

# 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 Ferreira, 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 Référence 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	

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# 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
Lilette 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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