

# breakthrough

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## Ode to Joy

Truly Patient-Centered

Capturing the Moment

The Real Risks of Sickle Cell Trait

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THE JOHNS HOPKINS CENTER  
FOR INNOVATIVE MEDICINE

# breakthrough



David B. Hellmann,  
MD., M.A.C.P.  
*Aliki Perroti Professor  
of Medicine; Vice Dean,  
Johns Hopkins Bayview  
Medical Center;  
Chairman, Department  
of Medicine*

## BEETHOVEN AND THE AMBASSADOR

You may be wondering why we have musical notes on our cover, and what Beethoven's 9th Symphony could possibly have to do with the Center for Innovative Medicine. Quite a lot; the music itself is a song of triumph, and it has become our anthem here at the CIM. I hope that when you read the story (see Page 4), you will be inspired, as well. Despite circumstances that would have been enough to discourage anybody – family stress, financial woes, chronic illness, disability, and pain – Beethoven found joy. He overcame.

You may wonder, too, when I tell you that a recent speaker here at the CIM was Robert S. Ford, who served as the U.S. Ambassador to Syria from 2010 to 2014. He didn't talk about anything remotely medical. But what he did talk about – making change happen under enormous constraints, being a leader through difficult, seemingly unnavigable terrain, being there for your people, never forgetting what your job is – resonated with all of us who heard him. The obstacles he faced, much like Beethoven's, could have defeated him; instead, he overcame them and found greater good. Here at the CIM, we're not in a war zone, of course; but things go wrong, we face many challenges, and although many of our patients get better, not all of them do. But every day, we do our best to overcome, to change the terrain for the better. We draw inspiration from many fields, from literature, business, the arts, and even diplomacy. We hope always to be learning and improving, and we will gladly listen to anyone who has the potential to teach us something new.

This time of the year, many of our headlines around here involve the Miller and Coulson families. We just celebrated our 7th Annual Excellence in Patient Care Symposium at the Miller-Coulson Academy, and each year we have more to celebrate (see Page 14). Our 12th Annual Miller Lecture was delivered by Tom Duffy, a world-class clinician who shares some beautiful thoughts with us (see Page 17) about service, and where true fulfillment lies in medicine.

Also in this issue: Some good science, recently published by Rakhi Naik in *JAMA*, and new insights into sickle cell trait, which may make a huge difference for African Americans at risk of chronic kidney disease (see Page 12). We discuss another *JAMA* article, too; this one was written by our Miller Professor, Roy Ziegelstein, Vice Dean for Education at the Johns Hopkins School of Medicine, on what he calls "Personomics." This is a core belief of the CIM's Aliki Initiative: Know the person who is the patient. Knowing the real-life variables, such as a patient's ability to pay for a prescription, is just as important as understanding the patient's molecular biology or lab values. You'll also hear from one of our Aliki graduates, Sujay Pathak, now practicing medicine in Baltimore. The Aliki approach has made a huge difference to his patients, but it has also made a difference for him personally. "I find myself incredibly happy in my medical practice," he says. Wonderful words – words we'd like to hear more often.

And this brings us back to joy.

*David B. Hellmann, M.D.*

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## on the web

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# Ode to Joy

What is joy? It's not cheerfulness, or even happiness. No, joy isn't dependent on circumstances; in fact, true joy can be present in the face of grief, or pain, or disappointment. Joy is a deep, abiding thing. It overcomes; it even triumphs.



For nearly 200 years, since Ludwig van Beethoven composed it in 1824, joy has had a melody: It's the last movement of his Ninth symphony, which features singers soaring to reach impossibly high notes and a powerful melody that has come to represent joy, and greatness that overcomes, to people around the world. The last movement of the Ninth, also known as the Ode to Joy, transcends cultures. Protestors played it over loudspeakers at Tiananmen Square during the bloody demonstrations of 1989. It blared from the rooftops again in 1989, half a world away, when reunited East and West Germans danced together at the fall of the Berlin Wall. In Japan, the Ninth is associated with the freedom and new hope experienced when those held in prison camps were released after World War II; thousands of Japanese gather every December 9th to sing along with the melody. To Christians, it's a beloved hymn, whose lyrics include the phrase, "Joyful music leads us sunward in the triumph song of life."

