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Education

1992	AB, summa cum laude	Psychology	Occidental College
1996	MD	School of Medicine	University of California, Los Angeles

Postdoctoral Training

1996 – 1999	Resident	Boston Combined Residency in Pediatrics	Children's Hospital Boston and Boston Medical Center
1999 – 2000	Chief Resident in Pediatrics	Boston Combined Residency in Pediatrics	Children's Hospital Boston and Boston Medical Center
2000 – 2004	Fellow	Pediatric Critical Care Medicine	Children's Hospital Boston

Faculty Academic Appointments

2004 – 2010	Instructor	Department of Anaesthesia	Harvard Medical School
2010 - 2016	Assistant Professor	Department of Anaesthesia	Harvard Medical School
2015 – 2017	Clinical Assistant Professor (Honorary)	School of Social Work	Smith College
2016 -	Associate Professor	Department of Anaesthesia	Harvard Medical School

Appointments at Hospitals/Affiliated Institutions

1999 – 2000	Pediatrician	Coordinated Care Program	Boston Medical Center
2001 – 2003	Pediatrician	Hospitalist	Franciscan Children's Hospital and Rehabilitation Center

2004	Assistant in General Pediatrics	Department of Medicine	Children's Hospital Boston
2004 – 2005	Assistant in Critical Care Medicine	Department of Anesthesiology, Perioperative and Pain Medicine	Children's Hospital Boston
2005 – 2018	Associate in Critical Care Medicine	Department of Anesthesiology, Perioperative and Pain Medicine	Children's Hospital Boston
2018-	Senior Associate in Critical Care Medicine	Department of Anesthesiology, Critical Care and Pain Medicine	Boston Children's Hospital

Other Professional Positions

1999 – 2000	Physician Staff, Critical Care Transport Team		Children's Hospital Boston
1999 – 2000	Pediatrician, Newborn Services		Mount Auburn Hospital
2000 – 2003	Consultant Pediatrician (Volunteer)		Child Development Center Alewife
2001 - 2007	Member of Pediatric Advanced Care Team (PACT)		Children's Hospital Boston
2001	Consultant Pediatrician (One time)		Novazyme Pharmaceuticals, Inc.
2002 – 2007	Consultant Pediatrician (Volunteer)		YMCA, Framingham, MA
2002 – 2007	Consultant Pediatrician (Volunteer)		Cambridge Economic Opportunity Committee Child Care Center Somerville, MA
2006 - 2012	Consultant Pediatrician (Volunteer)		Cabot After School Program (CASP), Newton Public Schools
2006	Consultant Critical Care Provider		Franciscan Hospital for Children
2006 - 2017	Consultant Pediatrician (Volunteer)		YMCA, Newton, MA – Camp Chickami
2007 -	Faculty, Institute for Professionalism and Ethical Practice		Children's Hospital Boston
2008 – 2009	Medical Control Physician (Backup), Critical Care Transport Team		Children's Hospital Boston
2010	Consultant (One time)		Norfolk County District Attorney's Office, Child Fatality Review Board
2014 – 2015	Consultant on Advisory Board, Pre-Phase I trial planning for spinal muscular atrophy intervention (Three sessions), Moonfish		Hoffman- La Roche, Inc. (Pharmaceuticals)
2014-2017	Consultant on Respiratory Advisory Board, Pre- Phase I and clinical trial planning for X-linked Myotubular Myopathy gene therapy intervention, INCEPTUS and ASPIRO		Audentes Therapeutics, Inc. (Pharmaceuticals)
2015-2016	Consultant on Advisory Board, Pre-Phase I trial planning for spinal muscular atrophy intervention, Olesoxime		Genentech, Hoffman- La Roche, Inc. (Pharmaceuticals)

2016-2017	Consultant on Advisory Board, Phase III and IV planning for spinal muscular atrophy therapy, Nusinersen	Biogen (Pharmaceuticals)
2017	Consultant on Advisory Board, Gene Replacement Therapy Trials, AVXS-101	Avexis (Pharmaceuticals)
2018-	Board of Scientific and Clinical Advisors for X-linked Myotubular Myopathy program	Audentes Therapeutics, Inc. (Pharmaceuticals)
2018-	Pompe Advisor Board	Audentes Therapeutics, Inc. (Pharmaceuticals)
2019-	MILOS Respiratory Advisory Board	Santhera Pharmaceuticals

Major Administrative Leadership Positions

Local

2005 – 2006	Clinical Director, Pediatric Intensive Care	The Floating Hospital for Children, Tufts-New England Medical Center
2005 – 2006	Rotation Director for Residents in Pediatric Critical Care	The Floating Hospital for Children, Tufts-New England Medical Center
2005 – 2006	Clerkship Director for Medical Students in Pediatric Critical Care	The Floating Hospital for Children, Tufts-New England Medical Center
2007 – 2012	Director of Resident Education for the Division of Critical Care Medicine	Children’s Hospital Boston
2007 – 2012	Director of Medical Student Education for Division of Critical Care Medicine	Children’s Hospital Boston
2007 -	Clinical Director, Critical Care, Anesthesia, and Perioperative Extension (CAPE) and Home Ventilation Program	Children’s Hospital Boston
2008 -	Module Director, Program to Enhance Relational and Communication Skills (PERCS)- Critical Care, The Institute for Professionalism and Ethical Practice (IPEP)	Children’s Hospital Boston
2008 – 2012	Coordinator, Observership Program for Division of Critical Care Medicine	Children’s Hospital Boston
2008 – 2011	Director of Anesthesia Fellow Rotation for the Division of Critical Care Medicine	Children’s Hospital Boston
2017 -	Advisory Board, Accountable Care Organization	Boston Children’s Hospital
2017 -	Children’s Hospital Integrated Care Organization (CHICO), Advisory Board	Boston Children’s Hospital

Committee Service

Local

1996 – 2000	Residency Program Training Committee	Children’s Hospital Boston and Boston Medical Center
1998 –2000,	Pediatric Residency selection Committee	Children’s Hospital Boston and Boston Medical Center
2006 - 2010		Resident/ Chief Resident Member
2001 – 2003	Research Planning committee	Faculty Interviewer
		Franciscan Children’s Hospital and Rehabilitation Center
2001 – 2003	Safety and Monitoring Committee	Franciscan Children’s Hospital and Rehabilitation Center
2001 – 2003	Resuscitation and Code Committee	Franciscan Children’s Hospital and Rehabilitation Center
2002 – 2003	Inpatient Service Steering Committee	Franciscan Children’s Hospital and Rehabilitation Center
2004 – 2005	Paul Contini Memorial Education Series Committee	Children’s Hospital Boston
2011-	Physical Therapy and occupational Therapy Advisory Committee	Children’s Hospital Boston
2012 -	High Risk Spine Team	Boston Children’s Hospital
2012 - 2015	Ethics Committee	Boston Children’s Hospital
2013 - 2014	Massachusetts Medical Orders for Life Sustaining Treatment (MOLST) Task Force	Boston Children’s Hospital
2013-	Boston Children’s Hospital/ Franciscan Children’s Hospital Joint Task Force	Boston Children’s Hospital and Franciscan Children’s Hospital
2015-	Tracheostomy Care Team	Boston Children’s Hospital

National and International

2007	The Medical Home Model for Children After Life-Threatening Illness or Injury	National Institutes of Health, National Institute of Child Health and Human Development
2007	ACP/SGIM/SHM Transitions of Care Consensus Conference	American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine
2009 - 2018	Medical Advisory Council	Families of Spinal Muscular Atrophy (FSMA) – now CureSMA
2010 - 2014	Panel for Development of Guidelines for Care of Individuals with Congenital Muscular Dystrophy	American Academy of Neurology
2015-2017	Spinal Muscular Atrophy Standards of Care and Guideline Committee	European Neuromuscular Centre (ENMC)
2015-2016	Pediatric Neuromuscular Clinical Research	Multicenter PNCr Network, Coordinated

	(PNCR) Network for Spinal Muscular Atrophy, Pulmonary, Outcomes, and Quality of Life Working Groups	through the University of Rochester Medical Center
2015-2016	Ventilator-Associated Pneumonia (VAP) National Working Group, Boston Children's Hospital Physician Leader of Subgroup for Ventilator-Dependent Patients	National Solutions for Patient Safety (SPS) Network
2017-	Long-term Ventilation Subgroup, Chair	Pediatric Acute Lung Injury & Sepsis Investigators (PALISI)
2017-	PREVENT Subgroup, Member	Pediatric Acute Lung Injury & Sepsis Investigators (PALISI)
2018-	Outcomes Subgroup, Member	Pediatric Acute Lung Injury & Sepsis Investigators (PALISI)
2018	Emergency / Critical Care Subcommittee, Chair	CureSMA, Medical Advisory Council
2018-	Executive Board of Directors, Member Science and Medicine Committee, Chair	CureSMA

Professional Societies

1992 – 1996	American Medical Association	Member
1996 -	American Academy of Pediatrics	Fellow
2000 -	Society of Critical Care Medicine	Member
2004 -	Massachusetts Medical Society	Member

Grant Review Activities

2007	Research Funding and Policy Division	National Health Research Board, Ireland
2010	Innovation Acceleration Program	Children's Hospital Boston
2011	National Children's Research Centre	Crumlin, Ireland
2013	Clinical Care Research Projects	Families of Spinal Muscular Atrophy
2014	Clinical Care Research Projects	Cure Spinal Muscular Atrophy
2015	Clinical Grant Review, Telethon- Unione Italiana Lotta Alla Distrofia Muscolare (UILDM)	Muscular Dystrophy Association, Italy

Editorial Activities

Ad hoc Review

Pediatrics

European Journal of Pediatrics

Critical Care Medicine

Pediatric Rehabilitation

European Respiratory Journal

Journal of Palliative Care

Archives of Pediatrics and Adolescent Medicine

World Journal of Pediatrics

Journal of Pediatrics

Archives of Disease in Childhood

Child: Care, Health and Development

OPENPediatrics (peer reviewed **Home Care videos** for an open access, peer reviewed website openpediatrics.org)

The Lancet, Respiratory Medicine

Pediatric Anesthesia

Pediatric Pulmonology

Annals of the American Thoracic Society

Healthcare Policy – Politiques de Sante

Honors and Prizes

1991	Phi Beta Kappa (Junior Year Electee)	Occidental College	
1994	American Society of Clinical Pathologist's Award for Academic Excellence and	University of California, Los Angeles	Outstanding Medical Student in Pathology

	Achievement		
1995	Alpha Omega Alpha (Junior Year Electee)	University of California, Los Angeles	
1996	Pilgrim Group Scholarship for Obstetrics and Gynecology	University of California, Los Angeles and The University of Edinburgh, Scotland	Outstanding Medical Student in OB/GYN – Rotation Scholarship
2006	New Edited Book Award	Society of Authors and the Royal Society of Medicine	Oxford Textbook of Palliative Care for Children
2007	AAMC Humanitarian in Medicine, Nominee	Harvard Medical School	
2013	Compassionate Caregiver Award, Honorable Mention	Schwartz Center	
2014	Compassionate Caregiver Award, Honorable Mention	Schwartz Center	
2017	ISOQOL Outstanding Article of the Year Award (3 rd Place)	International Society for Quality of Life Research (ISOQOL)	Journal of Patient Reported Outcomes - <i>Leveraging pediatric PROMIS item banks to assess physical functioning in children at risk for severe functional loss</i>
2018	Silver Lion – Health Track (Industry Craft: Illustration)	Cannes Lions 2018 International Festival of Creativity	Zac’s Play Day

