

## **A Three State Collaboration and Public Health Response to the Myriad™ Genetics Direct to Consumer Marketing Campaign for *BRCA1* and *BRCA2* Testing**

Karen Greendale, Heather Dacus, Cynthia Boddie-Willis, Elaini Negussie, and Beverly Burke

**Background and objectives:** A direct to consumer marketing campaign by Myriad Genetics, Inc. was launched in New York State, Massachusetts and Connecticut in September 2007. The NYSDOH, MDPH and CT DPH, acknowledging the public health impact of such a campaign, developed and distributed materials to address both professional and public education. Teleconference discussions beginning in June 2007 were held with all three states as well as with the CDC Office of Genomics and Cancer.

### **Objectives:**

- Develop professional education materials to be distributed to health care clinicians across all three states that inform providers about genetic testing for *BRCA1* and *BRCA2* and the importance and availability of genetic counselors.
- Develop a public web site on each state's main public health web page with public education material related to cancer genetics and the *BRCA1* and *BRCA2* tests.
- Develop genetic counselor and genetic testing center contact lists separately for all three states in order to inform clinicians and the public about where to locate a genetic counselor or testing center in their area. Include, when possible, information about counselors that see patients without health insurance.
- For NYS, publicize a toll free hotline with genetic counselor contact information through the development of a marketing poster distributed to primary care clinician offices across NYS.
- Collaborate with key stakeholders in each state and regionally, such as: genetic counselor professional organizations, the Ferre Institute in NYS, the American College of Obstetrics/Gynecology, the American Cancer Society, the New England Regional Genetics Group in Massachusetts, the Massachusetts Ovarian Cancer Awareness Coalition and the CDC's Office of Public Health Genomics.

### **Methods**

#### **Development of materials:**

- Letter to health care clinicians alerting them to the marketing campaign, adapted for use by each state.
- Question and Answer document developed for clinicians addressing key information about *BRCA1* and *BRCA2* testing.
- In NYS, poster to inform clinicians and the public about how to find a genetic counselor if concerned about a personal or family history of cancer.
- In MA letter to genetic counselors and genetic testing centers alerting them their contact information has been distributed to healthcare providers throughout the state in response to the Myriad Genetics Inc., campaign.
- Public website/web pages developed for the NYSDOH, CT DPH and MDPH main web sites.
- In Massachusetts, addition of a link on the Ovarian Cancer Awareness Coalition website to provide information related to cancer genetics and the *BRCA1/2* tests.
- Once developed, post the question and answer document on NYS's Health Provider Network (HPN) – this network is accessed by hospitals, county health departments and a variety of health care professionals.

Plan for evaluation (At this time most of the evaluation plan is in NYS, however each state will contribute available qualitative and, if available, quantitative data.):

- In NYS, track data from the toll free hotline on the number of calls received to locate a genetic counselor, including basic demographic information about callers.

- In NYS, track access to the Q&A document on the HPN.
- In NYS, survey genetic counselors listed with the toll free hotline about change in referral patterns since the start of the Myriad campaign and how clients are being referred to them (i.e. did the poster and toll free hotline change referral patterns?).
- Track hits to the each state's website, where possible.
- In all states, gather qualitative or quantitative feedback collected in regards to the above efforts.
- In CT, collect and analyze data from a new question on awareness of genetic testing for breast cancer to be included in BRFSS, 2008 effort.
- Collect qualitative feedback from collaborating organizations, especially from those that have incorporated the developed materials and messages into their newsletters/websites, etc.

## Results

### Development of materials:

- All materials listed above have been developed, or are near completion.
- Letter, question & answer document and poster were mailed to 22,000 primary care clinicians across NYS during the 2<sup>nd</sup> week of September, 2007.
- Letter, question & answer document and a list of genetic counselors and genetic testing centers will be mailed out to primary care providers, Nurse Practitioners, Obstetricians/Gynecologists and Health Editors across the Commonwealth of Massachusetts the week of October 22, 2007.
- Question and answer document was posted on NYS's HPN during the 3<sup>rd</sup> week of September, 2007.
- In Massachusetts, a link to provide information related to cancer genetics and the *BRCA1/2* tests was added to the Ovarian Cancer Awareness Coalition website in September 2007.
- NYS's toll free hotline began providing information about genetic counselors during the 2<sup>nd</sup> week of September, 2007.
- CT DPH new web pages to be launched October, 2007
- NYS website anticipated to be launched early November, 2007.
- MDPH website development will begin November 2007

### Evaluating the response:

- As of the 1<sup>st</sup> week of October, 60 calls to NYS's toll free hotline had occurred related to the location of a genetic counselor.
- As of the 1<sup>st</sup> week of October, 45 separate agencies had downloaded the Q&A document from NYS's HPN.
- A survey of genetic counselors in NYS is in development. Plan to distribute electronically in late November and collect feedback during December/Early January.
- Will track hits to each website after each is up and running.
- Qualitative feedback will be collected from emails and phone calls received in response to our efforts thus far.
- (A survey for providers in NYS who received the materials in early September is planned, but results will not be ready for January 2008).

## Discussion/Conclusion

- The NYSDOH, MDPH and CT DPH have approached the direct-to-consumer marketing by Myriad Genetics, Inc. as an opportunity to educate both clinicians and the public about cancer genetic testing, specifically *BRCA1* and *BRCA2* testing. Genetics/Genomics is a growing field, the pace of which has been rapid, and the public health community needs to acknowledge it as an integral part of the overall health care climate. Additionally, the NYSDOH, MDPH and CT DPH feel strongly that the role of genetic counselors should be made evident to clinicians so they can work jointly together to meet the needs of the public. This has never been more evident than now, when consumers are being targeted directly with messages telling them they may be carrying a mutated gene that can

cause disease in them and their families. Collaboration between these three public health departments, as well as a number of professional organizations, has allowed for a wide segment of the population to be reached with this important information.

- This poster will display the steps that have been taken by three states to collaboratively address professional and public education surrounding *BRCA1* and *BRCA2* testing. Additionally this poster will display the quantitative and qualitative data that has been collected thus far in evaluating these efforts.