MyCode: Revealing the links between our genes and our health
Geisinger’s ambitious effort advances research while helping patients and families
In every issue

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We want to hear from you

Please write to us! We want to hear your thoughts on what you see here and your ideas for future stories. Email us at: GeisingerMagazine@geisinger.edu.

Include your name, email address, city and state. If you are a Geisinger staff member or alumnus/a of our education programs, also include your current (or past) positions and the years that you worked or trained here.

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On the cover: DNA strands formed out of linked human figures suggest the thousands of participants who have already signed up for MyCode.
Illustration: Scott Roberts
I receive several emails and letters from patients and staff members every week, but one recent story perfectly captures what I view as Geisinger’s purpose. A care provider at Geisinger Wyoming Valley Cardiology told me that after she was diagnosed with breast cancer, she had no one to turn to for help. She had lost both of her parents as a child and had only a loose connection to her foster family many miles away. Her next day at work, Dr. Al Casale, chairman of cardiothoracic surgery, gave her “the hug I needed,” she wrote, and the day before surgery, her colleagues all wore pink and ordered in a good-luck luncheon.

You might think that initial flurry of support would die down as time passed and people returned to their own lives, but in this case, it didn’t. Her letter went on to detail how all of her colleagues — physicians, nurses, physician assistants, office staff and others — continued to support her by driving her to appointments, cutting her lawn and helping with grocery shopping and chores. They brought her meals. They called her on their days off. Cardiologist Dr. Martin Matsumura served as her advocate and was by her side when her doctor told her she needed chemotherapy. As she concluded, “I am not alone. My Geisinger family will get me through this!”

We are one Geisinger family, and our purpose is to make sure all patients and their families get the support they need as they face health issues that can range from fairly routine to life-threatening. A number of recent initiatives have focused on making their care more seamless and more convenient: We are starting same-day scheduling, trying out online scheduling through a new app, and continuing to seek feedback through our ProvenExperience™ refund promise, which has awarded more than $400,000 in refunds to 300 Geisinger patients. But even more vital than such innovations is the care that passes from each Geisinger staff member to each patient — one human being to another. During the 2016 fiscal year, we hired more than 3,000 new Geisinger family members, including 145 physicians and 450 nurses, and we will continue to grow. And I am confident that each one of them can adopt the same attitude of caring that is so evident in the letter I received about GWV Cardiology.

This focus on caring and on partnering with patients as one Geisinger family is at the heart of this issue of Geisinger Magazine. You will meet patients who are part of the MyCode® Community Health Initiative, some of whom have received genetic information that is empowering them and their doctors to take steps to prevent disease and improve their health. You’ll hear from a former ICU nurse who now directs the customer experience at AtlantiCare, A Member of Geisinger Health System, pouring all of his time and energy into helping colleagues get things right for patients and families. You also will read about how Geisinger uses volunteer actors to teach residents and medical students how to have caring interactions with patients, so that they can get it right when the time comes to deliver difficult news, give health advice or offer a shoulder to cry on.

Through these and other stories, I hope you’ll see that caring is much more than a tagline for Geisinger. It is our core purpose.

David Feinberg, MD, MBA
President and CEO
Research and innovation have been key to Geisinger’s purpose since Abigail Geisinger opened her hospital more than 100 years ago. Research infuses all aspects of healthcare, from disease prevention and treatment to healthcare delivery.

We focus our innovation and research efforts on what can be done best at Geisinger, using the combination of characteristics that make the hospital system unique:

- High-quality patient care
- Fully integrated healthcare system
- Large, stable patient population
- Advanced electronic health record
- Clinical data warehouse

Our goal is to create healthcare services and delivery that will improve quality of care while enhancing access and affordability.

In 2009, we completed a research strategic planning process that confirmed and elevated the role of research in Geisinger’s purpose. It emphasized research that improves health and healthcare — not only for our own patients, but also for patients nationally and globally through scholarly publications, presentations and commercialization of new discoveries.

This section of Geisinger Magazine features just a sampling of the many important contributions to research made by Geisinger staff members in 2015 and early 2016. For a fuller picture of research at Geisinger, visit our website at geisinger.org/for-researchers.
Using the DiaRem score to predict diabetes cure after weight loss surgery

Weight-loss surgery is currently the most effective treatment in reversing insulin resistance in patients with Type 2 diabetes. (Insulin resistance means that the body cannot effectively use the hormone insulin, which leads to elevated blood sugar levels.) However, the likelihood of being cured by surgery varies widely based on certain patient characteristics.

A few years ago, researchers with the Geisinger Obesity Institute created the DiaRem score, which uses just four pieces of information to predict whether a person’s Type 2 diabetes is likely to go into short-term remission after weight-loss surgery (“DiaRem” stands for diabetes remission). These factors include:

- Age
- Hemoglobin A1c level (a test used to measure blood sugar control)
- Use of any diabetes medications
- Dependence on insulin

Each factor has a certain number of points associated with it, with score results ranging from 0 to 22. Researchers found that the lower the score, the more likely a patient’s Type 2 diabetes was to improve after Roux-en-Y bypass surgery (RYGB). This type of weight-loss surgery reduces the size of the stomach to a small pouch, which in turn decreases the amount of food a person can eat. The pouch is attached directly to the small intestine, which also reduces the absorption of fat and calories.

Now, Geisinger Medical Center (GMC) researchers have reported that the DiaRem score can actually be used before weight-loss surgery to predict whether a patient’s diabetes is likely to be cured. “Cure” means that the patient’s hemoglobin A1c levels (HbA1c) and fasting glucose levels remain in the normal range for five years or longer without any diabetes.

Proportion of patients with remission and cure of Type 2 diabetes following Roux-en-Y gastric bypass by DiaRem score
treatment. The study results were published in a research letter in the April 20, 2016 online edition of *JAMA Surgery*. The team included G. Craig Wood, MS, and Christopher D. Still, DO, of the Obesity Institute; Tooraj Mirshahi, PhD, of the Weis Center for Research; and Annemarie Hirsch, PhD, MPH, of the Center for Health Research.

The researchers reviewed the electronic health records of 407 patients with Type 2 diabetes who had RYGB surgery at GMC between 2001 and 2010. Half of the 100 patients with the lowest DiaRem score (0 to 2) were cured of their diabetes after surgery. In contrast, none of the patients with DiaRem scores over 18 were cured. Overall, there was a clear correlation between lower DiaRem scores and the likelihood of complete remission of diabetes.

The researchers concluded that this easy-to-use score can help predict which Type 2 diabetes patients are most likely to benefit from bariatric surgery. “Precision medicine does not have to be complicated,” they wrote in the research letter. “The DiaRem score is an algorithm based only on age, medication use and HbA1c level that can predict the likelihood that a patient with Type 2 diabetes will be cured by surgery.” This can help physicians better target treatment plans to the individual patient. National media outlets such as Reuters, Medscape, and *Endocrine Today* shared the results of this study. –K.C.

Cirrhosis of the liver in chronic hepatitis C (CHC) patients may be much more common than previously thought, according to researchers with a large national study funded by the Centers for Disease Control and Prevention. The study reported that tracking multiple cirrhosis-related codes and test results in electronic health records revealed that nearly 30 percent of 9,783 CHC patients had cirrhosis. This was a higher rate than reported in other studies that tracked only diagnostic codes. Cirrhosis occurs when the hepatitis C virus causes the liver to get inflamed and scar tissue forms, leading to liver damage. The study appeared in the August 2015 American Journal of Gastroenterology.

Joseph A. Boscarino, PhD, MPH, senior scientist with the Geisinger Center for Health Research in Danville, Pa., was part of this effort, called the Chronic Hepatitis Research Study (CHeCS). It aims to expand our understanding of the impact of chronic hepatitis C, which affects about 2.7 million people. The earlier patients can be diagnosed and treated with antiviral medications, the less likely they are to develop serious liver disease.

In this study, liver tissue biopsy (taking a sample of tissue for examination) identified the condition in only 7 percent of patients (661 total). But based on the results of nonsurgical tests that look for evidence of liver scarring, called FIB-4 scores, cirrhosis was found in 22 percent of patients (2,194 total). Diagnosis or procedure codes (or ICD 9 codes) in the medical record for either cirrhosis or liver failure symptoms identified 482 patients, or about 5 percent. When researchers added yet another blood test for liver scarring, called APRI (aspartate aminotransferase-to-platelet ratio index), about 13 to 19 percent of patients were found to have cirrhosis.

Based on biopsy, FIB-4 scores and diagnosis codes, the researchers concluded that about 28.5 percent of patients with CHC had cirrhosis. They also found that only about half of the patients with cirrhosis confirmed by biopsy had an ICD-9 disease diagnosis code in their medical records. This suggests that relying on the medical record alone would not be accurate. By using the additional criteria, researchers were able to identify four times more patients with cirrhosis than were revealed by biopsy alone. Also, relying on liver biopsy alone may underestimate the number of people with cirrhosis, as biopsies are usually not performed in everyday practice. The results suggest that multiple measures should be used to determine a person’s risk of cirrhosis when he or she has hepatitis C.

The study’s data came from health records of CHC patients who were treated between 2006 and 2010 at Geisinger Health System in Danville, Pa., and three other large health systems participating in the CHeCS project: Henry Ford Health System in Detroit, Mich.; Kaiser Permanente – Northwest, in Portland, Ore.; and Kaiser Permanente – Hawaii in Honolulu.

CHeCS is the first comprehensive U.S. research project that is observing approximately 20,000 patients with chronic viral hepatitis B and C to better understand these diseases and improve treatment and outcomes. —M.C.


Study suggests nearly 30 percent of chronic hepatitis C patients have cirrhosis

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<th>Proportion of patients with cirrhosis indicated vs. not indicated</th>
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<tr>
<td>N (%)</td>
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<tr>
<td>Cirrhosis not indicated</td>
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<tr>
<td>Cirrhosis indicated by FIB-4 scores, liver biopsy, or diagnostic/procedure codes for cirrhosis or manifestations of hepatic decompensation</td>
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<tr>
<td>By FIB-4 &gt;5.88</td>
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<tr>
<td>By liver biopsy</td>
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<tr>
<td>By diagnostic/procedure codes (for cirrhosis or manifestations of hepatic decompensation)</td>
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<td>By ICD-9-CM diagnostic codes for cirrhosis</td>
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<tr>
<td>By ICD-9 diagnostic codes/CPT codes for manifestations of hepatic decompensation</td>
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<tr>
<td>By APRI &gt;1.0a</td>
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<td>By APRI &gt;1.5a</td>
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<td>By APRI &gt;2.0a</td>
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aAPRI scores served as additional criteria for determination of cirrhosis in sensitivity analyses.
Each year, nearly 30,000 people worldwide become living kidney donors. These donors improve or even save the lives of many patients with kidney failure. Typically, they have to be in good health and well informed about kidney donation before they can donate. Although donation is considered fairly safe in healthy individuals, there are risks involved, including a slightly higher long-term risk of kidney failure. These risks have to be discussed carefully between the transplant team and the potential kidney donor.

Geisinger kidney specialist and internal medicine physician Alex Chang, MD, MS, was recently part of a team of experts who developed a more precise way to evaluate and counsel potential kidney donors based on characteristics such as health, ethnicity, gender and age. In an article published in a February 2016 print issue of The New England Journal of Medicine, the team described their new online risk tool, available at TransplantModels.com/esrdrisk. The tool allows patients and their doctors to quickly estimate their 15-year and lifetime risk of developing kidney failure — also called end-stage renal disease, or ESRD — without donating a kidney. Overall, the 15-year risk of ESRD is very low; for a healthy white woman aged 40, for example, it would be just 0.04 percent. However, certain other factors can increase that risk. “Some donors might have a higher future risk of ESRD than they realize, and with this information they might choose not to donate if the risk is higher than what they would be willing to accept,” says Dr. Chang.

