**ALS Guidance Participants**

The following individuals were leading participants in the patient-centered, community-led ALS Guidance initiative.*

**Steering Committee:**

- **Barbara Newhouse**, President and CEO, The ALS Association; *Steering Committee Chair*
- **Lucie Bruijn**, PhD, MBA, The ALS Association; *Steering Committee Vice Chair*
- **Hiroshi Mitumoto**, MD, DSc, Columbia University Medical Center; *Steering Committee Vice Chair*
- **Richard Bedlack**, MD, PhD, Duke University Medical Center; *chair, Public Policy working group*
- **James Berry**, MD, Massachusetts General Hospital; *chair, Biomarkers working group*
- **Benjamin Rix Brooks**, MD, Carolinas HealthCare System, University of North Carolina School of Medicine – Charlotte; *chair, Benefit/Risk working group*
- **Merit Cudkowicz**, MD, Massachusetts General Hospital; *co-chair, Clinical Trials and Outcome Measures working group*
- **Valerie Cwik**, MD, Muscular Dystrophy Association; *Steering Committee Member*
- **Ted Harada**, Person with ALS, ALS Association National Trustee; *co-chair, Patient & Caregiver Advisory Committee*
- **Donald Johns**, MD, Biogen; *Steering Committee Member*
- **Catherine Lomen-Hoerth**, MD, PhD, University of California, San Francisco; *chair, FTD/ALS working group*
- **Nicholas J. Maragakis**, MD, Johns Hopkins University, School of Medicine; *chair, Diagnosis working group*
- **Timothy M. Miller**, MD, PhD, Washington University School of Medicine; *chair, Natural History working group*
- **Elizabeth Ottinger PhD**, National Institutes of Health / National Center for Advancing Translational Sciences; *Steering Committee Member*
- **Steve Perrin**, PhD, ALS Therapy Development Institute; *Steering Committee Member*
- **Jeremy Shefner MD, PhD**, Barrow Neurological Institute; *co-chair, Clinical Trials and Outcome Measures working group*
- **Stephen Winthrop**, Person with ALS, ALS Association National Trustee, Research Ambassador; *co-chair, Patient & Caregiver Advisory Committee*

**Benefit/Risk Working Group:**

- **Benjamin Rix Brooks**, MD, Carolinas HealthCare System, University of North Carolina School of Medicine – Charlotte, *Working Group Chair*
- **William Cho**, MD, Genentech
Stephen Finan, Person with ALS
Stephen Finger, Person with ALS, HopeNow4ALS
Eric Gascho, National Health Council
Kimberly L. Goslin MD, PhD, Providence ALS Center
Stephen Goutman, MD, MS, University of Michigan
Laurie Gutmann, MD, University of Iowa Carver College of Medicine
Christopher D. Lee, MD, MPH, Vanderbilt University Medical Center
Joseph Lewcock, PhD, Genentech
Björn Oskarsson, MD, University of California, Davis School of Medicine and the Mayo Clinic
Stephen N. Scelsa, MD, Icahn School of Medicine at Mount Sinai
Katalin Scherer, MD, University of Arizona School of Medicine & Banner University Medical Center
Ericka P. Simpson, MD, Houston Methodist Neurological Institute & Weill Cornell Medical College
Andrew A. Wolff, MD, Cytokinetics, Inc.

Natural History Working Group:

Timothy M. Miller, MD, PhD, Washington University School of Medicine; Working Group Chair
Patricia L. Andres, MS, DPT, Massachusetts General Hospital
Mary Kay Floeter, MD, PhD, National Institute of Neurological Disorders and Stroke
Matthew Harms, MD, Columbia University
Catherine Lomen-Hoerth, MD, PhD, University of California, San Francisco
Eric Macklin, PhD, Massachusetts General Hospital
Bernard Ravina, MD, MS, Voyager Therapeutics
John Ravits, MD, University of California San Diego
Stacy Rudnicki, MD, Cytokinetics, Inc.
Steven Ziegler, MS, Person with ALS and Research Ambassador

Diagnosis Working Group:

Nicholas J. Maragakis, MD, Johns Hopkins University, School of Medicine; Working Group Chair
Nazem Atassi, MD, Massachusetts General Hospital
Kevin Boylan, MD, Mayo Clinic
David Ennist, PhD, Origent Data Sciences
Amanda Haidet-Phillips, PhD, Muscular Dystrophy Association
Carlayne Jackson, MD, University of Texas San Antonio
Sabrina Paganoni, MD, PhD, Spaulding Rehabilitation Hospital and Massachusetts General Hospital
Karen Shideleff, RN, Person with ALS and Research Ambassador
Bryan Traynor, MD, PhD, National Institute of Neurological Disorders and Stroke
Biomarkers Working Group:

- **James Berry, MD**, Massachusetts General Hospital; *Working Group Chair*
- **Michael Benatar, MD, PhD**, University of Miami
- **Gil Block, MD, PhD**, Neuraltus Pharmaceuticals
- **Robert Bowser, PhD**, Barrow Neurological Institute
- **Terry Heiman-Patterson, MD**, Drexel University College of Medicine and ALS Hope Foundation
- **Andreas Jeromin, PhD**, Iron Horse Diagnostics
- **Melanie Leitner, PhD**, Biogen Idec
- **Terry Ann McNearney, MD**, Eli Lilly and Company
- **Lyle W. Ostrow, MD, PhD**, Johns Hopkins University School of Medicine
- **Erik Pioro, MD, PhD**, Cleveland Clinic
- **Wes Rose**, Person with ALS
- **Seward Rutkove, MD**, Beth Israel Deaconess Medical Center