Report of Funded and Unfunded Projects

Funding Information

Past

2005	Massachusetts Census of Children with Chronic Mechanical Respiratory Support Needs The Thoracic Foundations PI (\$25,000) Supported health services and epidemiologic research resulting in two peer-reviewed publications.
2011 – 2012	Adaptor Program for Children with Respiratory Technology Dependence Children’s Hospital Collaborative clinical Effectiveness Fund/ Payor- Provider Quality Initiative PI (\$1,476,000) Support program development and outcomes assessment including healthcare economics, resource utilization, impact on family, and quality of life measures.
2011-2013	Noninvasive Ventilation Integrated Gas Exchange Monitoring Prototype (PI- Nilesh Mehta) Innovation Acceleration Program (IAP) Investment Grant, Children’s Hospital Boston

- Collaborator
Development of potential tools to perform calorimetry for BiPAP dependent patients.
- 2011- 2013 Pilot of TeleCAPE Program (PI- David Casavant)
Innovation Acceleration Program (IAP) Investment Grant, Children’s Hospital Boston
Co- Investigator
Pilot of telemedicine program to demonstrate feasibility and limited outcomes for children with chronic respiratory failure in the community.
- 2012 An Open-label, Escalating Dose Study to Assess the Safety, Tolerability and Dose Range Finding of a Single Intrathecal Dose of ISIS 396443 - CS1 in Patients with Spinal Muscular Atrophy, Types II and III (ages 2-14 years)
ISIS Pharmaceuticals
Site Investigator (Site PI- Basil Darras)
- 2013 An Open-label, Escalating Dose Study to Assess the Safety, Tolerability and Dose Range Finding of a Single Intrathecal Dose of ISIS 396443 - CS10 in Patients with Spinal Muscular Atrophy, Types II and III (ages 2-14 years) who completed CS1
ISIS Pharmaceuticals
Site Investigator (Site PI- Basil Darras)
- 2012 - 2014 An Open-Label, Dose Escalation Study to Assess the Safety, Tolerability and Dose-Range Finding of Multiple Doses of ISIS 396443 – CS12 Delivered Intrathecally to Patients with Spinal Muscular Atrophy, Types II and III (ages 2-14 years)
ISIS Pharmaceuticals
Site Investigator (Site PI- Basil Darras)
- 2013 – 2014 Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program Bridge Support
Children’s Hospital Collaborative Clinical Effectiveness Fund / Payer-Provider Quality Initiative
PI (\$1,589,269)
Support ongoing program development and outcomes assessment including healthcare economics, resource utilization, provider needs assessment, and alternative payment model development.
- 2013 – 2014 CAPE Care Delivery Model Pilot Program
Harvard Pilgrim Health Care, Inc
Co-Investigator, (CoI, Michael McManus)
Describe and analyze resource utilization and clinical outcomes for children with chronic respiratory insufficiency enrolled in the CAPE and Home Ventilation Program.
- 2014 - 2016 Role of Individualized Metabolic Measurement in Children with Spinal Muscular Atrophy CureSMA
Co-Investigator (CoI, Nilesh Mehta)
Implementation of comprehensive nutritional assessment and intervention program for children and young adults with SMA Types II and III.
- 2015 – 2016 CAPE Comprehensive Care Program,
Harvard Pilgrim Health Care, Quality Grant
PI (\$100,000)
- Current**
- 2009 - Pediatric Neuromuscular Clinical Research Network (Site PI – Basil Darras)
Spinal Muscular Atrophy Foundation

Clinical Staff

Support participation as respiratory provider in multidisciplinary spinal muscular atrophy clinic.

- 2014 - A Phase 3, Randomized, Double-blind, Sham-Procedure Controlled Study to Assess the Clinical Efficacy and Safety of ISIS 396443-CS3b Delivered Intrathecally to Infants with Spinal Muscular Atrophy, Type I (age <7months) (Site PI - Basil Darras)
ISIS Pharmaceuticals
Site Investigator
- 2014 - An Open-Label Study to Assess the Safety and Tolerability of ISIS 396443-CS12 Delivered Intrathecally to Patients with Spinal Muscular Atrophy who previously enrolled in ISIS 396443 – CS2 or CS10 (Site PI - Basil Darras)
ISIS Pharmaceuticals
Site Investigator
- 2015 - A Phase 3, Randomized, Double-blind, Sham-Procedure Controlled Study to Assess the Clinical Efficacy and Safety of ISIS 396443-CS4 Delivered Intrathecally to Children with Spinal Muscular Atrophy, Type II (age 2-12 years) (Site PI –Basil Darras)
ISIS Pharmaceuticals
Site Investigator
- 2015 - An Open-Label Study to Assess the Safety and Tolerability of ISIS 396443-CS11 Delivered Intrathecally to Patients with Spinal Muscular Atrophy who previously enrolled in ISIS 396443 – CS1 (Site PI - Basil Darras)
ISIS Pharmaceuticals
Site Investigator
- 2016-2018 Efficacy and Feasibility of Tele-Psychotherapy Intervention to Support Parents Caring For Technology-dependent Children At Home (CoI, Yudy Muneton-Castano)
The Deborah Munroe Noonan Research Fund
Co-Investigator
- 2016 - An Open-Label Study to Assess the Safety and Tolerability of CY 5021 Delivered Orally to Patients with Spinal Muscular Atrophy Type III (Site PI - Basil Darras)
Cytokinetics Pharmaceuticals
Site Co-Investigator
- 2018 - An Open-Label Study to Assess the Safety and Tolerability of AVXS-101 (STRONG) Delivered Intrathecally to Patients with Spinal Muscular Atrophy Type II (Site PI - Basil Darras)
Avexis Pharmaceuticals
Site Co-Investigator
- 2018 – An Open-Label Study to Assess the Safety and Tolerability of AVXS-101 (STRIVE) Delivered Intravenously to Patients with Spinal Muscular Atrophy Type I (Site PI - Basil Darras)
Avexis Pharmaceuticals
Site Co-Investigator
- 2018 Simulation Training for Caregivers of Tracheostomy Dependent Children
Boston Children’s Hospital, Accountable Care Organization Fund
Co-Investigator (Mentor for Laura Amar-Dolan)
- 2018 Bringing the ICU Home: A Community-based Care Model for Children with Chronic Respiratory Failure
Boston Children’s Hospital, Accountable Care Organization Fund
Principle Investigator

Report of Local Teaching and Training

No presentations below were sponsored by outside entities.

Teaching of Students in Courses

2002 – 2003	Core Clinical Clerkship in Pediatrics Boston University Medical Students	Franciscan Children’s Hospital Daily supervision on month long rotation
2006	Mentored Clinical Casebook – “A Patient’s Soundtrack: The Story of a Young Burn Survivor”	Harvard University
2010	Harvard medical student - Phillip Williams Mentored Clinical Casebook – “like the phoenix, a family’s journey” Harvard medical student – Michael Honigberg	Regular meetings and review Harvard University Regular meetings and review

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

1999 – 2000	Case of the Week, Grand rounds Pediatric Residents	Boston University 1 hr lecture once a week?
2000 – 2004	Hot Topics in Critical Care Critical Care Fellows	Children’s Hospital Boston Bi-annual one house session
2004 -	Noninvasive Ventilator Support Pediatric Residents	Children’s Hospital Boston Monthly one hour lecture
2005	Resuscitation and Crisis Management Pediatric Residents	The Floating Hospital for Children, Tufts- New England Medical Center One hour lecture once a week
2005 – 2006	Respiratory Distress - Aberrant Breathing Pediatric Residents	The Floating Hospital for Children, Tufts- New England Medical Center Annual one house lecture
2005 – 2006	PICU Resident Core Curriculum Lectures on “Neuroresuscitation I & II,” “Noninvasive Ventilator Support,” “ARDS,” and “Cardiopulmonary Resuscitation” Pediatric Residents	The Floating Hospital for Children, Tufts- New England Medical Center Monthly one hour lecture
2005	Pediatric Sedation Hematology and Oncology Fellows	Dana Farber Cancer Institute One hour lecture
2007 - 2013	Senior Resident Rounds Pediatric residents	Children’s Hospital Boston Weekly one hour participation
2008	Acute Respiratory Distress Syndrome Pulmonology Fellows	Children's Hospital Boston One hour lecture
2008	Perioperative Tracheostomy Care and Home Ventilation	Children's Hospital Boston

2009	Critical Care Fellows Mechanical Ventilation Pulmonology Fellows	One hour lecture Children's Hospital Boston
2012	Faculty Research Presentation Critical Care Fellows and Staff	One hour lecture Division of Critical Care Medicine, Boston Children's Hospital One hour lecture

Formally Supervised Trainees

2005 – 2006	Jeffrey Edwards/ Staff in Pediatric Critical Care Medicine, Columbia Mentored throughout pediatric residency with three collaborative publications.	
2006 – 2008	Maria T. Wachendorf Fradinho / Staff in Obstetric/GYN, Beth Israel Deaconess Medical Center Mentored during medical school at HMS and one resultant publication	
2006 – 2009	Rahul Panesar/ Staff in Pediatric Critical Care Medicine , SUNY Stonybrook Advisor throughout fellowship	
2007 – 2010	Michael Green/ Clinical staff in Pediatric Critical Care Medicine, Texas Children's Advisor throughout pediatric critical care fellowship	
2007 – 2009	Shan Susan Zhu/ Student, Harvard University (elected not to pursue premed studies)	
2008 – 2011	Kerri LaRovere/ Staff in Pediatric Neurology, Boston Children's Hospital Advisor throughout pediatric critical care fellowship and one resultant publication.	
2008 – 2011	Silvia Hartmann/ Fellow in Pediatric Critical Care Medicine, Children's Hospital Seattle Advisor throughout pediatric residency	
2008 – 2011	Benjamin Kozyak/ Fellow in Pediatric Cardiology, Boston Children's Hospital Advisor throughout pediatric residency	
2010 – 2013	Ryan Wilkes/Fellow in Pediatric Critical Care Medicine, Boston Children's Hospital Advisor throughout pediatric critical care fellowship	
2013-2018	Madeline Coquillet/ Resident in Pediatrics, Boston Combined Residency Program in Pediatrics Research and career mentor, while at Harvard Medical School; completed clinical investigation of tracheostomy biome	
2014-2016	Angie Mae Rodday/ Doctoral Candidate in Statistics, Sackler School of Graduate Biomedical Sciences, Tufts University PhD Thesis Advisory Committee; collaborated on multiple patient-centered outcomes studies for children with chronic disabilities	
2015-	Yudy F. Muneton / Doctoral Candidate in Social Work, Smith College, School for Social Work Administrative Supervisor for clinical internship, PhD studies	
2018-	Sarah Sobotka / Fellow in Developmental Behavioral Pediatrics, Lurie Children's Hospital Mentorship for NICHD K23 Proposal Predictors of Days at Home for Children with Mechanical Ventilator Assistance	

