

Outcome Measures and Infrastructure for Phase III Studies in Batten Disease (JNCL)
December 6-7, 2013. Rochester, New York USA

Participant Roster

Heather R. Adams, PhD

Assistant Professor of Neurology and Pediatrics
Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center
& BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Erika F. Augustine, MD

Assistant Professor of Neurology and Pediatrics
Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center
& BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Ellen Bletsoe

Parent
Trustee, Batten Disease Family Association
Thrapston, Northamptonshire
England

BDFa

PO Box 605
Fleet GU51 9GE
England
tel: +44 01252 416110
www.bdfa-uk.org.uk/

Gary D. Clark, MD

Texas Children's Hospital
Department of Pediatric Medicine, Neurology
Section Chief, Neurology and Developmental Neuroscience
Houston, Texas, USA

The Blue Bird Circle Clinic Batten Disease Center of
Excellence

www.thebluebirdcircle.com/clinics/

Elisabeth A. deBlieck, MPA CCRC

Program Manager, Clinical Trials Coordination Center
Center for Human Experimental Therapeutics
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center
& BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Emily C. de los Reyes, MD

Professor of Pediatrics and Neurology, The Ohio State
University
Associate Director, Department of Pediatric Neurology
Nationwide Children's Hospital
Columbus, Ohio, USA

Batten Disease Center of Excellence
www.nationwidechildrens.org/batten-disease

Lisa Beth Ferstenberg, MD

Principal, Orphan Solutions

On behalf of:

Beyond Batten Disease Foundation
P.O. Box 200998
Austin, TX 78720
USA
tel: +1.877.6BATTEN or 1.877.622.8836
www.beyondbatten.org

Robert C. Griggs, MD FAAN

University of Rochester Medical Center
Professor of Neurology, Medicine, Pathology and Laboratory
Medicine, Pediatrics and Center for Human Experimental
Therapeutics
Channelopathy and Muscle Study Projects
Rochester, New York, USA

Outcome Measures and Infrastructure for Phase III Studies in Batten Disease (JNCL)
December 6-7, 2013. Rochester, New York USA

Participant Roster

Silvia Guerra, MD

Paediatric Neurology Fellow
Evelina London Children's Hospital, Dept. of Neurosciences
London, England

Resident in Child Neurology and Psychiatry – Univ. of Verona
Verona, Italy

Poster Title

Parents' perspectives on scientific research in Batten disease
and Dravet syndrome

Tina Kissenbeck, MD

Resident
Children's Hospital
University Medical Centre Hamburg-Eppendorf
Hamburg, Germany

Poster Title

Psychopathology in CLN3 disease: Correlation with disease
progression and quality of life

Jennifer M. Kwon, MD MPH

Associate Professor of Neurology and Pediatrics
Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center
& BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Lenora M. Lehwald, MD

Assistant Professor of Clinical Pediatrics, Neurology and Sleep
Medicine
Nationwide Children's Hospital and The Ohio State University
Columbus, Ohio, USA

Poster Title

Neuronal Ceroid Lipofuscinoses and associated sleep
abnormalities

Christopher Leonard, PhD

Science Officer
Batten Disease Support and Research Association
1175 Dublin Road
Columbus, OH 43215
USA
tel: +1.800.448.4570
www.bdsra.org

Frederick J. Marshall, MD

Associate Professor, Department of Neurology
Unit Chief, Geriatric Neurology Unit
Director, Memory Care Program
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center
& BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Michael P. McDermott, PhD

Associate Chair and Professor, Department of Biostatistics and
Computational Biology; Professor, Center for Human
Experimental Therapeutics; Neurology
Rochester, New York, USA

Albee Messing, VMD, PhD

Professor of Neuropathology
Waisman Center and Dept of Comparative Biosciences
University of Wisconsin-Madison
Madison, Wisconsin, USA

Outcome Measures and Infrastructure for Phase III Studies in Batten Disease (JNCL)
December 6-7, 2013. Rochester, New York USA

