

Curriculum Vitae

Date Prepared: January 31, 2017
Name: Brian G. Skotko, M.D., M.P.P.
Office Address: 185 Cambridge Street, Room 2222, Boston, MA 02114
Home Address: 32 Traveler Street, Unit 410, Boston, MA 02118
Work Phone: 617-643-3196
Work Email: bskotko@mgh.harvard.edu
Work FAX: 617-726-1566
Place of Birth: Cleveland, OH

Education

1999	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-	Assistant 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 Human Genetics Research	Massachusetts General Hospital
10/13-	Member	Leukemia Program	Dana-Farber/Harvard Cancer Center

Other Professional Positions

2003-2006	Program Coordinator, More to Life Than Genes	Harvard Medical School
2016-	Associate Member	Ariadne Lab, Boston, MA

Major Administrative Leadership Positions

Local

2012-	Clinical Co-Director, Down Syndrome Program	Massachusetts General Hospital
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Committee Service

Local

2007-2009	Advocacy in Clinical Training (ACT)	Children's Hospital Boston
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Committee

2012- T32 Steering Committee Harvard Medical School American Board of Medical Genetics Training Program

Professional Societies

2006-2009 American Academy of Pediatrics Member
2009- American College of Medical Genetics and Genomics Member
2012 and 2016 Member, Working Group for ACMG Consensus statement on Noninvasive Prenatal Screening
2009- American Society of Human Genetics Member
2015- Society for Pediatric Research Member

Editorial Activities

Ad hoc Reviewer

American Journal of Obstetrics and Gynecology
Obstetrics & Gynecology
Pediatrics
British Journal of Obstetrics & Gynecology
American Journal of Medical Genetics, Part A
American Journal of Medical Genetics, Part B
American Journal of Medical Genetics, Part C
Research in Developmental Disabilities
Archives of Diseases in Childhood
Therapeutics and Clinical Risk Management
The Journal of Pediatrics
Journal of Psychology and Psychotherapy
Journal of Genetic Counseling
Child: Care, Health & Development
Perspectives in Biology and Medicine
Genetics in Medicine
Journal of Intellectual Disability Research
American Journal of Bioethics – Primary Research
Journal on Developmental Disabilities
Neuropsychiatric Disease and Treatment
PLOS ONE
CNS Drugs

Honors and Prizes

1997-2001 Angier B. Duke Duke University Merit scholarship for top students
Memorial Scholarship
1999 Lord Rothermere Duke University/Oxford Merit scholarship for

	Scholarship	University	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 RO5186582 (Study BP28947)
F. Hoffmann-La Roche Ltd.
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
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
- 2014-2016 A Multi-Center, Randomized, Double-Blind, Placebo-Controlled Phase 2 Study of the Efficacy, Safety and Tolerability of RO5186582 in Adults and Adolescents with Down Syndrome (Study BP27832)
F. Hoffmann-La Roche Ltd.
Site P.I.
Industry-initiated Phase 2 clinical drug trial on a pharmaceutical that might enhance cognition, memory, and language in adults with Down syndrome
- 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.
Site P.I.
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.
Site P.I.
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 RO5186582 in Adults and Adolescents with Down Syndrome (Study BP27832)
F. Hoffmann-La Roche Ltd.
Site P.I.
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

Current

- 2016- Making Activity and Nutritional Goals Obtainable (MANGO)
Institutional funds
P.I. (\$75,000)
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.
- 2016- Virtual Evidence-based Healthcare for Underserved Patients with Down Syndrome
Patient-Centered Outcomes Research Institute (PCORI)
P.I. (\$2,100,000)
Through a randomized-control national trial, we will be creating and testing 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.

