Muscular Dystrophy Research and Clinical Care Family Conference

2012 Registration Form

Session I is for Adult/Teens
Session II is for School Age Children (age 7-12)
Session III is Child Care (Age 3-6)

I. Workshop Selection for Adults/Teens *(choose one per person per breakout time).*

1-2 p.m. Workshops
A. Genetics of DMD and Implication for Family Members
B. Living a QUALITY Life
C. Keys for Success Movie

2:15-3:15 p.m. Workshops
D. Pulmonary Best Practices
E. Cardiac Best Practices
F. Neuropsychological Aspects of MD

	√ if has MD		Age *(if under 18)*
Name _____	❒		_____
Workshop choices (circle one)	A	B	C
Workshop choices (circle one)	D	E	F
Name _____	❒		_____
Workshop choices (circle one)	A	B	C
Workshop choices (circle one)	D	E	F
Name _____	❒		_____
Workshop choices (circle one)	A	B	C
Workshop choices (circle one)	D	E	F

II. School Age Children (Age 7-12):

Name_____ ❒ _____

Name_____ ❒ _____

III. For Child Care ages 3-6: *(must be potty-trained)*

Name_____ ❒ _____

Name_____ ❒ _____

Address_____

City _____ State _____ Zip_____

County _____

Daytime phone (____) _____

Fax _____

E-mail _____

School District _____

Please mark if you need:

❒ Vegetarian lunch ❒ Wheelchair seating ❒ Sign language interpreter

❒ Other special needs _____

You will be notified of your confirmed space.

Mail this form to:
Community Education
Nationwide Children's Hospital
700 Children's Drive | Columbus, Ohio 43205

or register online at NationwideChildrens.org/Edu

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NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.℠

Nationwide Children's Hospital
ATTN: Community Education
700 Children's Drive
Columbus, OH 43205-2696

Muscular Dystrophy Research and Clinical Care Family Conference

presented by The Wellstone Center
April 21, 2012

NATIONWIDE CHILDREN'S
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Muscular Dystrophy Research and Clinical Care Family Conference

Adult and Teen Sessions: Session I

8 a.m.	**Check in opens** Music provided by Chris Moneyhun and the Potter's Wheel
8:45 a.m.	**Welcome and housekeeping**
9 a.m.	**The Potential of Gene Therapy for DMD** Jerry Mendell, MD
10 a.m.	**Treatment of DMD – Present and Future** Kevin Flanigan, MD
11 a.m.	**Parenting the Chronically Ill Child** Kristen Gsanger, Ph.D.
Noon	**Lunch and Networking in Stecker Auditorium**
1 p.m.	**Workshop Sessions I** A. The Genetics of DMD & Implications For Other Family Members Matthew Pastore, MS, CGC B. Living a QUALITY Life Barbara Draheim, MSN, PNP-BC C. Keys for Success MD Stories Moderator: Brent Yetter
2 p.m.	**Break**
2:15 p.m.	**Workshop Sessions II** D. Pulmonary Best Practices Richard Shell, MD E. Cardiac Best Practices Hugh D Allen, MD F. Neuropsychological Aspects of Muscular Dystrophy Keith Yeates, PhD
3:15 p.m.	**Back to Auditorium**
3:30 p.m.	**What MDA Can Do For You** Melissa Wright
3:45 p.m.	**Evaluation/Wrap up**
4 p.m.	**Tours of Wellstone Center (optional)**

School-age Agenda (ages 7-12): Session II

8:45 a.m.	**Activities and Opportunities** Moderator: Brent Yetter
10 a.m.	**Feeling Good About Yourself** Kristen Gsanger, PhD
10:45 a.m.	**Break**
11 a.m.	**Stinky U**
Noon	**Lunch**
1 p.m.	**Taking Care of your Lungs** Richard Shell, MD
1:30 p.m.	**How Does Your Brain Work?** Keith Yeates, PhD
2 p.m.	**It's Not Cool to be Cruel**
3 p.m.	**MDA- Camp and other cool Stuff** Melissa Wright
3:30 pm	**Healthy Snacks to Grab and Go** Laura Giddens, DTR, CDM, CFPP
4:30 p.m.	**Adjourn**