Dr. Chang worked with colleagues at Johns Hopkins University, Tufts Medical Center, the University of Minnesota and several other academic institutions to develop the science behind the online tool. Their work was funded in part by the National Institute of Diabetes and Digestive and Kidney Diseases. Together, the researchers examined data that had been previously gathered on nearly 5 million people in the U.S., Canada and Israel through seven population-based studies, including one at Geisinger.
Participants were followed for anywhere from 4 to 16 years. The researchers found that certain characteristics were associated with a higher risk of ESRD in people who had never donated a kidney. These included:

- Black race
- Hypertension, or high blood pressure
- Being a current or former smoker
- Diabetes
- Obesity
- Lower eGFR, or estimated glomerular filtration rate (a test used to screen for and detect early kidney damage)
- Higher albuminuria (having too much protein in the urine, which also can be a sign of early kidney damage)

The researchers then used these as a basis for creating the tool, which asks the user to answer a series of simple questions to estimate their long-term risk of kidney failure. This is important information for potential donors and their physicians to have. The risk of kidney failure among kidney donors in the U.S. was about 3.5 to 5.3 times higher than the estimated risk of healthy individuals who might consider donating. Thanks to this data-driven tool, transplant teams and candidates can now make a more educated decision about kidney donation. –K.C.


**ESRD risk tool for kidney donor candidates**

The pre-donation risks represent projections if a person does not donate a kidney. Details about estimating post-donation risk are provided below.

**Projected incidence of end-stage renal disease:**

<table>
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<th>Pre-donation 15-year*</th>
<th>Pre-donation lifetime*</th>
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<tr>
<td>0.04%</td>
<td>0.30%</td>
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The risk varies depending on a donor candidate's demographic and health characteristics. At the present time we do not have data on the lifetime post-donation risk of ESRD according to a donor candidate's characteristics.

**Patient characteristics:**

- **Age (18 – 80yrs)**: 40
- **Gender**: Female
- **Race (white or black)**: White
- **eGFR (ml/min/1.73m²)**: 90
- **Systolic blood pressure (mmHg)**: 120
- **Hypertension medication**: No medication
- **BMI (kg/m²)**: 25
- **Non-insulin-dependent diabetes**: No diabetes
- **Urine albumin to creatinine (mg/g)**: 4
- **Smoking history**: Nonsmoker

*Pre-donation projected risk of end-stage renal disease (in the absence of kidney donation): This model is intended for low-risk adults considering living kidney donation in the United States. It provides an estimate of the 15-year and lifetime incidence of end-stage renal disease given a set of demographic and baseline (pre-donation) health characteristics.

**Post-donation projected risk of end-stage renal disease (after kidney donation):** Previous studies have estimated that the 15-year absolute increase in the risk of ESRD from kidney donation averages 0.27%. This risk varies depending on a donor candidate's demographic and health characteristics. At the present time we do not have data on the lifetime post-donation risk of ESRD according to a donor candidate's characteristics.
Access to doctors’ notes improves the care experience for patients and care partners.

About 1,700 Geisinger clinicians provide patients and their care partners with access to office visit notes through MyGeisinger.org.

Photo: Patrick Pacacha
Giving patients and their designated "care partners" access to doctors’ notes improves their ability to manage care decisions, according to a recent Geisinger study. The project made use of the electronic patient portal, MyGeisinger, and its OpenNotes feature, which provides access to doctors’ notes after office visits. The study was done in partnership with Beth Israel Deaconess Medical Center and Johns Hopkins Bloomberg School of Public Health, with funding from The Robert Wood Johnson Foundation. The results were published in the Journal of the American Medical Informatics Association in August 2016.

The researchers surveyed adult patients’ and care partners’ opinions about their ability to manage care and communicate before they started receiving electronic invitations to access OpenNotes. They surveyed them again 12 months later, with 184 patients and 252 care partners responding. About 64 percent of patients and 88 percent of care partners reported viewing one or more doctors’ notes. More than 1 in 3 care partners (35.5 percent) reported they viewed the notes because they were not able to attend a particular office visit. Other reasons included wanting to learn about the patient’s health, to remember or better understand what was said by the provider, or to verify the notes’ accuracy.

Patients and care partners reported that using OpenNotes improved their ability to communicate about the plan of care. They said they were more likely to agree about the treatment plan (85 percent and 79 percent, respectively), had more productive discussions (86 percent and 82 percent) and were better able to develop questions for the doctor (88 percent and 86 percent).

In addition, 89 to 94 percent of patients and care partners reported the following benefits:

• Better understanding of the patient’s health conditions
• Improved ability to remember the patient’s care plan
• Feeling more in control of the care

After one year of using OpenNotes, patients also felt more confident in their ability to manage health information and prepare for office visits. Care partners reported a high level of confidence before using OpenNotes, so their levels did not increase significantly, but they were more likely to report improved communication with healthcare providers.

The researchers concluded that since care partners were more likely to access OpenNotes than patients, the notes could play an important role in opening lines of communication about the care. Those patients who did read the notes often shared them with their care partners as well, improving collaboration. The Geisinger team included Deserae Clarke, MPA, and Rebecca Stametz, DEd, MPH, of the Center for Clinical Innovation, along with former Center director Jonathan Darer, MD; and Andrea Berger, MAS, and Jamie Green, MD, MS, of the Center for Health Research.

In 2010, Geisinger was 1 of 3 hospitals that participated in a demonstration and evaluation project where more than 100 primary care physicians invited patients to read their visit notes. Today, Geisinger has over 1,700 primary care and specialty physicians, case managers, advanced practitioners and pharmacists who participate in OpenNotes. For more information, visit OpenNotes.org.

Think about having the worst sinus infection of your life — but it never goes away. You have nasal congestion, mucus discharge and facial pain and pressure. You can’t read. You can’t sleep. You can’t be physically active. Plus, you’re exhausted. Medication and surgery may help, but in some cases, they may not provide any relief. This is the burden faced by some 31 million people in the United States who suffer from chronic rhinosinusitis (CRS), a condition suspected to affect more adults than asthma or diabetes.

Researchers with the Geisinger Center for Health Research set out to determine whether any other diseases are associated with CRS, which could eventually pave the way toward new treatments. To do so, they took advantage of the data contained in electronic health records for CRS patients. The study results appeared in an article titled “Five-Year Risk of Incident Disease Following a Diagnosis of Chronic Rhinosinusitis,” in the August 2015 issue of the journal *Allergy*.

“We really only know about the tip of the CRS iceberg,” says Annemarie Hirsch, PhD, MPH, lead author of the study and a chronic disease epidemiologist with Geisinger’s Center for Health Research.

The study was part of a five-year National Institutes of Health (NIH) grant that is enabling Geisinger researchers to build a knowledge base about CRS by analyzing electronic health record data, conducting patient surveys, performing CT scans and collecting DNA samples. They have teamed up with researchers from the University of Chicago, who are tackling the genetics of CRS, and Northwestern University, who are focusing on the cell-level mechanisms involved in CRS development, to form the Chronic Rhinosinusitis Integrative Studies Program (CRISP).

“In this study we found that having a diagnosis of CRS is associated with an increased risk of onset of other diseases within five years,” says Dr. Hirsch. “While we don’t know if CRS causes it or if there is a common disease mechanism, we did find associations that could have implications for how doctors should be caring for CRS patients — and [how they can] know what diseases to look out for in the years following a CRS diagnosis.”

The *Allergy* study looked at patients with two different kinds of chronic rhinosinusitis: those with nasal polyps (growths along the linings of the nasal passages) and those without nasal polyps, labeled CRSwNP and CRSsNP, respectively. The 3,612 CRS patients without nasal polyps had a higher incidence of upper and lower respiratory diseases and increased blood pressure, Dr. Hirsch says.

“We also found that epithelial conditions [conditions affecting tissue linings] such as conjunctivitis [eye infection], urinary tract infection, atopic dermatitis — skin rashes and skin tissue diseases — were associated with this type as well,” she adds. “There is a theory that a defect in your epithelial barrier might predispose you to these diseases and maybe CRS. If that’s the case, it can really help us understand the root causes of the disease.”

As for the 241 cases where CRS included nasal polyps, that sample size didn’t allow for strong correlations, although the condition was associated with a higher risk of obesity.

Dr. Hirsch’s team came up with their results by digging into the data contained in Geisinger’s 400,000 patient electronic health records (EHRs), which revealed any diseases diagnosed within 5 years of the initial CRS diagnosis. Her Geisinger coauthors included epidemiologist Brian Schwartz, MD, MS, principal investigator for the NIH study who is also affiliated with Johns Hopkins University Bloomberg School of Public Health; Thomas Kennedy, MD, FACS, chairman and director of the Department of Otolaryngology; otolaryngologist Scott Green, MD, FACS; and Agnes Sundaresan, MD, internal medicine physician and clinical investigator.

Says Dr. Hirsch, “The great thing about the electronic health record is that it’s not just specialty care. We are able to look at all primary care patients who are coming into the system and get a much broader picture about how CRS is
Adjusted hazard ratios comparing incident disease among patients with CRSwNP and patients with CRSsNP compared to control patients (dotted red line). As you can see, patients who had CRS without nasal polyps had a higher incidence of several conditions. (GERD, gastrointestinal esophageal reflux disease; UTI, urinary tract infection; COPD, chronic obstructive pulmonary disease)

A key question now is whether these conditions cause CRS, are promoted by CRS or share a disease process with CRS.

The researchers have continued to gather data as part of the five-year NIH grant. For example, they surveyed CRS patients to identify their symptoms, which aren’t typically listed in the EHR. “Close to 8,000 CRS people responded to our initial survey and we followed them for 16 months approximately quarterly to capture their CRS symptoms. To our knowledge, it’s the largest longitudinal symptom database affecting the population. Plus, the approach will allow us to continue following the patients to see if we can glean additional insights.”

This study is the first to report on the increased risk of certain diseases after CRS diagnoses in a primary care population, Dr. Hirsch adds. A key question now is whether these conditions cause CRS, are promoted by CRS or share a disease process with CRS.

The researchers are using these data as the basis for additional studies. While they are not focusing on CRS treatments, their hope is that by understanding the disease and what other conditions may be related to it, they can help develop better methods of prevention, treatment and management.

“Chronic rhinosinusitis has been dubbed an unrecognized epidemic,” Dr. Hirsch says. “Our collaboration hopefully will make an impact on people who suffer from it.”

The heart’s left ventricle, or lower left chamber, is responsible for pumping oxygen-rich blood throughout the body. In people who are obese, some studies have found that the left ventricle doesn’t work as well as it should — a condition called left ventricular dysfunction (LVD). This may explain why they have a higher risk of cardiovascular disease. But other studies have not found evidence of such problems.

One issue might be that most tests of how the left ventricle is working, such as medical imaging, are done while a person is at rest. The heart is not being stressed to work as hard as it can. This might hide any problems with left ventricle function. In addition, testing usually looks at the ventricle’s ejection fraction, which is a measure of how much blood goes out of the heart with each pump, or contraction. More advanced measures of heart contraction, called ventricular mechanics, may be better at detecting problems. For example, a measure known as strain looks at the change in length of the heart tissue. Another, called torsion, measures the heart’s normal twisting motion, akin to wringing out a wet towel.

Three researchers with Geisinger Health System’s Institute for Advanced Application — Christopher Haggerty, PhD, Linyuan Jing, PhD, and Brandon Fornwalt, MD, PhD — recently worked with colleagues at the University of Kentucky and the University of Virginia to study the impact of obesity on left ventricle function using mice. The researchers assigned 100 mice to either a normal diet or a high-fat diet that led to obesity. The mice were on the diet for anywhere from 4 to 55 weeks’ time. Over the course of the study, researchers used cardiovascular magnetic resonance imaging (MRI) to examine measures of left ventricular mechanics while the heart was (1) at rest or (2) stressed using medication that makes it pump faster.

They found that obese mice did develop changes in left ventricle mass and mechanics over time — both signs of problems with function — but did not have major changes in the ejection fraction. Also, obese mice whose hearts were stressed had mechanical changes that could be detected much earlier than when they were at rest. This stress also made the changes more intense over time. The team’s results were published online by the Journal of Cardiovascular Magnetic Resonance in August 2015.

The researchers concluded that obese people who appear to have normal left ventricle function, as measured by resting ejection fraction, might actually have early signs of mechanical changes that go undetected. Examining the mechanics of the heart under stress could reveal problems that eventually contribute to cardiovascular disease. —K.C.

More than 100 years ago, Abigail Geisinger made one — and only one — request of the leaders of her new hospital:

“Make it the best.”

Today, Geisinger is one of the most scientifically advanced and innovative healthcare organizations in America.

But we also know that to be the best, we must care the best.

Caring. It’s such an old idea it almost seems brand new.

