

It's All In The Genes

Researchers uncover your genetic profile

If you knew you had a high risk of getting heart disease, would you eat fewer cheeseburgers? If your doctor learned you were likely to develop cancer, would she order extra tests to safeguard your health?

That's the hope of SJ researchers, who have launched a groundbreaking project to map local residents' genes – which can show your risk of disease and other health issues. Such findings will help doctors “personalize” medicine based on each patient's particular genetic makeup.

The project – called the Coriell Personalized Medicine Collaborative[®] – aims to gather genetic data from 10,000 volunteers over the next few years, and ultimately reach 100,000 participants. About 2,000 people have already enrolled in the project, which is open to the public at no cost.

“The promise is better healthcare for all of us,” says Michael Christman, PhD, president of the Coriell Institute for Medical Research, an internationally known Camden facility that's spearheading the project. “Personalized medicine will improve the effectiveness and lower

the cost of medical care.”

Indeed, a person's genetic profile or “genome” can reveal a range of genetic variations specific to that individual, including risks for various illnesses and sensitivities to certain drugs. The new gene-mapping technology also raises a number of difficult questions about ethics, privacy and other concerns.

The Coriell initiative “will literally change the way healthcare is delivered in this country and the world,” notes George Norcross, III, chairman of Cooper University Hospital, a leading partner in the effort.

Individualized care

For instance, if your genome reveals a high risk of diabetes, your doctor could advise you to lower that risk by attaining a healthy weight, exercising and eating more healthfully.

A woman in a dark suit and a man in a light blue shirt are standing in a server room. They are looking at a laptop that the woman is holding. The room is filled with server racks and has a blue ambient light. The background is a stylized graphic of a molecular structure with blue spheres and lines.

How **genes** make us similar but different

Our genes are made of strings of DNA. Together, all of a person's genes make up his genome. The DNA of all living things has four forms, represented by the letters A, T, G and C. Each person's genome contains three billion of these four "letters," and 99.9 percent are identical across all people – indicating that humans are very closely related.

However, one of every 1,000 letters is likely to be different in some individuals. For instance, someone may have a T at a given position, while others have a G. These differences – which account for 0.1 percent of a person's genome – are what make each of us unique.

Some of these genetic variations have no health consequences, such as those that determine eye color or height. But others can impact health, such as variants that elevate risks for certain diseases or that cause adverse reactions to specific drugs.

Today, scientists know of six million genetic variants. Of those, about two dozen are considered "medically actionable" – meaning that medical or lifestyle changes could lower a person's risk. Over the next five years, researchers expect to discover hundreds more medically actionable variants.

Coriell Institute plans to gather genetic data from 100,000 participants.

If your genetic risk of breast cancer is elevated, your doctor might prescribe more frequent testing or different types of tests, says Jim Dwyer, DO, chief medical officer for Virtua Health – also a collaborator on the project. “This allows the opportunity to intervene before illness occurs.

“It’s a two-way thing,” Dr. Dwyer observes. “The physician is more attuned... the patient would be more engaged because they now realize they have a risk. That combination can change behavior.”

Kathleen Yhlen – one of the project’s first participants – is looking forward to receiving her genomic profile this summer (the process takes about six months).

“Cardiovascular disease runs in my family,” says the 47-year-old Washington Township woman, who exercises and eats right most days. “If I knew I had a genetic tendency to have a heart attack or high blood pressure, I might even be better... I might not cheat as much.”

Yhlen notes that her genetic data could also help her in the future, should she become ill. “Some people can’t take certain chemotherapy agents because of their genetic make-up,” says the Cooper

nursing instructor and registered nurse. “Instead of trial-and-error type of care, they’ll put me on something they’ll know I’ll respond to.”

Research into genes’ impact on medications can save both lives and dollars, experts note. “Six percent of hospital admissions are driven by adverse reactions to drugs,” explains Dr. Christman. “Billions are wasted on drugs that don’t work.”

Dramatic potential

While the project will bring immediate benefits to thousands of SJ participants, it will also enable future discoveries about genes and how they affect health.

“This will mean more to my children and grandchildren as this evolves,” says John Sheridan, Cooper’s president and CEO. “(Genetic) information will exponentially increase in coming years.”

In other words, scientists will identify more genes that contribute to disease, learn more about how genes interact with each other and the environment, and discover more connections between genes and drug reactions.

For instance, if researchers find a gene that raises the risk of obesity, drug



Coriell's president Dr. Michael Christman is leading groundbreaking research on genetic data.

C'mon let's go...

...Celebrate summer with the Malvern School!

The Malvern School For Early Childhood Education

Celebrating 10 Years

Alex's Lemonade Stand Day At The Malvern School
Join us at any of our 16 locations
July 16th • 9 am - 2 pm
Help support the fight against pediatric cancer!

- Camp programs for infants, toddlers, preschool, pre-Kindergarten and school age children!
- Includes specialty days like Multicultural Mondays!
- Weekly special visitors for all ages!
- Weekly field trips and swimming for children over age 4!
- School age children enjoy additional off-site trips!
- Degreed teachers
- Full and half day programs

1-877-MALVERN • WWW.MALVERNSCHOOL.COM

companies may be able to develop an anti-obesity medicine, Dr. Christman says. In another scenario, a potential new drug that would otherwise fail to get FDA approval could still be approved, if it were found to benefit a segment of the population with a certain genetic variation.

