

University of Southern California (USC-KECK) School of Neurology
St. Francis Medical Center (SFMC)
Muscular Dystrophy Association (MDA)
Myotonic Dystrophy Foundation (MDF)
A Healthy Life for Every One (AHLIFE)
Myotonic Dystrophy Assistance and Awareness Support Group

together present the

MDA's
2008 Annual
Myotonic Dystrophy Conference
“YEAR OF THE CHILDREN”

September 19th, 20th and 21st, 2008

Friday, Sept. 19th – Welcome Reception Under The Eaves
Saturday, Sept. 20th – Workshops
Sunday, Sept. 21st - Conference

Marriott – Manhattan Beach
1400 Parkview Ave.
Manhattan Beach, California 90266

MDA has made special arrangements with
Those needing lodging, please call:
(310) 546-7511

Ask for “MDA room rates”

Block room rate reservations must be made prior to Sept. 2nd

GUEST SPEAKERS

(alphabetical order)

THOMAS COOPER, MD

Baylor University, Houston

2007 recipient of MDAASG medical research funds on the changes that occur in the MMD brain.

WILLIAM GROH, MD

University of Indianapolis Indiana, Krannert Institute of Cardiology
Research in MMD cardiac treatment and prevention

JULIE HELGREN, CTRS, RTII

Rancho Los Amigos National Rehabilitation Center

RICHARD LYMN, PhD

NIH (retired)

Expert in the physical, mental and social burdens of neuromuscular diseases.

Saturday, September 20, 2008

“YEAR OF THE CHILDREN”

WORKSHOPS

(Free)

YOUNG ADULTS ALL DAY RETREAT

(16 years of age and older)

9:00 a.m. – 4:00 p.m.

Presidential Suite

Share life challenges and develop a “support” network

Speakers: Brad Adams, PhD, Richard Lymn, PhD

Facilitators: Barry Cohen, PhD, Kathleen Austria, RT

4:00 p.m. – 11:30

View To A Cure Fundraiser

“Bye, Bye Birdie” night at the theater

11:30 p.m. – a.m.

Pizza Party!! – Presidential Suite

CAREGIVERS BREAKFAST WORKSHOP

Terrace Ballroom - A

(Non-affected caregivers of DM1 and DM2 individuals ONLY)

9:00 a.m. – Noon

Facilitators: Diane Bade RN, Phyllis Cooper MN, Alice Gunderson

**CONGENITAL & CHILDHOOD “FAMILY” LUNCHEON
WORKSHOP**

Room 228 – Overlooking the Golf Course

Noon

Facilitators: Diane Bade RN, Julie Helgren, CTRS,RTII, Lisa Vittek

DM2 & DM1 AFFECTED ADULT LUNCHEON WORKSHOP

Room 230 – Overlooking the Golf Course

Noon

Facilitators: Brad Adams, PhD, Bette Bershak, John Brekka, Phyllis Cooper, MN
William Groh, MD, Lander Warren

Sunday, September 21, 2008

“YEAR OF THE CHILDREN”

Family Conference
11:00 a.m. – 5:00 p.m.
Grand Ballroom Salon

BE PREPARED AND GET INVOLVED!!

11:00 a.m. – 12:00 noon
Registration and Exhibitors

12:00 noon – 12:15 p.m.
Welcome and Introduction
Alice Gunderson

12:15 p.m. – 1:05 p.m.
Brain Function Changes in MMD
Thomas Cooper, MD

1:10 p.m. – 2:00 p.m.
The Heart is a Muscle Also: Heart Issues in MMD
William Groh, MD

2:00 p.m. – 2:15 p.m.
How to be Prepared for 911
LA Country Paramedic and Fire Department

2:15 p.m. – 3:00 p.m.
Break and Exhibits

3:00 p.m. – 4:00 p.m.
Being Prepared for the Burdens of Neuromuscular Diseases
Richard Lymn PhD

4:00 p.m. – 4:30 p.m.
Advocacy
Medical Registry
Medical Trials

4:30 p.m. – 5:00 p.m.
Preparing “Us” for Life with MMD
Young Adult Panel

Register in Advance

In order to accommodate all in attendance, please register prior to the event.

For phone, e-mail or mail registration, please contact:

MaryBeth Stephens, MDA at (562) 498-4923, MStephens@mdausa.org
4510 E. Pacific Coast Highway, Suite 430, Long Beach, California, 90804

**MYOTONIC DYSTROPHY WORKSHOP AND CONFERENCE
(Free)**

Registration Form

Registration MUST be received by September 15th

Name _____

Address _____

City _____ State _____ Zip _____

Day Phone: _____ Evening Phone _____

E-Mail Address: _____

I/We will be attending the following venues:

Friday, September 19th:

8:00 p.m. Family Welcome Reception – Open Bar # attending: _____

Saturday, September 20th – Workshops:

Young Adults Retreat # attending: _____

Name(s)/Age(s): _____

Caregivers (non-affected) Workshop: # attending: _____

Name(s): _____

Congenital and Childhood Family Workshop # attending: _____

Name(s)/Age(s): _____

DM2 and DM1 (affected) Adult Workshop: # attending: _____

Name(s) _____

Sunday, September 21st:

Noon – ***FAMILY CONFERENCE*** # attending: _____