



Focus on the Family Care Forum

Talking to Kids About HD

Convener: Janet K. Williams, PhD, RN, FAAN
The University of Iowa



Huntington's Disease Society of America

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Presenter Disclosures

Janet K Williams

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

No relationships to disclose
or list

Talking to Kids about HD

- Parents and teens in family study
- How HD was talked about in their family

Sparbel et al, 2008; Williams et al., 2009

Talking to Kids about HD: US & Canada

What parents said

- Why is [grandma, grandma, dad, mom] acting differently
- What does this mean for you
- What is important for you to know about our family and HD

What youth said

- How I found out
- What I want to know about HD **and** my parent or grandparent
- What I can do

Talking with Kids about HD: Our Panel

- What is important for your kids to know about your family and HD
- Where do kids learn about HD
- When do you talk about HD in your family
- How do you talk about HD in your family

Talking with Kids about HD: Our Panel

- Panel members experiences and perspectives
- Questions/answers- please be brief
- Panel and Facilitator wrap up

Resources

- National Youth Alliance. <http://www.hdsa.org/nya.html>
- Hennig, B. *Talking to Kids about Huntington Disease*. 45 page booklet, \$14.99 <http://www.talkikngtokidsabout> hd.com/book.html
- Forrest Keenen, K., et al. (2007). Young people's experiences of growing up in a family affected by Huntington's disease. *Clinical Genetics* 71, 120-129.
- Sparbel, K.J.H., et al.(2008). Teens' experiences living with Huntington Disease. *Journal of Genetic Counseling*. 17, 327-335.
- Williams, J.K., et al. (2009). The emotional experiences of family carers in Huntington disease. *Journal of Advanced Nursing* 65 (4), 789-798.