It's also our official anthem here at the Center for Innovative Medicine, and the music has more to do with medicine than you might think.

How this came to be is a story that involves five key players. It started with David Hellmann, who has always been inspired by the Ninth. "In the Fourth Movement, there is one part that really speaks to me," he says. "I play it over and over. It begins with a beautiful melody, played softly on the cello. Then it is played on the viola, and then even louder on the violin. Then the entire orchestra plays this melody – which is now familiar, but it's also strikingly new, and beautiful in a new way because it is being played by everyone." Hellmann sees this as a metaphor for what he hopes the CIM will accomplish. "Our goal is to do for medicine what Beethoven did for music."

One day in late 2014, philanthropist Stephanie Cooper Greenberg, the head of our International Advisory Board, happened to be outside Hellmann's office when he was playing it. "He said, 'Hold on a second, I want you to listen to something.' It was the Ode to Joy," she recalls. Hellmann told her how he felt it captured the CIM's mission. Intrigued, Greenberg did some research on the Ninth, "to see why it mattered so much, why it was the adopted anthem." Then she came across a trailer for a new documentary film called *Following the Ninth: In the Footsteps of Beethoven's Final Symphony*, written and directed by Kerry Candaele, and filmed on five continents and in 12 countries. The film followed people whose lives have been "transformed, repaired and healed by the movie's message," she says. "I clicked on this trailer and was totally blown away. It was everything that David Hellmann spoke of, and it became very apparent why he believes Ode to Joy represents the CIM. It's the ultimate collaborative work, and it's also an anthem of freedom – from constraint, systems, oppression. The CIM is not exactly fighting tanks, but metaphorically it is doing things that are different in health care from anybody else out there." More than that, she realized the music's enduring, life-changing significance to so many people.

**"It's the ultimate collaborative work, and it's also an anthem of freedom – from constraint, systems, oppression. The CIM is not exactly fighting tanks, but metaphorically it is doing things that are different in health care from anybody else out there."**

**"Beethoven was never one to take the easy path. Instead, he took all of the things that should have made him weak, and found the strength to create beauty."**

Greenberg clicked on a hyperlink for those who were interested in screening the film, which had not yet been widely released. She sent a brief message by e-mail. Not too long afterward, "the phone rings, and it's the filmmaker. Oh, my gosh! I was pretty much babbling through the conversation." It turns out that Kerry Candaele, the third person in our story, is also a musicologist and teacher in addition to being a noted filmmaker. "He was so captivated by the Ninth that he created this film to document the trajectory of this piece of music. He was kind enough to send me the whole film." Greenberg loved it; Hellmann loved it. They decided to hold a special screening, sponsored by the CIM, at Johns Hopkins Bayview. "That's how it came to be. It was purely serendipitous."

The timing couldn't have been better: at the Asthma and Allergy Center, after work on February 11, in the dregs of a cold, snowy Baltimore winter. The movie was shown to a packed auditorium in two parts. In between came the fourth key player in our story: Tom Hall, Director of the Baltimore Choral Arts Society. Greenberg had reached out to him, too, introducing herself and springing what she calls now "a ridiculous request, when I think about it: Can you explain Beethoven's Ninth in 10 minutes? Why it's relevant." Hall agreed, and "he was really the star of the show."

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**“Within every person, no matter how difficult the disease might be, there is the potential to embrace joy.”**

During his brief talk, Hall told the crowd that his own cancer had been cured at Johns Hopkins, and he “began weaving the narrative of the Ninth and the story of the music with how you can be doing something and it creates something else that’s bigger than you ever imagined. How the CIM does the same thing, doing very hard work, but at the end of the day, helping, inspiring, and lifting people up, promoting change in the right direction,” says Greenberg. “And all of a sudden, it becomes not about Beethoven, or Tiananmen Square; it becomes about what everyone in the room is there for. He unified the notion that the CIM is about all of us together. The audience totally got what it was all about – that if we do things together, we can be better, do more, and really change the way we practice medicine. Sometimes one thing comes along and defines something else that’s completely different. It helped define what was right there all along.”

Hellmann says, “it was a magical night. Many in the audience made a point of telling me afterward that they felt restored and renewed.”