Report of Local Teaching and Training

Teaching of Students in Courses

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|-----------|---|--|
| 2015-2016 | Human Genetics Course

1 st year MD and PhD students in Health, Sciences, & Technology Program | Harvard Medical School and Massachusetts Institutes of Technology
Presented 90-minute lecture on prenatal testing for Down syndrome and how best to deliver prenatal diagnoses to expectant parents |
| 2015-2016 | PhD Program in Biological and Biomedical Sciences
1 st year PhD students | Harvard Medical School

Organized and presented 3-hour course on Down syndrome |

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

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| 2009-
current | Introduction to Metabolic Disorders

1 st 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 | Massachusetts General Hospital |

	Med-Peds Residency Program,	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

Laboratory and Other Research Supervisory and Training Responsibilities

2011-2012	Supervision of Research Assistant for Division of Developmental and Behavioral Pediatrics, Children's Hospital Boston	Weekly supervision for 12 months
2012-current	Supervision of Research Assistant and Clinical Research Coordinator for the MassGeneral Hospital Down Syndrome Program	Weekly supervision

Formally Supervised Trainees

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-	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
2016-	Ibrahim Elsharkawi, MB, BCH / Research Fellow, Massachusetts General Hospital Multiple manuscripts published

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

2010-	Down Syndrome: Healthcare Updates for the Primary Care Pediatrician Harvard Medical School	Single presentation Online CME course
2010-	What the Other Children Without Down Syndrome Are Thinking: Sibling Issues for the Pediatrician Nemours/Alfred I. duPont Hospital for Children	Single presentation Online CME course
2013-	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 th Annual Primary Care Pediatrics Conference	Single presentation 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 CME course

Local Invited Presentations

No presentations below were sponsored by 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
- 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

Report of Regional, National and International Invited Teaching and Presentations

No presentations below were sponsored by outside entities

[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 OB/GYN, Mount Auburn Hospital, Cambridge, 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

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

International

- 2011 Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical

Updates that Parents Need to Know / Lecture
Albert Einstein Hospital, Sao Paulo, 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 University, 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

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 Provider
- 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

Practice Activities

- | | | | |
|-------|--------------------------|--|---|
| 2012- | Ambulatory Care | Medical Genetics,
Massachusetts General
Hospital | 2-3 sessions per week |
| 2012- | In-patient consultations | Medical Genetics,
Massachusetts General
Hospital | 1 day per week and 1
weekend per month |

Clinical Innovations

- Creating of a Virtual Down Syndrome Clinic (2016 to current) As the P.I. on this PCORI grant, I am overseeing a multidisciplinary team of clinicians and caregivers from around the country to transform the way that healthcare can be delivered to overwhelming majority of patients with Down syndrome who do not have access to a specialty clinic like the one

that I co-direct at MGH. We will be building a Virtual Clinic, seeking to automate personalized responses to caregivers who answer questions online. We will be testing the efficacy of our model in a randomized, controlled national trial.

- Creating a New Screening Tool for Obstructive Sleep Apnea in Patients with Down Syndrome (2010 to current) As the P.I. on grants from the NIH and HRSA, I am overseeing a team of researchers who have identified a novel assessment that may rule out the presence of significant sleep apnea in patients with Down syndrome. As the future of reimbursements is uncertain in our country, we hope that this simple tool, which can be performed by primary care physicians, can be game changing. This work has been published, and we are currently validating our findings at MGH.
- 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 am overseeing a multidisciplinary team of clinicians and software engineers to design a mobile app which will empower 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.
- 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 current) 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 Massachusetts General Hospital (2012 to current) As co-Director of the MGH Down Syndrome Program, I helped create a now internationally renowned program of clinical excellence. Each year, my team of 15 healthcare professionals see ~500 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.
- Creation of a National Down Syndrome Patient Database I oversee a multi-institutional Patient Database, collecting and tracking clinical data on patients with Down syndrome seen in specialty clinics

- (2012 to current) around the country. Under my leadership, we have published research papers in top-tier medical journals, and I have presented on the Patient Database at national and 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.
- 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 below were sponsored by outside entities.