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

2002	Sedation	Single lecture
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	Pediatric Advanced Life Support Certification Training	Boston Children's Hospital
2005	Pediatric Sedation Outside of the Operating Room CME Course on Systems for Sedation/Analgesia in Pediatrics	Single lecture Boston Children's Hospital
2006 -	Noninvasive Ventilation	Single lecture and ongoing use of video
	Orientation Lecture and Video for Critical Care Nurses	Boston Children's Hospital
2008 -	Enhance Relational and Communication Skills - Critical Care	4-6 day-long sessions per year
	The Institute for Professional and Ethical Practice (IPEP)	Boston Children's Hospital
2008 - 2009	Noninvasive Ventilation Physician and Nursing CME	Three hour long sessions Seven Hills at Groton Pediatric Center

Local Invited Presentations

1998	Cases from the Wards - A Nodable Case: Anaplastic Large Cell Lymphoma/ Grand Rounds Department of Medicine, Children's Hospital Boston
2002	When Chronic Care Becomes End of Life Care/ Pediatric Advanced Care Rounds Children's Hospital Boston and Dana Farber Cancer Institute
2002	Outcome Measures in the ICU/ Nursing Grand Rounds Franciscan Children's Hospital and Rehabilitation Center
2002	Outcome Measures in the ICU/ Medical Grand Rounds Franciscan Children's Hospital and Rehabilitation Center
2004	Intracranial Hypertension/ Firm Rounds Department of Medicine, Children's Hospital Boston
2007	Acute Respiratory Distress Syndrome/ Firm Rounds Department of Medicine/ Children's Hospital Boston
2010	To Trach or Not to Trach... Schwartz Center Rounds, Children's Hospital Boston
2010	Outcomes and Measurement in Pediatric Critical Care/ Resident Conference Department of Pediatrics, Boston Medical Center
2010	Noninvasive Mechanical Ventilation/ Resident Conference Department of Pediatrics, Boston Medical Center
2010	Tracheostomy in the Cardiac Intensive Care/ Ethics Rounds Children's Hospital Boston
2010	Facilitating the Care of Children with Home Ventilation Innovator's Forum, Children's Hospital Boston
2012	Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community/ Grand Rounds Department of Medicine, Boston Children's Hospital
2012	Pediatric Interest Group Harvard Medical School
2013	To Trach, or Not to Trach/ Nursing Ethics Rounds

- MISCU, Boston Children’s Hospital
- 2013 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community/ Fellow’s Conference
Pediatric Advanced Care Team (PACT), Dana-Farber Cancer Institute
- 2013 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community
Hematopoietic Stem Cell Transplantation Service, Dana-Farber Cancer Institute
- 2013 Communication with the “Difficult Parent”/ Nursing Education Day
Pediatric Critical Care, Boston Children’s Hospital
- 2014 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community/ Issues and Hot Topics
Pediatric Critical Care, Boston Children’s Hospital
- 2015 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community/ Grand Rounds
Neonatology, Harvard
- 2015 Spinal Muscular Atrophy and Severe Malnutrition/ Nutrition Seminar
- 2016 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community / Nursing Education Day, Pediatric Critical Care, Boston Children’s Hospital
- 2016 Clinical Innovation – Introducing Novel Ways to Deliver Care, Innovation Academy Session, Boston Children’s Hospital
- 2016 Pediatric Critical Care: Need(ing) an Obvious Career, Critical Care Fellows’ Colloquium, Boston Children’s Hospital
- 2017 Spinal Muscular Atrophy 2017: Critical Care for a Changing Landscape, Hot Topics in Critical Care Medicine, Boston Children’s Hospital
- 2017 Work-Life Balance/How to Avoid Burn Out, Critical Care Fellow Research and Academic Development Retreat, Boston Children’s Hospital
- 2017 Spinal Muscular Atrophy 2017: A Changing Landscape, Department of Surgery Grand Rounds, Boston Children’s Hospital
- 2018 Spinal Muscular Atrophy 2018: A Changing Landscape, Department of Anesthesia Grand Rounds, Boston Children’s Hospital
- 2018 Chronic Illness in Pediatric Critical Care, Critical Care Fellows’ Colloquium, Boston Children’s Hospital
- 2018 Pediatric Home Mechanical Ventilation: Serving a Complex Community, Critical Care Nursing Education Day, Boston Children’s Hospital
- 2018 Work-Life Balance/How to Avoid Burn Out, Critical Care Fellow Research and Academic Development Retreat, Boston Children’s Hospital
- 2018 Neuromuscular Disease and Respiratory Considerations, Physical and Occupational Therapy Department, Boston Children’s Hospital
- 2018 Pediatric Home Mechanical Ventilation: Serving a Complex Community, Emergency Medicine Departmental Conference, Boston Children’s Hospital
- 2018 Spinal Muscular Atrophy 2018: A Changing Landscape, Division of Pulmonary Medicine Conference, Boston Children’s Hospital

Report of Regional, National and International Invited Teaching and Presentations

No presentations below were sponsored by outside entities.

Invited Presentations and Courses

Regional

- 2008 Chronic Respiratory Support
Boston College Campus School, Boston College
- 2009 Ethical Aspects and End of Life Decisions for Children and Adolescents with
Neuromuscular Disorders/ Grand Rounds
Department of Pediatrics, Boston Medical Center
- 2010 Outcomes and Measurement in Pediatric Critical Care/ Grand Rounds
Department of Pediatrics, Lawrence General Hospital
- 2011 Pediatric Home Mechanical Ventilation: Brining Critical Care into the Community
Massachusetts Society for Respiratory Care, Boston
- 2011 Pediatric Home Mechanical Ventilation: Brining Critical Care into the Community
South Shore Hospital, Weymouth MA
- 2012 Pediatric Home Mechanical Ventilation: Brining Critical Care into the Community
Rhode Island Society for Respiratory Care, Newport
- 2013 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community
University of Massachusetts Medical Center, Worcester MA
- 2015 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community and
Blending Principles of Palliative Care
Massachusetts Department of Public Health, Natick (Pediatric Palliative Care Network)
- 2015 Caring for Children and Youth with Special Health Care Needs: How to Make it Work in
the World of Health Care Reform – Innovative State Models
2015 Massachusetts Chapter of the American Academy of Pediatrics Annual CME
Program, Waltham MA
- 2016 Ethics in Research – Vulnerable Pediatric Populations and Family Considerations, Ethics
of Clinical Investigation Seminar, Graduate Program in Clinical and Translational Science
Sackler School of Graduate Biomedical Sciences, Tufts University, Boston MA
- 2017 Serving the Underserved Retreat, Addressing Health Disparities for People with
Disabilities, Research Panel
- 2017 Harvard Medical School – General Medicine and Pediatric Health Services Research
Fellowship, Boston MA
- 2017 Program to Enhance Relational and Communication Skills – End of Life Discussions,
Brain Death, and Organ Donation, University of Massachusetts Medical Center,
Worcester, MA
- 2017 Spinal Muscular Atrophy 2017 – A Changing Landscape, Franciscan Hospital for
Children, Boston, MA
- 2017 Ethic in Research – Vulnerable Pediatric Populations, Family Considerations, and
Emerging Challenges, Ethics of Clinical Investigations Seminar, Graduate Program in
Clinical and Translational Science, Sackler School of Graduate Biomedical Sciences, Tufts
University, Boston MA

National

- 2004 Congenital neurodevelopmental disabilities and the intensive care: defining a population
Society of Critical Care Medicine, 33rd Congress, Orlando, FL
- 2007 Sedation and Analgesia in Pediatric Patients
Puerto Rico Society of Anesthesiologists and The Puerto Rico College of Physicians and
Surgeons, Anesthesia Section

- 2012 Caring for the Child with SMA within the Medical Home, Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role
Gillette Children's Hospital and Families of SMA, Minneapolis, MN (Professionals Conference and Course)
- 2012 Interdisciplinary Perspectives on Spinal Muscular Atrophy: Cardiopulmonary Care (Expert Panel)
Gillette Children's Hospital and Families of SMA, Minneapolis, MN (Professionals Conference and Course)
- 2013 Blending Principles of Palliative Care Early into Treatment for Children with Medical Complexity/ Visiting Professorship
Seattle Children's Hospital
- 2013 Communication and Decision-making for Children with Special Healthcare Needs in the ICU/ Visiting Professorship
Seattle Children's Hospital
- 2013 Blending Principles of Palliative Care Early into Treatment for Children with Medical Complexity/ Grand Rounds
Doernbecker Children's Hospital, Oregon Health Sciences University
- 2013 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community/ Visiting Professorship
Children's Healthcare of Atlanta/Emory, Egleston
- 2013 Strategies in the Chronic Ventilatory Support of Children with Neuromuscular and Myopathic Disorders/ Visiting Professorship
Children's Healthcare of Atlanta/Emory, Egleston
- 2013 Blending Principles of Palliative Care Early into Treatment for Children with Medical Complexity/ Visiting Professorship
Children's Healthcare of Atlanta/Emory, Egleston
- 2013 Caring for the Child with SMA within the Medical Home, Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role
Families of SMA and University of Wisconsin, School of Public Health and Medicine, Anaheim, CA (Professionals Conference and Course)
- 2014 Caring for the Child with SMA within the Medical Home, Interdisciplinary Perspectives on Spinal Muscular Atrophy: Defining Your Role
Families of SMA and University of Wisconsin, School of Public Health and Medicine, National Harbor, MD (Professionals Conference and Course)
- 2014 Navigating Choices for Care – A Palliative Care Paradigm
Families of SMA and University of Wisconsin, School of Public Health and Medicine, National Harbor, MD (Professionals Conference and Course)
- 2015 Pediatric Home Mechanical Ventilation: Supporting a Burgeoning Community
Connect-Share-Impact: Pediatric and Neonatal Critical Care Nursing Summit, Boston Children's Hospital
- 2015 Acute and Chronic Respiratory Management of Neuromuscular Disorders
University of Florida, Pediatric Grandrounds / Visiting Professorship
- 2016 Caring for Ventilator-Dependent Children
The Physician Innovator - Step Forward, Lead Innovation, Fix Health Care Webinar with Chris Trimble, www.physicianinnovators.net
- 2016 Acute Management – Home and Inpatient
Spinal Muscular Atrophy Symposium on Optimizing Care
Penn Medicine Orphan Disease Center, Children's Hospital of Philadelphia