“It won’t be long before we know what a great deal of the genome means in medical terms,” adds Dr. Christman. This project will be “part of the infrastructure” of such research, he says.

Presently, Coriell is working with Cooper and Virtua to recruit employees as participants, educate doctors, and determine how genetic information can be used most effectively by healthcare providers.

How it works

The public can enroll in the project, which began last winter, by visiting coriell.org. The program’s costs are covered by private donations, which to date have reached \$5 million.

To provide your genes for testing, you simply give a saliva sample. Participants



Participants need only give a saliva sample to participate in the project.

Get the skinny on your genes

Members of the community can enroll in Coriell's free genome-profiling project at coriell.org.

Several for-profit companies offer a similar service for \$1,000 to \$2,500. However, these firms' findings are not always backed by scientific research.



The project keeps participants' medical data in an anonymous form to protect their privacy.

are also asked to update their health records annually, to further aid in research.

Starting this fall, people will be able to access their personal genomic data via Coriell's secure Internet portal.

"You can choose, one at a time, whether to view your status (for particular diseases) such as breast cancer," Dr. Christman explains.

To help alleviate potential worry, the person must first play a short video by a genetic counselor. "We want to do this in a responsible way," says Dr. Christman. "For most diseases, half of risk is determined by environment and half is genetic." Even the genetic component can be complex, often depending on 10 to 15 genes, the scientist notes.

In addition to educating the public, one of the project's biggest challenges is to help healthcare providers develop systems to use patients' genetic information efficiently and effectively.

"The amount of data from a genomic profile is huge and will be increasing exponentially," says Simon Samaha, MD, Cooper's chief medical officer. "Physicians (typically) have 15 to 20 minutes with a patient. They don't have time to review two million bits of information."

Plus, several for-profit companies have already begun offering genome profiling, and healthcare providers must be ready to handle this information, says Virtua's Dr. Dwyer. The Coriell collaborative "gives us a jump, to help our clinicians understand and manage (genomic) data."

Ethical issues

Mining people's genetic information brings a host of legal and ethical concerns, researchers acknowledge.

For instance, genes can indicate a predisposition for diseases like Alzheimer's and Huntington's, which are currently incurable. The Coriell project will not reveal such information to participants until an effective treatment becomes available.

Some experts disagree with this approach. "My opinion is the disclosure should be open," says Dr. Samaha, who favors leaving such decisions up to the patient in conjunction with his physician.

In Dr. Samaha's case, an increased risk of Alzheimer's would "change how I live my life...my lifestyle, my investment strategy?"

Still, he admits that our healthcare system "is not ready to deal with these issues."

Dr. Christman advocates a gradual

Simplify & Organize



ClosetGallery
your life... organized

Customized Closets/Mudrooms/Laundry rooms and more!

FREE CONSULTATION

609-714-8282

Surpassing your expectations is where we begin

www.theclosetgallery.com

approach. "Ultimately, as a society, we probably will reveal all aspects of the genome," he predicts. "If we take it slowly, we will be better educated about what it means."

Privacy concerns

Some day, every American will probably have his genome mapped at birth, experts say. "It will be part of the standard electronic medical record," projects Dr. Christman. "Whatever doctor you go to will consult it with your consent."

But as we embark on this new era, some question the security of genetic records and cite the potential for genetic discrimination.

Coriell and its partners say they've adequately addressed such concerns. The project maintains participants' medical data in an anonymous form and uses state-of-the-art security measures, they report.

The collaborative also cites a protective state law. "It is illegal in New Jersey for an employer to discriminate for purposes of employment or health insurance, based on a person's genetic profile," states the project.

Dr. Samaha equates the security situation with online shopping. "Seven or eight years ago, people were afraid to use the Internet for transactions," he notes. "Now it's the biggest economy."

Still, your healthcare provider may share your genetic data – like all medical records – under certain circumstances. For instance, if you grant your doctor access to your genetic profile, she may prescribe a certain drug, test or procedure based on that information. Your health-insurance company may then require documentation to justify payment for that medical service.

"Your insurer would get to see the genetic information," says Dr. Christman, "but they couldn't discriminate based on that."

Jennifer Morales, 26, feels the benefits of knowing her genetic makeup outweigh any concerns about privacy.

"I'm not too worried about it," says the Cooper employee, who enrolled in the project in March. "Since it's anonymous, it won't hinder me."

Morales' bigger concern: Whether her genome will show elevated risks for diabetes or cancer, which run in her family.

"My doctor needs to have all the information to give me the correct diagnosis and treatment," says the Pennsauken woman. "It's always good to know what's going on, rather than being in the dark." ■



• UNDER THE SUN •
CHILDREN'S BOUTIQUE

Featuring the most unique and distinctive children's wear for all occasions

66 East Main Street
Moorestown, New Jersey
856-234-3535

www.underthesunboutique.com

Get ready to soak up the fun
WITH OUR SUMMER COLLECTION

WHICH IS CURRENTLY
30% OFF!