We think Abigail would be pleased.
Meet Dwight W. McBee

Dwight W. McBee, MBA, BSN, RN, corporate director of customer experience at AtlantiCare, A Member of Geisinger Health System, talks about sharing best ideas with his new colleagues.

By Susan L. Worley
In 2015, AtlantiCare of southeastern New Jersey became the newest member of Geisinger Health System (GHS), bringing with it more than 5,500 employees, 2 hospitals, a large community-based care network and a Malcolm Baldrige Award-winning reputation. (The award is the nation’s highest presidential honor given to organizations for quality and performance excellence.) AtlantiCare also brought some unique approaches to improving patient experience.

“Geisinger defines ‘patient experience’ as the patient’s and family’s perception of the level of service and compassion they receive from us,” says Chief Patient Experience Officer Greg Burke, MD. “We have been excited by the cross-fertilization of ideas taking place at our patient experience team and committee meetings ever since our colleagues at AtlantiCare joined us.”

Perhaps most exciting for Dr. Burke’s colleagues at Geisinger has been the opportunity to learn about the “Starfish Experience” from AtlantiCare’s Corporate Director of Customer Experience Dwight W. McBee, MBA, BSN, RN. This signature program, which features retreat-style training, has been used to enhance awareness among providers and staff as they go about their work, giving them tools to provide an exceptional patient experience at all of AtlantiCare’s locations. While some elements of the Starfish Experience overlap with Geisinger’s C.I.CARE program (see sidebar on page 17), Dr. Burke says that as the two systems become more entwined, they will enhance each other.

“Our two cultures have a deep respect for one another and we are committed to learning from each other,” says Dr. Burke. He expects that some unique aspects of the starfish program will remain unchanged. The starfish symbol, for example, which is proudly worn by AtlantiCare employees and has been presented as a token of friendship to Geisinger employees, will likely always remain a symbol of high-quality care at facilities located near the seashore.

Could you talk a little bit about your career path at AtlantiCare?

Mr. McBee: I started as a bedside nurse in our medical ICU [intensive care unit]. One experience that helped me change course from nursing to administration involved a gravely ill young man I cared for. He had some complications and his family felt we were to blame. As I cared for him, my focus was on treating him as if he were my own family. Days later, my patient passed away, and as all nurses do I grieved him even as I moved on to care for my other patients. A few weeks later my manager pulled me aside and shared a letter that the family sent to senior administration, detailing all of the ways that they felt we were responsible for his poor experience. But the final line complimented the care and compassion I had shown toward them and their loved one. I realized then that I wanted to have a larger influence on our organization.

Why is the starfish such an important symbol of your corporate culture?

Mr. McBee: The starfish symbol was borrowed from a story that was written decades ago by Loren Eiseley (see sidebar). It’s a story about facing insurmountable odds and yet contributing in a way that ends up making an important difference for a single individual. That concept is at the heart of AtlantiCare’s Starfish Experience. It’s at the root of everything we do.

Did you bring the story to AtlantiCare?

Mr. McBee: No, I can’t take credit for that. Back in the 1980s, our CEO at the time, George Lynn, of what was then known as the Atlantic City Medical Center, found the story. Lynn shared the story, based on Eiseley’s The Star Thrower, as an example of how we could make a difference for people one person at a time. He was focused on elevating the quality of care, and it was during his tenure that the name of the center changed to AtlantiCare.

THE STARFISH STORY
Paraphrased from the writings of Loren Eiseley

A man was walking along the beach one morning after a storm. Thousands of starfish had been washed ashore. The man noticed a boy in the distance, picking up starfish one by one and gently throwing them back into the ocean. Approaching the boy he asked, “What are you doing? There are miles and miles of beach and thousands of starfish. You can’t possibly make a difference!” After listening politely, the boy bent down, picked up another starfish and tossed it into the surf. He smiled and said, “I made a difference for that one.”
What are some of the issues that you hoped to solve with the Starfish Experience?

Mr. McBee: We recognized that compassion fatigue and physician or clinician burnout are a growing epidemic in healthcare. One article in a 2009 issue of the *Journal of the American Medical Association* stated that up to 60 percent of primary care physicians report symptoms of burnout. Research has shown that burnout can be linked to a decreased ability to express empathy, and in turn to lower quality of care and greater patient dissatisfaction. When we examined our own practices, we found that when there was a service issue, the root cause was often compassion fatigue or burnout. Consequently, improving the well-being of our employees became an important part of our program.

What are some other important features of the program?

Mr. McBee: We decided it was important to pull our staff out of the work environment to train them in a retreat-style setting, so they could focus without interruption. We put together a three-hour program and made a commitment, as an organization, to ensure that all of our employees participated in this training. We called these sessions “Starfish Experience labs.” We train about 15 to 25 employees at a time. We designed the labs to be interdisciplinary, which means that each lab brings together providers and staff. They might work in the hospital as clinicians, in food and nutrition services, or they might be environmental services employees, housekeepers or administrative leaders. They might work in our school-based behavioral health centers; our primary, urgent or specialty care offices; our LifeCenter fitness centers; or other areas throughout the organization. Our program was designed to be able to speak to individuals in all of those roles, and give them tools they can use throughout the care and service delivery process.

After they leave the labs, three core components of the program remain a part of each employee’s everyday experience. We call these components “narrate the story,” trusting interactions and sacred moments.

Could you talk a little bit about these?

Mr. McBee: Sure. Narrating the story has to do with communication. When we designed the Starfish Experience, we wanted to harness the power of storytelling. Lori Herndon, president and CEO of AtlantiCare, shares starfish stories regularly — as do all members of our leadership team. We’ve seen that Geisinger does this, too. For example, Dr. Feinberg is really great at storytelling. He opens many of his meetings with stories.

At AtlantiCare, employees exchange stories about making a difference every single week, throughout the entire organization. We also make sure our providers and staff understand that they are not just deliverers of care but also *narrators* of care. If we fail to tell our patients the story of their care — that is, what we did, how we did it, how long we expect treatment will take and so forth — we risk misunderstanding or confusion on their part. So we reinforce the importance of providing meaningful communication at key points during care.

What is “trusting interactions” about?

Mr. McBee: Every time we interact with someone, it is an opportunity to make a difference for them — just like the little boy on the beach picking up a starfish and throwing it back into the ocean. And a critical goal during any interaction is to build trust.

When I explain this concept to people during the experience labs, I often share a part of my personal experience to help illustrate it. I’m an African-American male nurse. So you could say that I am a minority among minorities. When I walk into the room, I might very well be the last person a patient expects to see coming through the door. Early in my career, one of the things I found myself doing very quickly was establishing trust. It was critical for me to send the message that I was a reliable, well-trained healthcare professional.
And building that kind of trust is also at the core of the Starfish Experience?

Mr. McBee: Yes, exactly. We are teaching our staff to do essentially the same thing. We want to go out of our way to make sure that when we walk into the room, a patient knows exactly who we are and what we are capable of doing. We work in an environment where patients frequently feel powerless. By letting them feel confident that they are dealing with trusted professionals, we shift some of the power back to the patient.

Could you explain what “sacred moments” are?

Mr. McBee: The concept of sacred moments is very simple. We all know that there are some moments in healthcare that just take your breath away: when someone gives birth to a child, for example, or when someone passes away. Sacred moments also include times when people are at their most vulnerable. Part of the Starfish Experience is looking for opportunities to do something special in these moments. This concept is different from that of building trust. It’s about going out of our way to do something unique or creative for an individual patient.

Can you give an example?

Mr. McBee: We have a post-anesthesia care unit nurse who wanted to do something special for patients after surgery. That’s because patients are vulnerable and often anxious or even crying when they wake up. She happened to be a skilled artist, so she would take ordinary white Styrofoam® cups and draw a flower or something that was familiar or meaningful for each individual and leave it for the patient to see when he or she woke. Her aim was to make them feel welcome and comfortable.

Recently she shared with her colleagues that she ran into one of her former patients in a shopping mall. Her patient came running up to her saying, “Oh it’s you. I remember you! I still have the cup you gave me, with the drawing on it! I hold on to that cup because it reminds me of how I survived breast cancer.”

That’s a wonderful story. It sounds similar to stories about care received at Geisinger.

Mr. McBee: That’s exactly right. There is a lot of overlap in the way the two systems approach things. C.I.CARE provides a very similar framework and incorporates many of the components of the Starfish Experience. All of C.I.CARE is about building trust and narrating care.

Are you working on aligning the two programs?

Mr. McBee: Yes. I’m part of Geisinger’s steering team for patient experience — I am one of the ambassadors from AtlantiCare. I’ve been involved in a number of exciting initiatives already. For example, I played a significant role in revising Geisinger’s new employee orientation, which now includes elements of the Starfish Experience. We also are developing a training institute, and I have been working closely with our new colleagues to make sure that we weave in elements of the starfish labs into the institute.

What would you say has been the best part about joining Geisinger?

Mr. McBee: Geisinger is well-respected within the national and international healthcare community. I am most excited by the enormous potential that lies in bringing AtlantiCare and Geisinger together. I believe we can change the way that healthcare is delivered around the world. I am excited by Dr. Feinberg’s leadership and what he has already brought to Geisinger. I’m proud of how AtlantiCare, a Baldrige Award-winning organization, has changed the care experience. We look forward to continuing to enhance the care experience with our Geisinger family.
Imagine a world in which you could learn your personal risk for certain medical conditions — such as types of heart disease or cancer — before they even happen.

With that knowledge, you and your doctors can take steps to lower your risk, treat the disease early or prevent it entirely. You can also alert family members who might have inherited a similar risk. What’s more, your information helps researchers find ways to speed medical advances and improve health for everyone.

That possibility is reality for Geisinger patients taking part in the MyCode® Community Health Initiative, one of the largest research projects of its kind in the world. MyCode collects and analyzes genetic information sequenced from DNA in small amounts of blood given by participating patients. Genetic sequencing, which reads the genes in a person’s genome, finds differences — think of them as spelling mistakes — in individual genes. The gene is “changed” from the way you would normally expect it to look. Some of these mistakes can increase risk for certain medical conditions. Others are even helpful, providing protection from disease.
Researchers then combine this information with data from Geisinger Health System’s electronic health record. This enables them to make connections between people’s genetic makeup and factors such as age and medical history. The combined data goes into MyCode’s vast database with all personal identification replaced by code numbers for privacy and security, and biological samples are kept in a secure biobank. The database is an amazing tool that will help Geisinger researchers and their partners unlock new discoveries about the human genome.

But MyCode is already helping patients gain important guidance about their own health. Right now, MyCode analyzes participants’ genetic information for those so-called spelling mistakes — technically known as disease-causing variants or sometimes, mutations — in 76 genes that increase the risk for 27 medical conditions. Many of these conditions could be life-threatening but can be prevented or treated if risk is known. (See sidebar, Genetic results found, on page 22.) When MyCode identifies such findings, participants are notified about their results. Then they can meet with a team of Geisinger genetic experts and receive medical guidance.
That happened for James Larkin, of Moscow, Pa. His MyCode sample showed he had a change in a certain gene that put him at greater risk for colon cancer and several other cancers, including stomach and liver cancer. The condition is known as Lynch syndrome. “I had never heard of it,” says Mr. Larkin, who is 74 and retired. After talking with a Geisinger genetics team, he decided to have more frequent colonoscopies (a screening test that examines the inner lining of the colon) to check for early signs of cancer. He later shared risk information with close relatives who might have inherited the same gene mutation. Women with Lynch syndrome are also at increased risk for cancer of the uterus and ovaries.

“I was very pleased that somebody told me of this possible problem I had,” he says. “My wife and I are very proactive about our health.”

Most MyCode participants don’t have harmful changes in any of the 76 genes, but their DNA contributions are still vital to research. With about 20,000 genes in the human genome, the function and health impact of most genes are still not well understood. By creating an enormous database of participants’ genetic information, MyCode is providing the foundation for genomic research, which looks at how genes interact with each other. It explores gene changes linked to disease, associations between genes and health, and ways to apply new discoveries to the individualized care known as “precision medicine.” This approach aims to precisely focus disease prevention and treatment based on a person’s genes, lifestyle and environment. For years, Geisinger has been a leader in this emerging field of research.