- 1999-2004 American Red Cross / Chair, Disability Task Force
Created a new Disability Awareness Curriculum, used by Red Cross units across country to educate employees and volunteers
- 2001- Massachusetts Down Syndrome Congress / Board of Directors (Chair 2009-2011)
Responsible for overseeing the organization's \$1M budget, annual Strategic Plan, and Executive Director reviews
- 2001-2008 Massachusetts Developmental Disabilities Council / Board of Directors
Review health-related grant proposals from disability-related agencies
- 2004-2007 American Red Cross / Board of Governors
Responsible for overseeing all functions of the American Red Cross, including fiduciary oversight of the \$4 billion budget
- 2005-2007 Special Olympics / Clinical Director, Health Promotion
Responsible for collecting health statistics and promoting healthy living among athletes at MA Special Olympics
- 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
- 2007-2013 National Down Syndrome Congress / Professional Advisory Council
Provide guidance to the national organization on clinical and research trends for people with Down syndrome
- 2007- Band of Angels Foundation / Board of Directors
Responsible for advancing the educational outreach support from Foundation to medical professionals and new parents
- 2007-2012 National Down Syndrome Society / Secretary, Board of Directors
Responsible for development and management of research, education, and advocacy efforts for Down syndrome
- 2007-2012 National Down Syndrome Society / Chair, Clinical Advisory Board
Respond to requests from members and community leaders on current topics in Down syndrome research
- 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 (national)
- 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 (national)
- 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
- 2010-2011 Lettercase / Medical Advisor, Board of Directors
Served as Medical Advisor, providing critical feedback on the clinical landscape for expectant parents
- 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- Massachusetts Down Syndrome Congress / Chair, Medical and Science Advisory Board
Provide guidance to organization on clinical and research trends for people with Down syndrome
- 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)

Educational Material for Patients and the Lay Community

Books, monographs, articles and presentations in other media

No educational materials below were sponsored by outside entities.

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|------|--|-----------|--|
| 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)
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”

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)
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”

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
2016	Patriots Difference Maker of the Week	New England Patriots Charitable Foundation

Report of Scholarship

Publications

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.**, Kensinger, E., Locascio, J., Einstein, G., Rubin, D., Tupler L., Krendl, A., & Corkin, S. (2004). Puzzling thoughts for H.M.: Can new semantic information be anchored to old semantic memories? *Neuropsychology*, 18: 756–69.
4. **Skotko, B.**, & Canal, R. (2004). Apoyo postnatal para madres de niños con síndrome de Down. *Revista Síndrome de Down*, 21: 54-71.
5. **Skotko, B.**, Koppenhaver, D., & Erickson, K. (2004). Parent reading behaviors and communication outcomes in girls with Rett syndrome. *Exceptional Children*, 70(2): 145-66.
6. **Skotko, B.**, Bedia, R. (2005). Continuing a Pregnancy After Receiving a Prenatal Diagnosis of Down Syndrome in Spain. *Progresos en Diagnostico y Tratamiento Prenatal*, 17: 189-92.
7. **Skotko, B.**, Andrews, A., & Einstein, G. (2005). Language and the Medial Temporal Lobe: Evidence from H.M.'s Spontaneous Discourse. *Journal of Memory and Language*, 53: 397-415.
8. **Skotko, B.** (2005). Communicating the postnatal diagnosis of Down syndrome: An international call for change. *Italian Journal of Pediatrics*, 31: 237-243.
9. **Skotko, B.**, & Canal, R. (2005). Postnatal support for mothers of children with Down syndrome. *Mental Retardation*, 43: 196-212.
10. **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.
11. **Skotko, B.** (2005). Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics*. 115: 64–77.
12. **Skotko, B.**, & Levine, S. P. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 142C:180-6.
13. **Skotko, B.**, Rubin, D., & Tupler, L. (2008). H.M.'s personal crossword puzzles: Understanding memory and language. *Memory*, 16: 89-96.
14. 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.
15. **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.
16. **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.

17. **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.
18. **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.
19. 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.
20. **Skotko, B.G.**, Levine, S.P., Macklin, E.A., Goldstein, R.D. (2015). Family Perspectives about Down Syndrome. *American Journal of Medical Genetics Part A*, 170(4): 930-941.
21. 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.
22. 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., Lyerly, 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.
23. de Graaf, G., Buckley, F., **Skotko, B.G.** (2016). Live Birth, Natural Losses, and Elective Terminations with Down Syndrome in Massachusetts. 18:459-466.
24. de Graaf G, Buckley F, **Skotko B.** (2016). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine*. Early view online.
25. Sharr C, Lavigne J, Elsharkawi IMA, 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 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.
26. 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.
27. Kageleiry A, Samuelson D, Duh MS, Lefebvre P, Campbell J, **Skotko BG.** (2016). Out-of-pocket medical costs and third-party healthcare costs for children with Down syndrome. *American Journal of Medical Genetics Part A*. Early view online.
28. **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*.