- 2017 CMD – Critical Care and Hospitalization, Overview of the CAPE Program
2017 Congenital Muscular Dystrophy Scientific and Family Conference (CureCMD),
Arlington, VA
- 2017 Development of CMD Pulmonary Care Guidelines (moderator)
2017 Congenital Muscular Dystrophy Scientific and Family Conference (CureCMD),
Arlington, VA
- 2018 Spinal Muscular Atrophy Standard of Care panel discussion, 2018 Inaugural Spinal
Muscular Atrophy Clinical Care Meeting, Dallas, TX
- 2019 Pediatric Home Mechanical Ventilation: Serving a Complex Community,
Visiting Professorship, Divisions of Critical Care Medicine
Texas Children’s Hospital, Houston, TX
- 2019 Spinal Muscular Atrophy 2019: A Changing Landscape,
Visiting Professorship, Divisions of Critical Care Medicine
Texas Children’s Hospital, Houston, TX

International

- 2003 Critical Care Outcomes Research Session at 4th World Congress on Pediatric Intensive
Care/ Comoderator (Abstract)
World Federation of Pediatric and Intensive Care Societies, Boston, MA
- 2007 The Changing Demographics of Pediatric Critical Care: The Numbers and Considerations
in Care (Plenary Presentation)
American College of Chest Physicians, Chicago, IL
- 2008 Ethical Aspects and End of Life Decisions for Children and Adolescents with
Neuromuscular Disorders (Postgraduate Course)
American Thoracic Society, Toronto
- 2012 Blending Principles of Palliative Care Early into Treatment for Children with Medical
Complexity (Meet the Expert), American Academy of Pediatrics, AAP National
Conference and Exhibition 2012, New Orleans
- 2016 The Growing Issue of Managing Chronic Illness in Pediatric Critical Care,
Society of Critical Care Medicine, SCCM Current Concepts in Pediatric Critical Care, Pre-
Congress Educational Session, Orlando

Report of Clinical Activities and Innovations

Current Licensure and Certification

- 1994 United States Medical Licensing Examination, Step I
- 1995 United States Medical Licensing Examination, Step II
- 1997 United States Medical Licensing Examination, Step III
- 1999 - License, Commonwealth of Massachusetts Board of Medicine
- 1999 - Certification in Pediatrics, American Board of Pediatrics
- 2004 - Certification in Pediatric Critical Care, American Board of Pediatrics
- 2004 – 2006 Provider, Advanced Cardiac Life Support, American Heart Association (renewed 2010)
- 2006 - Basic Life Support for HealthCare, Provider, American Heart Association
- 2007 - Pediatric Advanced Life Support, Provider, American Heart Association

Practice Activities

2004 -	ICU Attending	Pediatric Critical Care, Boston Children's Hospital	12- 25 weeks per year, plus night call
2007 -	Comprehensive care including home visits, remote, inpatient and clinic session.	Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program, Boston Children's Hospital	Two clinic sessions per week, continuous pager access 24/7

Clinical Innovations

Critical Care, Anesthesia, Perioperative, Extension (CAPE) and Home Ventilation Program The Critical Care, Anesthesia, and Perioperative Extension (CAPE) and Home Ventilation Program is the only home visit program in New England dedicated to the care and support of families and children with long-term mechanical ventilation needs. In recognizing the complexity of care, limited community resources, difficulties in transitions from acute care to rehabilitation or homecare, and the vulnerability of children with the most extensive special healthcare needs, this program was designed to serve as direct extension of critical care into the homecare setting. Teaching, research, and community outreach are critical components of the CAPE Program to complement direct patient care.

Report of Education of Patients and Service to the Community

Activities

Regional Presentations

2006	Children with Chronic Mechanical Respiratory Support Needs in Massachusetts TrachCare (Parent Advocacy Group), Boston, MA
2007	Participatory Action Research New England Serve - Family Professional Partnership Institute
2007	Medical Culture and Children with Special Health Care Needs New England Serve - Family Professional Partnership Institute
2009	Respiratory Evaluation, Support Options, and Decision-making with Neuromuscular Disorders, Muscular Dystrophy Association Annual Duchene and Becker Muscular Family Conference, Boston
2011	Long-term Home Ventilation – Bringing the Hospital Home TrachCare (Parent Advocacy Group), Boston, MA
2011	Respiratory Evaluation, Support Options, and Decision-making with Neuromuscular Disorders, Muscular Dystrophy Association Annual Duchene and Becker Muscular Family Conference, Boston
2013	Respiratory Evaluation, Support Options, and Decision-making with Neuromuscular Disorders Muscular Dystrophy Association, Spinal Muscular Atrophy Day – Family and Research Conference, Boston

National Presentations

2010	Pre Hospital & Emergency Medical Care: Navigating and Optimizing Acute Care for Children, Adolescents, and Adults with Spinal Muscular Atrophy
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2010 Families of SMA National Family and Professionals Conference, Santa Clara, CA

2011 Community Emergency Services and Spinal Muscular Atrophy

2011 Families of SMA National Family and Professionals Conference, Orlando, FL

2011 Choices, Evidence, Hope and Hype

2011 Families of SMA National Family and Professionals Conference, Orlando, FL

2012 Choices, Evidence, Hope and Hype

2012 Families of SMA National Family and Professionals Conference, Minneapolis, MN

2012 SMA Type I – Optimal Care for SMA

2012 Families of SMA National Family and Professionals Conference, Minneapolis, MN

2013 Evidence, Hope and Hype: Finding the Balance

2013 Families of SMA National Family and Professionals Conference, Los Angeles, CA

2013 911, Ambulance & Emergency Medical Care: Navigating and Optimizing Acute Care for Children, Adolescents, and Adults with Spinal Muscular Atrophy

2013 Families of SMA National Family and Professionals Conference, Los Angeles

2014 Evidence, Hope and Hype: Finding the Balance (Newly Diagnosed Program)

2014 Families of SMA National Family and Professionals Conference, National Harbor, MD

2014 Optimal Care for SMA, Type I

2014 Families of SMA National Family and Professionals Conference, National Harbor, MD

2014 Breathing Basics

Families of SMA and University of Wisconsin, School of Public Health and Medicine, National Harbor, MD

2014 Ethics in Research

2014 Families of SMA National Family and Professionals Conference, National Harbor, MD

2015 Understanding Clinical Trials

2015 Cure SMA National Family and Professionals Conference, Kansas City

2015 Family Readiness for Emergencies

2015 CureSMA National Family and Professionals Conference, Kansas City

2015 Ethics in Research

2015 CureSMA National Family and Professionals Conference, Kansas City

2016 Understanding Clinical Trials

2016 Cure SMA National Family and Professionals Conference, Anaheim

2016 Family Readiness for Emergencies

2016 Cure SMA National Family and Professionals Conference, Anaheim

2016 Ethics in Research

2016 Cure SMA National Family and Professionals Conference, Anaheim

2017 Understanding Treatment and Trials

2017 Cure SMA National Family and Professionals Conference, Orlando

2017 Ethics and Realities in SMA Research and Emerging Therapies

2017 Cure SMA National Family and Professionals Conference, Orlando

2017 Family Readiness for Emergencies

2017 Cure SMA National Family and Professionals Conference, Orlando

2017 CMD How to Prepare for Surgery / What to Do Post-op

2017 Congenital Muscular Dystrophy Scientific and Family Conference, Arlington, VA

2017 CMD COL6 and LAMA2 Respiratory Care

- 2017 Congenital Muscular Dystrophy Scientific and Family Conference, Arlington, VA
- 2018 Understanding Treatment and Trials
- 2018 2018 Cure SMA National Family and Professionals Conference, Dallas
- 2018 Ethics and Realities in SMA Research and Emerging Therapies
- 2018 2018 Cure SMA National Family and Professionals Conference, Dallas
- 2018 Family Readiness for Emergencies
- 2018 2018 Cure SMA National Family and Professionals Conference, Dallas
- 2018 Family Readiness for Emergencies
- 2018 2018 SMA Boston Summit of Strength
- 2018 Understanding Treatment and Trials
- 2018 2018 SMA Boston Summit of Strength
- 2018 Family Readiness for Emergencies
- 2018 2018 SMA Milwaukee Summit of Strength
- 2018 Understanding Treatment and Trials
- 2018 2018 SMA Milwaukee Summit of Strength
- 2019 Family Readiness for Emergencies
- 2019 2019 SMA Dallas Summit of Strength

Educational Material for Patients and the Lay Community

Patient educational material

- 2011 Battista V, Crawford T, **Graham R**, Kissel J, Kravitz R, Schroth MK. CARING CHOICES - For Families of Infants Newly Diagnosed with SMA Type I. SMA Care Series: Booklet #1. Families of Spinal Muscular Atrophy, www.fsma.org . Revised August 2011
- 2012 Battista V(primary author, alphabetical thereafter per publication), Apkon S, Battista J, Clark J, Craford T, Cuevas D, Finkel RS, Freedman A, Godshall BJ, **Graham R**, Grayhack J, Kissel J, Kravitz R, Krosschell KJ, O’Toole CM, Mosher P, Noritz G, O’Brien S, O’Brien K, Patterson K, Pearson J, Saxton P, Schroth MK, Shell R, Silver K, Snyder B, St. Onge D. UNDERSTANDING SPINAL MUSCULAR ATROPHY- A Guide for Parents and Professionals. (co-author) SMA Care Series: Booklet #1. Families of Spinal Muscular Atrophy, www.fsma.org . Revised September 2012
- 2015 Battista V, **Graham R**, Shell R, and Kissell J. LEARNING ABOUT CLINICAL TRIALS- A Guide for Individuals and Families Affected by Spinal Muscular Atrophy (co-author) SMA Care Series. CURE Spinal Muscular Atrophy, www.curesma.org. First Edition 2015

Recognition

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| 1998 | Humanitarian Award | The Scotty Luce Coalition | Care of children and families with complex health care needs |
| 2007 | REACH Award of Excellence in Pediatric Medicine | REACH Program, Caritas St. Elizabeth Medical Center (Humanitarian) | Family Nominated Award through The REACH Foundation for families |

Report of Scholarship

Peer reviewed publications in print or other media

Research investigations

1. **Graham RJ**, Dumas HM, O'Brien JE, Burns JP. Congenital neurodevelopmental diagnoses and an intensive care unit: defining a population. *Pediatr Crit Care Med*. 2004;5(4):321-8. (*featured article*)
2. O'Brien JE, **Graham RJ**, Dumas HM, and Kharasch VS. Inpatient pediatric pulmonary rehabilitation: development of a minimum data set. *Advance for Directors in Rehabilitation*. 2005;14(2):57-68.
3. O'Brien JE, Birnkrant DJ, Dumas HM, Haley SM, Burke SA, **Graham RJ**, Kharasch VS. Weaning children from mechanical ventilation in a post-acute care setting. *Pediatr Rehabil*. 2006;9(4):365-72.
4. **Graham RJ**, Fleegler EW, Robinson WM. Chronic Ventilator Need in the Community: A 2005 Pediatric Census of Massachusetts. *Pediatrics*. 2007;119(6):e1280-1287.
5. **Graham RJ**, Pemstein DM, Palfrey JS. Included but isolated: early intervention programmes provision for children and families with chronic respiratory support needs. *Child Care Health Dev*. 2008;34(3):373-9.
6. **Graham RJ**, Wachendorf MT, Burns JP, Mancuso TJ. Successful and Safe Delivery of Anesthesia and perioperative care for children with complex special healthcare needs. *J Clin Anesth*. 2009;21(3):165-172.
7. **Graham RJ**, Pemstein DM, Curley MAQ. Experiencing the pediatric intensive care unit: Perspective of parents of children with severe antecedent disabilities. *Crit Care Med*. 2009; 37(6):2064-2070.
8. Berry JG, Graham DA, **Graham RJ**, Zhou J, Putney HL, O'Brien JE, Roberson DW, Goldman DA. Predictors of clinical outcomes and hospital resource use of children following tracheostomy. *Pediatrics*. 2009; 124(2):563-572.
9. **Graham RJ**, Athiraman U, Laubach AE, Sehtna NF. Anesthesia and perioperative medical management of children with spinal muscular atrophy. *Paediatr Anaesth*. 2009; 19:1054-63.
10. Berry JG, **Graham RJ**, Roberson DW, Rhein L, Graham DA, Zhou J, O'Brien J, Putney H, Goldman DA. Patient characteristics associated with in-hospital mortality in children following

tracheostomy. *Arch Dis Child*. 2010; 95(9):703-710.