Geisinger at the forefront

Genomic research requires data from thousands of volunteers like James Larkin. Having a large pool of participants makes it possible to find genetic changes that occur in a very small percentage of people. It also helps trace patterns in broad populations that reveal links between genes and specific health conditions, outcomes or even protection against disease.

More than a decade ago, Geisinger leaders realized the health system would be an excellent place to conduct genomic research. It has a large and stable patient population, often with three or more generations of Geisinger patients within families. As one of the first healthcare institutions to adopt electronic health records, Geisinger also has 20 years of comprehensive medical data. Those factors provide the number of participants and depth of information needed that “allows you to look for a genetic component in things that have been hard to tease out, like diabetes,” says W. Andrew Faucett, MS, LGC, professor and director of policy and education for research, Geisinger Health System.

MyCode began in 2007, eight years before President Obama announced in his State of the Union address that there would be a national focus on genomic research through the Precision Medicine Initiative. MyCode has been enrolling participants and building a biobank of samples ever since. “Our patient population was very supportive and willing to participate,” says David H.Ledbetter, PhD, chief scientific officer. Dr. Ledbetter is a co-principal investigator for MyCode, along with Mr. Faucett and David J. Carey, PhD, professor and chair of the Department of Molecular and Functional Genomics.
What happens to my sample?

After signing up for MyCode, your blood sample is taken at your next lab visit.*
Your sample arrives at Geisinger’s research lab.
Your sample has all personal identification removed and gets a code number.
DNA is extracted, stored and preserved.
Sample is shipped to Regeneron for sequencing.
Genetic sequencing is done and data is stored in the cloud.
Geisinger analyzes the genetic data.
No result found for any of the 76 genes.
Your information goes into the MyCode database for research use.
Genetic change results sent to your doctor and you, with invitation to meet with Geisinger’s genetic team for medical advice. Your information goes into MyCode database for research use.
Report is returned to Geisinger.
If genetic change is found, result is sent to outside clinical laboratory for confirmation.

*For some, a saliva sample may be used but it does not provide as much information.
About 90 percent of patients who are asked to participate in MyCode sign up. That’s much higher than elsewhere. “When we go around the country and say we have a biobank project with a 90 percent consent rate, people [other researchers] are floored,” Dr. Ledbetter says. He attributes the willingness to participate to “Geisinger’s close, trusting relationship with the community.”

It takes years to develop such a project. While Geisinger had knowledgeable people on its team at the start, over time more experts arrived in genomic medicine, genetic counseling, bioethics, information technology and security, and biomedical informatics, the science of studying and using medical data.

Now, with more than 115,000 MyCode participants signed up by September 2016 and more than 50,000 DNA samples sequenced and ready for research use, the project is producing a significant amount of research data. It is also beginning to return genetic results to patients and helping them learn what those results mean. MyCode aims to enroll up to 250,000 participants. All Geisinger patients can sign up, regardless of age, location or health condition.

“This is cutting-edge medicine and cutting-edge research for everyone,” Mr. Faucett says.

### Patients as partners

People join MyCode for many reasons. “I’m curious to see whether they find anything in our genes that correlates with my or my wife’s medical history. That would be really interesting,” says Ralph W. Moss, 73, a science writer from State College, Pa. Mr. Moss and his wife gave samples earlier this year but have not gotten any results.

They might never hear anything. As noted, most participants do not have harmful changes in the 76 genes for which MyCode now returns results.

Yet about 4 percent of people taking part — 1 in every 25 — do learn they have changes in one of the genes related to health risks. They and their families are offered genetic counseling, medical advice and social support from Geisinger’s genomic medicine team and other specialists.

Barbara Barnes, a homemaker from Hazleton, Pa., signed up for MyCode at the suggestion of her doctor, Michael J. Komar, MD, FACG, director of Gastroenterology. She gave

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of patients receiving results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hereditary breast and ovarian cancer (BRCA1 and BRCA2) early breast, ovarian, prostate, other cancers</td>
<td>79</td>
</tr>
<tr>
<td>Familial hypercholesterolemia (FH) early heart attacks, strokes</td>
<td>29</td>
</tr>
<tr>
<td>Lynch syndrome early colon, uterine, other cancers</td>
<td>16</td>
</tr>
<tr>
<td>Cardiomyopathy heart muscle diseases with dangerous complications</td>
<td>11</td>
</tr>
<tr>
<td>Long QT syndrome irregular heartbeat with dangerous complications</td>
<td>4</td>
</tr>
<tr>
<td>Malignant hyperthermia life-threatening, triggered by certain anesthesia drugs</td>
<td>2</td>
</tr>
<tr>
<td>Arrhythmogenic right ventricular cardiomyopathy heart muscle disease with dangerous complications, different genetics than other cardiomyopathies</td>
<td>4</td>
</tr>
<tr>
<td>Multiple endocrine neoplasia type 2 early thyroid cancer</td>
<td>2</td>
</tr>
<tr>
<td>Tuberous sclerosis non-cancerous tumors</td>
<td>1</td>
</tr>
<tr>
<td>Hereditary pheochromocytomas and paragangliomas tumors of the adrenal gland</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>149</td>
</tr>
</tbody>
</table>
two extra tablespoons of blood for the study while having regular blood work done. Then she forgot about it.

Months later, after her results had been analyzed and confirmed, Dr. Komar told Ms. Barnes she has a harmful change, or mutation, in a gene known as BRCA1. A BRCA1 mutation gives her a much higher lifetime risk of developing breast cancer and ovarian cancer. A related mutation in a gene known as BRCA2, which Ms. Barnes does not have, also increases breast and ovarian cancer risk. Her results mean that close biological relatives also could have a BRCA1 mutation. About 5 to 10 percent of all breast cancers are linked to one of these two mutations.

Ms. Barnes, who is 57, and her husband are bringing up three grandchildren, ages 3, 5 and 14. That responsibility kept her calm when she heard her result. “I just said, ‘Okay, so what do we do next?’” she recalls. “I have 15 more years to go until they’re raised.”

A mammogram showed no breast cancer. She and her daughter met with a Geisinger genetic counselor. Her daughter was tested for the BRCA1 mutation. Ms. Barnes talked about prevention with breast surgeon and an oncologist, or cancer doctor. She will have more frequent mammograms and MRIs to closely monitor her breast health. She also decided to have her ovaries and fallopian tubes surgically removed as a preventive measure, lowering her risk of ovarian cancer to almost none.

During the surgery this past summer, her doctor, Ashlee Linn Smith, DO, a gynecologic oncologist, found cancer in one of Ms. Barnes’ fallopian tubes. Such cancer is sometimes found during the preventive surgery. The cancer was removed and Ms. Barnes is having chemotherapy. “If I hadn’t been in MyCode, I wouldn’t have known,” she says.

Listening to patients

From the beginning of MyCode, project organizers talked with and listened to patients in focus group discussions. “We found, overwhelmingly, that people wanted their [genetic] results. They wanted the information for their families and to help the community in general,” says Carroll Flansburg, community engagement coordinator and MyCode project manager.

The original plan did not include returning results to participants. That was research tradition when MyCode was first developed — but scientific attitudes have been changing nationwide and at Geisinger.

“We decided we’re first and foremost a healthcare institution,” Mr. Faucett says. “So if there’s something we find out that is beneficial or might be helpful to our patients, we have a moral and ethical duty to help them learn that.”
In 2014, Geisinger formed a collaboration with the Regeneron Genetics Center (RGC), part of Regeneron Pharmaceuticals Inc., to conduct the DNA sequencing for MyCode. The RGC receives samples with personal identification removed. After performing the DNA sequencing, the company securely delivers data back to Geisinger for analysis. [See graphic, page 21, What happens to my sample?]

Participants’ views continue to shape MyCode. “They’re telling us what they want, where they want to see the project go and how they want to see it evolve,” says Marylyn D. Ritchie, PhD, professor and chair, Biomedical and Translational Informatics. “Our researchers are adapting and evolving the plans based on that.”

“Everyone can help.”

Dylan E. Cawley, MPH, enrolls patients in MyCode at Geisinger Mt. Pleasant in Scranton, Pa. She’s called a “consenter” because patients must give informed consent to be in the study. Over 2 years, she has enrolled 5,700 participants.

Ms. Cawley greets people in clinic waiting rooms, tells them about MyCode basics, explains what happens if there’s a result and answers questions. Patients can provide saliva samples when they sign up. Blood samples are usually taken the next time they go for blood work. There is no charge.

People she talks with sometimes mistakenly think they can’t take part because they have a medical condition or are older. “Everyone can help,” she says.

The range of participants is wide. Donna Mensch, an 87-year-old from Danville, Pa., talked with a consenter at Geisinger Medical Center. She wanted to be part of the genetic research because “I’m concerned about my children and grandchildren,” she says, noting that several relatives have had cancer.

Loudon Tisinger, now age 1, was signed up when he was born at Geisinger Wyoming Valley. His parents and grandmother are also participating in MyCode. The infant’s blood sample was taken after birth from the umbilical cord, so he had no needle stick. “That way, we could participate as a family and have generations involved,” explains his mother,
Cheryl A. Connolly, 43, a Geisinger employee from Forty Fort, Pa. The newborn enrollment was a first for MyCode.

A plan is being developed to sign up more newborns, but pediatric patients can take part now. Many children and family members visiting Geisinger’s Autism & Developmental Medicine Institute (ADMI) have signed up. “Families are excited to participate in research,” says Christa Lese Martin, PhD, FACMG, director of the institute. A specially trained ADMI staff member draws blood, so MyCode samples are taken there. Pediatric results have not yet begun to be returned.

While everyone can sign up for MyCode, people who know they have a strong family history for a disease or condition should talk with a genetic counselor about having clinical genetic testing. The clinical testing process focuses in on the specific gene (or genes) that appears to be causing the condition that runs in the family. “MyCode is not a replacement for clinical testing and may miss genetic changes because it is a research test,” says Mr. Faucett.

You can do both, but there are important differences. Among them: Clinical genetic testing “can have information back to patients much faster than MyCode,” with results in two to three weeks, notes Miranda Hallquist, LG C, a genetic counselor for Geisinger’s Western region. Because MyCode is a research project, results may take six months or longer.

Improving health right now

In addition to benefiting individuals and families, MyCode can help improve community health.

“We think we have the opportunity, in the next few years, to identify every person in the Geisinger system who has a potential disease-causing variant in BRCA1 or BRCA2 and is therefore at increased risk for cancers of the breast, ovaries, prostate and pancreas,” says Michael F. Murray, MD, professor and director of Clinical Genomics. As many as half of those with BRCA mutations, he adds, will not have the kind of family history that might have otherwise prompted clinical genetic testing. So early warnings from MyCode results could save lives.

Michael G. Lesko, DO, chief of Cardiology for Geisinger’s Western region, sees MyCode helping patients who have genetic mutations that cause familial hypercholesterolemia, or FH. This condition produces very high levels of cholesterol, leading to premature heart attacks and strokes. Children of FH parents often also have FH and should begin taking medicine by age 8 to avoid heart damage. Without genetic testing, the disease can go undiagnosed.

In the Weis Center for Research, blood samples have personal identifying information replaced with numeric codes and are then prepared for DNA extraction.

Photo: Josiah Lewis

AtlantiCare joins MyCode

After AtlantiCare, the largest healthcare organization in southeastern New Jersey, became a member of Geisinger Health System in 2015, its doctors and leaders were enthusiastic about bringing MyCode to AtlantiCare patients. “The opportunity to be part of such a strong and exciting research project appeals to everyone here,” says Marilouise Venditti, MD, AtlantiCare’s chief medical officer.

This fall, MyCode consenters will begin enrolling participants at AtlantiCare locations in Hammonton, Galloway, Northfield and Cape May County, N.J. Genetic counseling and medical guidance will be provided to participants receiving results.
Although FH was believed to occur in about 1 in 500 people, through MyCode “we’re finding that FH is actually affecting 1 in 222 patients, at least in this area,” Dr. Lesko says. For participants with that result, he adds, “we will be able to identify them and their kids as high risk and treat them much earlier with medicines that will be effective.”

Genes related to brain disorders such as autism, intellectual disability and bipolar disorder are being considered as additions to the MyCode list of 76 genes analyzed for results, according to Dr. Martin. Many patients “could have clinical diagnoses but might not know the underlying genetic etiology [causation],” she says. “By providing that information, we actually can better tailor their care.”