Early view online.

Other Peer-reviewed Publications

1. **Skotko, B.**, Kishnani, P., & Capone, G. for the Down Syndrome Diagnosis Study Group (2009). Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics, Part A*, 149A: 2361-7.
2. **Skotko, B.**, Capone, G., & Kishnani, P. for the Down Syndrome Diagnosis Study Group (2009). Postnatal diagnosis of Down syndrome: Synthesis of the evidence on how best to deliver the news. *Pediatrics*, 124: e751-e758.
3. **Skotko, B.** (2009). With new prenatal testing, will babies with Down syndrome slowly disappear? *Archives of Disease in Childhood*, 94: 823-826.
4. Gregg, A.R., Gross, S.J., Best, R.G., Monaghan, K.G., Bajaj, K., **Skotko, B.G.**, Thompson, B.H., Watson, M.S., are the Noninvasive Prenatal Screening Working Group of the American College of Medical Genetics (2013). ACMG Statement on Noninvasive Prenatal Screening for Fetal Aneuploidy. *Genetics in Medicine* 15(5): 395-398.
5. 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.
6. Jacobs, J., Schwartz, A., McDougle, C., **Skotko, B.G.** (2016). Rapid Clinical Deterioration in an Individual with Down Syndrome. *American Journal of Medical Genetics Part A*. Early view online.
7. 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.

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*. 4th edition. Medford, MA: Springer Publishing.
2. Roberts, M., **Skotko, B.** (2016). Down syndrome. In Domino FJ (Ed.), www.5MinuteConsult.com, Philadelphia: Wolters Kluwer.

Letters to the Editor

1. **Skotko, B.** (2006). A surprising postnatal diagnosis. (Letter to the Editor) *Obstetrics and Gynecology*, 108: 1297.
2. **Skotko, B.** (2006). Words matter: The importance of nondirective language in first-trimester assessments for Down syndrome. (Letter to the Editor). *American Journal of Obstetrics and Gynecology*. 195:625-26.
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.
5. **Skotko, B.G.**, Leach, M. (2011). Physicians need to offer up-to-date information about Down syndrome to expectant couples to inform decision-making [E-letter]. *Pediatrics*. October 17, 2011. http://pediatrics.aappublications.org/content/128/2/393.full/reply#pediatrics_el_51755 (Accessed October 17, 2011.)
6. Leach, M., **Skotko, B.G.** (2012). Resources available for informed prenatal decisions. (Letter to the Editor). *Genetics in Medicine*: 14:348-349.

Narrative Report (limit to 500 words)

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 80% of my time dedicated to research activities, 15% 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 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 20 other first-author, peer-review manuscripts about clinical care, many of which have resulted in national television and radio appearances. I most recently was first author on a chapter about clinical care for patients Down syndrome in a definitive internationally utilized textbook for medical provides. 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. I also created and oversee a national, longitudinal, multi-center Down syndrome patient registry, which has resulted in peer-review publications, helping to change the way that clinical care is delivered by providers across the country. 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 five trainees, and I also educate 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 150 lectures and Grand Rounds in academic settings and 100 presentations to the lay community in national and international arenas.

In the significant support 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) With nearly \$5 million in NIH, HRSA, PCORI, and industry funding, I am leading a 12-person research team investigating a novel method to screen for obstructive sleep apnea in patients with Down syndrome. I have also been the Principal Investigator on multiple significant Phase II clinical drug trials, the first in the country for patients with Down syndrome. My team and I are building and testing a virtual Down syndrome clinic, enabling patients with Down syndrome across the country to have access to high level clinical care.

(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. 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.