

## Genetic Counseling Issues

### *Workshop No. 2*

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Among the strongest recommendations to come from this workshop was the reaffirmation that patient counseling must take place prior to genetic testing, and that counseling should be independent of testing. In other words, counseling is a prelude to the decision of whether to be tested. Genetic test results carry immense implications for patients and families, and competent clinical, psychosocial, and counseling support is needed for individuals who are considering testing, as well as those who chose to undergo testing. Workgroup participants identified a range of immediate needs related to infrastructure, access to care, public and provider education, and the cultivation of an emerging specialty in genetic counseling for individuals at risk for inherited cancer syndromes.

#### Recommendations

1. The American Cancer Society (ACS) can be an influential advocate at the state and national level for the importance of quality assurance in genetic testing and patient needs. The ACS should work with state officials to develop regulations regarding genetic testing, and should be an advocate for greater accessibility of testing and counseling, including the elimination of financial barriers.
2. The public can be informed about the scientific evidence supporting a particular test for a genetic alteration. The ACS should develop a comprehensive information data base on genetic testing in collaboration with other organizations that are supporting the development of similar data bases; organizations should not duplicate each other's efforts. The ACS should also develop an educational brochure written at a widely accessible educational level that describes inherited cancer syndromes, the importance of family histories, and the difference between investigational and clinical research, and that identifies who should be tested and how to get tested.
3. The ACS should develop a simple and straightforward educational brochure for providers that outlines criteria for referral and testing, existing levels of evidence regarding the accuracy and implication of genetic test results, and institutions to which patients can be referred for high quality counseling and testing services. Providers need to be educated regarding the importance of taking a detailed family history. To heighten awareness of the importance of inherited susceptibility to cancer, greater attention should be given to the field of hereditary cancers and genetics in ACS professional journals.

The ACS should advocate a team approach to meet the needs of

patients. Educational materials should identify the domains of knowledge needed to support patients with known or suspected inherited cancer syndromes, i.e., oncology clinical management should be provided by the oncologist/oncology nurse; psychosocial support should be provided by the psychologist/social worker/nurse; and genetic counseling should be provided by the geneticist/genetics counselor. These individuals should be appropriately trained and certified.

4. The ACS should develop guidelines for genetic testing, and should include a position on whether testing should be done only in investigational protocols. The Workgroup recommended that the ACS endorse the American Society for Clinical Oncology (ASCO) and National Action Plan on Breast Cancer positions on informed consent, and pre- and post-test counseling.
5. The ACS should foster greater interest in genetic counseling, and could do so through collaboration with other organizations, and the following initiatives. The ACS should expand its existing scholarship and training programs to include genetic counseling education. The ACS should also support postgraduate fellowships in cancer genetics for oncologists, nurses, genetics counselors, and behavioral scientists. The ACS should also collaborate with and support ASCO's efforts to train oncologists. The ACS should work with the Oncology Nursing Society and support efforts to define what education is needed for nurses to become genetic counselors. The ACS should endorse reimbursement for counseling.
6. The ACS should develop a relationship with geneticists and genetic counselors and their representative organizations. The ACS also should collaborate with other organizations to develop training programs for physicians and other health care providers. In particular, there is a need to influence medical school curricula.
7. The ACS should support research to evaluate: 1) the medical, psychosocial, and economic outcomes of genetic testing and counseling for cancer susceptibility, and identify predictors of positive and adverse outcomes; 2) the relative effectiveness of alternate strategies for genetics education and counseling (e.g., length of counseling follow-up), alternate settings (e.g., primary care, cancer centers), and alternate providers of counseling (e.g., nurses, genetic counselors, physicians); 3) strategies for education of health care providers involved in genetic testing and counseling; 4) determinants of participation and barriers to genetic testing; and 5) the needs of children of parents who have been tested. Additional high priority research needs are: 1) penetrance of mutations; 2) environmental modifiers of gene effects; and 3) clinical outcomes in carriers after medical and/or surgical and behavioral treatments.