



**National Tay-Sachs & Allied Diseases Association
and
Brigham & Women's Hospital
present**

**Diagnosis, Management & Treatment of Progressive Neurological
Disease from Infancy to Adult using Tay-Sachs Disease as a Model**

A CME Conference for Specialized Clinicians and General Practitioners

Monday, September 21, 2009

1:00 – 5:10 PM

Reception to follow

**The Joseph B. Martin Conference Center at Harvard Medical School
77 Avenue Louis Pasteur, Boston, MA**

Also available by Webcast

Faculty:

Florian Eichler, MD
Assistant Professor
Department of Neurology
Massachusetts General Hospital
Harvard Medical School

Edwin Kolodny, MD
Chairman
Department of Neurology
New York University Medical Center

Gustavo H.B. Maegawa, MD, PhD
Assistant Professor
McKusick-Nathans Institute
of Genetic Medicine
Johns Hopkins University
School of Medicine

Miguel Sena-Esteves, PhD
Associate Professor
Department of Neurology and
Gene Therapy Center
University of Massachusetts
Medical School

Cynthia Tifft, MD, PhD
Deputy Clinical Director
National Human Genome
Research Institute

Program Director:
Michael F. Murray, MD
Clinical Chief of Genetics Division
Brigham & Women's Hospital
Harvard Medical School

***IMPROVE YOUR
Differential diagnosis
Clinical care
Understanding of the family perspective***



About the Program:

Lysosomal diseases comprise a group of approximately 50 disorders including gangliosidoses, mucopolysaccharidoses, glycogen storage diseases, and sphingolipidoses. Individually rare, in aggregate these disorders account for 1 in 5,000 live births. The range of severity in Tay-Sachs, a lysosomal disease provides an excellent model for the diagnosis, management and treatment of progressive neurological disease from infancy to adult.

This program is designed for neurologists, general practitioners, pediatricians, palliative and complex care pediatricians and physicians, psychologists, physical, occupational and speech therapists, nurses and others interested in improving differential diagnosis, clinical care and understanding of the family perspective.

The program consists of leading lysosomal clinicians discussing case studies along the continuum of severity; several include the family perspective. Topics include road to diagnosis, critical moments in care and providing compassionate symptom management.

Program Objectives:

- Improved differential diagnosis of neurodegenerative disease
- Improved clinical care of progressive neurological diseases along the spectrum from acute to chronic
- Improved understanding of the family perspective, their road to diagnosis & providing family centered-care
- Secondary goal: improved knowledge of neurodegenerative lysosomal disease

CME Accreditation: Harvard Medical School is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing education for physicians.

Harvard Medical School designates this educational activity for a maximum of 4 AMA PRA Category 1 credits.™

Program Schedule Monday, September 21, 2009

12:30 – 1:00	Registration
1:00 – 1:10	Welcome and Introductions , Mike Murray, MD
1:10 – 1:30	Epidemiology , Edwin Kolodny, MD
1:30 – 2:30	Infantile Lysosomal Cases Studies of Different Care Approaches Florian Eichler, MD, Edwin Kolodny, MD & Cynthia Tiff, MD, PhD
2:30 – 3:30	Juvenile GM-1/GM-2 Case Studies of Early and Later Onsets Gustavo Maegawa, MD, PhD & Cynthia Tiff, MD, PhD
3:30 – 3:40	<i>BREAK</i>
3:40 – 4:40	Late Onset Tay-Sachs Phenotypic Variations Among Siblings Florian Eichler, MD, Edwin Kolodny, MD & Gustavo Maegawa, MD, PhD
4:40 – 5:10	Tay-Sachs Research & Implications for other Neurodegenerative Diseases Miguel Sena-Esteves, PhD
5:10 – 7:00	Reception

Advance registration is appreciated but not required.

This conference is free of charge.

To register, send an email to Kim@ntsad.org, Subject Header: RSVP CME Seminar. Include: Name, Address, Email, Phone and Specialty. For more information or to register by phone, call 617-277-4463.

With special appreciation to Genzyme Therapeutics for their support of this program.