11. Edwards JD, Davidson EJ, Houtrow AJ, **Graham RJ**. Pediatric resident attitudes toward caring for children with severe disabilities. *Am J Phys Med Rehabil*. 2010; 89(9):765-771.
12. Edwards JD, Kun SS, **Graham RJ**, Keens TG. End-of-Life Discussions and Advance Care Planning for Ventilator-Dependent Children with Life-Limiting Conditions. *J Palliative Care*. 2012; 28(1):21-27.
13. Edwards JD, Houtrow AJ, Vasilevskis EE, Rehm RS, Markovitz BP, **Graham RJ**, Dudley A. Chronic conditions among children admitted to U.S. PICUs: their prevalence and impact on risk for mortality and prolonged length of stay. *Crit Care Med*. 2012; 40(7): 2196-2203.
14. Larovere KL, **Graham RJ**, Tasker RC. Pediatric neurocritical care: a neurology consultation model and implications for education and training. *Pediatr Neurol*. 2013; 48(3): 206-211.
15. **Graham RJ**, Rodday AM, Parsons SK. Family centered assessment and function for children with chronic mechanical respiratory support. *J Pediatr Health Care*. 2014; 28(4): 295-304.
16. Mehta NM, Smallwood C, **Graham RJ**. Current applications of metabolic monitoring in the pediatric intensive care unit. *Nutrition in Clinical Practice*. 2014; 29(3): 338-347.
17. Casavant DW, McManus ML, Parsons SK, Zurakowski D, **Graham RJ**. Trial of telemedicine for patients on home ventilator support: feasibility, confidence in clinical management and use in medical decision-making. *J Telemed Telecare*. 2014; 20(8):441-449.
18. Martinez EE, Smallwood CD, Bechard LJ, **Graham RJ**, Mehta NM. Metabolic assessment and individualized nutrition in children dependent on mechanical ventilation at home. *J. Pediatr*. 2015; 166(2):350-357.
19. Kang PB, Morrison L, Iannacone ST, **Graham RJ**, Bonnemann CG, Rutkowski A, Hornyak A, Wang CH, North K, Oskoui M, Getchius TS, Cox JA, Hagen EE, Gronseth G, Griggs RC. Evidence-based guidelines summary: Evaluation, diagnosis, and management of congenital muscular dystrophy: Report of the Guideline Development Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular and Electrodagnostic Medicine. *Neurology*. 2015; 84(13): 1369-1378.
20. Martinez EE, Bechard LJ, Smallwood CD, Duggan CP, **Graham RJ**, Mehta NM. Impact of individualized diet intervention on body composition and respiratory variables in children with respiratory insufficiency: A pilot intervention study. *Pediatr Crit Care Med*. 2015; 16(6):e157-64.
21. Mehta NM, Newman H, Tarrant S, **Graham RJ**. Nutrition status and nutrient intake challenges in children with spinal muscular atrophy. *Pediatr Neurol*. 2016; 57:80-83.
22. Watters K, O'Neill M, Zhu H, **Graham RJ**, Hall M, Berry J. Two-year mortality, complications, and healthcare use in children with Medicaid following tracheostomy. *Laryngoscope*. 2016; 126(11):2611-2617.
23. **Graham RJ**, McManus ML, Rodday AM, Weidner RA, Parsons SK. The impact on family of

- pediatric chronic respiratory failure in the home. *J Pediatr*. 2016; 175:40-46.
24. **Graham RJ**, McManus ML, Rodday AM, Weidner RA, Parsons SK. Chronic Respiratory Failure: utilization of a pediatric specialty integrated care program. *Healthcare: The Journal of Delivery Science and Innovation*. 2017; 5(1-2):23-28.
 25. Rodday AM, Terrin N, Leslie LK, **Graham RJ**, Parsons SK. Understanding the relationship between child health-related quality of life and parent emotional functioning in hematopoietic stem cell transplant. *Journal of Pediatric Psychology*. 2017; 42(7): 804-814.
 26. Rodday AM, **Graham RJ**, Weidner RA, Terrin N, Leslie LK, Parsons SK. Predicting health care utilization for children with respiratory insufficiency using parent-proxy ratings of children's health-related quality of life. *J Pediatr Health Care*. 2017; 31(6): 654-662.
 27. Perez-Losada M, **Graham RJ**, Coquillet M, Jafarey A, Castro-Nallar E, Aira M, Freishtat RJ, Mansbach JM. The temporal dynamics of the tracheal microbiome in tracheostomised patients with and without lower respiratory infections. *PLoS One*. 2017; 12(8): e0182520.
 28. Rodday AM, **Graham RJ**, Weidner RA, Rothrock NE, Dewalt DA, Parsons SK. Leveraging pediatric PROMIS item banks to assess physical functioning in children at risk for severe functional loss. *Journal of Patient Reported Outcome*. 2017; 1(1):10 e-pub DOI: <http://dx.doi.org/10.1186/s41687-017-0011-8>
 29. Mercuri E, Finkel RS, Muntoni F, Wirth B, Montes J, Montes J, Main M, Mazzone ED, Vitale M, Snyder B, Quijano-Roy S, Bertini E, Hurst-Davis R, Meyer, OH, Simonds AK, Schroth MK, **Graham RJ**, Kirschner J, Iannaccone ST, Crawford TO, Woods S, Qian Y, Sejersen T for the SMA Care group. Diagnosis and management of spinal muscular atrophy: part 1: recommendations for diagnosis, rehabilitation, orthopedic and nutritional care. *Neuromuscul Disord*. 2017; e-pub Nov 23, 2017 ahead of print
DOI: <http://dx.doi.org/10.1016/j.nmd.2017.11.005>
 30. Finkel RS, Mercuri E, Meyer, OH, Simonds AK, Schroth MK, **Graham RJ**, Kirschner J, Iannaccone ST, Crawford TO, Woods S, Muntoni F, Wirth B, Montes J, Main M, Mazzone ED, Vitale M, Snyder B, Quijano-Roy S, Bertini E, Hurst-Davis R, Qian Y, Sejersen T for the SMA Care group. Diagnosis and management of Spinal Muscular Atrophy: Part 2: pulmonary and acute care; medications, supplements and immunizations; other organ systems; and ethics. *Neuromuscul Disord*. 2017; e-pub Nov 22, 2017 ahead of print.
DOI: <http://dx.doi.org/10.1016/j.nmd.2017.11.004>
 31. **Graham RJ**, McManus ML, Rodday AM, Weidner RA, Parsons SK. Pediatric Specialty Care Model for Management of Chronic Respiratory Failure: Cost and Savings Implications and Misalignment with Payment Models. *Pediatr Crit Care Med*. 2018; 19(5):412-420. (Featured article) DOI: 10.1097/PCC.0000000000001472
 32. Perez-Losada M, **Graham RJ**, Coquillet M, Jafarey A, Castro-Nallar E, Aira M, Hoptay C, Freishtat RJ, Mansbach JM. The tracheal microbiota in patients with a tracheostomy before, during, and after an acute respiratory infection. *Pediatric Infectious Disease Journal*. 2018; 37(11): e269-e271.

33. Martinez EE, Quinn N, Arouchon K, Anzaldi R, Tarrant S, Ma NS, Darras BT, **Graham RJ**, Mehta NM. Comprehensive nutritional and metabolic assessment in patients with spinal muscular atrophy: opportunity for an individualized approach. *Neuromuscul Disord*. 2018; 28(6):512-519. DOI: 10.1016/j.nmd.2018.03.009.
34. Sobotka SA, Gaur DS, Goodman DM, Agrawal RK, Berry JG, **Graham RJ**. Pediatric patients with home mechanical ventilation: The health services landscape. *Pediatr Pulmonol*. 2018 Nov 20 [Epub ahead of print] doi: 10.1002/ppul.24196.

Other Peer-reviewed publications

1. Babl FE and **Graham R**. A pain in the heel: sneaker puncture wounds. *Infectious Diseases in Children*. 1999;12(2):32.
2. **Graham RJ**. An opportunity: Critical care beyond the intensive care unit. *Pediatr Crit Care Med*. 2005;6(3):327-328.
3. **Graham RJ**, Robinson WM. Integrating Palliative Care into Chronic Care for Children with Severe Neurodevelopmental Disabilities. *J Dev Behav Pediatr*. 2005;26(5):361-365.
4. **Graham RJ**, Stein P. Gastric outlet obstruction in an infant: lactobezoar. *Am J Emerg Med*. 2007;25(1):98-9.
5. **Graham RJ**. Medicine and Children with Special Health Care Needs: Conflict with the Cult of Cure. *J Dev Behav Peds*. 2008;29(4):309-310.
6. Puri AS, Rahbar R, Dearden J, **Graham RJ**, Lillehei C, Orbach DB. Stretched and sheared microcatheter retained after onyx embolization of infantile myofibromatosis. *Interv Neuroradiol*. 2011;17(2):261-6.
7. Lee Jr M, Franca UL, **Graham RJ**, McManus ML. Pre-nusinersen hospitalization costs of children with spinal muscular atrophy. *Pediatr Neurol*. 2018 Nov 22 [Epub ahead of print] doi: 10.1016/j.pediatrneurol.2018.11.002
8. **Graham RJ**, Amar-Dolan LR, Roussin CJ, Weinstock PH. Bridging the stressful gap between ICU and home: Medical simulation for pediatric patients and their families. *Pediatr Crit Care Med*. 2019; Jan 18 [Epub ahead of print].