It’s likely that MyCode will draw more connections between other genetic mutations and health conditions. Project researchers use the motto “No news is no news” to explain to patients that not hearing results does not mean results won’t be found later. If new genetic changes are added to the MyCode list, existing data will be rechecked and patients with results will be contacted.

Making choices

After a MyCode result is confirmed, the participant’s primary care provider is notified. The patient receives the news a few days later. That way, the provider has time to learn about identified risks before talking with the patient, says John F. Pagnotto, DO, a family medicine physician and Geisinger’s Western regional medical director. “The value for physicians is we can identify people who are at risk for certain genetic diseases that we may not have been able to pick up on otherwise,” Dr. Pagnotto says.

Those who have MyCode results can meet with the genetics team, talk with their doctor, do both or do nothing. It’s their choice. The project will contact participants receiving results several times to invite them to talk. “They may need a little more time before being ready to face this head on,” says genetic counselor Ms. Hallquist.

Once inherited genetic risks have been identified, further testing and treatment are often covered by health insurance, including by Geisinger Health Plan.

Elizabeth Hancock, a Danville, Pa., resident and Geisinger nurse, was surprised to learn she had a BRCA2 mutation. She knew her family had a strong prostate cancer history, but didn’t think it was related to breast or ovarian cancer. The genetics team told her BRCA2 increases prostate cancer risk as well. “They were very kind and knowledgeable,” she says.

She was counseled about genetic risks for her children, ages 9, 13 and 20, and her sisters. Her sisters went for testing; the children will be tested when they are older. She also met with an oncologist, a surgeon and a psychologist from the Geisinger Cancer Institute’s Inherited Risk Clinic. “We talked about the pros and cons of what to do,” says Ms. Hancock, who is 45. “I thought, ‘I put sunscreen on myself so I don’t get skin cancer...if I remove my ovaries and tubes, that’s another preventive step.’” She had that procedure and is thinking about having surgery to remove both breasts to further reduce her cancer risk.

Donna Mensch also had a BRCA2 result. She took her daughters with her when she met
with the genetics team. They arranged testing for one daughter. Ms. Mensch also told her son, who lives at a distance. She had a mammogram, which was negative, and has not taken any further steps. “I think I’m doing very well for 87,” she says.

Talking with the genetics team helped ease Kim Mummert’s anxiety about finding out she has a gene mutation associated with Lynch syndrome. “They were very good at giving me more information and spelling out my options,” says Ms. Mummert, 66, a Geisinger employee from Williamsport, Pa. “It made me more calm because there’s things to do.” She talked with her son and daughter, who are in their 20s. They too will meet with a genetic counselor.

Dr. Pagnotto recalls the excitement he felt when he first heard about MyCode. He still feels the same way about the project. “This is the future of medicine,” he says.

MyCode in research

Geisinger scientists and others have already launched research based on the genomic information in MyCode. This includes studies of genetic variations and risk factors in diseases such as Type 2 diabetes, obesity and cancer.

“The scientific productivity is off the charts!” says Dr. Ledbetter.

One project seeks to identify those with a gene mutation for a condition that leads to sudden cardiac death in young people. Another is looking at genetic differences in blood traits. Some research hunts for new medication targets. MyCode information also is being used to see how certain genes influence medication responses. Findings may help determine proper dosing, risk of side effects and who might benefit most from specific medicines.

MyCode itself is being studied to find the best ways to conduct such work, from data gathering to return of results. Geisinger researchers have received grants from the National Institutes of Health and other funders for studies using project information.

“How to take part in MyCode

Every Geisinger patient can participate in MyCode. You may sign up in person with a consenter at a Geisinger location. To find a consenter near you, contact 855-636-0019 or JoinMyCode@geisinger.edu.

Patients can enroll online anytime via MyGeisinger. Consent forms are also online and may be scanned, completed and mailed. Right now, only Geisinger patients may enroll in MyCode.
A week after Mrs. White’s knee-replacement surgery, something seemed wrong.

“I woke up with pain up and down my leg two days ago,” she told a young doctor at a checkup at Geisinger Medical Center (GMC) in Danville. She pointed to the blue brace on her right leg and frowned. “My knee looks swollen. I think my foot does, too. Could I put my leg up on something? That really helps it feel better.”

The doctor nodded encouragingly and told Mrs. White her concerns were important. She moved an extra chair closer so that Mrs. White could rest her leg. Then the doctor gently quizzed her about how she was coping. “Are you sleeping? How’s your mood? Are you eating well?” As Mrs. White described her first week post-surgery in detail, the doctor listened intently.

“I take a pain pill before I go to bed, so I’m sleeping well,” she said. “Friends and family are making meals and visiting. They’re so supportive, but honestly, sometimes I feel like a burden. It’s hard letting others do so much for me.”

Then her voice shook. “I can’t stop worrying about this pain,” Mrs. White said, looking into the doctor’s eyes. “Is it a side effect of my medications? Am I working too hard in physical therapy? Could it be an infection or even a blood clot?” The young doctor asked for details, then told Mrs. White she would consult with her primary care physician right away about her concerns.

Suddenly, a voice came from behind a screen in a corner of the exam room: “OK. You can stop now!”

It was as if a movie director had yelled “Cut!” The doctor and patient relaxed. Mary Harris, MD, a Geisinger internist and director of Clinical Skills Education, leaned out from behind the screen. “I saw you do a lot of good things there,” she told the young doctor. “What went well for you?”
ny situation
This was no ordinary checkup. The doctor was a first-year psychiatry resident at Geisinger; the patient, a professional actor with the Bloomsburg Theatre Ensemble. The exam room was a “set” complete with basic medical equipment hanging on the wall, a desk and a few chairs. And the scene itself was part of a new Geisinger Health System program that gives medical residents the opportunity to practice communication skills in situations that look and feel just like the real thing. The program is also used with medical students, fellows and other healthcare providers.

“Great doctor-patient communication is at the center of great healthcare,” says Nicole Woll, PhD, MEd, vice president for faculty and curriculum development in Geisinger’s Office of Academic Affairs. She developed the program with Dr. Harris under the leadership and guidance of Chief Academic Officer Linda Famiglio, MD, FAAP. “Patients whose doctors listen well and connect with them feel more satisfied with their care. They’re more likely to follow the steps their doctor recommends, such as taking medications as directed and coming back for follow-up appointments. Patients are also less likely to feel anxious about their health.”

Practice, make mistakes and learn

Called the Standardized Patient Program or SPP, this educational experience employs trained actors, community residents and Geisinger Health System staffers to play a variety of patient roles. With a trained Geisinger faculty member observing and giving feedback, each scenario is designed to help young doctors and other learners hone new and challenging skills. Some roles, like Mrs. White’s, are low-key. Other scenarios involve patients who are hostile, uncooperative or just learning they have a life-threatening illness. Situations like these are dramatic and can get quite emotional for the patient-actors and learners alike.

“Some of the situations seem simple, but can be just as challenging for the learners as the explosive situations,” says Aaron White of Williamsport, a standardized patient at Geisinger and a professional actor who has appeared at the Bloomsburg Ensemble Theater, the Virginia Shakespeare Festival and the Texas Shakespeare Festival, among others.

“A learning interpersonal skills like making eye contact while a patient answers your questions will be important every day of a doctor’s career.”

The “performances” are standardized, which means that the actor presents the person and medical issue they’re portraying the same way with every learner, Dr. Woll explains. “We want every clinician to have the same experience, so that they learn specific skills and can be evaluated fairly by doctors and faculty in Geisinger’s educational programs.”

The SPP has been an official part of the educational curriculum for graduate medical education since 2015. For example, it plays an important role in the education of residents: new doctors, just graduated from medical school, who are now learning a specialty. Geisinger offers 24 residency specialties including family medicine, neurology and pediatrics. Some residencies, such as those in internal medicine and obstetrics/gynecology, have used standardized patients for as long as 15 years at Geisinger, Dr. Harris says. “Now we want every resident to have these experiences and to be observed so that they can learn,” she notes. Residents receive verbal and

A glimpse at the “script”

Three standardized patient scenarios

In reality, there’s no script for a standardized patient scenario. Instead, the “patient” receives an in-depth description of their character and information about the skills the scenario is intended to teach. Here are just three examples:

Breaking bad news: An elderly man collapses while doing yard work. Doctors must tell the standardized patients — the man’s brother and sister — that he was in cardiac arrest and could not be revived.

Interpersonal conflict: The standardized patient is actually a nurse who is angry with the doctor because he or she did not respond quickly to an urgent call to meet with a family. “In the scenario, the young doctor is in a meeting with another family that cannot be interrupted. So the chief of internal medicine is called in to help. The young doctor has to discuss the situation with the nurse without casting blame or being defensive,” explains resident Saquib Saddiqi, MD.

Hidden agenda: The standardized patient is extremely worried about her heart — but why? “She’s healthy,” actress Carrie Pisieczko notes. “At her checkup, the doctor has to get to the bottom of her concerns. It turns out her neighbor recently had a heart attack and so she’s thinking a lot about her own heart health.”
written feedback. Scenarios are often video-recorded so groups of students can watch and learn together, too.

The program fills an important need. “Doctor-patient communication is getting more attention than ever before in medical school, but more training is key,” Dr. Woll says. “The Standardized Patient Program puts residents into safe but completely realistic situations where they can practice, make mistakes and learn. Because there’s a faculty member observing every scenario, the resident gets useful feedback. Sometimes, we replay scenes so they can try out something new. You can’t do that with real patients!”

Dr. Woll and Dr. Harris began developing the program about four years ago. “We took a certification course in standardized patient-based education at the University of Illinois College of Medicine at Chicago,” Dr. Woll says. “Then we began planning the program. It was important to get Geisinger faculty from many specialties involved. We needed them to help write accurate scenario descriptions and serve as observers as the residents go through the sessions.”

Research suggests that residents, medical students and other health professionals who practice their exam skills and “people skills” through a standardized patient program learn a great deal. First-year medical students became more empathetic and had more confidence in their communications abilities when dealing with overweight patients, according to a 2014 study at Northwestern University’s Feinberg School of Medicine. Dental students were better at teamwork after a Standardized Patient Program, a 2016 University of Buffalo study found. And in another 2016 study from the University of Buffalo, third-year medical students said standardized-patient training with the same patient over consecutive weeks helped them learn to build ongoing relationships — valuable for helping patients make healthy lifestyle changes and manage chronic diseases.

True to life

Like a great play or a terrific movie, the SPP works thanks to a talented cast, compelling plots and real-life settings.

The cast: Geisinger’s standardized patients include trained actors as well as a college physics professor, a switchboard operator, several stay-at-home moms, some emergency medical technicians and about 20 Geisinger Health System employees who’ve signed up. It’s a part-time paid position. As standardized patients, they learn a patient role thoroughly, including the body language that goes along with their health condition. They might wear their own clothes or, sometimes, hospital gowns. Basic physical exams can be part of a scenario — like checking the heart with a stethoscope — but more personal exams are not. Needles, medicines and other medical procedures are not part of a scenario, either.

“You have to stay in character and respond as the patient would — not as you, the real individual, would,” explains Cassandra Pisieczko of Bloomsburg, a member of the Bloomsburg Ensemble Theater and a long-time standardized patient at Geisinger. She played the knee-replacement patient Mrs. White in a training for new residents last summer at GMC. “And you might replay a role many times with different residents. It’s really important to stay in character for all of them. Doing this calls on all my skills as an actor and as a director.”

The plots: Scenarios range from routine checkups to the most challenging situations doctors face. “Residents will encounter angry patients, patients who are hiding serious issues such as domestic abuse, and families who’ve lost a loved one. This year, we’re also planning a scenario in which a resident has to disclose to a patient that they’ve made a medical error. They must also talk through a disagreement with another healthcare practitioner,” says Dr. Harris.

Making the situations feel real requires great writing. Dr. Harris and Dr. Woll work with Geisinger specialists to develop each scenario, which includes a detailed description of the standardized patient, the situation and suggested dialogue. “We want everything to be accurate,” she explains. “If someone’s in pain, for instance, we want to know how they’ll move and how they’ll hold their body.”