Clinical Trials & Outcome Measures Working Group:

- **Merit Cudkowicz, MD**, Massachusetts General Hospital, *Co-Chair CTOM Working Group*
- **Jeremy Shefner, MD, PhD**, Barrow Neurological Institute, *Co-Chair CTOM Working Group*
- **Jinsy A. Andrews, MD, MSc**, Cytokinetics, Inc.
- **Frank Bennett, PhD**, Ionis Pharmaceuticals
- **Christopher Coffey, PhD**, University of Iowa
- **Robin Conwit, MD**, National Institute of Neurological Disorders and Stroke
- **David Ennist, PhD**, Origent Data Sciences
- **Toby Ferguson, MD, PhD**, Biogen
- **Madeline Kennedy**, Person with ALS and Research Ambassador
- **Steve Kolb**, Family Member and Research Ambassador
- **Michael McDermott, PhD**, University of Rochester Medical Center
- **David Schoenfeld, PhD**, Massachusetts General Hospital

Public Policy Working Group:

- **Richard Bedlack, MD, PhD**, Duke University Medical Center, *Working Group Chair*
- **Tricia DeSantis**, Biogen Idec
- **Steve Gibson**, The ALS Association
- **Michael Gollin**, Person with ALS
- **Ghazala Hayat, MD**, St. Louis University
- **Edward J. Kasarskis, MD, PhD**, University of Kentucky
- **Jon Katz, MD**, Forbes-Norris
- **K. Kimberly McCleary**, FasterCures
- **Paul Mehta, MD**, Centers for Disease Control and Prevention
- **Jess Rabourn**, Ax-S Pharma and WideTrial
- Kristin Stephenson, Muscular Dystrophy Association
- Patrick Wildman, The ALS Association, VP Public Policy
- Stephen Winthrop, Person with ALS, Research Ambassador and ALS Association National Trustee

**Frontotemporal Dementia (FTD) and ALS Working Group** (material for this section was developed on FTD in ALS and then incorporated into other guidance sections as appropriate)

- Catherine Lomen-Hoerth, MD, PhD, University of California San Francisco, *Working Group Chair*
- Sharon Abrahams, PhD, University of Edinburgh
- Lora Clawson, MSN, CRNP, Johns Hopkins Medicine
- Laura H. Goldstein, PhD, MPhil, King’s College London
- Murray Grossman, MD, University of Pennsylvania
- Jennifer Murphy, PhD, University of California San Francisco
- Steve Reznick, PhD, University of North Carolina, Person with ALS, and Research Ambassador
- Susan Woolley, PhD, ABPP, Forbes Norris ALS Research Center, Sutter Pacific Medical Foundation

**ALS Patient & Caregiver Advisory Committee:**

- Ted Harada, Person with ALS, ALS Association National Trustee; *Co-Chair*
- Stephen Winthrop, Person with ALS, ALS Association National Trustee, Research Ambassador; *Co-Chair*
- Clay Ahrens, Person with ALS
- Pat Bradley, Person with ALS
- Steve Byer, ALS Worldwide, Co-Executive Director and family member
- Mike Cherepov, Person with ALS
- Clare Durrett, Team Gleason, Associate Executive Director
- Stephen Finan, Person with ALS
- Stephen Finger, Person with ALS, HopeNow4ALS
- Deb Gaudet, Person with ALS
- Michael Gollin, Person with ALS
- Bob Hebron, HopeNow4ALS, family member
- Shelly Hoover, Ed.D. Person with ALS
- Madeline Kennedy, R.N., MSN, Person with ALS, Research Ambassador
- Robert Kleiner, Project ALS
- Steve Kolb, Family Member, Research Ambassador
- Christopher Leidigh, Person with ALS
- Jehad Majed, Family Member, HopeNow4ALS
- Bob Murray, Family Member and Research Ambassador
- Steve Reznick, PhD, University of North Carolina, Person with ALS and Research Ambassador
- Col. (Rez.) Shay Rishoni, MBA, Prize4Life, CEO, and Person with ALS
- Wes Rose, PhD, Arcadia University, Person with ALS
• Craig Sanderson, Kevin Turner Foundation
• Karen Shideleff, RN, Person with ALS and Research Ambassador
• Kathy Thomas, Family Member and Research Ambassador
• Joe Wise, Person with ALS
• Evan Yegelwel, Person with ALS
• Steven Ziegler, MS, Person with ALS and Research Ambassador

Technical Support:
• Lisa Bain, Science & Medical Writer
• Timothy Franson, MD, YourEncore
• Steve Gibson, The ALS Association
• Allison Durham Martin, MSc, FaegreBD Consulting
• Patrick Wildman, The ALS Association
• Dave Zook, FaegreBD Consulting

*affiliations as of September 2016