Participant Roster

Jonathan W. Mink, MD, PhD

Vice Chair, Department of Neurology
Chief, Division of Child Neurology
Professor, Departments of Neurology, Pediatrics, Brain and
Cognitive Sciences; Neurobiology and Anatomy
University of Rochester Medical Center
Rochester, New York, USA

Director, URM C Batten Disease Diagnostic & Clinical
Research Center & BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Aimee Morris

Medical Student
University of Rochester School of Medicine
Rochester, New York, USA

Poster Title

Treatment of Tremor in Ataxic Cerebral Palsy with Deep Brain
Stimulation

John R. Østergaard DMSc

Centre for Rare Diseases / Center for Sjældne Sygdomme
(CSS)
Department of Clinical Medicine – The Department of
Paediatrics
Aarhus University Hospital
Aarhus, Denmark

<http://www.auh.dk/om+auh>

David A. Pearce, PhD

Director Sanford Children's Health Research Center, Sanford
Research USD
Professor, Department of Pediatrics
Sanford School of Medicine of the University of South Dakota
Sioux Falls, South Dakota, USA

Pearce Lab for Genetically Inherited Diseases of Children
www.sanfordresearch.org/researchcenters/childrenshealth/pearcelab/

Lori Sikorra

Parent
Westlake Village, California, USA

Angela Schulz, MD

Children's Hospital, Department of Pediatrics
University Medical Centre Hamburg-Eppendorf
Hamburg, Germany

Coordinator – DEM-CHILD
<http://www.dem-child.eu/index.php/background-16.html>

Katherine B. Sims, MD

Professor of Neurology, Harvard Medical School
Massachusetts General Hospital
Boston, Massachusetts, USA

Director, NCL Disorders Clinic, MGH-CHGR Batten
Center of Excellence
Clinical Registry and Tissue Bank for the Neuronal Ceroid
Lipofuscinoses (NCL) disorders

<http://www.massgeneral.org/neurology/doctors>

John F. Staropoli MD, PhD

Scientist II, Translational Medicine
Biogen Idec
Cambridge, Massachusetts, USA

<http://www.biogenidec.com/>

Outcome Measures and Infrastructure for Phase III Studies in Batten Disease (JNCL)
December 6-7, 2013. Rochester, New York USA

Participant Roster

Robert D. Steiner, MD FAAP

Executive Director, Marshfield Clinic Research Foundation
Chief Science Officer, Marshfield Clinic
Executive Associate Director, Institute for Clinical and
Translational Research, University of Wisconsin
Marshfield, Wisconsin, USA

www.marshfieldclinic.org

Danilo Tagle, PhD

Associate Director for Special Initiatives
National Center for Advancing Translational Sciences (NCATS) at
the National Institutes of Health (NIH)
Bethesda, Maryland, USA

www.ncats.nih.gov

Amy Vierhile, MS PNP

Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research
Center & BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Ruth E. Williams, MD

Consultant Paediatric Neurologist
Children's Neurosciences Centre, Newcomen Centre
St Thomas' Hospital
London, England

Batten Disease Service, Evelina London Children's Hospital
<http://www.guysandstthomas.nhs.uk/our-services/consultant-profiles/childrens-neuroscience/ruth-williams.aspx>

Conference Administrative Support Team

Alyssa Thatcher

Study Coordinator
Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research
Center & BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Sara Defendorf

Study Coordinator
Division of Child Neurology
University of Rochester Medical Center
Rochester, New York, USA

URMC Batten Disease Diagnostic & Clinical Research Center &
BDSRA Batten Center of Excellence
www.urmc.rochester.edu/neurology/batten-disease-center/

Daniel Parr

Administrator, University of Rochester Medical Center
Strong Epilepsy Center & Division of Child Neurology
Rochester, New York, USA

Magda Ramzy

Administrative Assistant
University of Rochester Medical Center – Child Neurology
Rochester, New York, USA