Skotko BG** (2020). Epileptic Spasms in Patients With Down Syndrome: Experiences From Caregivers. *Journal of Child Neurology*, 35(12):813-819
48. Oreskovic NM, Cottrell C., Torres A, Patsiogiannis V, Santoro S, Nichols D, Moore C, **Skotko BG**. (2020). Physical activity patterns in adults with Down Syndrome. *Journal of Applied Research in Intellectual Disabilities*, 33(6):1457-1464.
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50. de Graaf G, Buckley F, **Skotko BG**. (2021). Estimation of the number of people with Down syndrome in Europe. *European Journal of Human Genetics*. 29(3):402-410
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### Other Peer-reviewed Publications

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5. **Skotko, B.**, Rubin, D., & Tupler, L. (2008). H.M.'s personal crossword puzzles: Understanding memory and language. *Memory*, 16: 89-96.
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10. Diercks, G.R., Keamy D., Kinane, T.B., **Skotko, B.**, Schwartz, A., Grealish, E., Dobrowski, J., Soose, R., Hartnick, C. (2016). Hypoglossal Nerve Stimulator Implantation in an Adolescent with Down Syndrome and Sleep Apnea. *Pediatrics* 137(5):e20153663.
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12. Gregg, A.R., **Skotko, B.G.**, Benkendorf, J.L., Monaghan, K.G., Bajaj, K., Best, R.G., Klugman, S., and Watson, M.S.; on behalf of the ACMG Noninvasive Prenatal Screening Work Group. (2016). Noninvasive prenatal screening for fetal aneuploidy, 2016 update: a position statement of the American College of Medical Genetics and Genomics. *Genetics in Medicine* 18(10):1056-1065. [Consensus Statement, which is now being implemented nationally by providers. This was developed as part of a Working Group and an update to the previous one in 2013. My contribution was to help review the literature, discuss recommendations with national expert colleagues, and draft/review/approve final manuscript.]
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## Non-peer reviewed scientific or medical publications/materials in print or other media

### Reviews, chapters, monographs and editorials

1. **Skotko, B.**, Tenenbaum, A. (2016). Down syndrome. In Rubin, L., Merrick, J. (eds.) *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*. 4<sup>th</sup> edition. Medford, MA: Springer Publishing.
2. Roberts, M., **Skotko, B.** (2016, 2017, 2018, 2019, 2020, 2021, 2022, 2023, 2024). Down syndrome. In Domino FJ (Ed.), [www.5MinuteConsult.com](http://www.5MinuteConsult.com), Philadelphia: Wolters Kluwer.

### Letters to the Editor

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3. **Skotko, B.** (2006). Comparing Three Screening Strategies for Combining First- and Second-Trimester Down Syndrome Markers. (Letter to the Editor). *Obstetrics & Gynecology*. 107:1170.
4. **Skotko, B.** (2007). First- and Second-Trimester Evaluation of Risk for Down Syndrome. (Letter to the Editor). *Obstetrics and Gynecology*, 110: 1426.
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## Narrative Report

I have dedicated my professional energies toward children with cognitive and developmental disabilities, with a particular focus and expertise on Down syndrome. I spend approximately 75% of my time dedicated to research activities, 20% on clinical excellence, and 5% on administrative responsibilities.

