

Congenital Muscular Dystrophy Common Data Element (CDE) Working Group Roster

CMD International Registry Working Group, November 2008

Richard Cloud - Cure CMD, Chair

Anne Rutkowski, MD - Cure CMD, Vice Chair

Carsten Bonnemann, MD - Children's Hospital of Philadelphia	Kathy Mathews, MD - University of Iowa
Anne Connolly, MD - Washington University, St. Louis	Steven Moore, MD, PhD - University of Iowa
Tatiana Foroud, PhD - Indiana University	Anna Sarkozy, MD - TREAT-NMD, Center for Life, Newcastle, England
Susan Iannaccone, MD - University of Texas Southwestern Medical Center	Susan Sparks, MD, PhD - Carolinas Medical Center
Jackie Jackson, Research Coordinator - Indiana University	Tom Winder, PhD - Prevention Genetics

Cure CMD/TREAT-NMD CMD International Registry Working Group, March 2009

Richard Cloud - Cure CMD, Chair

Anne Rutkowski, MD - Cure CMD, Vice Chair

Christophe Bérout, PhD – Assistant Professor, Laboratoire de Génétique Moléculaire and INSERM U827, Montpellier, France	Stephen Lynn, Project Manager - TREAT-NMD, Newcastle, England
Enrico Bertini, MD - Gesu Bambino Hospital	Susana Quijano-Roy, MD, PhD - de Reference Maladies Neuromusculaires (GNMH), Service de Pédiatrie, Hôpital Raymond Poincaré, Garches, France
Carsten Bönemann, MD - Children's Hospital of Philadelphia	Thomas Sejersen, MD - Karolinska Institut, Sweden
Kate Bushby, MD - TREAT-NMD, Center for Life, Newcastle, England	Volker Straub, MD - TREAT-NMD, Newcastle Center for Life
James Collins, MD, PhD - Cincinnati Children's Hospital Medical Center	Rachel Thompson, UK SMA Patient Registry and SMA Clinical Research Communications - TREAT-NMD
Emma Heslop, Assistant Project Manager - TREAT-NMD	Tracey Willis, MD - TREAT-NMD, FKRP registry

Please note that the institutions for all individuals acknowledged in this section were those they belonged to when they joined the Working Group

Congenital Muscular Dystrophy Common Data Element (CDE) Working Group Roster

ENMC CMD Outcome Measure Working Group, March 2010

Anne Rutkowski, MD - Cure CMD, Chair

Eunice Kim - Cure CMD, Vice Chair

Enrico Bertini, MD - Unit of Molecular Medicine, Dept. of Laboratory Medicine, Ospedale Bambino, Rome, Italy	Anna Mayhew - Consultant Research Physiotherapist, England
Carsten Bonnemann, MD - Children's Hospital of Philadelphia	Elena Mazzone, Physiotherapist - Pediatric Neurology Unit, Catholic University, Rome
Stefan Cano, Chartered Psychologist - Senior Lecturer in Psychometrics, Peninsula College of Medicine and Dentistry	Thomas Meier, PhD - Chief Scientific Officer, Santhera Pharmaceuticals Holding Ltd.
Michelle Chatwin, Consultant Physiotherapist - Respiratory Support, Royal Brompton Hospital	Eugenio Mercuri, MD - Neuopsichiatria Infantile, Policlinico Gemelli, Largo Gemelli, Rome, Italy
Nicholas Coppard, PhD - Senior Vice President Development, Santhera Pharmaceuticals Holding Ltd.	Francesco Muntoni, MD - Dubowitz Neuromuscular Centre, Institute of Child Health, London
Michelle Eagle, PhD, MSc, MCSP - Consultant Physiotherapist, University of Newcastle	Marika Pane, MD - Institute of Neurology, Catholic University, Rome, Italy
Ana Ferreiro, MD, PhD - UMR 787 Groupe Myologie Faculté de Médecine, Groupe Hospitalier Pitié-Salpêtrière, Paris, France	Khazal Paradis, MD - Senior Vice President Clinical Research, Genzyme Europe
Allan Glanzman, PT, DPT, PCS, ATP - Pediatric Physical Therapist, Children's Hospital of Philadelphia	Christine Payan, MD - Institut de Myologie, Hôpital Pitié-Salpêtrière
Jeremy Hobart, MD - Senior Lecturer and Honorary Consultant Neurologist, Department of Clinical Neuroscience, Peninsula Medical School	Susana Quijano-Roy, MD, PhD - Centre de Reference Maladies Neuromusculaires (GNMH), Service de Pédiatrie, Hôpital Raymond Poincaré, Garches, France
Linda Hynan, PhD - Professor of Biostatistics, Departments of Clinical Sciences and Psychiatry at UT Southwestern Medical Center	Laurent Servais, PhD - Institut of Myology, Paris, France
Marion Main, MA, MCSP - Consultant Physiotherapist in Paediatric Neuromuscular Disorders, Dubowitz Neuromuscular Centre	Volker Straub, MD - TREAT-NMD, Center for Life, Newcastle, England
Kathy Mathews, MD - University of Iowa	

