

Plunging into the gene pool

“Genomic medicine can change the whole paradigm of medicine from one that focuses on treating and curing disease to one that focuses on avoiding disease and maintaining a healthy life.”

— Dr. Vincent Henrich

ONCE UPON A TIME, THE IDEA OF LOOKING TO GENES TO PREDICT future health was the stuff of science fiction. But no longer. And UNCG, as part of the Guilford Genomic Medicine Initiative, is at the forefront of bringing that change to doctors and local residents.

The Guilford Genomic Medicine Initiative, or GGMI, is the first comprehensive attempt in the United States to translate genetic discoveries into everyday community health care. For patients, this will mean personalized information about their risk for developing life-threatening diseases with an eye to delay or prevent them altogether.

Genomics is, simply, the science of inheritance. Technological advances have given us the ability to decode much of the human blueprint contained in our DNA. But genomics does not turn our cells into crystal balls showing us a future already fixed. Its value lies mostly in showing us not what will be, but what might be.

By doing so, by providing clues that might point to a possible predisposition for certain diseases, it gives us the opportunity to better safeguard our own health. “We are not slaves to our genes,” said Dr. Vincent Henrich, director of UNCG’s Center for Biotechnology, Genomics and Health Research.

For example: “If you look at a population of half a million people in a metropolitan area such as Greensboro, the number with a lifetime risk of colon cancer is something on the order of 35,000 and about 30 percent of these people can be recognized as at-risk for the disease based on family medical history,” Henrich said. “Genomic medicine makes it possible to reduce or eliminate the risk of the disease developing in 10,000 to 15,000 people — and that’s just in Guilford County alone — by recognizing that they are at risk and having them start routine cancer screening at an earlier age than would be typical.”

While local residents will be the first to benefit from the initiative, the overriding goal is to create a template that can be used in health care systems everywhere — including



“ Why is the project being conducted here? ”

Guilford County is a good community for this type of study because we have a major health care provider in Moses Cone and also because we have families with multiple generations that live in the area. So we have a relatively stable family environment. And we have demographics that are really reflective of national demographics. Aside from that, this is a good area to implement genomic medicine because you have all the features in place that allow it to work. There’s a strong alignment between what genomic medicine is about and what UNCG health research is about. We focus on things like pre-symptomatic diagnosis, reducing the risk of disease and helping people become knowledgeable about what they need to do to stay productive and happy. So I think there’s an excellent alignment of philosophies here.

What’s behind military funding of the initiative?

The military is the largest health care system in the nation, and like all systems, is projecting to have a huge expansion in the next several years. Look at the number of military personnel we have now and project out — think about the fact that these people will be veterans who will be eligible for military health care in the future and you’re talking about a tremendous cost as these people continue to age. Genomic medicine really offers them the possibility of reducing costs while maintaining high-quality care. The millions the Department of Defense is spending in support of this project will save it billions in the future.

What are public concerns about use of genetic information?

There are a lot of concerns that revolve around privacy, confidentiality and insurance, and I wouldn’t be playing my role properly if I didn’t say that those concerns need to be continually monitored. North Carolina law prohibits discrimination, and federal legislation has been proposed protecting the privacy of genetic information. Notwithstanding those safeguards, I think being vigilant about this is perfectly appropriate. Individuals participating in GGMI will be advised of the steps necessary for them to protect their interests. Our genetic counselors will talk to patients about what they need to do in terms of insurance and so forth before even requesting a genetics test.

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the U.S. military, which is providing \$10 million in funding through April 2008 (and likely at least a year beyond that).

The pilot phase of the program will get under way in Greensboro in 2007, focusing on those who are at risk for breast/ovarian cancer, colon cancer and thrombosis (blood clots). Later, the initiative is expected to expand to heart disease, adverse drug reactions and neurological disorders such as Alzheimer’s disease. In cases where treatment is necessary, genomic testing has the potential to indicate which options would be most effective.

Participants will be actual patients of physicians who volunteer to take part in the program. “The GGMI is unique in that it targets the primary-care physician, where if

successful, genomic medicine will have its greatest impact,” said Henrich.

UNCG is one of three partners in the project, along with Duke University’s Center for Human Genetics and Moses Cone Health System, and each brings distinct areas of expertise. UNCG is leading the education component, acquainting the community, patients and health care providers with genomic medicine and gaining their support. In addition, genetic counselors affiliated with UNCG will talk to participants when appropriate about genetically based risks, options for treatment and prevention, and interpretation of test results.

Moses Cone is the program administrator and will work with patients in its network who choose to participate. Duke is develop-

ing materials for family history collection and risk assessment and, when appropriate, will analyze DNA.

It’s important for people to know genotyping, the laboratory process of mapping genes, won’t be done for everyone. “You don’t necessarily need a genetic test,” Henrich said. “If your family has no history of cancer, for instance, a genetic test for cancer risk is not an effective use of medical resources.”

And that is the heart of the matter. Learning your family medical history — something as simple as a conversation — is the most important element of genomic medicine. “There’s a lot of valuable information there,” Henrich said. “Let’s start with the most valuable information that can be collected most

easily and go from there. And Moses Cone and Duke University will certainly take care of those individuals who choose to participate in GGMI and take it one step further.”

From the very beginning, UNCG has sought community input by hosting focus groups and conducting telephone surveys. Rather than going to the community and telling them what they needed to know, “We asked them to tell us what they know and what they think,” Henrich said.

