Partnering to Integrate Genomics, Chronic Disease, and Public Health in Ohio

“Genomics is a huge overarching and highly specialized scientific field, but we don’t have a big budget or tons of people working in it. [You keep up momentum] by taking a small program and working to integrate genomics into other public health activities as you can.”

—Shelley Nottingham, Genetics Program Coordinator, Ohio Department of Health

In states with limited funding for public health genomics activities, maintaining momentum often relies on meaningful partnerships to push forward a shared agenda. While it’s not unusual for state genetics program staff to work with colleagues in other public health programs or with partners outside of the agency, Ohio underscores the importance of productive and strategic partnerships as an effective strategy for integrating genomics and public health. “Like a lot of states, we’re a small program and we don’t have a lot of funding. We have to network as effectively as possible to get things done,” explains Shelley Nottingham, genetics program coordinator in the Ohio Department of Health.

The Ohio Department of Health (ODH) engages partners to maximize the impact of public health resources. “Genomics is a huge overarching and highly specialized scientific field, but we don’t have a big budget or tons of people working on it,” Nottingham says. “[You keep up momentum] by taking a small program and working to integrate genomics into other public health activities as you can.”

Regionalized Approach Facilitates Integration

Ohio has a long-standing history of delivering genetic services through a network of Regional Comprehensive Genetic Centers (RCGC) and outreach clinics. When the genetics program was established in 1974, Nottingham says, Ohio became one of the first states to develop a state genetics plan that utilized a regional approach for delivering services. Today, the ODH awards grants to eight regional centers and 20 outreach clinics that are funded to provide comprehensive and accessible clinical genetic services and deliver outreach and education to health providers and the general public.

The regional system not only promotes access through its multiple sites, but it also provides an effective tool for achieving other health department priorities and objectives—which are integrated into the RCGC competitive funding process. To receive funding, the centers must meet specific guidelines related to clinical services, staffing, and patient and provider education. Recently, the ODH required every comprehensive genetics center to employ a genetic counselor with specialized training in cancer genetics; the department now also requires centers to have a genetic counselor on staff specializing in heart disease and stroke. Cancer genetic counselors work with patients and providers to increase their knowledge about family history and increase appropriate referrals for genetic counseling and testing. Working hand in hand with other providers and patients, genetic counselors with specialized training promote an integrated approach to education, prevention, and treatment. As Nottingham sees it, “This is a good team approach.”
Integrating Genetics Into Cancer and Cardiovascular State Plans

Integrating genomics and public health is not a new strategy in Ohio. About a dozen years ago, the genetics program “started to concentrate on integrating genomics into other areas of public health,” Nottingham says. Today, those efforts have paid off in many ways, including integration of genetics into the state’s cardiovascular and cancer plans.

*Integrating Genetics Into the State Cancer Plan.* According to Nottingham, the genetics program has a long history of working with partners (both inside and outside of the health department) to integrate cancer and genomics into education and clinical services. Dating back about a decade, the genetics program worked closely with the department’s Cancer Control Program to integrate cancer and genomics. “We met with them and looked at different activities that would help us get the word out about cancer genetics, genetic counseling, and appropriate referrals,” Nottingham says.

In 2006, the genetics program formed the Ohio Cancer Genetics Network, a group of about 30 cancer genetic counselors (many of whom work in state-funded regional genetic centers) and key staff from the Ohio Department of Health. Organizing key stakeholders resulted in significant outcomes—namely, having a voice in the state cancer plan process led to the inclusion of a cancer genetics objective in the new state plan. According to Heather Hampel, associate director of the Ohio State University Comprehensive Cancer Center’s Division of Human Genetics, having a voice in the cancer state plan process was invaluable. “There was no genetics objective in the last cancer plan,” Hampel says. “If nobody is at the table to represent a specific niche, then it doesn’t [always] make it into the plan.”

The plan’s new objective is to increase the use of hereditary cancer risk assessment, including genetic counseling and appropriate genetic testing. To achieve that objective, the plan includes strategies aimed at promoting appropriate referrals, providing outreach and education to enhance public and provider knowledge, advocating for health insurance reimbursement for genetic counseling and testing, and increasing the number of patients seen for genetic testing.