The setting: Most scenarios take place in a former nursing school building on GMC’s campus in Danville. Dorm rooms that once housed students have been converted into exam rooms and hospital rooms. Like a real exam room, each has a file holder on the outside of the door. Each scenario begins with the familiar sound of the doctor removing the patient’s file from the holder. After a pause, the doctor knocks and comes in.
“The more you feel you’re in a real clinic with a real patient, the better,” Dr. Harris says. “Residents learn the most when they set their disbelief aside. When I watch a scenario from behind the screen it doesn’t feel like I’m watching a play or a movie. It feels like I’m right in the room during a true-to-life moment between a patient and a doctor.”

From high drama to everyday health challenges

According to third-year internal medicine resident Saquib Sadiqqi, MD, the lessons learned in a standardized patient scenario can be surprising. “One scenario from last year involved a patient staying overnight in the hospital after a surgery. He wanted more pain medication. But he was already addicted to painkillers,” Dr. Sadiqqi recalls. “Everything got real very quickly. He was yelling very loudly, cursing and upset. The truth was, he had a legitimate need for more pain relievers — due to his addiction, he needed a larger dose. But prescribing more pain medication to an addict can be difficult for a doctor to accept. Scenarios like this uncover your own biases. This patient needed more pain medication for a medical condition; we would deal with his addiction separately.”

Often, several standardized patients train in the same role so that groups of residents can receive one-on-one training at the same time. “They’re wholeheartedly committed to their roles,” Dr. Sadiqqi says. According to Dr. Harris, that “angry patient” scenario deeply affected the residents. “One of the standardized patients really had that role down cold,” she says. “The screaming and cursing were so real that residents were crying.” But, she adds, it was an extremely realistic portrayal of a situation that comes up. “You’ll have a patient who’s been asking all day for more help with pain. Now it’s night and things are getting worse. The shift changes, a new doctor comes to check, and all of the patient’s anger and frustration get aimed at him or her.”

Once a scenario ends, a faculty member who has been observing the scene from behind a screen provides feedback. Sometimes the standardized patient is also asked to contribute. “The people watching you point out things you may not have noticed. It’s really helpful,” Dr. Sadiqqi says. “One of the lessons of that scenario was about eye contact and where you stand in a patient’s room. The man’s left arm was bandaged and he was leaning over in pain. If you stood on one side of the bed, you couldn’t see his face and he couldn’t see yours. So there was no eye contact. You had to move around the bed. Subtle things like that are fantastic to learn.”

The scenario also deeply affected Lindsay Campbell, MD, a second-year resident in Geisinger’s new psychiatry program. “As a psychiatrist, it isn’t uncommon to encounter patients who are aggressive or agitated. I found the feedback I received from this scenario to be particularly important in defusing tense situations,” Dr. Campbell says. “The program has been an invaluable experience because it allowed me to hone my skills in front of professionals who have been practicing medicine much longer than I have.”

Other scenarios involve delivering the worst possible news — that a family member has died, for example, or that the patient has a life-threatening condition. “In one, I was given the prognosis of a terminal brain tumor,” actor Aaron White says. “You’re operating on adrenaline and emotions.”

In another, Cassandra Pisieczko portrayed a mother whose young son drowned in the backyard swimming pool. “In the scene my husband and I hope the Emergency Department doctors can save him, but they have just come to tell us he didn’t survive,” says Ms. Pisieczko. “But there’s more to the story: The woman I portray wasn’t at home during the drowning. She’d gone across the street. Her husband was in the house, so no one was watching the pool. So it’s a very emotional situation,” she adds. “The doctors ask us if we’d like to be in the room as they remove life-support equipment. It was very inspiring and moving to see the young doctors working so hard to explain the situation to these grieving parents and to deal with their own grief at the same time. Dr. Woll was extremely supportive.”

The training isn’t just about working through major crises, though. Many scenarios develop providers’ ability to help patients with daily challenges that are so important for good health. “I’ve been the patient in scenes where the doctor wants to motivate me to stop smoking, for example,” Ms. Pisieczko says. “In one, I have a child in the hospital with pneumonia. The doctor is trying to use it as inspiration to help me quit.”

Motivational interviewing is an important part of healthcare, Dr. Woll notes. “Helping people lose weight, eat better, exercise more often and stop smoking can have a major impact on their health,” she says. “We want our residents to be prepared to do this for their patients.”

Residents agree that this true-to-life role-playing prepares them in a unique and powerful way for working with real patients. “Communicating with patients as a new doctor can feel awkward and unfamiliar. It’s new for us,” Dr. Sadiqqi says. “Thanks to this program, I’m much more confident and much more aware of how to do this well.”
A fresh approach to treating diabetes

By Maura C. Ciccarelli

This past summer, six patients with diabetes at Geisinger-Shamokin Area Community Hospital* (GSACH) received somewhat unusual prescriptions. The Fresh Food Pharmacy pilot program gave them directions for eating heart-healthy meals to meet specific targets for calorie and carbohydrate intake. They also received free groceries and other support to help them follow through.

Food insecurity and obesity don’t seem to go together, but they do, says Houssam Abdul-Al, MD, the pilot patients’ primary care physician. “After well-paying coal mining and manufacturing jobs disappeared from the Shamokin area over the last 40 years, we were left with residents who are really hard-working, honorable people, but they often don’t have the resources to purchase healthy foods,” he says. “Many bought any food they could to stretch their budgets and they ended up with obesity, which leads to diabetes.”

Today, nearly 50 percent of Shamokin residents are predisposed to diabetes, mainly because of obesity. About 12 percent of residents over age 20 actually have diabetes. These rates place Shamokin above regional, state and national averages. Also, about 1 in 3 residents are considered food insecure, meaning they lack access to enough affordable, nutritious food. This makes them eligible for federal and local food programs.

The Fresh Food Pharmacy pilot is a free service that gives patients a week’s worth of fresh fruit, vegetables and other groceries at a time, along with recipes to help them meet specific dietary goals. The two men and four women in the pilot range from ages 24 to 68; some live on their own, some with another person or with a family. To help them with their dietary “prescription,” the participants received a reusable grocery bag, measuring cups and spoons and a portion plate for keeping to their goals. The groceries also come with three weeks’ worth of menus.

“We’re providing five suppers per week for them and their families,” says Anna Ziegler, RDN, LDN, lead dietitian for the Fresh Food Pharmacy program and a member of Geisinger Clinical Nutrition Services Department. She is writing the food prescriptions. “We built the approach around the ‘MyPlate’ concept, which is to include a fruit, vegetables and sometimes dairy with each meal.”

Weis Markets provided the pilot program’s food. After assessing the pilot’s effectiveness, Geisinger will expand the Fresh Food Pharmacy program to include another 188 Shamokin participants later this year. That’s when the program will team up with the Central Pennsylvania Food Bank to make up the weekly grocery bags.

“When Geisinger approached us with the wellness initiative overall, we jumped on the opportunity,” says Joe Arthur, the food bank’s executive director. “Our goal is to close the meal gap in our 27-county area by providing three square meals a day for people in need. While doing that, we also aim to improve nutritional content in all of the meals.”

GSACH also is working with the Shamokin Area School District to help children on the free lunch program have access to healthy foods at home. The hospital is developing community outreach programs to educate people about diet, obesity and food insecurity. There are plans to launch the Fresh Food Pharmacy approach at Geisinger Lewistown Hospital as well.

“If you really want to control diabetes, you have to remove obstacles for patients,” says Dr. Abdul-Al. “If they are on medication and they are not getting good results because of how they are eating, you can get better control when the diet is improved. This means a lower incidence of heart disease, retinopathy [eye problems] and kidney disease.”

*a campus of Geisinger Medical Center
Investing in our member hospitals

By Maura C. Ciccarelli

When Geisinger Health System welcomes a new member hospital or affiliate, our goal is to identify ways we can help that institution serve its community’s healthcare needs even more effectively. Often this means investing in facilities. The following are two recent examples of how GHS has partnered with Geisinger Community Medical Center in Scranton and Holy Spirit–A Geisinger Affiliate in Camp Hill to improve care and expand services for residents in their regions.
Diane Bottjer of Hawley, Pa., has loved to dance all her life, but that activity was out of the question until just recently. The 70-year-old’s right knee was damaged by arthritis, with the joint worn down until it was just bone on bone.

“I haven’t walked right in six years and I wanted to dance again with my husband, John. We are very good dancers,” Mrs. Bottjer says with a smile.

Cutting the rug is back on the schedule again since she had a partial knee replacement at Geisinger Community Medical Center (GCMC) this spring. Orthopaedic surgeon Harry W. Schmaltz, MD, performed the surgery in one of GCMC’s new operating rooms (ORs), which opened in fall 2015.

With 14 ORs, the modern surgical suite on the second floor of the Scranton hospital nearly doubles the size of the previous facilities. It’s all part of a $97.1 million expansion and renovation project at GCMC that also includes a state-of-the-art Intensive Care Unit, which opened in spring 2015, and a new Gastrointestinal/Endoscopy Suite, open as of August 2016. This is one of the largest capital investments that Geisinger Health System has made in any of its member hospitals.

The benefits to Scranton area residents are obvious, says GCMC Chief Medical Officer Anthony Aquilina, DO. Patients have access to a range of minimally invasive surgeries, which use small, image-guided instruments to operate through smaller incisions. Examples include heart valve replacement, open heart and other cardiac surgeries, as well as spinal surgeries, bowel resection (removing part of the intestine) and bariatric (weight loss) surgery. Even when patients need more traditional open surgeries, they know they are being done with the most advanced technology.

“The bottom line is that we can perform almost any surgery imaginable for patients with virtually any condition in facilities that rival the best in the world. This is a first for northeast Pennsylvania,” Dr. Aquilina says.

Each year, more than 7,200 surgical patients rely on GCMC. The hospital has been recruiting new surgeons, specialists and support professionals to expand the care team. The new space also includes the region’s only hybrid OR.
Eleven-year-old Peter Glinatsis had plenty of questions when he was admitted last December to the new pediatric inpatient unit at Holy Spirit–A Geisinger Affiliate in Camp Hill for a rare skin infection related to his broken arm.

“I was kind of scared because I didn’t know what to expect,” says the now-seventh-grader from Mechanicsburg. He spent a week getting strong IV antibiotics, regular wound care, treatments by infectious diseases doctors and support from the pediatric nursing staff.

“The doctors and the nurses were really nice,” he says. “They answered my questions and helped me when I didn’t know what was going on.”

Peter’s father, Mike Glinatsis, says the staff also involved Peter’s siblings: Anthony, 10, and Litsa, 7. “Anything they could have a child do, they had them do, like cutting the bandage or applying a cream to his arm. It really made them and Peter feel like they were all taking part in making him get better,” he explains.

“To this day, when we drive by, he asks, ‘Can we go to the hospital so I can see how everybody is doing?’” Mr. Glinatsis adds. “It’s rare to find a child who felt so cared for that he wants to go back when he isn’t hurt.”

Peter is just one of many children who have benefited from Holy Spirit’s expansion of its pediatric services for communities straddling the Susquehanna River in Pennsylvania. When the hospital became a Geisinger affiliate in 2014, it lacked a dedicated unit for hospitalizing children from infants to age 18.

The new Janet Weis Children’s Hospital at Holy Spirit opened in July 2015 after a year of planning. This meant designing the inpatient unit, hiring nurses and pediatric hospitalists (physicians trained to care for children in the hospital) and renovating a section of the adult inpatient floor to focus just on kids. The new space has a calming and child-centered sea life theme. Today, pediatric care begins with

**Family-focused and kid-friendly**

Holy Spirit expands to provide inpatient pediatric care as part of Janet Weis Children’s Hospital

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maternity care at The Birthplace and includes outpatient and inpatient pediatric services as well as rehabilitation services, according to Lisa F. Torchia, Holy Spirit’s chief nursing officer and vice president of patient care services. The pediatricians are from both Holy Spirit and Danville’s Geisinger Medical Center.

“The new unit is very family-focused,” says Ms. Torchia. “We have four private children’s rooms, each equipped with a pull-out bed where parents can stay with their children. There is a playroom with tables, games and activities for the patients and their siblings. A family lounge with an internet connection helps parents manage their lives.”

“This is part of the wider plan to serve the community,” explains Michael E. Ryan, DO, FAAP, FACOP, chairman of Geisinger Janet Weis Children’s Hospital. “Now that we’ve gotten into the area and have had a chance to look around, we’ve seen ways we can help Holy Spirit meet the needs of local children and families.”