But the story would be incomplete without the fifth person, and that is Beethoven himself. Beethoven, despite a legacy of composing some of the world’s greatest music, did not have a very happy life. He had family troubles, money worries, and more stress than most of us could handle gracefully; his own temperament tended to be difficult, and on top of everything, he had health problems, chronic abdominal pain and digestive illness, and degenerative hearing loss that led to deafness.

The options for Beethoven were the same that many of us face: He could have decided, with some justification, that he’d been given more than anyone should have to bear. He could have withdrawn and given up on life, becoming increasingly bitter, self-pitying and defeated. But Beethoven was never one to take the easy path. Instead, he took all of the things that should have made him weak, and found the strength to create beauty. He transcended his physical limitations, and achieved greatness. He overcame. “Beethoven hungered for this joy,” says Hellmann. “He captured it in his music, and it lives in us today.” In addition to everything else it does, “the Ninth reminds us, as caregivers, that within every person, no matter how difficult the disease might be, there is the potential to embrace joy.” ■

# Truly Patient-Centered

What comes to mind when you hear the words, “rheumatoid arthritis?” Well, if you don’t have it, you might think of terribly swollen joints, or pain. Ask people who suffer from RA what they’re concerned about, and the answers may surprise you. There’s pain, sure. But also fatigue, trouble sleeping, depression, anxiety, and worries about being able to handle normal daily activities and chores.

Unfortunately, these are not usually the things that people with RA generally discuss with their doctors. Which is why Johns Hopkins Bayview rheumatologists are doing something revolutionary to find out how their patients are really doing: They’re asking them.

Rheumatologists can look at numbers until the cows come home. They can determine precise things – such as how many swollen and tender joints their patients are dealing with; and which inflammatory markers, as determined by lab tests, are in their blood, and what those numbers are. “Those numbers have been determined by experts as the best outcomes to measure,” says rheumatologist Clifton Bingham, M.D., Director of the Johns Hopkins Arthritis Center, and of the new Center for Patient-Centered Outcomes Research in Rheumatology “But they don’t always reflect what’s really happening in our patients’ lives – what they’re not doing because of pain, or fatigue, or depression, or something else. And maybe the whole visit would come and go and we wouldn’t know something was wrong because we didn’t ask the right questions.”

**“It’s hard to believe, but most traditional research never considered the patient’s opinion or reaction to the treatment.”**

Numbers hardly ever tell the whole story. “It’s hard to believe,” says David Hellmann, M.D., a rheumatologist and also Director of the Center for Innovative Medicine, “but most traditional research never considered the patient’s opinion or reaction to the treatment. Imagine reading a restaurant review that discusses the temperature of the butter, meat and wine – but not how any of it tasted! – and you will have a sense of how previous research on treatment left out the patient. The good news is that the creation of this new Center is a systematic effort to measure the patient’s perspective.”

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Bingham has long worked on finding ways to make care for people with RA more patient-centered. For years, he has reached out to patients and gotten their perspective, asking them questions such as: What aspects of your life are most affected by RA? What do you want to be able to do? And how can we work with you so that you can make this happen?

The goals between patients can vary widely, says Bingham: Maybe Patient A's goal is to continue a job that's pretty demanding physically – teaching middle school and coaching the girl's volleyball team. But Patient B just wants to be able to drive to the grocery store and go to church, and go out with her friends for lunch afterwards. And Patient C is taking care of his wife, who is an invalid. Continuing to do this is what matters to him the most; in fact, it's what gets him out of bed in the morning and keeps him going all day.

These patients need personalized medicine.

A couple of years ago, Bingham was one of a few in the country to receive Federal funding for a pilot project from the Patient-Centered Outcomes Research Institute (PCORI, pronounced "picori"). His project: to test a NIH-developed system called PROMIS (Patient-Reported Outcomes Measurement Information System) in clinic patients with RA. He implemented an interactive questionnaire that tackled not only physical manifestations of disease, but lifestyle issues – activities at home and work, and how satisfied patients feel with their ability to function in various areas. Patients filled out the questionnaire before they saw the doctor in the clinic, and together, after the regular check-up, they looked at the questionnaire to see what might have been missed in the visit. The questionnaire, Bingham found, "enabled conversation that might not have happened otherwise."