Hampel says that the new objective helps to focus the network’s activities: “Now we will be actively pursuing goals around the new cancer objective.” In some cases, the activities represent new work for the network’s members, while other strategies expand on what they are already doing. “We have always tracked the number of patients we see or the number of genetics talks we give to healthcare professionals,” Hampel says. “Now we’re just trying to increase those numbers.” Hampel notes that the group continues to move forward even without new funding because the network’s members are “extremely motivated and passionate, so they give of their time so freely and get things done.”

*Integrating Genetic Risk Factors and Family History Into the State Cardiovascular Health Plan.* Prior to forming the Cancer Genetics Network, the Ohio Department of Health founded the Cardiovascular Genetics Working Group in 2005, which included ODH staff and cardiovascular genetic counselors. According to Amy Sturm, a cardiovascular genetic counselor and work group member, early on the work group developed fact sheets, web resources, and other educational materials aimed at educating providers and the public about the role of family history as a risk factor for heart disease and stroke. Integrating cardiovascular genetics into the state plan was an important goal, Sturm says: “Cardiovascular disease is the number one killer of both men and women, and it can be highly preventable if you have early detection.”
When it was time to update the state’s cardiovascular plan, the Cardiovascular Genetics Working Group was poised to participate in the process. As a result of their participation, for the first time, the 2008-2012 Ohio Plan to Prevent Heart Disease and Stroke includes strategies related to increasing provider awareness about genetic risk factors for cardiovascular disease. By June 2012, the plan aims to “increase the percentage of healthcare providers who discuss genetic risk for certain diseases (including cardiovascular disease) and provide patients with recommendations based on family history.” A number of strategies will help achieve the objective, including continuing education, grand rounds in each of the Regional Comprehensive Genetics Centers, and dissemination of genetics and family history information to primary care physicians and clinics.

**Strategic Public and Provider Education**

Many healthcare providers do not know when they should refer patients on for genetic services and counseling. As a result, Nottingham says, a concerted effort is needed to increase provider awareness about referral guidelines: “We are meeting demand for services at this point, but we need to do a lot more with cancer specialists to make referrals. We’re not getting the referrals we should be getting.” In response, cancer genetics counselors give talks to healthcare providers and disseminate information to promote appropriate referrals for cancer genetics services. Because of the high cost of genetic testing—genetic testing for hereditary breast cancer, for example, can cost more than $3,000—Nottingham says, “We don’t want to just order the test for anybody.” Like Michigan, Ohio disseminates a “pocket guide” that helps providers know when and how to make appropriate cancer genetics referrals.

In addition to provider education, the ODH and its partners develop resources for the general public, including information about family health history and cancer risk assessment as well as fact sheets about hereditary breast cancer, colon cancer, and heart health. In addition, in 2010 the ODH partnered with the RCGC directors to develop a policy statement about direct-to-consumer marketing of genetic tests. “This area is very complex,” Nottingham says. “[If] providers can’t keep up with it, you know it’s very difficult for consumers.”

Moving forward, partnerships will be increasingly important to meet the new objectives in the updated state plans, as well as new and emerging challenges. “The field of genomics is growing so rapidly, and it is relevant to chronic disease and public health,” Nottingham says. In the absence of federal and state funding for public health genomics activities, Nottingham says, integration is the critical path to success: “This is just a good time to be moving in that direction.”

**For more information on Ohio’s public health genomics and related initiatives:**

Ohio Department of Health
http://www.odh.ohio.gov/

Ohio Department of Health Genetic Services Program
http://www.odh.ohio.gov/odhPrograms/cmh/genserv/genserv1.aspx

The Genetics Program of Ohio’s Standards and Criteria for Regional Comprehensive Genetics Centers
http://www.odh.ohio.gov/ASSETS/F1FB00CBFA0A4BE08187B0690E4C7190/Genetics-web.pdf
Ohio Adult Genetics and Chronic Disease web resources, including cancer genetics and cardiovascular genetics resources
http://www.odh.ohio.gov/odhPrograms/cmh/genserv/adultgen.aspx

Ohio Partners for Cancer Control

Ohio Cancer Plan 2010: Our Call to Action

Ohio Cancer Incidence and Surveillance System

Family History Bookmark

Hereditary Colon Cancer Fact Sheet

Criteria for Cancer Genetics Referrals

Ohio Plan to Prevent Heart Disease and Stroke 2008-2012
http://www.odh.ohio.gov/ASSETS/B491AE7C8ADF4D86AC544498A7FACCA/heart%20disease%20and%20stroke%203-4-10.pdf

Family History and Heart Health

ODH Policy Statement on Direct-to-Consumer Marketing of Genetic Tests