Focus on the Family Care Forum

Talking to Kids About HD

Convener: Janet K. Williams, PhD, RN, FAAN
The University of Iowa
The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2010 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

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