



Niemann-Pick Disease Resources



National Niemann-Pick Disease Foundation, Inc. **(Providing Family Services to the U.S. and Canada)**

Chris Klauer

P.O. Box 49; 401 Madison Avenue, Suite B
Fort Atkinson, WI 53538-0049

Toll Free: 1-877-287-3672

Tele: (920) 563-0930; Fax: (920) 563-0931

Email: nnpdf@nnpdf.org Web Site: www.nnpdf.org

Niemann-Pick Disease Type C (NPC)

National Institute of Child Health & Human Development National Institutes of Health

Dr. Forbes "Denny" Porter, M.D., Ph.D.

Senior Investigator, Sect. on Molecular Dysmorphology

Tele: (301) 435-4432

Email: fdporter@mail.nih.gov

Nicole Farhat, C.R.N.P.

Developmental Endocrinology & Genetics

Tele: (301) 594-1765

Email: nicole.farhat@nih.gov

Lee Ann Keener

Clinical Research Nurse

(301)-594-2005

Email: leeann.keener@nih.gov

Mailing Address for Dr. Porter, Nicole Farhat & Lee Ann Keener

National Institutes of Health

10CRC, Room 5-271

10 Center Drive

Bethesda, MD 20892

Mayo Clinic, Department of Neurology

Dr. Marc C. Patterson, M.D.

Chair, Div. of Child & Adolescent Neurology

200 First Street SW

Rochester, MN 55905

Tele: (507) 284-3351; Fax: (507) 284-0727

Email: patterson.marc@mayo.edu

Washington University School of Medicine

Dr. Daniel Ory, M.D.

***Alan A. & Edith L. Wolff Distinguished Professor of
Medicine***

600 South Euclid Ave., Box 8086

St. Louis, MO 63110

Tele: 314-362-8737

Email: dory@wustl.edu

Niemann-Pick Disease Types A & B/ASMD **(Acid Sphingomyelinase Deficiency)**

Dr. Andrew Lieberman, MD PhD

Abrams Collegiate Professor of Pathology

Director of Neuropathology

University of Michigan Medical School
3510 MSRB 1, 1150 W. Medical Center Dr.

Ann Arbor, Michigan 48109-0605

Phone: 734-647-4624

Email: liebermn@med.umich.edu

Mount Sinai International Center for Types A and B Niemann-Pick Disease Web site: www.mssm.edu/niemann-pick/

Dr. Edward H. Schuchman, Ph.D.

Director, Intl. Ctr. for Types A & B NPD

Mount Sinai School of Medicine

1425 Madison Ave., Rm. 14-20A

New York, NY 10029

Tele: (212) 659-6711; Fax: (212) 849-2447

Email: edward.schuchman@mssm.edu

George A. Diaz, M.D., Ph.D.

Division Chief of Medical Genetics

Mount Sinai School of Medicine

Atran Berg Laboratory Building, 1 – 45

1428 Madison Avenue

New York, NY 10029

Tele: 212-241-0858

Email: george.diaz@mssm.edu

Chrystelle Montagne, Ph.D.

Associate Researcher II / Study Coordinator

Department of Genetics and Genomic Sciences

Icahn School of Medicine at Mount Sinai

One Gustave L. Levy Place, Box 1498

New York, NY 10029

Tele: 212-659-1456

Email: chrystelle.montagne@mssm.edu

Canada – ASMD (Types A & B) and NPC

Hospital for Sick Children (SickKids Hospital)

Margaret Mackrell, R.N., B.H.Sc.N.

Research Nurse Coordinator

Div. of Clinical & Metabolic Genetics

Hospital for Sick Children

555 University Avenue

Toronto, Ontario M5G 1X8

Tele: 416-813-8367

Email: margaret.mackrell@sickkids.ca