Program Description:

This program is intended to educate parents, caregivers and patients with muscular dystrophy (MD) about advances in research and how this applies to future treatments and therapies. We will also share treatment best practices while answering any questions that participants may have. An opportunity to take part in a workshop sessions will provide focus and insight about specific MD issues. Light refreshments and lunch will be provided.

Program Date:

April 21, 2012
8 a.m. to 4:30 p.m.

Child Care:

Child care is available for children age 3-6. Children must be potty-trained.

Location:

Nationwide Children's Hospital Education Center
700 Children's Drive, Columbus, Ohio

Who Should Attend?

Parents and caregivers of children with muscular dystrophy, as well as interested patients.

Cost:

No charge

Parking:

Wheel chair accessible parking is located in the flat lot outside the Education Center and in the Visitor Garage. Parking charge is $2 per car all day.

Confirmation:

A confirmation letter will be sent to all participants who register two weeks before the program. After that time, no confirmation will be sent.

Questions:

Call (614) 355-0662

About the Wellstone Center:

The Wellstone Center is a Muscular Dystrophy Cooperative Research Center (MDCRC) and is a part of The Research Institute at Nationwide Children's Hospital. MDCRCs were established by the MD-Care Act and are overseen by The National Institutes of Health. These centers are a part of university and hospital research institutions across the country and strengthen the MD community by conducting basic, translational and clinical research on the muscular dystrophies. This collaborative program at Nationwide Children's Hospital is committed to finding a treatment in muscular dystrophy.

Keynote Speakers:

Jerry Mendell, MD
Director, Wellstone Muscular Dystrophy Cooperative Research Center, Nationwide Children's Hospital, Director, Center for Gene Therapy, The Research Institute at Nationwide Children's Hospital

Kevin Flanigan, MD
Co-Investigator, Wellstone Muscular Dystrophy Cooperative Research Center, Nationwide Children's Hospital, Researcher, Center for Gene Therapy, The Research Institute at Nationwide Children's Hospital

Kristen Gsanger, Ph.D.
Clinical Assistant Professor , Nationwide Children's Hospital, Department of Psychology

Melissa Wright
Health Care Service Coordinator for Muscular Dystrophy Association, Inc. for Central & Southeast Ohio.

Workshop Presenters:

Hugh D. Allen, MD
Professor of Pediatrics and Medicine, Vice Chair for Academic Affairs, Clinical Cardiologist at The Heart Center at Nationwide Children's Hospital. Dr. Allen's main research interest is the heart as it relates to muscular dystrophy.

Barbara Draheim MSN, PNP-BC
Palliative Care Team, Clinical Services & Care Coordination Dept., Nationwide Chidlren's Hospital

Laura Giddens, DTR, CDM, CFPP
Dietetic Technician, Clinical Nutrition Services, Nationwide Children's Hospital

Matthew Pastore, MS, CGC
Certified Genetic Counselor, Clinical Assistant Professor of Pediatrics, Program Coordinator, Medical Genetics Residency, Nationwide Children's Hospital

Richard Shell, MD
Section of Pulmonary Medicine at Nationwide Children's Hospital. Dr. Shell's research interests include complications of Neuromuscular disease.

Keith Yeates, PhD
Director, Center for Biobehavioral Health, The Research Institute at Nationwide Children's Hospital, Chief, Section of Pediatric Psychology and Neuropsychology, Nationwide Children's Hospital, Professor of Pediatrics, Psychology, and Psychiatry, The Ohio State University.

Brent Yetter
Research Assistant, Wellstone Muscular Dystrophy Cooperative Research Center, Nationwide Children's Hospital

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