Scholarships without named authorship

1. Finkel RS, Sejersen T, Mercuri E; ENMC SMA Workshop Study Group.* 218th ENMC International Workshop: Revisiting the consensus on standards of care in SMA, Naarden, The Netherlands, 19-21 February 2016. *Neuromuscul Disord*. 2017; 27(6):596-605. (*participant workshop study group)
2. Finkel RS, Mercuri E, Darras BT, Connolly AM, Kuntz NL, Kirschner J, Chiriboga CA, Saito K, Servais L, Tizzano E, Topaloglu H, Tulinius M, Montes J, Glanzman AM, Bishop KM, Zhong

ZJ, Gheuens S, Bennett CF, Schneider E, Farwell W, and De Vivo DC, for the ENDEAR Study Group.* Nusinersen versus sham control in infantile-onset Spinal Muscular Atrophy. *New England Journal of Medicine*. 2017; 377:1723-32. (*multicenter trial – site investigator)

3. Mercuri E, Darras BT, Chiriboga CA, Day JW, Campbell C, Connolly AM, Iannaccone ST, Kirschner J, Kuntz NL, Saito K, Sheih PB, Tulinius M, Mazzone ES, Montes J, Bishop KM, Yang Q, Foster R, Gheuens S, Bennett CF, Farwell W, Schneider E, De Vivo DC, and Finkel RS for the CHERISH Study Group.* Nusinersen versus sham control in later-onset Spinal Muscular Atrophy. *New England Journal of Medicine*. 2018; 378:625-635. (*multicenter trial – site investigator)

[Non-peer reviewed scientific or medical publications/materials in print or other media](#)

Reviews, chapters, monographs and editorials

1. Randolph AG and **Graham R**. Measuring the health status of pediatric ICU survivors. In: *Surviving Intensive Care*. New York (NY): Springer;2003. p. 107-115.
2. Haley SM, **Graham RJ**, Dumas HM. Outcome rating scales for pediatric head injury. *J Intensive Care Med*. 2004;19(4):205-19. (*invited review article*)
3. **Graham R**, Dussel V, Wolfe J. Research. In: *Oxford Textbook of Palliative Care for Children*, Goldman A, Hain R, Liben S (eds). Oxford (UK): Oxford University Press;2006. p. 615-647.
4. **Graham RJ**. Intensive Care: A Narrative. In: *Medical Care for Children and Adults with Developmental Disabilities*, Rubin IL and Crocker AC (eds). Baltimore (MD): Paul H. Brookes Publishing Co.;2006. p. 613-622.
5. **Graham RJ**. Specialty services for children with special health care needs: supplement not supplant the medical home. *Arch Dis Child*. 2008;93(1):2-4. (*invited editorial*)
6. **Graham RJ**, Levetown M, Comeau M. Decision Making. In: *Palliative Care for Infants, Children and Adolescents: A Practical Handbook*, Carter, BS, Levetown M, and Friebert SE (eds). Baltimore: The Johns Hopkins University Press; 2011. p. 139-168.
7. **Graham RJ**. Long-term ventilation: charting a pathway home. *Archives of disease in childhood*. 2013; 98(9):653.
8. Trovato MK, Bosques G, **Graham RJ**, Kramer ME, Pidcock FS, Prestwich SV, Sadowsky CL, Schultz SC. Rehabilitation. In: *Rogers' Textbook of Pediatric Intensive Care, 5th Edition*, Shaffner DH and Nichols DG (eds). Wolters Kluwer; 2015. p. 196-207.
9. Kang PB, Morrison L, Iannaccone ST, **Graham RJ**, Bonneman CG, Rutkowski A, Hornyak J, Wang CH, Christi C, North K. *Editorial Responses to Evidence-based guidelines summary: Evaluation, diagnosis, and management of congenital muscular dystrophy: Report of the Guideline*

Development Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular and Electrodiagnostic Medicine. *Neurology*. 2015; 85(16): 1432-1433.

10. **Graham RJ**. The growing issue of managing chronic illness in pediatric critical care. In: *Current Concepts in Pediatric Critical Care*, 2016 Edition, Turner DA and Killinger JS (eds). Society of Critical Care Medicine; 2016. p. 49-54.
11. Burgart AM, Magnus D, Tabor HK, Paquette EDT, Frader J, Glover JJ, Jackson BM, Harrison CH, Urion DK, **Graham RJ**, Brandsema JF, Feudtner C. Ethical challenges confronted when providing nusinersen treatment for spinal muscular atrophy. *JAMA Peds*. 2017; e-pub Dec 11: E1-5.

Case reports

1. Peacock WJ and **Graham R**. Advances in pediatric neurosurgery - surgical management of epileptic surgery. *Headlines*. 1993:12-14.

Letters to the Editor

1. **Graham RJ**. Jading. *Pediatr Crit Care Med*. 2005;6(1):93; author reply 93.
2. **Graham RJ**. Acute respiratory distress syndrome in children with severe motor and intellectual disabilities. *Brain Dev*. 2006;28(5):342.

Professional educational materials or reports, in print or other media

- 2009 Pediatric Critical Care Medicine Curriculum for the senior pediatric residents in the Boston Combined Residency Program in Pediatrics who rotate through the Boston Medical Center PICU. The curriculum was devised and implemented in conjunction with Juliette Hunt, MD (Chief Resident). It is a 4 week program which includes tutorial lectures, hands-on skill sessions, select review of sentinel critical care journal articles integrating evidence-based medicine, mock-code preparation and review, and bedside as well as operating room teaching.
- 2009 Boston Combined Residency Program in Pediatrics – Pediatric Code Card. Faculty resource and advisor for Dr. Dennis Simon (Senior Resident), who prepared reference as part of career development project.
- 2009 Boston Combined Residency Program in Pediatrics – Housestaff Manual. Faculty resource and advisor for Dr. Rebekah Hofstra Shappley (Senior Resident) for the Critical Care Section, including the following topics - Cardiovascular: Shock, Septic Shock, Inotropic Agents and Formulas, Hypertensive Emergency, Extracorporeal Membrane Oxygenation (ECMO), Respiratory: Respiratory Failure, Acute Lung Injury (ALI) and Acute Respiratory Distress Syndrome (ARDS), Mechanical Ventilation, Neurology: Evaluation of the Comatose Child, Increased Intracranial Pressure, Status Epilepticus,

Miscellaneous: Anaphylaxis, Hyperkalemia, Hypothermia, Relative Adrenal Insufficiency, Submersion Injuries.

- 2009 PICU Without Walls – Noninvasive Ventilator Support. Video lecture for international training and in-service aid to improve the education of health care providers in respiratory care topics in underserved regions.
<http://www.childrenshospital.org/clinicalservices/Site2248/mainpageS2248P0.html>
- 2013 **Graham, R**, Wolbrink, TA. Non-invasive Ventilation: Complications. Online video. Boston (MA): OPENPediatrics; 2013. <<https://hq.app.openpediatrics.org/webUI>>
- 2013 **Graham, R**, Wolbrink, TA. Non-invasive Ventilation: Key Concepts. Online video. Boston (MA): OPENPediatrics; 2013.
<<https://hq.app.openpediatrics.org/webUI>>
- 2013 **Graham, R**, Wolbrink, TA. Non-invasive Ventilation: Practical Issues. Online video. Boston (MA): OPENPediatrics; 2013. <<https://hq.app.openpediatrics.org/webUI>>
- 2015 Advancing Relational Learning Worldwide, Course 1: Disclosure and Apology after Medical Errs and Adverse Events. (Reviewer-Editor) Institute for Professionalism and Ethical Practice (IPEP) and OPENPediatrics; 2015
<<https://hq.app.openpediatrics.org/webUI>> Sections:
-The Role of Peer Support
-Developing and Institutional Support Structure
-Resolution and Compensation after Medical Injury
-Creating a Just Decision-Making Culture for Clinicians Involved in Errors
-Clinician Support Across Settings
- 2018 Zac’s Play Day, Illustrated Children’s Book on Spinal Muscular Atrophy, Biogen, Contributing author, <https://cdn.biogen.com/aus/specialty/tisma/index.html#p=1> (e-book) and print 2018. (Cannes Lions – Silver Lion Award Winning)
- 2018 **Graham, R**, Robertson, A, Daniel, D, Burns, JP. The Role of Critical Care for Children with Special Healthcare Needs. Online video. Boston (MA): OPENPediatrics; May 2018
<https://www.openpediatrics.org/assets/video/role-critical-care-children-special-healthcare-needs>.
- 2018 **Graham RJ**, Darras BT. Management of Patients with SMA: Standards of Care. Webcast CME. Wayne (PA): AcademicCME: 2018.
<http://academiccme.com/courses/management-patients-sma-standards-care/>
- 2018 Darras BT, **Graham RJ**. Clinical Trial Data: New and Emerging Therapies for SMA. Webcast CME. Wayne (PA): AcademicCME: 2018.
<http://academiccme.com/courses/clinical-trial-data-new-emerging-therapies-sma/>
- 2018 Darras BT, **Graham RJ**. Understanding the Characteristics of SMA and Diagnostic Criteria. Webcast CME. Wayne (PA): AcademicCME: 2018.
<http://academiccme.com/courses/understanding-characteristics-sma-diagnostic-criteria/>

Clinical Guidelines and Reports

1. The informed patient (columnist - Laura Landro): Pediatric hospitals teach doctors ways to convey

tragic news. Cited in article. Wall Street Journal. 2006.

2. House calls are making a comeback: Visiting patients at home yielding cost savings, hospitals find. (columnist – Julie M. Donnelly) Boston Business Journal 2011; 31 (36): pp 3, 35. [*C.A.P.E. and Home Ventilation Program as article focus*]
3. CAPE: Home visits make a comeback. Children’s News (Children’s Hospital Boston) November 2011. [*lead article*]
4. Clinical Innovation: Home Ventilation Program. Pediatric Views (Children’s Hospital Boston) February 2012. [*lead article*]
5. Clinical Innovation: Home Ventilation Program. Children’s e-Dose (Children’s Hospital Boston) February 2012. <http://www.childrenshospital.org/chnews/subscribe/>
6. Addressing Complex Healthcare Needs: The Critical Care, Anesthesia, Perioperative Extension(CAPE) and Home Ventilation Program at Boston Children’s Hospital. Tao - Department of Anesthesiology, Perioperative and Pain Medicine Newsletter Boston Children’s Hospital Newsletter: Edition III, November 2012.
7. Can telemedicine deliver value for home-ventilated patients? Vector (Boston Children’s Hospital’s Science and Clinical Innovation Blog) April 2, 2014 <http://vectorblog.org/2014/04/can-telemedicine-deliver-value-for-home-ventilated-patients/> [*lead article*]
8. Affordable Care Solutions, Reinventing Home Visits, Improving the lives of technology-dependent children. Blue Cross Blue Shield of Massachusetts Annual Report, Leading through change – Health Care Solutions for the Reform Era, March 19, 2014. www.bluecrossma.com/visitor/annual-report/annual-report-2013/index.html
9. Life with Vivienne: Clinical trial brings new hope for girl with spinal muscular atrophy. (THRIVING - Boston Children’s Hospital’s Pediatric Health Blog) September 22, 2015 <http://thriving.childrenshospital.org/life-vivienne-clinical-trial-brings-new-hope-girl-spinal-muscular-atrophy/>
10. The Faces of Innovation (Boston Children’s Hospital) November 2015
11. Pulse of Longwood (columnist – Melissa Bailey): House calls make a critical difference. The Boston Globe, Business Section. March 15, 2016 <http://www.statnews.com/2016/03/15/house-calls-doctors-boston-childrens-hospital/>
12. Caring for Ventilator-Dependent Children. The Physician Innovator, Steps Forward, Lead Innovation, Fix Health Care Blog – Chris Trimble. April 4, 2016 <http://physicianinnovators.net/stories/>
13. Critical Care Comes Home. Harvard Pilgrim Health Care Annual Report, We are a health services company. April 2016. (print pages 8-9) www.harvardpilgrim.org/portal/page?_pageid=213,271658&_dad=portal&_schema=portal
14. As Experimental Treatments Grow, Families Face Tough Choices; Parents of children with rare

diseases once had no options. Now, experimental therapies offer hope but hard decisions. (columnist – Amy Dockser Marcus) Wall Street Journal. 2017: November 1.