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Congenital Muscular Dystrophy Common Data Element (CDE) Working Group Roster

CMD Comparative Outcome Measure Study, June 2010

Anne Rutkowski, MD - Cure CMD, Chair

Eunice Kim - Cure CMD, Vice Chair

Carsten Bonnemann, MD - Children's Hospital of Philadelphia	Robert Leschner, MD - Children's National Medical Center
Courtney Broadley, PT, DPT - Kennedy Krieger Institute	Melissa Luhmann, MSPT - Physical Therapist, Rehabilitation Medicine Department, Mark O. Hatfield Clinical Research Center, National Institutes of Health
James Collins, MD, PhD - Cincinnati Children's Hospital Medical Center	Marion Main, MA MCSP - Consultant Physiotherapist Paediatric Neuromuscular Disorders, Dubowitz Neuromuscular Centre
Robert Fee, MA - Project Coordination, Columbia University DMD/BMD Project	Ami Mankodi, MD - NINDS
Kurt Fischbeck, MD - NIH Distinguished Investigator, NINDS	Michelle McGuire, PT, MPT - Division of Occupational Therapy and Physical Therapy, Cincinnati Children's Hospital Medical Center
Reghan Foley, MD - Neuromuscular Research Fellow, Dubowitz Neuromuscular Center, London	Katy Meilleur, RN, NP - NINDS
Allan Glanzman, PT, DPT, PCS, ATP - Pediatric Physical Therapist, Children's Hospital of Philadelphia	Kathryn North, M.D., F.R.A.C.P. - Children's Hospital at Westmead Clinical School Faculty of Medicine, University of Sydney
Veronica J. Hinton, Ph.D. - G.H. Sergievsky Center & Department of Neurology, Columbia University	Shamaine Price, Coordinator - NINDS
Linda Hynan, PhD - Professor of Biostatistics, Departments of Clinical Sciences and Psychiatry at UT Southwestern Medical Center	Kristy Rose, Physiotherapist - Institute for Neuroscience and Muscle Research, Children's Hospital at Westmead
Mina Jain, PT, DSc, PCS - Pediatric Clinical Specialist, National Institutes of Health	Alice Schindler, MS, CGC - Genetic Counselor, Neurogenetics Branch, National Institutes of Health/NINDS
Peter Kelly, RRT - STAT Lab Manager, Clinical Center, Critical Care Medicine Department, NIH	Kathryn Wagner, MD, PhD - Director of the Center for Genetic Muscle Disorders, Kennedy Krieger Institute
Angela Kokkinis, BSN, RN - Research Nurse, Neurogenetics Branch, NIH	

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Congenital Muscular Dystrophy Common Data Element (CDE) Working Group Roster