Recently, he and his team received additional PCORI funding for a second project to expand this work and move it forward. Bingham hopes that what he and colleagues are learning about incorporating patients' wishes and concerns into their health care plan will expand beyond rheumatology, and eventually spread throughout Hopkins. "Our first project was working to see what would happen if

we used this system and provided the information to patients and their doctors," Bingham says. "The results of the first study very clearly demonstrated the many areas of health that are affected by RA," and how they change as the disease is more or less active. "These new measures are able to reflect the impact of the disease even when patients are having what we would define clinically as 'low disease activity' – which is very important, because then we can see that there is considerable impairment."

In the treatment of many diseases – cancer, for instance – new research has shown that "there tends to be considerable discordance between the perception of a doctor or nurse, compared with the opinion of the person who actually has the disease. Physicians consistently underestimate the magnitude or impact of symptoms on the patient. What we hope is that through this work, we can provide clinicians with a better understanding of how a disease is affecting the patient."

Currently, Bingham and colleagues are asking patients to fill out a questionnaire every time they come in for a visit, so they can track and measure changes in how the patient's doing over time. For example: "One of my patients, when she is in remission of her RA and things are extremely well-controlled, her physical function is such that she can run a half-marathon. But when her arthritis begins to flare, she can only run a mile, and that's a huge difference in her physical function. Both her starting point and her endpoint, using a standard measure of physical function, would be considered 'normal' – but the change from Point A to Point B, what's important to her, has been dramatic and huge." The traditional measurements would only signal trouble if she couldn't walk a mile. "But for her, that first sign of trouble is that change in how far she can run." Using these far more sensitive guidelines can help Bingham anticipate and prevent trouble sooner.

At the new Center for Patient-Centered Outcomes Research, Bingham and investigators are expanding this type of research to encompass different types of arthritis, myositis, and Sjogren's syndrome, and soon they plan to include other diseases, as well. ■

## Capturing the Moment

Michelangelo nailed it, of course. His “Creation of Adam” on the ceiling of the Vatican’s Sistine Chapel captures the ultimate action shot – that first spark of life. But for most of us, armed with a camera instead of a paintbrush, it’s not that easy to capture a special moment. It’s especially tricky in the world of medicine, where some of the events we see are heartbreaking, and some are breathtaking, and

all of them are fleeting. This kind of moment-capturing is impossible to manufacture; you can’t make it happen – think of any staged photos you’ve seen in medical ads and slick annual reports. No, for us non-Michelangelos attempting to freeze-frame an encounter, the best we can hope for is that we’ll have the wit to recognize it and the presence of mind to click the shutter in time.

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## **“He really did capture people at the magic moment, and what’s behind the skin leaps out.”**

Sheldon Gottlieb, M.D., has both in spades. He’s been taking pictures since he was a kid, and has learned how to anticipate when a moment is about to happen. On top of that, he is a gifted clinician, a cardiologist who knows what good teaching is, how doctors are supposed to talk to patients and how to listen to them, and how to tell when the message is getting across. In 2010, David Hellmann, M.D., Director of the CIM, gave him an unusual challenge: He asked Gottlieb to illustrate, photographically, the process of caring.

“What was special about this opportunity was that David didn’t tell me what to do or how to do it,” says Gottlieb. So the first thing he needed to do was “figure out exactly what caring was. You know it when you see it, but what is it, really? I spent a lot of time reading about caring, and then I began carrying my camera around in the hospital, and asking permission to take pictures. I tried to capture that special moment where people really interact with each other – that decisive moment when people connect, or that special thing happens that’s never going to happen again.”

As he started watching the countless interactions that went on around him, Gottlieb says, he started to notice things: that “some of the house staff have a way of connecting with the patient,” for example. “They really go eye to eye, and you can see that special spark of recognition, the electricity flowing between two people. In other cases, it’s just not there.

“When you start to see with your photographer’s eye,” he continues, “you see these moments and think, ‘That was a picture,’ if you don’t have your camera. If you do have a camera, you’ve got a split second. If you’re there and you’re ready, you can catch it.”

