

30TH ANNUAL HDSA CONVENTION PRELIMINARY PROGRAM
ALL WORKSHOPS, SPEAKERS AND TIMES SUBJECT TO CHANGE
As of April 24, 2015

Thursday, June 25
2:00 PM - 7:00 PM

Convention Registration
Exhibit Hall

5:30 PM

Team Hope Walk
Join us in the lobby at 5:30 PM
Registration 5:30 PM/ Walk 6:00 PM

7:00 PM - 10:00 PM

HDSA Convention Reception
Join Us for a Special Welcome Reception
"Dallas Style"
After the Team Hope Walk
Ice Cream Social for Youth, Teens and Young Adults
Hosted by the National Youth Alliance (NYA)

Friday, June 26

HDSA 30th ANNUAL CONVENTION OPENS

7:00 AM - 6:00 PM
8:00 AM - 6:00 PM

Convention Registration
Exhibit Hall

8:00 AM - 5:00 PM

Special Convention Activity
NYA Silent Auction
To Benefit the NYA Scholarship Program

9:00 AM - 10:30 AM

OPENING CEREMONY
Welcome
Jang-Ho Cha, MD, PhD, HDSA Chairman of the Board
State of the Society
Louise Vetter, HDSA CEO
Keynote Speaker

10:30 AM - 11:00 AM

Coffee Break
Exhibit Hall

Educational Tracks

FOR FRIDAY ONLY

Behavior and HD
Living with HD
Movement and HD
New to HD
All Attendees
Youth/Teens/Young Adults
Volunteer Engagement
JHD Parents
Special Convention Activity

11:00 AM - 12:15 PM

Workshops

**Behavior Issues
Coping with Unawareness**
Arik Johnson, PsyD

**Living with HD
When to Call A Physical or Occupational Therapist?**
Chris Lamb, PT, DPT, ATC/LAT

**New to HD
HD 101**
Michelle Fox, MS, LCGC

**Youth/NYA
National Youth Alliance 101**
Morgan McLane and Angela Mabry

**All Attendees
Defining Yourself and Not the Disease**
Amanda Butterworth and Lauren Holder

HDSA Research
**Clinical Trials Demystified: What Is It Like to
Participate and Why Am I Needed?**
Welcome and Introductions
Jimmy Pollard
Consultant, CHDI Foundation
What to Expect from a Clinical Trial: A Medical Professional Perspective
Stacey K. Barton, MSW, LCSW, Clinical Social Worker
HDSA Center of Excellence at Washington University School of Medicine
Clinical Trial Experience: A Patient Perspective
Mackenzie Platten, HDSA Research Champion & Advocate
"Why Am I Needed?"
Ed Wild, MD, PhD, Clinician Scientist
University College of London, Institute of Neurology
HD TrialFinder: Find Clinical Trials in Your Area
George Yohrling, PhD
HDSA Senior Director, Mission & Scientific Affairs

12:30 PM - 1:45 PM

CHAPTER AWARDS LUNCHEON
All Convention Attendees and Exhibitors Invited
Exhibit Hall Closed During Luncheon

2:00 PM - 3:15 PM

Workshops

Behavior Issues
Recognizing Apathy and Depression
Peggy Nopoulos, MD

Living with HD
When to Call a Speech-Language Pathologist
Cheryl Giddens, PhD

Youth/NYA
To Test or Not to Test
Moderator: Katie Plunkett, MS, CGC
Panel: Sarah Boulavasky, Seth Rotberg and Melissa Ryant

New to HD
A Roadmap for HD - What Comes Next?
Erin Furr Stimming, MD

All Attendees
How to Talk with Law Enforcement about HD
Lauren Holder

Volunteer Engagement
Advocacy in Action
Jason Gromley, Esq. and Jennifer Simpson, LMSW

3:15 PM - 3:45 PM

Coffee Break
Exhibit Hall

3:45 PM - 5:00 PM

Workshops
Behavior Issues
Coping with Perseveration
Christopher Ross, MD, PhD

Living with HD
Family Planning
Michelle Fix, MS, LCGC

HDSA Research
Introduction to the Biology and Genetics of HD
Ed Wild, MD, PhD and Jeff Carroll, PhD

Youth/NYA
Youth Sharing Session

Moderators: Misty Daniel (ages 9-13) and
Chandler Swope, LICSW (ages 14-17)

Volunteer Engagement
Mastering Social Media & Marketing: Innovative Awareness and
Marketing Ideas to Get More Likes, Comments and Shares Online!
Nancy Rhodes and Chris Cosentino

5:15 PM - 6:15 PM

SPECIAL CONVENTION ACTIVITY
Advocacy Meet and Greet for Texas Residents

6:00 PM

EXHIBIT HALL CLOSES

7:00 PM - 9:00 PM

SPECIAL CONVENTION ACTIVITY
NYA Talent Show

Saturday, June 27

7:30 AM - 3:00 PM

Convention Registration

7:30 AM - 3:00 PM

Exhibit Hall

8:00 AM - 9:00 AM

Research Breakfast

9:00 - 10:30 a.m.