CMD Common Data Element Working Group Kick-off Meeting, September 2010

Anne Rutkowski, MD - Cure CMD, Chair

Eunice Kim - Cure CMD, Vice Chair

Carsten Bonnemann, MD - Senior Investigator, NINDS	Hank Mayer, MD - Division of Pulmonary Medicine, Children's Hospital of Philadelphia
James Collins, MD, PhD - Cincinnati Children's Hospital Medical Center	Erin McGuirk, Cure CMD Grant Writing Team – Harvard University
Nicholas Coppard, PhD - Senior Vice President Development, Santhera Pharmaceuticals Holding Ltd.	Thomas Meier, PhD - Chief Scientific Officer, Santhera Pharmaceuticals Holding Ltd.
Reghan Foley, MD - Neuromuscular Research Fellow, Dubowitz Neuromuscular Center, London	Joanne Odenkirchen, MPH - CDE Project Officer, NINDS
Stacie Grinnon, MS - CDE Co-Project Manager, KAI Research, Inc. (An Altarum Company), Rockville, Maryland, USA	John Porter, PhD - Program Director, NINDS
Susan Iannaccone, MD - Southwestern Medical Center, UT Southwestern Medical Center at Dallas	Rachel Richesson, MS, PhD, MPH - University of South Florida
Cynthia Joyce, Executive Director - Spinal Muscular Atrophy Foundation	Ulrike Schara, MD - Universitätsklinikum Essen, Zentrum für Kinderheilkunde, Essen, Germany
Petra Kaufmann, MD - Associate Director for Clinical Research, NINDS	Karen Lohmann Siegel, PT, MA - Chief Therapist Officer, Agency for Healthcare Research and Quality
Anastassios C. Koumbourlis, MD, MPH - Children's National Medical Center	Christina You, MSPH - CMD CDE Lead, KAI Research, Inc. (An Altarum Company), Rockville, Maryland, USA
William Martens, Associate - Department of Neurology, NMD (SMD) - University of Rochester	

Please note that the institutions for all individuals acknowledged in this section were those they belonged to when they joined the Working Group

Congenital Muscular Dystrophy Common Data Element (CDE) Working Group Roster

CMD Motor Data Working Group, October 2010

Anne Rutkowski, MD - Cure CMD, Chair

Eunice Kim, MBA - Cure CMD, Vice Chair

Maria Ash, Research Physiotherapist - Dubowitz Neuromuscular Centre, London	Marion Main, Consultant Physiotherapist - Dubowitz Neuromuscular Centre, London
Carsten Bonnemann, MD - NINDS	Hank Mayer, MD - Children's Hospital of Philadelphia
Michelle Chatwin, PhD – Clinical Specialist Physiotherapist at the Clinical and Academic Dept of Sleep and Breathing at the Royal Brompton	Anna Mayhew, PhD, M Med Sci, MCSP - Consultant Research Physiotherapist, Imperial College, London, England
Nicolas Coppard, PhD - Santhera Pharmaceuticals	Thomas Meier, PhD - Santhera Pharmaceuticals
Lillette Eskelinen, Clinical Research Associate - Santhera Pharmaceuticals	Katy Meilleur, RNP, PhD - NINDS
Ana Ferreiro, MD, PhD - INSERM, Paris	Jane and Kate Mellor
Reghan Foley, MD - Neuromuscular Research Fellow, Dubowitz Neuromuscular Center, London	Eugenio Mercuri, MD – Pediatric Neurology Unit, Catholic University, Rome
Allan Glanzman, PT, DPT, PCS, ATP - Pediatric Physical Therapist, Children's Hospital of Philadelphia	Francesco Muntoni, MD - Dubowitz Neuromuscular Centre, Institute of Child Health, London
Andy Hisock - Paediatric Neuromuscular Physiotherapy Research Team at ICH/GOSH; Adult Physiotherapy Research Team at Dubowitz Neuromuscular Centre	Christine Payan, MD - Institut de Myologie, Hôpital Pitié-Salpêtrière
Linda Hynan, PhD - UT Southwestern, Texas	Susana Quijano-Roy, MD, PhD - Centre de Reference Maladies Neuromusculaires (GNMH) Service de Pédiatrie, Hôpital Raymond Poincaré, Garches, France
Mina Jain, PT - NINDS	Sarah Rose

NINDS CDE Team

Stacie Grinnon MS - KAI Research, Inc. (An Altarum Company), Rockville, Maryland, USA	John Porter, PhD - National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH)
Petra Kaufmann, MD, MSc - National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH)	Christina You, MSPH - KAI Research, Inc. (An Altarum Company), Rockville, Maryland, USA
Joanne Odenkirchen, MPH - National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH)	

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