In the area of **Clinical Expertise and Innovation**, I helped launch two nationally recognized Down syndrome clinics, first at Boston Children’s Hospital and now at Massachusetts General Hospital. I secured a \$2.0M philanthropic donation to establish the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital, of which I have the privilege of being the inaugural incumbent. I have also permanently endowed the full Down Syndrome Program with an additional \$10.1M in philanthropic donations, which will cover the annual operating expenses and clinical salaries not fully reimbursed by insurances. Under my leadership, our clinic also built the first-ever HIPAA-compliant electronic intake form allows families and caregivers to input clinically relevant information in advance of clinical appointments at the MGH Down Syndrome Program. Funded by a national PCORI grant, I also led a multidisciplinary team that created “Down Syndrome Clinic to You (DSC2U), a virtual platform that has democratized evidence-based health and wellness information about Down syndrome to caregivers and clinicians across the globe. I am frequently invited to give lectures and Grand Rounds on topics related to Down syndrome around the world. My scholarship has also included two books about Down syndrome, and more than 50 other first-or senior-author, peer-review manuscripts about clinical care, many of which have resulted in national television and radio appearances. I am also the first author on a chapter about clinical care for patients Down syndrome in a definitive internationally utilized textbook for medical provides. I created and oversee an international, longitudinal, multi-center Down syndrome patient registry, which has resulted in numerous peer-review publications, helping to change the way that clinical care is delivered by providers across the world. I have also served on committees for the American College of Medical Genetics and Genomics, helping to write practice guidelines for prenatal testing for Down syndrome and other genetic conditions.

In the area of **Teaching and Education**, I have formally supervised numerous trainees, and I have also educated fellows on an annual basis about genetic and metabolic disorders. In addition to the two nationally available CME courses that I have created on topics related to Down syndrome, I have given over the past five years more than 250 lectures and Grand Rounds in academic settings, including many invited international presentations in Sweden, Japan, Brazil, Singapore, Paris, and UK, among others. My clinical supervision including precepting in my medical genetics clinic and Down Syndrome Program at Massachusetts General Hospital. I also serve as one of the supervising attendings to the fellows in our Harvard Medical School Medical Genetics Training Program during their rotations at Massachusetts General Hospital. I have also been a preceptor for the tDPI course for first-year Harvard medical students. What a privilege to be involved with so many accomplished and eager students and residents!

In the significant supporting activity of **Investigation**, I have served as principal investigator in two main areas of research: (1) interdisciplinary, translational research for patients with Down syndrome and (2) informed decision-making with prenatal genetic testing.

(1) I have secured nearly \$14M in NIH, HRSA, PCORI, and industry funding. As a Co-PI, I am examining strategies for keeping people with intellectual disabilities safe in congregative living arrangements during a pandemic like COVID-19. I am also looking at the impacts of a new sleep apnea device (the “hypoglossal nerve stimulator”) on speech and cognition in people with Down syndrome. After conducting a national randomized controlled trial, I also helped launch a first-of-its-kind technology (“Down Syndrome Clinic to You”), which has now transformed the way health information is delivered to caregivers and families around the globe. I have also been the Principal Investigator on multiple significant Phase II clinical drug trials, many among the first in the country for patients with Down syndrome.

(2) Combining robust datasets, my team and I have also looked at the impact of prenatal testing over the years, estimating the number of livebirths, natural losses, and selective terminations with Down syndrome from 1900–2010 in both the U.S. and Europe. I also led a 29-member research team of Down syndrome experts around the country to write the most definitive research review on how expectant parents can make informed decisions regarding prenatal testing for Down syndrome. My team and I also conducted a robust assessment of family life when a member has Down syndrome. I also helped co-author a policy statement, now widely used, for the American College of Medical Genetics and Genomics on noninvasive prenatal screening, and my team examined the extent to which prenatal testing companies are adhering to these recommendations.

In the significant supporting activity of **Education of Patients and Service to the Community**, I have co-authored two award-winning books about Down syndrome for families and am frequently asked to provide expert commentary in national print, radio, and television media, including the *New York Times*, *The Wall Street Journal*, ABC News, NPR, and CNN, among others. I have enjoyed the deeply fulfilling experience of speaking to parents, caregivers, and patients at conferences organized by non-profit disability organizations. My more than 300 talks over the years have provided meaningful opportunities to engage with families as far away as Japan, Netherlands, India, Sweden, and South Africa, among others. Humbled, I have been honored with the highest honors from the Down syndrome community including awards from the National Down Syndrome Society and National Down Syndrome Congress. I have also enjoyed serving as Chairman of the Board of Directors for the Massachusetts Down Syndrome Congress and have also served on the non-profit boards of the American Red Cross, the National Down Syndrome Society, and the Band of Angels Foundation.