“There is a lot of mythology about genomic medicine. It’s important that people understand it’s not about cloning and it’s not about stem-cell research, per se. Those types of technologies may have tremendous medical value, but they are really separate from the practice of genomic medicine that we’re talking about in our initiative.”

The survey suggested that many believe genetic tests already exist for a wide variety of diseases, which is untrue. “Many also believe that genetic tests are more or less definitive in terms of telling someone about their risk. Except in a few specific instances, this is also untrue because there’s simply not enough information from research yet. Genomic medicine is relatively mundane actually. It starts with family medical history, and that’s the true emphasis of our project.”

Next up is a broader-based education effort for physicians. And in late November, a campaign will be rolled out encouraging local families to sit down together during the holidays, talk about medical history and record essential information — whether they’re participating in the project or not.

Henrich sees potential significant local impact, much like at Framingham, Mass., site of a famous long-term study of heart disease. “We could become the Framingham of genomic medicine.”

And with that, he added, come economic benefits, business opportunities and the possibility of developing expansive new technologies in genomic medicine. “I think there’s a lot of business opportunity in focusing on early diagnostics, risk reduction, technologies around health care that really focus on that part of the action.

“I believe UNCG can put itself in the center of all this. It’s worth emphasizing this is only the cornerstone. We really need to build out and think about how we’re going to make this notion of health maintenance and extension of productive lifespan a mainstay of our community.”

Stay Informed

Visit the Guilford Genomic Medicine Initiative’s web site — www.genomic-medicine.org for the latest project news. The survey used earlier this year to gather information from the general public is also posted there, and visitors 18 or older are invited to fill it out.

Genetic counselors play key role

UNCG’s genetic counseling program is playing a pivotal role in the Guilford Genomic Medicine Initiative — as it has since the days when the project was just in the talking stages.

“This program is something absolutely outstanding that we’re bringing to the table,” said Dr. Vincent Henrich. “In many ways, it was a focal point for the development of GGMI and certainly was one of the reasons the project is taking place here.”

The graduate program, established in 2000, is the only one of its kind in North Carolina and among only a handful in the country. As many as 100 applicants vie for eight slots each year.

Three UNCG genetic counselors are involved full time in the initiative. “Their role will be to take family history information and sit down with a patient and explain what it means, what the options are, who needs to know, and so forth,” Henrich said. “The physician is far too busy and has far too many other things to be concerned about to be able to focus in on what the family issues are.”

On the physicians’ side of things, he added, one of the major points of education is to help them understand what the role of the genetic counselor is. “Clearly studies have shown that physicians have not had much access to genetic counselors,” Henrich said. “But when they see what this professional does and recognizes that this project has made referrals to genetic counselors the mainstay of the program, they are really quite happy about that possibility.”



“ The forefront

One of the connections that’s extremely important to make here is what this means for UNCG students. We’re an educational institution; we haven’t forgotten that in all of this. Insofar that the students are involved in health research in the future, this focus on reducing health care needs and maintaining health, we really are giving our students and the researchers who work with these students the opportunity to get on the front end of these trends. With its nursing school, its exercise and sports science program, its public health education, communication disorders program, psychology, nutrition, and such areas of study, UNCG really has the opportunity to be in the forefront of developing the educational programs, as well as the research, that are going to make a big difference.



Our emphasis

There is a lot of mythology about genomic medicine. It’s important that people understand it’s not about cloning and it’s not about stem-cell research, per se. Those types of technologies may have tremendous medical value, but they are really separate from the practice of genomic medicine that we’re talking about in our initiative. Our community survey suggested that many folks believe there’s a genetic test for a wide variety of diseases right now. This is not true. Many also believe that genetic tests are more or less definitive in terms of telling someone about their risk. Except in a few specific instances, this is also untrue because there’s simply not enough information from research yet. Genomic medicine is relatively mundane actually. It starts with family medical history, and that’s the true emphasis of our project.



An investment

The true potential of GGMI is to become a thriving source of growth in many ways — economically, in terms of its recognition, as a major metropolitan area, in developing business opportunities, as a go-to place, and so forth. For that to happen, there needs to be a continuing investment and the recognition that the community itself has to be involved. If alumni could see what the value is for our institution and for our current students and future students as well as the community in terms of having something like this, I think they would [support it] because it’s a good investment. That is the future. That is what a top-tier 21st century university has to be about.



Vincent Henrich talks about what the Center for Biotechnology, Genomics, and Health Research needs to realize its potential.

Our ability to direct our research depends on us putting in place the infrastructure that allows our investigators to pursue their interests and not be dependent on another institution. Nothing against Duke, they’re a great partner, but we have to make our own road if we’re going to maximize the value this can have for Guilford County.

We’re seeking support from alumni to allow our faculty researchers to develop their own research agendas focused on promoting health. To do this in a meaningful way in the next two years requires roughly a million dollars. We need infrastructure so our investigators can begin to mobilize.

We have a number of researchers who compete toe to toe with researchers at other major research universities. We have those researchers now. But they are constantly faced with resource limitations.

To maximize their ability to get and sustain grant funding, we need equipment and trained personnel. We need graduate students and postdoctoral fellows. That would allow our faculty members to move quickly on their ideas.

That is the future. That is what a top-tier 21st century university has to be about. If we have that, combined with what we already do well, we can make a difference.

For more information about the Guilford Genomic Medicine Initiative, contact Henrich at (336) 334-4775 or vincent_henrich@uncg.edu.