HDSA RESEARCH
Welcome and Introductions
George Yohrling, PhD
HDSA Senior Director, Mission and Scientific Affairs
A Focus on Huntingtin
Huntingtin Lowering Approaches to Treat HD
Neil Aronin, MD
Professor, University of Massachusetts Medical School
Hunt for Genetic Modifiers of HD
Marcy MacDonald, PhD
Professor, Massachusetts General Hospital/Harvard Medical School

10:30 - 11:00 a.m.

SESSION BREAK
Donald King Research Fellowship
Poster Session
Exhibit Hall

11:00 a.m. - noon

HDSA RESEARCH (con't)
Advances in HD Drug Discovery
Ed Wild, MD, PhD
University College of London, Institute of Neurology

Jeff Carroll, PhD
Assistant Professor, Western Washington University

12:15 PM - 1:30 PM

HDSA/HSG Clinical Trial Showcase (Lunch Provided)

12:15 PM - 1:30 PM

National Youth Alliance Luncheon

Educational Tracks

FOR SATURDAY ONLY

Behavior/Cognitive Issues

Caregiver Issues

All Attendees

Research

Youth/Teen/Young Adults

Motor Symptoms

Volunteer Engagement

JHD Parents

Special Convention Activity

1:45 PM - 2:45 PM

WORKSHOPS

Movement and HD

Managing Motor Symptoms

Erin Furr Stimming, MD

Behavior/Cognitive Issues

New Diagnostic Criteria for HD

Christopher Ross, MD, PhD

Youth/NYA

Relationships for Youth (ages 9-29)

Panel: Amanda Butterworth, Lauren Holder and Kaitlin Klarer

All Attendees

HDSA 101: An Overview of the Society from Its Leadership

Caregivers

Caregiver Burden

Debbie Pausig, MFT, CT, CCTP

Volunteer Engagement

**Corporate Responsibility: Engaging the Companies in
Your Community**

Nancy Rhodes, Rebecca Mooney and HDSA Field Team

JHD Parents
Diagnosing JHD
Peggy Nopoulos, MD

3:00 PM - 4:00 PM

WORKSHOPS

Behavior/Cognitive Issues
Managing Aggression
Garima Arora, MD

Movement and HD
Physical Therapy & Speech/Swallowing Roundtable
Chris Lamb, PT, DPT, ATC/LAT and Cheryl Giddens, PhD

All Attendees
When to Think About Long Term Care
Cheryl Lenheiser, LCSW

Youth/NYA
Being a Young Caregiver, Living with HD/JHD and Autonomy
Moderated by: Melinda Kavanaugh, PhD, LCSW
Panel: Kaitlin Klarer, Angela Mabry and Melissa Ryant

Caregivers
Spirituality for Caregivers
Cheryl Erwin, JD and Tom McGovern, EdD

JHD Parents
Your Dependent with Special Needs
Making Their Future More Secure

HDSA Research
Emerging Topics in HD Research
Chris Ross, MD, PhD, Neil Aronin, MD and Ed Wild, MD, PhD

Volunteer Engagement
Team Hope in Your Town: HDSA's Largest Grassroots Campaign
HDSA Field Team

4:15 PM - 5:15 PM

WORKSHOPS

Behavior/Cognitive Issues
Managing Cognitive Decline
Paul Schultz, MD

All Attendees
Assessing Disability
Art Spencer

Youth/NYA
Young Adult Sharing
Moderators: Chandler Swope, LICSW (ages 18-24) and
Amanda Butterworth (ages 25-29)

Caregivers
Managing Marital Relationships in HD
Debbie Pausig, MFT, CT, CCTP

HDSA Research
Potential New Therapies
Welcome and Introductions
George Yohrling, PhD
HDSA Senior Director, Mission and Scientific Affairs
ASO's
C. Frank Bennett, PhD
Sr. VP Research
Isis Pharmaceuticals
Using Mesenchymal Stem Cells to Deliver
BDNF to Brains of HD Patients
Vicki Wheelock, MD
HDSA Center of Excellence
University of California, Davis Medical Center

Volunteer Engagement
Putting the "Fun" in Fundraising
HDSA Field Team

6:00 PM - 7:00 PM

Gala Reception

7:00 PM - 1:00 AM

HDSA Awards Dinner and Gala