

Potential Convention Agenda: Please note that this agenda may be subject to change.

**Friday June 5,
2009**

All Day

Convention Registration (closes at 5:00 p.m)

All Day

Reflections of Hope Meditation Room (closes at 5:00 p.m.)

All Day

Exhibit Hall (closes at 5:00 p.m.)

9:00 - 10:00 a.m.

Opening Session

10:00 - 10:30 a.m.

Coffee Break

Sponsored by Biotechnology Industry Organization (BIO)

10:00 - 10:30 a.m.

Book Reading

Connecting through Music with People with Dementia

Robin Rio

Reflections of Hope Meditation Room

Suite 314

10:30 - noon

Focus on the Family Care Forum

The Role of Denial, Uncertainty and Decision Making in HD

Randi Jones, Ph.D.

Anne Leserman, MSW

Marsha Miller, Ph.D.

Sponsored by Vertex Pharmaceuticals

10:30 a.m.

HDSA Activity Center Opens

Curtis A-B

11:00 a.m. - noon

HDSA Activity Center

Yoga

Laura Kokoska

Curtis A-B

noon - 1:00 p.m.

Lunch on Your Own

NYA Luncheon

noon - 1:00 p.m.

HDSA Activity Closed

noon - 1:00 p.m.

Author Signing

Robin Rio

Connecting through Music with People with Dementia

HDSA Marketplace

Educational Tracks

New to HD/At Risk

Living with HD

Caregiver Issues
All Attendees
Parents of Children with Juvenile Onset HD
NYA/Youth
HDSA Field Leadership
HDSA Activity Center

1:00 - 2:00 p.m.

HDSA Activity Center
Pottery Painting
Mikala Edwards and Students From Arizona State University
Curtis A-B

1:00 - 2:00 p.m.

WORKSHOPS
HD 101
Holly Shill, M.D.
Cowboy Artists Room

Meds for Early/Mid Stage HD
Vicki Wheelock, M.D.
Ellis East

Estate Planning
METDESK
Russell A-B-C

Safety in Clinical Trials
John Caviness, M.D.
Remington A-B-C

Overview JHD/Non Medical Options
Jane Paulsen, Ph.D.
Board Room

NYA/Youth Program
411 HD for Youth (ages 9-15)
Sam Frank, M.D.

HDSA Leadership
Team Hope Walk Program
Anthony Buffone and Mynelly Perez
Borein A-B

2:00 - 2:30 p.m.

BREAK

2:00 - 2:30 p.m.

Script Reading

**Reflections of Hope Meditation Room
Suite 314**

2:00 - 3:30 p.m.

**HDSA Activity Center
Music Therapy**
Robin Rio
Curtis A-B

2:30 - 3:30 p.m.

Genetic Issues
Katherine Hunt
Ellis East

Share the Care
Jane Barton, MTS, MASM
Cowboy Artists Room

Advocating for HR 678
Joseph LaMountain
Remington A-B-C

**NYA Program
Split Session - Young Adults Ages 18+**
Moderator: Leo Rafail, BSW
Russell A-B-C

**Youth Program
Split Session - Youth Up to Age 18**
Moderator: Amy Chesire, MSW
Borein A-B

HDSA Field Leadership
Fundraising Ideas
Bryan Viau, Scotti Hutton, Alex Roque
Phoenix Ballroom

3:30 - 4:00 p.m.

BREAK

4:00 - 5:00 p.m.

HDSA Activity Center

4:00 - 5:00 p.m.

**WORKSHOPS
Update on PREDICT-HD**
Jane Paulsen, Ph.D.
Remington A-B-C

Progression of HD
Sam Frank, M.D.

Ellis East

Wellness

Walter Nieri, M.D.

Phoenix Ballroom

Sharing Session for JHD Kids

Jan Jerome, MSW and Bonnie Hennig, MSW

Borein A-B

NYA/Youth Program

Panel: To Test or Not To Test

Moderator: Katherine Hunt

Panelists: Melinda Maher, Melinda Wagner, Tabitha Wagner

Russell A-B-C

HDSA Field Leadership

Chapter Treasurer's Supplemental Training

Joseph DiSibio

Board Room

5:00 - 5:30

Basic First Aid for the Home

American Red Cross

5:00 - 6:00

Yoga for All

Laura Kokoska

Curtis A-B

6:30 - 8:00 p.m.

**Convention Reception and
National Youth Alliance Dance Auction/Program**

Regency Ballroom

Sponsored by Alnylam

Saturday, June 6, 2009

7:00 a.m.

Walk for the Cure

8:30 - 9:00 a.m.

A Reading of the Quilts (Reflections of Hope room)

Convention Registration (closes at 3:00 p.m.)

All Day

Reflections of Hope Meditation Room (closes at 3:00 p.m.)

All Day

Exhibit Hall (closes at 3:00 p.m.)

9:00 - 10:30 a.m.

HDSA Research Forum - Part 1

Opening Comments

Louise Vetter, HDSA CEO

Patient Testimonial

Charles Sabine, NBC News Correspondent

Coalition for the Cure Research Update

Marcy MacDonald, Ph.D.