15. **Coordinated care for children on respiratory support saves money.** Vector (Boston Children's Hospital's Science and Clinical Innovation Blog) **March 20, 2018**
<https://vector.childrenshospital.org/2018/03/cape-program-coordinated-care-saves-money/>

NonPrint Materials

1. **Graham R.** Evidence-based medicine, quality of life review of Sheridan RL, Hinson MI, Liang MH, Nackel AF, Schoenfeld DA, Ryan CM, Mulligan JL, Tompkins RG. Longterm outcomes of children surviving massive burns (JAMA 2000; 283:69-73)
http://pedscm.wustl.edu/EBJournal_club.html. ;2001.
2. **Graham R.** Evidence-based medicine, predictive models review of Hatherill M, McIntyre AG, Wattie M, Murdoch IA. Early hyperlactatemia in critically ill children. (Intensive Care Medicine 2000; 26:314-318) http://pedscm.wustl.edu/EBJournal_club.html. ;2001.
3. **Graham R.** Evidence-based medicine, predictive model review of Robertson CMT, Joffe AR, Moore AJ, Watt JM. Neurodevelopmental outcome of young pediatric intensive care survivors of serious brain injury. (Pediatric Critical Care Medicine 2002; 3(4):345-350)
http://pedscm.wustl.edu/EBJournal_club.html. ;2003.

Abstracts, Poster Presentations and Exhibits Presented at Professional Meetings (not published in a journal to date)

1. Yuen S, Beno L, Blanchette S, **Graham R**, Maddock M, Munhall D, Nuss R, Perlman L, Petralia D, Rahbar R, Rhein L, Santiago R, Ward E, Wells S, Volk M, Watters K. A multidisciplinary approach to pediatric tracheostomy care at Boston Children's Hospital. European Society of Pediatric Otorhinolaryngology, 13th International Congress ESPO2016. (*Oral Presentation*)
2. **Robert Graham**, Barry J. Byrne, Sabine de Chastonay, Tmirah Haselkorn, Imelda Hughes, Emma S. James, Nancy L. Kuntz, Michelle L. Yang, Sabrina W. Yum, Mojtaba Noursalehi, Suyash Prasad, Salvador Rico, Alan H. Beggs. Mortality and respiratory support in X-linked myotubular myopathy (XLMTM): The RECENSUS Study, and internations, multicenter, retrospective medical record review. World Muscle Society, Mendoza, Argentina 2018.
3. Perry B. Sheih, Wolfgang Muller-Felber, Barbara Smith, Carsten Bonneman, James J. Dowling, Nancy L. Kuntz, Francesco Muntoni, Laurent Servais, Deborah Bilder, Tina Duong, **Robert J. Graham**, Minal Jain, Michael W. Lawlor, Victoria MacBean, Teresa Pitts, Mo Noursalehi, Gerrard Rafferty, Salvador Rico, Suyash Prasad. ICEPTUS Pre-Phase 1, prospective, non-interventional, natural history run-in study to evaluate subjects aged 3 years and younger with X-linked myotubular myopathy (XLMTM): preliminary findings. World Muscle Society, Mendoza, Argentina 2018.
4. Michael J. Troy, Patricia Miller, **Robert Graham**, Brian Snyder. Effect of EOS severity and

treatment on pulmonary function relative to stature (as represented by pelvic width) in children with SMA. Orthopedic Research Society Annual Meeting, Austin TX, 2019.

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.

Follow this format for each person. DO NOT EXCEED FIVE PAGES.

NAME: Graham, Robert Joel

eRA COMMONS USER NAME (agency login): ROBGRAHAM

POSITION TITLE: Associate Professor in Anesthesia (Pediatrics)

EDUCATION/TRAINING (*Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.*)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Occidental College, Los Angeles, CA	AB	05/1992	Psychobiology
U.C.L.A. School of Medicine, Los Angeles, CA	MD	06/1996	Medicine
Boston Combined Residency in Pediatrics, Children's Hospital Boston (BCH) and Boston Medical Center (BMC), Boston, MA	Resident	06/1999	General Pediatrics
Boston Combined Residency in Pediatrics, Boston, MA	Resident	06/2000	Chief Pediatric Resident
Boston Children's Hospital, Boston, MA	Fellow	06/2004	Pediatric Critical Care Medicine

A. PERSONAL STATEMENT

I am a pediatric critical care physician with a special interest in children with chronic technology dependence. Through research, clinical interventions, and teaching, I have extended critical care services beyond the confines of the intensive care unit to optimize outcomes, quality of care, and resource utilization for these children and their families. My clinical background and training reflect a consistent interest in the continuum of acute and chronic pediatric illness. After completing pediatric training, I pursued an extended critical care fellowship to allow for additional clinical experience as a staff physician at a pediatric rehabilitation center as well as in the complex care services at Boston Medical Center and Boston Children's Hospital (BCH). My health services and clinical research efforts focus on the interface between critical care services and children with chronic respiratory insufficiency and other complex special health care needs. After completing general pediatrics training, I pursued and published the first descriptive study of children with neurodevelopmental disabilities in the pediatric intensive care (ICU) setting. My qualitative needs assessment study for the parents of children with disabilities in the ICU was published in *Critical Care Medicine*, one of the premier journals in our field. Findings informed the development of a year-long curriculum in a local Program to Enhance Relational and Communications Skills (PERCS).

Health services research efforts to date have focus on extensive evaluation of health-related quality of life, impact on family, clinical outcomes, care models and resource utilization for the cohort of children enrolled in the Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program, which I established in 2007. Partnering with colleagues in other disciplines, I have pursued clinical investigation for cohorts of children with chronic respiratory failure, including multi-institutional therapeutic trials in spinal muscular atrophy, nutritional assessment and provision in chronic illness, and preliminary microbiome studies with Dr. Jonathan Mansbach, leading up to the current proposal. I recently established the Chronic Critical Illness and Long-term Ventilation subgroup within the Pediatric Acute Lung Injury and Sepsis Investigators (PALISI). I have the expertise, leadership and motivation necessary serve in the co-investigator role, contribute to the consortium, and to successfully carry out the proposed work. Ultimately, I am dedicated to the advancement of care children and young adults with acute and chronic disabilities.

1. Graham RJ, McManus ML, Rodday AM, Weidner RA, Parsons SK. The impact on family of pediatric chronic respiratory failure in the home. *J Pediatr*. 2016; 175:40-46.

2. Graham RJ, McManus ML, Rodday AM, Weidner RA, Parsons SK. Pediatric Specialty Care Model for Management of Chronic Respiratory Failure: Cost and Savings Implications and Misalignment with Payment Models. *Pediatr Crit Care Med*. 2018; 19(5): 412-420. DOI: 10.1097/PCC.0000000000001472
3. Perez-Losada M, Graham RJ, Coquillet M, Jafarey A, Castro-Nallar E, Aira M, Freishtat RJ, Mansbach JM. The temporal dynamics of the tracheal microbiome in tracheostomised patients with and without lower respiratory infections. *PLoS One*. 2017; 12(8): e0182520.
4. Perez-Losada M, Graham RJ, Coquillet M, Jafarey A, Castro-Nallar E, Aira M, Hoptay C, Freishtat RJ, Mansbach JM. The tracheal microbiota in patients with a tracheostomy before, during, and after an acute respiratory infection. *Pediatric Infectious Disease Journal*. 2018; in press.

B. POSITIONS AND HONORS

Positions and Employment

1999 - 2000	Pediatrician, Coordinated Care Program, Boston Medical Center , Boston, MA
1999 - 2000	Physician Staff, Critical Care Transport Team, BCH, Boston, MA
2001 - 2003	Pediatric Hospitalist, Franciscan Children's Hospital and Rehabilitation Center, Brighton, MA
2004 -	Assistant in General Pediatrics, Department of Medicine, BCH, Boston, MA
2004 - 2005	Assistant in Critical Care Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, BCH, Boston, MA
2004 - 2010	Instructor in Anesthesia, Harvard Medical School, Boston, MA
2005 -	Associate in Critical Care Medicine, Department of Anesthesiology, Perioperative, and Pain Medicine, BCH, Boston, MA (Senior Associate beginning 2016)
2005 - 2006	Associate Staff, Department of Pediatrics, Section of Critical Care, The Floating Hospital for Children, Tufts-New England Medical Center, Boston, MA
2007 -	Founder and Director, Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program, Boston, MA
2007 -	Faculty, Institute for Professionalism and Ethical Practice, Faculty Member, BCH (Director, Cardiovascular and Critical Care Curriculum), Boston, MA
2010 – 2016	Assistant Professor in Anesthesia (Pediatrics), Harvard Medical School, Boston, MA
2016 -	Associate Professor in Anesthesia (Pediatrics), Harvard Medical School, Boston, MA

Other Experience and Professional Memberships

1992 - 1996	Member, American Medical Association
1996 -	Member, American Academy of Pediatrics
2000 -	Member, Society of Critical Care Medicine
2004 -	Member, Massachusetts Medical Society
2007	Committee member, The Medical Home Model for Children After Life-Threatening Illness or Injury, National Institutes of Health, National Institute of Child Health and Human Development
2007	Invited Participant, , ACP/SGIM/SHM Transitions of Care Consensus Conference, American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine
2009 -	Council Member, Families of Spinal Muscular Atrophy (FSMA) Medical Advisory Council
2010 - 2015	Panel Member, American Academy of Neurology – Panel for Development of Guidelines for the Care of Individuals with Muscular Dystrophy

Honors

1991	Phi Beta Kappa (Junior Year Electee), Occidental College
1994	American Society of Clinical Pathologist's Award for Academic Excellence and Achievement, University of California, Los Angeles
1995	Alpha Omega Alpha (Junior Year Electee), University of California, Los Angeles
1996	Pilgrim Group Scholarship for Obstetrics and Gynecology, University of California, Los Angeles and The University of Edinburgh, Scotland
1998	Humanitarian Award, The Scotty Luce Coalition for care of children and families with complex health care challenges

2006	New Edited Book Award (awarded Oxford Textbook of Palliative Care for Children - contributing author), Society of Authors and the Royal Society of Medicine
2007	REACH Award of Excellence in the field of Pediatric Medicine, REACH Program, Caritas St. Elizabeth Medical Center (Humanitarian)
2007	AAMC Humanitarian in Medicine, Nominee, Harvard Medical School
2010	Unsung Hero Award, Room to Dream Foundation
2013, 2014	Schwartz Center Compassionate Caregiver Award, Honorable Mention