## **“It’s the sort of thing you can’t walk past without thinking, ‘Wait a minute, I’ve got to look at these.’ This is dramatic, in an extremely human way.”**

Gottlieb took pictures for many months, and then showed Hellmann a portfolio of what he had done. Hellmann, in turn, put Gottlieb in touch with Michael Linehan, the architect at the Bloomberg School of Public Health, so that they could create a long-term exhibit, a Gallery of Caring, now on display in the foyer outside the Department of Medicine on the third floor of the Mason F. Lord Building. “It’s almost like they created a sacred space,” says Gottlieb. “You come out of the elevator, make a left, go through double doors, and there is this big, empty space.”

**“This is kind of a corporate responsibility statement. It’s more than just demonstrating caring. It’s showing how the Department of Medicine itself is dedicated to that concept.”**

Some large corporations produce booklets or brochures to show the world that they are responsible citizens, Gottlieb notes. “This is kind of a corporate responsibility statement. It’s more than just demonstrating caring. It’s showing how the Department of Medicine itself is dedicated to that concept.”

Linehan’s touches to the exhibit are many. He cropped the pictures and printed them with similar tones, all black and white, so that an observer could move from one to the next seamlessly. “I think the thing for me,” he says, “although the title of the exhibit is Caring, as I began to work on them, the pictures struck me in a different way. Not that they didn’t exhibit caring, but “memento mori” (Latin for “remember that you have to die”) – pictures of people who realize that they are coming close to the end of their lives, and you can see in their faces their reaction to that understanding that they’re about to walk through the door. When you are reacting to photographs, you have no idea what they’re really thinking; you always read some of your own preconceptions into it. But that’s a legitimate thing to do. For me, I saw people thinking about that, and some of them were obviously afraid, some were putting on a brave face, and some were displaying their acceptance of the situation, and expressing faith,” with empathetic doctors and nurses in the background.

“He really did capture people at the magic moment, and what’s behind the skin leaps out,” Linehan says. “When you see them all together, I think they’re quite powerful. It’s the sort of thing you can’t walk past without thinking, ‘Wait a minute, I’ve got to look at these.’ This is dramatic, in an extremely human way.”

Because Linehan wanted to make the exhibit as interactive as possible, he did not hang the pictures on the walls. Instead, he put them smack in the middle of the space, on tables. They are tilted toward the viewer at a 45-degree angle, about four feet off the ground, two images per table. “The pictures are not easy to breeze past. They are very much in your personal space; they’re right there, somehow more confrontational than they would be on the wall. To see a photograph that size – two feet by four feet – on the wall, you would have to stand back to take it all in. But these you’re able to walk up to a little more closely. You don’t have to step back. Clearly these images are not part of the background.”

In putting the exhibit together, Linehan says, he “just reacted to each thing the way I saw it.” The sum total of the pictures “really kind of got to me. It was an emotional experience just to do the design work, and that’s a real tribute to Sheldon. It takes a particularly good photographer to do that.”

The exhibit is open to the public. All are welcome to come and view it. ■

# The Real Risks of Sickle Cell Trait

This is a story of a neglected disease, several bad health policy decisions, some good science, collaboration and outside-the-box thinking, and an insight that may make a huge difference for African Americans at risk of chronic kidney disease. In short, it's the kind of innovative medicine we love at the CIM.

Long, long ago, sickle cell trait (SCT) evolved as a beneficial thing in parts of the world plagued by a very bad thing: disease-bearing mosquitos. This inherited trait (see side story) caused a mutation in the genes for hemoglobin, the molecule in the red blood cells that carries oxygen. The change, generally subtle, was enough to protect the body from malaria.

Science has swung back and forth on the importance of SCT as a health risk. Nearly half a century ago, SCT was a cause of discrimination for African Americans, affecting employment, health insurance, even marriage policies, says hematologist Rakhi Naik, M.D. Then for a decade or so, SCT faded out of the limelight, taking a back seat to other conditions. It bounced back into the public radar in the 1970s, when four people who died during rigorous military training turned out to have the trait. Worried about the risk of sudden death during extreme exertion, as experienced in boot camp, the U.S. Army began screening everyone for SCT. "In the 1980s, that stopped," says Naik, "because of lack of good data. They had the suspicion that SCT increased the risk of sudden death, but no real scientific proof" that people with this particular set of genes were any more at risk than anyone else. Instead, the military changed its training protocol across the board, making sure everybody received better monitoring and care, better hydration to avoid heat-related illness, and longer recovery time after strenuous drills.