Observational Research Update

Jane Paulsen, Ph.D.

Clinical Research Update

Joseph Giuliano, Ph.D.

Regency Ballroom

10:30 - 11:00 a.m.

Session Break

10:30 a.m.

HDSA Activity Center Opens

Curtis A-B

11:00 - noon

Option A

**HDSA Research Forum - Part 2
Movement Disorders Associated with HD**

Christopher Ross, M.D., Ph.D.

Option B

Stem Cell Research and Its Implications for HD

Leslie Thompson, Ph.D.

11:00 - noon

HDSA Activity Center

Yoga

Laura Kokoska

Curtis A-B

noon - 1:00 p.m.

Lunch on your own

noon - 1:00 p.m.

HDSA Activity Center Closed for Lunch

noon - 1:00 p.m.

Author Reading

Lauren Holder

Reflections of Hope Meditation Room

Suite 314

noon - 1:00 p.m.

Yoga for All

Laura Kokoska

Curtis A-B

WORKSHOPS

1:00 - 2:00 p.m.

Safety in the Home

Margaret Coles

Phoenix Ballroom

Hospice/Palliative Care

Rose Anne Berry

Remington A-B-C

1:00 - 3:30 p.m.

this workshop only

Potential New Therapies

Plenary session runs for 150 minutes

Joakim Tedroff, Ph.D., NeuroSearch

Sarah Noonberg, M.D., Ph.D., Medivation

Pei Ge, Ph.D., Alnylam

1:00- 2:00 p.m.

NYA Program - Young Adults (18-29)

Dating/Relationship Issues

Randi Jones, Ph.D.

Russell A-B-C

Youth Program (Up to Age 17)

How to Talk to Your Friends About HD

Bonnie Hennig, MSW

JHD

Educational Options

Rita Kenison and Marta Urbina

Board Room

1:00 - 2:00 p.m.

HDSA Activity Center

Sitercise

Mikala Edwards and Students from Arizona State University

Curtis A-B

2:00 - 2:30 p.m.

BREAK

2:00 - 2:30 p.m.

Author Signing

Lauren Holder

HDSA Marketplace

2:00 - 3:30 p.m.

HDSA Activity Center

Music Therapy

Curtis A-B

2:30 - 3:30 p.m.

WORKSHOPS

Clinical Trials and COHORT

Vicki Wheelock, M.D.

Russell A-B-C

Genetic Inforamtion Nondiscrimination Act

GINA and What it Means For You

Cheryl Erwin, J.D.

Phoenix Ballroom East

NYA Program

Split Session - Young Adults Ages 18+

Sharing/Caring Session

Moderator: Leo Rafail, BSW
Remington A-B

**Youth Program
Split Session - Youth Up to Age 18**

Sharing/Caring Session
Stacey Barton, MSW
Remington C

3:30 - 4:00 p.m.

BREAK

WORKSHOPS

4:00 - 5:00 p.m.

Cognitive Issues and HD
Don Connor, M.D.
Phoenix Ballroom East

**Therapeutic Use of Supplements and Alternative
Therapies**

Sam Frank, M.D.
Ellis East

NYA/Youth

Future Business
Russell A-B-C

JHD

Sharing Session - Parents
Moderators: Jan Jerome, MSW and Bonnie Hennig, MSW
Board Room

4:00 - 5:00 p.m.

HDSA Activity Center

Curtis A-B

5:30 p.m. Activity Center Closes

6:00 p.m.

NYA Silent Auction and Reception
Atrium

7:00 p.m.

HDSA Awards Dinner and Gala
Regency Ballroom

Sunday June 7, 2008

8:00 - 9:30 a.m.

CONTINENTAL BREAKFAST AND ROUNDTABLES
Regency Ballroom

Advocating for HR 678
Joseph LaMountain

Safety in the Home

Margaret Coles

NYA Breakfast Club

Where to Find First Aid Courses in your Area

American Red Cross

HD 101

Holly Shill, M.D.

Medications for Early/Mid Stage HD

Vicki Whelock, M.D.

Estate Planning for Special Needs

MetDESK Specialists Anthony Recck and Denny Travis

Predict-HD Update

Jane Paulsen, Ph.D.

Supplements and Alternative Therapies

Sam Frank, M.D.

Share the Care

Jane Barton

Genetic Issues

Katherine Hunt

Disability Planning

Social Security Administration

Hospice/Palliative Care

Rose Anne Berry

GINA

Cheryl Erwin, J.D.

Caring Voice Coalition

Caring Voice Coalition Specialists

Suggestions for 2010 HDSA Convention

HDSA staff person

Pharma tables

HDSA Regional Tables

Upper Mid West Region

Northern California

Southern California

Southwest Region

Mid-Atlantic Region
Great Lakes Region
Southeast, Greater New York and New England Regions
Rocky Mountain Chapter
Pacific Northwest Region

9:30 - 10:00 a.m. **Closing Ceremony**

Educational Tracks

New to HD/AT Risk
Living with HD
Caregiver Issues
All Attendees
Parents of Children with Juvenile Onset HD
NYA/Youth
HDSA Field Leadership
HDSA Activity Center