Patients with Hereditary Cancer Syndromes: Information for mental health providers

The purpose of this handout is to offer information to mental health providers caring for patients facing unique challenges related to having a hereditary cancer predisposition syndrome. A hereditary cancer predisposition syndrome is typically diagnosed through genetic testing and indicates an increased risk for cancer for the patient and potentially their family members. Additional information on the specific syndrome may accompany this handout.

Every individual responds differently to receiving a diagnosis of a hereditary cancer predisposition syndrome. The following are examples of challenges patients with hereditary cancer predisposition syndromes can experience:

Personal

- Worry about when or if cancer will develop
- Concern about how increased cancer screening and/or medical appointments will impact daily life
- Anxiety about upcoming cancer screenings and the findings (scanxiety)
- Trauma from the loss of family members who may also have had this syndrome
- Stress of contemplating alternative reproductive options
- Feelings of isolation

Relationships

- Burden of having to explain the syndrome to friends and family
- Stress about how to communicate results with other at-risk family members and how to encourage them to get their own genetic testing
- Changes in family dynamics and other relationships
- Worry about passing the syndrome on to children
- Uncertainty about how/when to discuss the syndrome with their children
- Concern about when/if their children need to be tested for the syndrome

Systems/Structural

- Concerns about privacy and insurance discrimination
- Cost/financial concerns surrounding medical management related to the syndrome
- Difficulty finding a support network and resources
- Burden of having to explain the syndrome to medical providers

Note that the genetic counselor is available to both the patient and providers for additional resources and information.