The SCT policy world was fairly quiet until 2010, when a 19-year-old NCAA Division I football player at Rice University in Houston died after doing sprints. Autopsy results suggested that SCT might have been to blame for the cause of death, acute exertional rhabdomyolysis (muscle breakdown).

**"Knowledge is power, and we need evidence-based decisions instead of what's happening now, which is making blanket policies with no data."**

It turned out that this young man wasn't alone. Between 2000 and 2013, as many as 10 Division I college football players who died suddenly after hard workouts turned out to have SCT. In response, the NCAA instituted mandatory SCT screening for all incoming student athletes – a move to which several medical groups objected, calling the policy "medically groundless, perhaps even dangerous," and "focused more on protecting the NCAA from legal liability than protecting the health of student athletes." The American Society of Hematology proposed a Universal Precautions-type plan similar to what the Army was doing – preventive interventions, such as rest, hydration, heat acclimation, and monitoring, for everybody. The NCAA's policy, says Naik, is partly responsible for a resurgence of scientific interest in SCT – mainly because it "was another policy made without any data."



## What is Sickle Cell Trait?

**Sickle cell trait (SCT) is not the same thing as sickle cell disease, and won't ever turn into that much more serious condition. It is inherited, affecting about one out of every 12 African Americans and one out of every hundred Latinos; it can occur in people of other races, as well, but not nearly as commonly.**

**People who have SCT inherit one sickle cell gene and one normal gene. Their red blood cells reflect this dual heritage: The majority of their red blood cells have normal hemoglobin A, but some of them have the troublesome hemoglobin S. Because the normal red blood cells outnumber the abnormal ones, people with SCT generally have enough of the good hemoglobin to help their red blood cells deliver oxygen throughout the body.**

**However, when the body is stressed – from low oxygen, which could happen with strenuous exercise; or high altitudes; higher atmospheric pressure, the kind scuba divers experience; or dehydration – the normal-shaped hemoglobin can morph into the sickle-shaped cells in some parts of the body. These cells are more likely to logjam in tissues and organs, and to disrupt the supply of oxygen there; these clots can result in complications in the lungs, kidneys, blood vessels, and elsewhere.**

Naik became interested in SCT while she was earning her Master's of Public Health degree at the Bloomberg School of Public Health. With the encouragement of Sophie Lanzkron, M.D., director of the Johns Hopkins Sickle Cell Center for Adults, she began exploring some of the huge, ongoing population study groups of people with SCT being followed by the National Institutes of Health – some for 30 years or more. Naik noticed that one health problem, in particular, kept popping up: kidney disease. This was not necessarily new – again, there were policies based on it – and some organ donor programs rejected the kidneys of people with SCT. And again, “these policies were based on just a hunch, not on real data,” Naik says.

Naik notes that as a young researcher, she wouldn't have gotten nearly as far as she has without the mentorship and support of other investigators, in different disciplines. Two of them were rheumatologist James G. Wilson, head of the Genetics Committee of the University of Mississippi's Jackson Heart Cohort, a large study of cardiovascular disease among African Americans; and Alex Reiner, a genetic epidemiologist at the University of Washington. Gradually a research project took shape that has led, most recently, to the publication of an article in the *Journal of the American Medical Association (JAMA)*, with Naik as first author.

In this important study of nearly 16,000 African Americans with and without SCT, Naik, Wilson, Reiner, Lanzkron, and colleagues found a higher risk of chronic kidney disease in people with SCT. “Everybody has understood that African Americans have a greater frequency of renal disease, and nobody has understood why,” says Vice Dean David Hellmann, M.D., Director of the CIM. “What Rakhi just published in *JAMA* is a whole new concept that sickle cell trait is not necessarily a benign disease, and that it is a powerful predictor of developing kidney disease.” Stresses, such as insufficient oxygen, undoubtedly play a role. “So someone with SCT goes up 15,000 feet in an airplane, or gets operated on and develops pneumonia or hypoxia: these sickle trait cells can change shape and ‘sickle’ to some degree.”

And in the kidney, these sickle trait cells may do some things that lead to repetitive small injuries to the organ – and this may lead to kidney disease over time.

