

List of Presenters

(scheduled to present)

Craig Campbell, M.D.MSc
Children Hospital — London Health Sciences Centre
University of Western Ontario, Dept. Paediatrics and
Clinical Neurological Sciences

Anne-Berit Ekstrom, M.D.
Neuropediatrician
Department of Pediatrics
Northern Alvsborg County Hospital,
S-461 85 Trollhattan, Sweden

Cynthia Gagnon, erg, PhD(c)
Clinique de Maladies Neuromusculaires
CSSS de Jonquiere 2230 de L'Hopital cp 1200, G7X 7X2
Jonquiere, Canada

Louise Hakenas-Plate, PhD.
Child Neuropsychiatry Clinic
Sahlgrenska University Hospital
Otterhalleg. 12A, 41118 Goteborg, Sweden

Shri K Mishra MD, MS, ABMS
Professor of Neurology Keck School of Medicine
University of Southern California
Director Neuromuscular disease program
VA GLA and Olive View UCLA Medical Center
Medical Director IMDO

Jack Puymirat, M.D.
Professor of Neurology and Genetics
Universite de Laval
Unit of Human Genetics

Isabelle Schwartzbach
Neuromuscular Disease Rehabilitation Center
Kongsvangs Alle 23, Arhus C, Denmark, 8000



International Myotonic
Dystrophy Organization, Inc.
P.O. Box 1121
Sunland, California 91041-1121

**Conference
registration
now online —**

www.etoouches.com/myotonicdystrophy



An Overview of Congenital/ Childhood Myotonic Muscular Dystrophy (CCMMD)

**September 20-21, 2008
Eaglewood Resort & Spa
Itasca, Illinois**

**Presented by
International Myotonic Dystrophy
Organization, Inc.**

**In collaboration with
William Singeris National Center
for Myotonic Dystrophy and
Logan Paige Foundation**



Conference Objectives

This conference should give parents and caregivers a take-away of specific strategies for working with children in the following areas: education, medical and social strategies.

Participants will be encouraged to interact with professionals. Participants will be offered opportunities to provide data, prepare questions, and give needs to professionals prior to the conference.

Medical personnel attending the conference will be meeting separately to determine the Best Practice review for working with children with Myotonic Dystrophy. IMDO will be publishing and distributing a document of these medical strategies shortly after the close of the conference.

Register on-line at
www.etches.com/myotonicdystrophy

Scheduled Program

Saturday, September 20, 2008 — Morning Session

- 8:00 Continental Breakfast & Exhibits
- 8:30 Welcome — *Richard Weston*, President, IMDO
- 8:35 Opening remarks — *Dr. Shri K Mishra*, VP Medical Affairs, Chair of MSAB, IMDO
- 8:45 Looking Back, Going Forward: Perspectives in DM1 in Children
Dr. Craig Campbell
- 10:00 Q & A
- 10:15 Break & Exhibits
- 10:30 Educational Strategies in Children with Myotonic Dystrophy
Isabelle Schwartzbach
- 11:30 Recent Advances in Myotonic Dystrophy Research/IPLEX
Dr. Shri K Mishra
- 12:00 Q & A
- 12:15 Lunch & Exhibits

Accommodations

The conference will be held September 20–21, 2008 at the beautiful Eaglewood Resort & Spa in Itasca, Illinois. IMDO has negotiated a special conference rate of \$139 per night, plus resort fee & tax. Space is limited. Hotel reservations can be requested online when registering for the conference at www.etches.com/myotonicdystrophy or by calling the hotel directly.

Eaglewood Resort & Spa, 1401 Nordic Rd., Itasca, IL 60143
www.eaglewoodresort.com, phone: 630.773.1400

Conference Registration

Please visit our registration site at www.etches.com/myotonicdystrophy to register you and your family for the conference and see valuable information about the agenda, hotel and conference.

Conference registration is \$75 per family.*

*Registration includes breakfast, lunch, cocktail reception, dinner, and meeting materials. Registration does not include airfare, lodging, resort fee, taxes, parking or other incidental expenses.

Saturday, September 20, 2008 — Afternoon Session

- 1:30 Recent Advances in CCMMMD Research
Dr. Jack Puymirat
- 2:30 Social & Behavioral Issues Related to Congenital and Childhood Myotonic Muscular Dystrophy
Cynthia Gagnon
- 3:30 Break & Exhibits
- 3:40 Autism, cognition & adaptive skills in children and adolescents with Myotonic Dystrophy
Dr. Anne-Berit Ekström & Dr. Louise Hakenas-Plate
- 6:00 Cocktail Reception & Dinner

Financial Assistance

IMDO is pleased to be able to offer financial assistance for those patients and family members interested in attending the conference. Due to the limited amount of funding available, financial assistance will be provided based on a “Needs Analysis” and on a first come, first serve basis. For consideration please send a request to info@myotonicdystrophy.org or call Wendy Robinson at 760.918.0377.

Cancellation and Refund Policy

Our policy on refunding your registration fee is based on the costs incurred by us. Refunds on registration fees will be made if submitted in writing to info@myotonicdystrophy.org. Cancellations will include the following administrative fees:

- 100% refund by August 29, 2008
- 50% refund by September 12, 2008

We are unable to offer refunds for cancellations after September 13, 2008.

IMDO is a 501(c)3 Corporation. Tax ID #95-4827120

Sunday, September 21, 2008 — Morning Session

- 8:00 Continental Breakfast
- 9:00 Medical Management and Monitoring in Congenital & Childhood DM1
Dr. Craig Campbell
- 10:00 Motor function, orofacial problems & ophthalmological findings: Results from a Swedish multidisciplinary study
Dr. Anne-Berit Ekström
- 11:00 Break
- 11:15 Managing Children with CCMMMD: A Parent’s Perspective
Richard Weston and Anny Slazik
- 11:45 Recommendation/Summarization
Dr. Shri K. Mishra
- 12:15 Q & A
- 12:45 Adjournment