Outpatient services are another piece of the puzzle. Dr. Ryan adds that Geisinger will locate pediatricians in offices in Carlisle, Colonial Park and Enola: “When family members get sick and want to go to a doctor, they know what doctor they are going to get and that builds up their confidence.”

“We are just getting started with improving services on the West Shore area of Camp Hill,” says Kyle Snyder, chief administrative officer of Holy Spirit. “We also are expanding our subspecialties, such as adding Geisinger pediatric endocrinologists [doctors who treat hormonal disorders] in the Mechanicsburg office. We have a robust outreach program in the whole area.”

The new facility and staff were a real comfort after Nicholas Yanich, 27, and his wife Deshauna Hodges, 20, of Harrisburg had their first child, Gabriel, in March. A few days after his birth, he began showing signs of jaundice. (Jaundice occurs when an infant’s body is not yet able to break down and excrete old yellow-hued blood cells.) When their newborn son’s skin and eyes began showing the telltale yellow tint, the young family first went to the Emergency Department (ED). The baby was then admitted to the pediatric unit for a three-day stay. Two days after he was released, his levels were up again and his doctor suggested that Gabriel be readmitted for more light therapy, which helps the condition. This time, the family didn’t have to go through the ED. Everything was handled through the inpatient pediatric unit.

“I’ve been in the hospital a lot of times because I broke a lot of bones as a kid,” Mr. Yanich explains. “Usually, time is critical for nurses and doctors. But it never seemed like time was an issue. It was around St. Patrick’s Day and they put up shamrocks spelling out ‘Gabriel.’ It was very welcoming and inviting. He was in the second time for about a day. Everything was good after that.

“No one wants to see their child in the hospital set up with a bunch of machines,” he adds. “But [the staff] were there and they understood.”

As for Peter Glinatsis, he has three bumps and surgical scars on his arm but what he remembers is how well he was taken care of at Holy Spirit. He liked eating steak for dinner, helping the nurses by pushing the open button for the automatic doors, and, most of all, having a bedroom all to himself. “I liked sleeping alone. I liked kicking my dad out at night so I could go to sleep,” he says with a smile.

Mr. Glinatsis says that was a bittersweet moment for him but it also showed how comfortable his son felt there — like he was at a sleepaway camp.

As a father, he says it felt horrible that his son had to be hospitalized for the infection. “But honestly I wouldn’t have chosen to be anywhere else. The nurses were incredibly nurturing to my son, almost motherly, which was fantastic. To say that they went above and beyond their duty would be a drastic understatement. They were incredible then, but they were also incredible afterwards, making phone calls to check to see if Peter was okay.”

Rest assured that next time he drives by, Peter knows he’ll want to say hello and, once again, thanks.
Leftover medications? Here’s a safe and easy way to dispose of them

Don’t flush or toss unneeded medications or leave them in your medicine cabinet! A new Geisinger Health System program is putting take-back boxes in drugstores and supermarkets throughout central and northeast Pennsylvania.

Are there leftover medications in your cabinets at home? You’re not alone. In a recent Geisinger Center for Health Research study, one out of four people said they had unused prescription drugs at home. The list includes pain pills, antibiotics and medications for everything from high blood pressure and depression to high cholesterol and breathing problems.

There’s danger lurking in leftover medicines. “They can lead to accidental poisonings in children and to addiction and overdoses in teens and adults,” says John R. Jones, RPh, vice president of Enterprise Pharmacy for Geisinger Health System. “It’s wise to dispose of medications you and your loved ones aren’t using anymore.”

But throwing them in the trash or flushing them down the toilet can cause water pollution that harms the environment, Mr. Jones says.

Geisinger has a solution. The health system is installing medication take-back boxes in our own pharmacies and in supermarkets and independent drugstores throughout central and northeast Pennsylvania. Look for the blue-and-white boxes at the pharmacies inside the Knapper Clinic and Bush Pavilion at Geisinger Medical Center in Danville; at Geisinger’s CareSite Pharmacy in Dallas; in the Townville Pharmacy at Ben Franklin in Muncy; and in five Weis Markets throughout Lycoming County: Muncy, Montoursville, Jersey Shore and two in Williamsport communities. In late
summer and early fall 2016, boxes will be added to three additional independent pharmacies in Lycoming County and several more Weis Markets and independent pharmacies in Union, Snyder, Montour and Northumberland counties, as well as five Geisinger CareSite Pharmacies in Juniata and Mifflin Counties. Further expansion plans for 2017 include community pharmacies (Weis Markets, Geisinger CareSite and independent pharmacies) in Centre, Cumberland, Schuylkill, Columbia, Luzerne, Wyoming, Lackawanna and Monroe counties.

“Our ultimate goal is to have MedSafe disposal boxes in 57 locations in 2017 across 15 counties,” says Eric A. Wright, PharmD, MPH, co-director of the Center for Pharmacy Innovation and Outcomes at Geisinger.

The boxes accept prescription and over-the-counter pills and capsules as well as liquid medicines, prescription patches, medical creams and ointments, vitamins, nasal sprays and even pet medications. The Geisinger medication take-back project is one of the first hospital programs in Pennsylvania to accept controlled substances. These include narcotic pain killers like codeine, oxycodone, morphine and tramadol. “These drugs are highly addictive. Until now, the only way to dispose of them was at take-back days sponsored by the PA Drug Enforcement Agency or at local police stations. Those are good ways to get rid of leftover medicines, but not always convenient,” Dr. Wright says. “Our goal is for people in central and northeast Pennsylvania to be able to dispose of unneeded medicines within a 10-minute drive from their home, whether it’s at a pharmacy, supermarket or police station.”

The metal drug-disposal boxes look like mailboxes, but they’re secure. “They’re bolted to the floor,” Mr. Jones says. “Once you put medications inside, they cannot be pulled out.” Law enforcement agencies in the various communities empty the boxes and work with the National Guard to transport the drugs to an incinerator for safe disposal.

Protecting the environment, saving lives

“We were hearing about problems with the smallmouth bass in the Susquehanna River. The fish were developing male and female reproductive features, the Pennsylvania Fish and Boat Commission warned. Experts think one big reason is traces of medications, including hormones and hormone-disrupting medications, in the water,” says Homer “Skip” Wieder, emeritus vice president for Development for Geisinger Health System and director of the Susquehanna River Heartland Coalition for Environmental Studies. “Throughout Pennsylvania, district attorneys, local police and healthcare professionals were also becoming more concerned about addiction and overdoses involving narcotics.”

Geisinger’s original drug take-back program started in just three hospital-system pharmacies in 2012. It began accepting controlled substances in 2015, an important milestone, after getting the necessary permissions. So far, more than 4,380 pounds of medications have been collected. “This can save lives,” says Dr. Wright.

Partnerships make the program possible. “We are working closely with Weis Markets, with the Medicine Shoppe in Williamsport, Montgomery’s Pharmacies in Hughesville and Montgomery, and the Townville Pharmacy at Ben Franklin in Muncy,” Dr. Wright says. “And we have funding from the Williamsport Lycoming Community Fund at the First Community Foundation Partnership of Pennsylvania and the Degenstein Foundation. We also have research partnerships with Bucknell University, Susquehanna University and Wilkes University to study medication disposal methods and outcomes.” The Pennsylvania District Attorneys Association, local law enforcement and the National Guard are other key partners. And a recent Cardinal Health Foundation grant will let Geisinger staff work with students from Wilkes and from Pittston Area Senior High School to promote community awareness about leftover medications and the take-back program.

Researchers from Geisinger and Bucknell University estimate that Pennsylvania medication take-back programs saved 28 lives in 2015 by preventing overdoses. “Drug overdoses are responsible for more accidental deaths than any other cause in our country,” says Lorraine Tusing, research project manager at the Center for Pharmacy Innovation and Outcomes. “In addition, 80 percent of heroin users began by abusing prescription drugs. We want to demonstrate the benefits of this take-back program so that it can be a model for others around the United States.” –S.H.
Think about what it would be like to experience depression, anxiety, addiction or some other mental health disorder and then waiting six months or more to see a psychiatrist. That’s the situation many people in central Pennsylvania and in rural areas all over the nation currently face.

To address this problem, Geisinger recently created a Psychiatric Residency Program, now in its second year. Currently, eight residents are enrolled. As these new physicians prepare for the next chapter in their mental health careers, they also are participating in a larger mission: bringing much-needed behavioral healthcare to rural Pennsylvania.

“A major driving force behind the development of this new program has been a growing need for mental health services in this area,” says Stephen Paolucci, MD, chairman of the Division of Psychiatry for Geisinger Health System (GHS) and chief medical officer for Geisinger Bloomsburg Hospital. “We know that across the U.S. there has been a significant shortage of psychiatrists and many are approaching retirement age. Recruiting mental health providers to rural areas also is exceptionally difficult.”

After years of searching for ways to bring new providers to rural Pennsylvania, it made sense for Geisinger to develop its own residency program. “We realized that by training our own residents — here, in a rural setting — we could plant the seeds for our future,” says Dr. Paolucci.

Laying the groundwork for a brand new residency program and meeting all of the formal requirements of the Accreditation Council for Graduate Medical Education required an enormous commitment of time and skill on the part of Geisinger clinicians and administrators. However, the psychiatry department, which had always focused primarily on delivering patient care, met the challenge and successfully prepared experienced providers to take on new roles as teachers and mentors.

“Among the most important requirements for any successful residency program are the right faculty and the right physician leadership,” says Linda Famiglio, MD, FAAP, chief academic officer at GHS. A practicing child neurologist,
Dr. Famiglio has seen how lack of access to mental healthcare affects her patients. Many have disorders that require treatment by both psychiatrists and neurologists. “As soon as we found [psychiatric residency program director] Dr. Marie Rueve and her colleagues, we knew we were ready to move forward,” she says.

From the beginning, Dr. Rueve committed herself to developing a superior academic program designed to address the pressing needs of the community. “In rural areas such as ours, mental healthcare providers are few and far between,” she says. “Many individuals who already live far from providers may have further strikes against them if they are from low-income families or have difficulty arranging transportation to get to doctors’ appointments.”

Dr. Rueve adds that while some individuals can and do travel long distances — for example, to Philadelphia — to see providers, most simply face long wait times. Frustration over obstacles to timely care can result in the overuse or inefficient use of inpatient services.

“Some patients begin to feel hopeless because they can’t successfully navigate the local healthcare system to find a mental health provider. They can become so distressed that they feel compelled to seek care at an inpatient facility, which is not ideal,” she says.

Andre T. Nemoianu, MD, associate residency program director, adds that part of the burden of unmet need has fallen on primary care providers. “Our primary healthcare providers have made heroic efforts to try to address the need for psychiatric care,” he says. “However, the level of complexity can be such that they really want and need to consult with specialists.”

Even while the first classes of residents are still in training, Dr. Nemoianu notes, their presence is making a difference in the area. And with each year of participation in the program, their value will only increase.

“We know that a significant percentage of graduates from all residency programs tend to remain close to areas where they trained,” says Dr. Rueve. “We certainly hope that our residents will form strong ties while they train here and will choose to stay.”

For some residents, close ties to the area are already part of the attraction to Geisinger’s new program. Second-year residents Dr. Sarah Wagner and Dr. Ashley Dotson, for example, were drawn to the program in part to be close to family.

“By recruiting from within, our hope is to slowly begin populating central Pennsylvania with psychiatrists whom we have trained to know not only the needs of the community, but how best to serve those needs,” says Dr. Paolucci. –S.W.

Psychiatrists in short supply

59% of psychiatrists are 55 or older, the fourth-oldest of 41 medical specialties, signaling that many may soon be retiring or reducing their workload.

– Association of American Medical Colleges

Roughly 4% of medical school seniors chose to enter psychiatry residencies in 2013.

– Psychiatric News, American Psychiatric Association

The total number of physicians in the U.S. increased by 45 percent from 1995 to 2013, while the number of adult and child psychiatrists rose by only 12%, from 43,640 to 49,079. During that span, the U.S. population increased by about 37 percent.

– American Medical Association
Giving to advance women’s and children’s health

Private donors to the Geisinger Health System Foundation make a significant impact on the ability of our hospitals and clinical centers to advance care quality, the patient experience, research, facilities and technology. As a nonprofit organization, Geisinger Health System relies on the generosity of individuals and organizations throughout our communities to make improvements and expand our offerings in ways that otherwise wouldn’t be possible. Although donors can invest in any clinical area, service or specialty, this issue of Geisinger Magazine highlights examples of how private donations are enhancing pediatric services and women’s health.