Naik is collaborating with a handful of investigators at several institutions to determine “the next steps,” she says, “answering this question of whether kidney donors and recipients have problems with sickle trait, and whether or not SCT is associated with other outcomes, such as stroke and heart disease. All of these are speculative. Resolving these questions actually helps us – in terms of not making policies that are not based on data – figure out what we can do about it. This has been a neglected field.” She hopes that this research can determine some smart guidelines on how best to follow people with SCT over time.

“Knowledge is power, and we need evidence-based decisions,” she adds, “instead of what's happening now, which is making blanket policies with no data. It will be much better once we have the actual evidence – such as whether someone is at an increased risk or a moderate risk, and which markers we can follow over time. As opposed to general panic and the extreme, ‘Let's test everybody.’” ■

# Climbing That Mountain

If the mission to recognize and reward clinical excellence were a mountain, then every year at the Miller-Coulson Academy Excellence in Patient Care Symposium, the usual speakers – including Academy Director Scott Wright, M.D.; Vice Dean and CIM Director David Hellmann, M.D.; Dean and CEO Paul Rothman, M.D.; Hospital and Health System President Ron Peterson; Miller Scholar and Vice Dean Roy Ziegelstein, M.D. – and all of the newest members of the Academy would be standing on higher ground. Because every year, there is more progress to celebrate.

This year marked the 7th Annual Symposium, and the second year that the event was held at the Johns Hopkins Hospital. At the request of Rothman, the Academy expanded last year to include faculty from both the downtown and Bayview campuses, with a long-term goal of rewarding clinical excellence at all Johns Hopkins medical facilities. The Academy, made possible through the generosity and dedication to clinical excellence of the Miller-Coulson Family, has evolved over the years in other important ways, as well. For example: In honor of the late Frank L. Coulson, Jr., the Academy added an annual Award for Clinical Excellence to exceptional doctors-in-training (and potential future Academy members) in all 20 Hopkins residency programs. The Academy has started a coaching program, in which master clinicians serve as mentors to help new faculty develop and improve their clinical skills. Every class of interns in the Department of Medicine at Johns Hopkins Bayview crafts an oath, and develops an image – this year's comes from a photo an intern snapped of the North Star – to go with it, that reminds them to be clinically excellent. And this year, for the first time, there were awards for clinically excellent Nurse Practitioners and Physician Assistants, introduced by Patricia Davidson, Ph.D., Dean of the School of Nursing.

“The Academy is expanding in many important ways,” says Scott Wright, M.D., Director of the Miller-Coulson Academy. One of the areas of progress that he’s most excited about: “Dean Paul Rothman has asked the Academy to work with the Promotions Committee to come up with a way for the institution to recognize clinical excellence for the purposes of promotion. We have rigorous methods that we use to decide who gets into the Academy every year,” which have been adopted by Ohio State University and other medical schools around the country to help them determine which clinicians should be promoted. But at Hopkins, like most academic medical centers, “in the past, clinical performance has not been taken into consideration in determining promotion,” Wright notes.

