# Policy on Genetic Testing and the Jewish Community
## Passed 4/27/2015

Research shows that a quarter of the Jewish population carries at least one of the many preventable Ashkenazi Jewish genetic diseases (AJGD) – and the list is growing rapidly. The Jewish Healthcare Foundation (JHF) is the original funder and provider of community education about AJGD and supporter of appropriate pre-conception screening opportunities in Pittsburgh. The goal is to assure that families have the information they need to make informed decisions about advancing their health and the health of future generations.

JHF is evaluating ways to advance and measure the impact of education efforts aimed at the medical community, clergy who provide premarital counseling, Jewish families and young adults. Through the efforts of participants in Jewish Genetic Disease Program genetic screenings are now a covered medical benefit of Highmark and the UPMC Health Plan when prescribed by a physician. The statement is aimed at creating a cohesive community effort for continuing education about genetic diseases and inherited conditions.

Recent advances in genetic science have created hopeful new medical possibilities and have also raised serious concerns. As researchers race to identify mutations which might be predictive of the onset of disease, genetic tests, developed within a controlled research environment and now commercially available, may determine whether an individual might hold such a marker. In the future, these new technologies may also be translated into new drugs and/or therapies for treating and/or preventing disease. At the same time that we are encouraged by health benefits to be gained from these new tests, there is always the possibility for abuse of the genetic information revealed and the potential for employment and insurance discrimination.

The Jewish community has become increasingly aware of these risks, which affect all people, primarily as a result of findings that mutations in two genes linked to breast and ovarian cancer (called BRCAI and BRCA2) may be more prevalent among individuals of eastern and central European Jewish descent -- i.e., Ashkenazi Jews.

Because at this time there is no sure means of prevention against or cure for breast or ovarian cancer, the availability of genetic tests to determine the presence of mutations, and the corresponding genetic counseling raises important issues for Jewish women and their families.

**The Jewish Delegate Assembly of Greater Pittsburgh:**

Believes that we, as a Jewish community, recognize the importance and value of Jewish genetic disease awareness and commit to making education about the evolving field of recessive Jewish genetic diseases options available within our community, and assure access for pre-conception recessive gene screenings, where appropriate, for those persons between the ages of 18 and 45.

**The Community Relations field should:**

- Join with the Jewish Healthcare Foundation and the organized Jewish community of Western Pennsylvania to educate our members about Jewish genetic diseases.

- Support the members of the organized Jewish community in furthering their existing efforts to include the latest information on Jewish genetic diseases in their premarital counseling sessions, and to encourage couples to undergo carrier testing.
- Encourage all members of our community who are of Eastern/Central European descent and are between the ages of 18 and 45 to consider screening for Jewish genetic disease carrier status.
- Work with appropriate agencies to disseminate proper public health materials in order to combat misinformation and help individuals and families assess the risks and benefits of genetic testing.
- Encourages its affiliated congregations to educate its members about the benefits and concerns connected with genetic testing.
- Advocate that education about BRCA1 and BRCA2, dominant genetic mutations found more frequently in Ashkenazi Jewish women and men, is included in the awareness responsibility communities undertake for hereditary breast, ovarian and male cancers
- Continue the national, community-wide discussion on the issue of genetic diseases including breast cancer, their causes, risks, facts and myths: continue to promote study of the usefulness of genetic testing and to follow research measures to identify prevention strategies and find cures.
- Advocate for the inclusion of comprehensive genetic counseling performed by trained individuals, along with a detailed informed consent process (both written and interactive) as a part of any testing context prior to actually taking a sample.
- Work with the various entities connected to the commercial genetic testing market and others, including the genetic testing companies and the oncological community, to combat fear-based and stigmatizing marketing techniques and inappropriate uses of genetic tests.
- Continue its support of medical research aimed at ameliorating disease, including breast cancer, and including the identification of genetic mutations, which may be predictive of the onset of disease.
- Support continued funding for research on the ethical, legal and social implications of genetic testing, and;
- Communicate our concerns with the appropriate federal, state/provincial and local representatives.