Geisinger Auxiliary funds a mock MRI scanner for kids with developmental disabilities

Many people dislike having magnetic resonance imaging scans, better known as MRIs. You have to lie as still as possible inside the tunnel-like machine so that it can capture high-quality images. The MRI machine itself makes loud tapping or thumping noises. It can be unpleasant for anyone — so just imagine what that experience is like for a child with autism or other developmental disabilities.

But researchers with Geisinger’s Autism & Developmental Medicine Institute (ADMI) need brain MRIs of patients to build their understanding of these disabilities. Typically, only higher-functioning kids can have the test successfully, which is a real missed opportunity.

“We are focusing on patients with rare genetic syndromes and below-average IQ,” notes researcher Vanessa Troiani, PhD. “These are the types of patients that are often ignored in MRI research.”

The situation is improving, thanks to a mock MRI scanner funded by the Geisinger Medical Center Auxiliary and now in place at ADMI. The scanner mimics the sound and feel of a real MRI scanner, allowing kids to “practice” before having the real (and much more expensive) scan. The room features a welcoming mural with a spaceflight theme, along with a comic book and superhero badges that present the experience as an adventure. Kids also can watch a movie while they are in the mock scanner. Once they get comfortable after a few sessions, they are more likely to have a successful MRI using the real machine.
When her son Cullen, now 6, was 18 months old, Janell Weaver of Lewisburg could tell he was developing differently than other toddlers. After bouncing around to different pediatricians and specialists who discounted her concerns, the persistent mother ultimately found her way to Thomas Challman, MD, FAAP, medical director of Geisinger’s Autism & Developmental Medicine Institute (ADMI) in Lewisburg.

“It was the first place that heard me and actually saw my son — I mean really heard what I was saying and really saw my son,” Ms. Weaver says. “It felt like we finally were where we needed to be.”

At age 4, Cullen was officially diagnosed with autism and gained access to therapies targeted to his particular symptoms. Ms. Weaver was grateful — but also frustrated it had taken so long to get the right care. As she thought about how to channel that frustration to help other families, she read about the Operation Jack Autism Foundation, founded by the father of a severely autistic son who turned marathon events into fundraisers for autism research. A new runner herself, Ms. Weaver was training for the May 2014 River Towns Marathon in Danville and wondered if she, too, could raise funds for the cause.

First, she decided to organize her own event to raise autism awareness and support, turning to Operation Jack for guidance. In January 2014, she hosted the first CJ’s Resolution Challenge in R. B. Winter State Park in Mifflinburg, a racing event with options for trail runners of different ages and abilities. It has turned into an annual January event that in 2016 alone attracted 138 runners as well as 47 “virtual runners” from 20 different states and as far away as the United Kingdom, Tanzania and the South Pole. Ms. Weaver hopes the event will continue to grow in size and popularity. The next one is scheduled for Jan. 7, 2017.

A few months after the inaugural CJ’s Resolution Challenge in 2014, Ms. Weaver rallied a group of runners to participate in the Danville River Towns Marathon to raise money for autism. “Team CJ” was born, and the group continues to participate in the annual River Towns event as well as one or two other races per year to raise funds for Operation Jack and Geisinger’s ADMI. So far they have raised about $40,000.

Ms. Weaver combines all of this with a busy family life, which includes not just Cullen but her husband and a 5-year-old daughter, and she works as an acute pain nurse at Geisinger Medical Center in Danville. She is also a member of the advisory council for ADMI.

“Being involved reinforces my commitment to ADMI,” Ms. Weaver says. “The people are so smart and compassionate and totally committed to helping children and their families. I know that the money raised is going to do something great.”
Seiples, Degenstein family gifts support expanded Child Advocacy Center in Sunbury

In April 2016, the Child Advocacy Center (CAC) of the Central Susquehanna Valley, a division of Geisinger’s Janet Weis Children’s Hospital, marked the grand opening of a larger location in Sunbury. The CAC had outgrown its previous space in Northumberland, which opened in 2004 and initially served about 70 to 80 children per year. Changes in the way Pennsylvania reports and investigates child abuse had increased demand at CAC, which a decade later was serving 500 children per year.

Stan Seiple and his son, Penn, both of Mid State Realty and Seiple Architects Ltd. in Sunbury donated the building for this use. The Seiple Family Foundation contributed additional funding, as did The Degenstein Foundation, which supports projects related to the health and welfare of Sunbury area residents. The three-story, 6,900-square-foot building more than quadrupled the space of the old one.

“The Seiples, Degenstein family gifts support expanded Child Advocacy Center in Sunbury.”

The Sister Romaine Niemeyer, SCC, Fund for Women’s Health at Holy Spirit

On June 30, Sister Romaine Niemeyer retired from her position as chief administrative officer of Holy Spirit—A Geisinger Affiliate in Camp Hill, Pa., after more than four decades of service to Holy Spirit Hospital and Health System. To honor this incredible legacy of contribution to healthcare and the community, the hospital has established an endowment fund named for Sister Niemeyer that will support women’s health. Donations to the fund will advance obstetrics and gynecology services, including the treatment of gynecologic and reproductive health problems; women’s health education; and outreach to low-income women.

For more information or to make a gift, contact Gretchen L. Ramsey, director of advancement, at glramsey@geisinger.edu.

“Penn and I are good at bricks and mortar,” says Stan Seiple. “We know how to restore an older building so it can be put to good use. But we don’t know how to help kids in need. That’s what Geisinger does so well. The CAC program has been very successful, but they outgrew their space.”

By having investigators and agencies together in one place, victims of child abuse are spared the stress of multiple interviews and visits to different locations. The new Sunbury location features two interview rooms, an exam room, two therapy rooms and a conference/training room.

“We plan to use the conference room for cross-discipline trainings for police, child protective services and mental health providers, as well as have support groups for non-offending family members,” says center coordinator Melissa Wagner. “This space will allow us to provide additional services to child victims and their families while still maintaining the utmost privacy and comfort.”

Geisinger’s Child Advocacy Center is the only one of its kind in the Susquehanna Valley region.

“The Sister Romaine Niemeyer, SCC, Fund for Women’s Health at Holy Spirit.”
The Kozloffs: Improving the birth experience for women and families

Although they live in Arizona now, Drs. Jessica and Stephen Kozloff made Bloomsburg, Pa., their home from 1994 through 2007. Dr. Jessica Kozloff served as president of Bloomsburg University of Pennsylvania, while her husband led an obstetrics and gynecology practice caring for patients at what is now Geisinger Bloomsburg Hospital. Coming from 20 years of practice in Colorado, Dr. Stephen Kozloff knew that women had a much better experience when they could go through labor and delivery in a single birthing suite, supported by their families. He wanted to bring that approach to Bloomsburg.

“My goal after I arrived was to help the hospital transform to a new way of delivery,” Dr. Kozloff says. “We went from the older way of doing it — having mothers labor on a gurney and then move into a delivery room — to more homelike birthing rooms where families could participate.”

Dr. Jessica Kozloff could think of no better way to honor her husband’s contributions than by making what she calls a “surprise” $25,000 gift to support renovations of the birthing suite at Geisinger Bloomsburg Hospital. When complete, the unit will be named in Dr. Stephen Kozloff’s honor.

“When I learned they were going to do a major renovation and were looking for donors to help, it just made sense to get involved,” Dr. Jessica Kozloff says. “Geisinger Bloomsburg Hospital was very important to me as a partner during my presidency. Steve and I spent 13 years of our lives there and became attached to the community. We are excited about the improvements to come because we know how important that hospital is to the community.

“We’ve made gifts to Bloomsburg University, so now giving to the hospital was important to us,” she adds. “In healthcare there are many things that make a difference to patients that are not within the normal operating budget. Private gifts can make them possible.”

Ways to give

Gifts of any size are gratefully accepted and can support any number of priorities and initiatives throughout our health system, including state-of-the-art equipment and facilities for our patients, advanced training and education for our physicians, nurses and staff, and breakthroughs in medical research and treatment.

Charitable opportunities include annual and major gifts, endowments, estate planning, tribute gifts, naming opportunities and grants. Visit geisinger.org/foundation for more information and click “Make a Gift” to start your legacy today.
I am a nurse case manager for the Geisinger Health Plan working at the Geisinger Kistler Clinic in Wilkes-Barre, so I am used to helping patients navigate their way through complex health conditions. But the tables turned in summer 2015 when my dad experienced several months of sickness and coughing. We knew he had to be evaluated, so he followed up with his primary care physician here at Kistler, Dr. Richard Huntington, who ordered a chest X-ray that found a concerning spot in my dad’s lower right lung. Then things really began to roll into action. Further testing revealed mild-to-moderate chronic obstructive pulmonary disease, or COPD.
I requested that we go to Geisinger Medical Center to see a pulmonary specialist, as I had the advantage of knowing the group from my past work in the Intensive Care Unit (ICU). My dad had a chest CT scan and a bronchoscopy to perform a small biopsy. The area in question came back negative for cancer and standard practice was to repeat the CT scan in three months. In September 2015, my dad had the repeat scan, which found that the area of concern had grown. My gut told me this was serious. I spoke to Dr. Huntington, who listened to my concerns, ordered a more detailed PET scan and immediately spoke with a thoracic surgeon. They started formulating a plan and talked it over with my dad, who was happy to have a surgeon involved.

In a matter of days, we were sitting in the surgeon’s office. In collaboration with my dad, he concluded that the next best step was a VATS wedge resection: a video-assisted thoracic surgery procedure that would remove the suspicious area of tissue through small incisions. The surgeon really took his time with us, explaining that the area of concern could not be ruled out as cancer, but also could be a bacterial infection. He showed my dad precisely the area he would remove and what he could expect after the surgery.

My dad had his surgery in October 2015 and, much to our surprise, the area was cancerous, requiring removal of the entire lower lobe of the lung. My dad was diagnosed with early-stage non-small cell lung cancer; thankfully, his lymph nodes were all negative and he did not need chemotherapy.

In my entire nursing career, I have not experienced such a responsive physician as Dr. Huntington. He exudes an amazing bedside manner. He listens to his patients, explains what the plan is and encourages patients to ask questions. In this field of medicine, where we are being pulled in a million different directions, Dr. Huntington took the time to explain each and every step, all along knowing that my dad had not one but two (!) daughters who had trained as critical care nurses. He could have taken the approach of “the nurse daughters will explain this when I don’t have time.”

There are almost no words to describe the impact Dr. Huntington has made on my family. As a nurse, I am a tough critic, and it is an honor to know that I stand in the same health system as he does. My dad credits Dr. Huntington for sending him to a surgeon and saving his life. He gets tearful when he talks about it.

I also am so grateful for my former colleague Debbie Temerantz, who served as my dad’s case manager. She really clicked with him, and he listened to her in a way that he wouldn’t necessarily listen to me. Without her case management skills, even I would have struggled to put all of the pieces together at times. Through all of this, she was empathetic and incredibly caring and compassionate.

I could not be happier that my dad is a Geisinger Health Plan member and was able to benefit from her services.

I know my colleagues would all say that this is normal, everyday practice at Geisinger. But they should know they made a difference in not just one life, but the life of my entire family. I am grateful and proud to be part of the Geisinger family.

Amanda Sikora, RN, BSN, has been a case manager with Geisinger Health Plan at the Geisinger Kistler Clinic in Wilkes-Barre since 2014. Before that, she was a shock/trauma nurse in the Adult Intensive Care Unit at Geisinger Medical Center in Danville. The My Turn column will be a regular magazine feature that invites Geisinger staff members to share reflections about their day-to-day experiences here and the field of healthcare in general. If you are a Geisinger staff member with an interesting story to share, email us at GeisingerMagazine@geisinger.edu.

“In my entire nursing career, I have not experienced a physician like Dr. Huntington. He exudes an amazing bedside manner.”
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Include your name, email address, city and state. If you are a Geisinger staff member or alumnus/a of our education programs, also include your current (or past) positions and the years that you worked or trained here.

Violinist Mark Woodyatt and handpan player Jacob Cole perform as part of the Intensive Care Concert Series outside the new ICU at Geisinger Community Medical Center in Scranton (see page 35).