C. Contribution to Science

1. Defining Populations of Critical Special Health Care Needs: Building upon my first study describing the cohort of children with neurodevelopmental disabilities in the ICU, I have attempted to identify populations of children with special healthcare needs (CSHCN) whose vulnerabilities place them at high risk of requiring acute care services.
 - a. Graham RJ, Fleegler EW, Robinson WM. Chronic ventilator need in the community: a 2005 pediatric census of Massachusetts. *Pediatrics*. 2007 Jun;119(6):e1280-7. PubMed PMID: [17485451](#).
 - b. Berry JG, Graham RJ, Roberson DW, Rhein L, Graham DA, Zhou J, O'Brien J, Putney H, Goldmann DA. Patient characteristics associated with in-hospital mortality in children following tracheotomy. *Arch Dis Child*. 2010 Sep;95(9):703-10. PubMed PMID: [20522454](#); PubMed Central PMCID: [PMC3118570](#).
 - c. Edwards JD, Houtrow AJ, Vasilevskis EE, Rehm RS, Markovitz BP, Graham RJ, Dudley RA. Chronic conditions among children admitted to U.S. pediatric intensive care units: their prevalence and impact on risk for mortality and prolonged length of stay*. *Crit Care Med*. 2012 Jul;40(7):2196-203. PubMed PMID: [22564961](#); PubMed Central PMCID: [PMC3378726](#).
 - d. LaRovere KL, Graham RJ, Tasker RC. Pediatric neurocritical care: a neurology consultation model and implication for education and training. *Pediatr Neurol*. 2013 Mar;48(3):206-11. PubMed PMID: [23419471](#).
2. Clarifying Needs and Measuring Outcomes for CSHCN: The development of the CAPE and Home Ventilation Program was conceptually linked to the Chronic Care Model, (CCM) which was originally constructed to address the "quality chasm" characterized by the Institute of Medicine in chronic care management. The CCM, which has been widely applied to the treatment of chronic illnesses, outlines six tenets for effective care: integrated community resources, a committed healthcare organization, support for patient self-management of care, a balanced and functional treatment team, evidence-based care, and organized and accessible patient information. Thus, identify gaps in care are central to the evolution of my clinical program. In addition to the citations below, my ongoing efforts with Dr. Parsons are culminating in a series of manuscripts describing clinical outcomes, family experience with chronic disease and healthcare system interface, and resource utilization.
 - a. Graham RJ, Pemstein DM, Palfrey JS. Included but isolated: early intervention programmes provision for children and families with chronic respiratory support needs. *Child Care Health Dev*. 2008 May;34(3):373-9. PubMed PMID: [18410643](#).
 - b. Berry JG, Graham DA, Graham RJ, Zhou J, Putney HL, O'Brien JE, Roberson DW, Goldmann DA. Predictors of clinical outcomes and hospital resource use of children after tracheotomy. *Pediatrics*. 2009 Aug;124(2):563-72. PubMed PMID: [19596736](#); PubMed Central PMCID: [PMC3614342](#).
 - c. Graham RJ, Athiraman U, Laubach AE, Sethna NF. Anesthesia and perioperative medical management of children with spinal muscular atrophy. *Paediatr Anaesth*. 2009 Nov;19(11):1054-63. PubMed PMID: [19558636](#).
 - d. Martinez EE, Smallwood CD, Bechard LJ, Graham RJ, Mehta NM. Metabolic assessment and individualized nutrition in children dependent on mechanical ventilation at home. *J Pediatr*. 2015 Feb;166(2):350-7. PubMed PMID: [25444009](#).
3. Targeting Interventions to Improve Outcomes: The ultimate objective is to improve care delivery for a vulnerable pediatric populations, recognizing that there may be broader application to other CSHCN and adult chronic illnesses.
 - a. Casavant DW, McManus ML, Parsons SK, Zurakowski D, Graham RJ. Trial of telemedicine for patients on home ventilator support: feasibility, confidence in clinical management and use in medical decision-making. *J Telemed Telecare*. 2014 Dec;20(8):441-9. PubMed PMID: [25316042](#).

- b. Kang PB, Morrison L, Iannaccone ST, Graham RJ, Bönnemann CG, Rutkowski A, Hornyak J, Wang CH, North K, Oskoui M, Getchius TS, Cox JA, Hagen EE, Gronseth G, Griggs RC. Evidence-based guideline summary: Evaluation, diagnosis, and management of congenital muscular dystrophy: Report of the Guideline Development Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular & Electrodiagnostic Medicine. *Neurology*. 2015 Mar 31;84(13):1369-78. PubMed PMID: [25825463](#); PubMed Central PMCID: [PMC4388744](#).
- c. Martinez EE, Bechard LJ, Smallwood CD, Duggan CP, Graham RJ, Mehta NM. Impact of Individualized Diet Intervention on Body Composition and Respiratory Variables in Children With Respiratory Insufficiency: A Pilot Intervention Study. *Pediatr Crit Care Med*. 2015 Apr 30;PubMed PMID: [25944746](#).
- d. Finkel RS, Mercuri E, Darras BT, Connolly AM, Kuntz NL, Kirschner J, Chiriboga CA, Saito K, Servais L, Tizzano E, Topaloglu H, Tulinius M, Montes J, Glanzman AM, Bishop KM, Zhong ZJ, Gheuens S, Bennett CF, Schneider E, Farwell W, and De Vivo DC, for the ENDEAR Study Group.* Nusinersen versus sham control in infantile-onset Spinal Muscular Atrophy. *New England Journal of Medicine*. 2017; 377:1723-32. (*multicenter trial – site investigator)

D. RESEARCH SUPPORT

Ongoing Research Support

Deborah Monroe Noonan Foundation (Muneton) 2016/09/01-2018/12/31
Efficacy and Feasibility of Tele-Psychotherapy Intervention To Support Parents Caring For Technology-dependent Children at Home

The goal is to pilot a tele-psychotherapy intervention to support parents caring for a high-risk children in the homecare setting and linking parent-centered outcomes to child outcomes and resource utilization.

Role: Co-Investigator (Mentor)

Boston Children's Hospital Accountable Care Organization Fund (Amar-Dolan) 2018/03/01-2019/02/28
Simulation Training for Caregivers of Tracheostomy Dependent Children

The goal is to develop, implement, and evaluate simulation training for caregivers of tracheostomy dependent children with clinical and family-centered outcomes metrics.

Role: Co-Investigator (Mentor)

Boston Children's Hospital Accountable Care Organization Fund (Graham) 2018/03/01-2019/02/28
Bringing the ICU Home: A Community-based Care Model for Children with Chronic Respiratory Failure

The goal of this project is to develop alternative payment and care models for high-risk pediatric patients.

Role: PI

NCT03306277, Avexis Pharmaceuticals (Darras) 2017/10/11-open

STR1VE, Phase III, Open-label, single arm, single dose study of AVXS-101 (gene-replacement therapy) for infants with SMA, Type I (intravenous)

The goal of this study is to assess safety and efficacy of intravenous gene replacement therapy

Role: Site Co-Investigator

NCT02913482, Hoffmann-La Roche, Pharmaceuticals (Darras) 2016/09/23-open

Firefish, Phase I, Safety, tolerability, pharmacokinetics, pharmacodynamics, and efficacy of RO7034067 in infants with SMA, Type I

The goal of this study is to assess safety and efficacy of an enteral gene-targeting small molecule therapy

Role: Site Co-Investigator

Completed Research Support

ISIS Pharmaceuticals (Darras) 2015/03/01-2016/01/01

A Phase 3, Randomized, Double-blind, Sham-Procedure Controlled Study to Assess the Clinical Efficacy and Safety of ISIS 396443-CS4 Delivered Intrathecally to Children with SMA Type II (age 2-12 yrs).

The goal of this multicenter study was to determine efficacy of an SMN-targeted antisense-oligonucleotide.

Role: Site Co-Investigator

ISIS Pharmaceuticals (Darras) 2014/03/01-2015/12/01
An Open-Label Study to Assess the Safety and Tolerability of ISIS 396443-CS12 Delivered Intrathecally to Patients with SMA who previously enrolled in ISIS 396443 - CS2 or CS10.
The goal of this multicenter study was to determine efficacy of an SMN-targeted antisense-oligonucleotide.
Role: Site Co-Investigator

CureSMA (Mehta and Graham) 2014/12/01-2015/12/01
Role of Individualized Metabolic Measurement in Children with SMA, Implementation of comprehensive nutritional assessment and intervention program for children and young adults with SMA Types II and III.
The goal of this study was to evaluate baseline metabolic and nutritional status for children with SMA and implement a comprehensive assessment and intervention program
Role: Co-Principle Investigator

ISIS Pharmaceuticals (Darras) 2014/08/01-2015/08/01
A Phase 3, Randomized, Double-blind, Sham-Procedure Controlled Study to Assess the Clinical Efficacy and Safety of ISIS 396443-CS3b Delivered Intrathecally to Infants with SMA, Type I (age <7months).
The goal of this multicenter study was to determine efficacy of an SMN-targeted antisense-oligonucleotide in infants with SMA.
Role: Site Co-Investigator

Harvard Pilgrim Health Care (Graham and McManus) 2013/12/01-2014/12/01
CAPE Care Delivery Model Pilot Program
The goal of this project was to describe and analyze resource utilization and clinical outcomes for children with chronic respiratory insufficiency enrolled in the CAPE and Home Ventilation Program.
Role: Co-Principle Investigator

Children's Hospital Collaborative Clinical Effectiveness Fund (Graham) 2013/07/01-2014/12/01
Payer-Provider Quality Initiative, Critical Care, Anesthesia, Perioperative Extension (CAPE) and Home Ventilation Program Bridge Support following initial grant period 2011-2013
The goal of this project was to support ongoing program development and outcomes assessment including healthcare economics, resource utilization, provider needs assessment, and alternative payment model development.
Role: PI

ISIS Pharmaceuticals (Darras) 2012/01/01-2014/01/01
An Open-Label, Dose Escalation Study to Assess the Safety, Tolerability and Dose-Range Finding of Multiple Doses of ISIS 396443 - CS12 Delivered Intrathecally to Patients with SMA, Types II and III (ages 2-14 years)
The goal of this multicenter study was to determine safety and efficacy of an SMN-targeted antisense-oligonucleotide in children with SMA.
Role: Site Co-Investigator

Children's Hospital Boston, Innovation Acceleration Program (IAP) Investment Grant (Mehta)
2011/07/01-2013/06/01
Noninvasive Ventilation Integrated Gas Exchange Monitoring Prototype
The goal of this study was development of potential tools to perform calorimetry for BiPAP dependent patients.
Role: Co-Investigator

Children's Hospital Boston, Innovation Acceleration Program (IAP) Investment Grant (Casavant)
2011/07/01-2013/06/01
Telemedicine and Home Ventilator Patients
The goal of this study was to pilot of teleCAPE Program to demonstrate feasibility and limited outcomes for children with chronic respiratory failure in the community.
Role: Co-Investigator