Presymptomatic genetic testing for Huntington disease (HD) in 18-21 year olds: understanding their motivations.

What is HD?
- Huntington disease (HD) is a progressive brain disorder characterized by:
  - Uncontrolled movements
  - Emotional problems
  - Cognitive changes
- Most people with HD start showing signs or symptoms between the ages of 35-44
- If an individual has HD, their children each have a 50% chance of inheriting HD
- Direct genetic testing has been available since 1993 so that individuals at risk of developing HD can learn whether or not they will actually develop HD
- There is no cure for HD

Who should be on the team of providers to care for someone with HD (and their family)?
- Primary care physician
- Neurologist
- Physical therapist
- Occupational therapist
- Genetic counselor
- Speech language pathologist
- Social worker
- Nutritionist
- Many more depending on the needs of the individual

What unique challenges do young people at risk face?
- They may be caring for an affected parent
- They may have grown up knowing a test is available that they can consider at age 18
- Young people may be making decisions about a further education, a career, or a long term relationship
- They may feel they are “wasting time” because they may eventually get sick when they are older
- Young people may feel like they cannot talk to their family members about being at risk
- Accepting a negative testing result can be difficult as well (survivor guilt)

How can health care professionals help young people at risk of developing HD?
- Provide resources (some are listed below)
- Help coordinate referrals to the appropriate specialties
  - A young person may need help finding a neurologist for their affected parent
  - The at risk individual may benefit from speaking with a genetic counselor about their testing options and how testing would impact their life
• Refer them to online or in-person support groups
  o Discussions about caring for affected family members
  o Discussions about coping with life at risk

Resources for families:
• VCU Parkinson’s and Movement Disorders Center http://parkinsons.vcu.edu
• Information
• Support
  o Huntington’s Disease Society of America (HDSA) http://hdsa.org
    ▪ Annual convention
    ▪ Assistance locating doctors and support groups
    ▪ National Youth Alliance
  o Huntington’s Disease Youth Organization (HDYO) http://en.hdyo.org
    ▪ Support for young people impacted by HD around the world