



Talking About HD

HDSA Annual Convention
Baltimore, MD

Friday June 3
3:30 – 4:45 p.m.

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HDSA Center of Excellence
at Washington University
School of Medicine



Huntington's Disease
Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2016 HDSA Convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

Stacey Barton, MSW, LCSW

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose



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“The Rules”

- This is meant to be a safe place. Ideas and comments are to be accepted, supported and encouraged.
- Confidentiality is highly respected here. Please do not share the stories or identities of the storytellers outside of this space.

Topics

- How do you talk to others about HD being in your family?
- What do you share?
- Are there things you keep a secret?
- Are there certain people you DON'T want to know about HD in your family?

Tips on Talking to Others about HD

- Consider their age/development of the person you are talking to.
 - Little kids: Shorter attention span, little life experience, vivid imaginations. Keep the information simple.
 - Middle kids: Bigger world view. More knowledge of science and maybe even genetics. More empathetic. They can read well, so OK to provide written materials.
 - Big kids: Capable of adult conversation but may not like to talk. Emotions can change quickly. Be direct, honest and compassionate. Be prepared to talk about genetics and genetic testing.
- What do they really want/need to know?
- You don't have to know all the answers!

Creating your “Elevator Speech”

Getting Your Questions Answered

- How you ask about HD when you need your own questions answered?
- Who do you ask?
- How do you find reliable sources?

Resources

- National Youth Alliance – www.hdsa.org/nya
- HDYO – www.hdyo.org
- HDSA social workers – <http://hdsa.org/about-hdsa/social-workers>
- What are YOUR favorite resources?