## The Frank L. Coulson, Jr. Award for Clinical Excellence Resident Award Winners

**Crystal Agi**  
*Dermatology*

**Sara Alcorn**  
*Radiation Oncology*

**William Bain**  
*Internal Medicine*

**Jamal Carter**  
*Pathology*

**Jessica Chang**  
*Ophthalmology*

**Joshua Horowitz**  
*Anesthesiology &  
Critical Care Medicine*

**Helen Hughes**  
*Pediatrics*

**Dylan Kellogg**  
*Emergency Medicine*

**Arman Kilic**  
*Surgery*

**Jessica Klein**  
*Pediatric Neurology*

**Jason Liauw**  
*Neurosurgery*

**Gerhard Munding**  
*Plastic &  
Reconstructive Surgery*

**Andres O'Daly**  
*Orthopedic Surgery*

**Rachael Oxman**  
*Internal Medicine*

**Nathaniel Readal**  
*Urology*

**Steven Rowe**  
*Radiology*

**Karisa Schreck**  
*Neurology*

**Bryan Ward**  
*Otolaryngology  
Head & Neck Surgery*

## Nurse Practitioner / Physician Assistant Award Winners

**Oluwatope Alaofin, CNM**  
*Obstetrics and Gynecology*

**Diane Dritt Amin, PA-C**  
*Pediatrics*

**Tammy Aungst, PA-C**  
*Emergency Medicine*

**Sherilyn Brinkley, MSN, CRNP**  
*Medicine*

**Charnita Bryant, RN, MS, CPNP**  
*Pediatrics*

**Lora Clawson, MSN, CRNP**  
*Neurology*

**Nancy Crawford, PA-C**  
*Anesthesiology &  
Critical Care Medicine*

**Kamal Dhanjani, PA-C**  
*Anesthesiology*

**Amy Hacker-Prietz, PA**  
*Radiation Oncology*

**Sharonda Keith, PA-C**  
*Neurosurgery*

**Tom Killmond, PA-C**  
*Oncology*

**Amy Lee, DNP, ARNP, WHNP**  
*Obstetrics and Gynecology*

**Carol Maragos, NP**  
*Otolaryngology  
Head & Neck Surgery*

**Richard Marcinko, PA-C**  
*Medicine*

**Leah Maxwell, PA**  
*Orthopedic Surgery*

**Laura Phillips, PA**  
*Physical Medicine &  
Rehabilitation*

**Clare Scott, PA**  
*Emergency Medicine*

**Susan Renda, DNP, ANP-BC**  
*School of Nursing*

**Richard Syzmanski, PA-C**  
*Neurosurgery*

**Roseann Velez, DNP, CRNP, FNP-BC**  
*School of Nursing*

**Kristen Venuti, PNP**  
*Orthopedic Surgery*

**Tam Warczynski, MSN, ACNP**  
*Surgery*

**Linda White, NP**  
*Neurology*

## “Every year, there is more progress to celebrate.”

It is not unusual at Hopkins for an excellent, distinguished clinician, even after decades of practice and teaching, to hold the rank of assistant professor or instructor. In fact, out of the 14 outstanding Johns Hopkins physicians joining the Academy this year, the vast majority are associate professors. “I think it’s because we as an institution haven’t committed the resources to assessing clinical performance,” adds Wright, “and because we haven’t done that, we really aren’t able to consider clinical performance at the time of promotion.”

Wright is a member of the Promotions Committee for the Department of Medicine. “Each year, we look at people who spend 80 percent of their time doing clinical work, and we judge them for promotion based on what they do in the other 20 percent of their time. (We are) making decisions on their worthiness for advancement based on what they do in the minority of their time and effort.”

This is changing; Rothman and other Hopkins leaders agree with Wright’s assessment. Of the four pathways for faculty at Hopkins to get promoted, “there is a pathway in the promotions book called the ‘Clinician with Distinction Pathway,’” says Wright, “but nobody gets promoted on that pathway. The exciting news is that now the Academy is working with the Promotion Committee to reconsider that pathway and make it into a true avenue that will allow some of our best clinicians to get promoted.” The recommendation to do that came to the Dean from a committee, co-chaired by Wright with David Eisele, director of Otolaryngology-Head and Neck Surgery, that was specifically geared toward “thinking about how Hopkins is going to recruit or retain the best clinicians”—a committee that didn’t exist a few years ago. “The bottom line is that the Academy is a success, and due to this success, we’re being asked to help the institution with respect to all things related to clinical excellence.”

To see more of this year’s Symposium, please go to [hopkinscim.org](http://hopkinscim.org).

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**The 2015 Inductees into the Miller-Coulson Academy of Clinical Excellence are:**

**John O'Brien Clarke**, Associate Professor of Medicine in the Division of Gastroenterology and Hepatology; Clinical Director of the Johns Hopkins Center for Neurogastroenterology and Clinical Director of Johns Hopkins Bayview Gastroenterology & Hepatology.

**John Fetting**, Associate Professor of Oncology; he served as Associate Director for Clinical Practice for the Department of Oncology from 1998 until 2015, when he resigned to focus on his breast cancer practice and the Fetting Fund for Breast Cancer Prevention Research.

**Derek Fine**, Associate Professor of Medicine and Fellowship Program Director in the Division of Nephrology.

**Elliot K. Fishman**, Professor of Radiology, Surgery, and Oncology; Director of Diagnostic Imaging and Body CT at Johns Hopkins Hospital.

**Mitchell Goldstein**, Assistant Professor of Pediatrics; Director of the Hopkins Child Protection Team; Director of CHAMP, a statewide system for managing child maltreatment.

**Carol Ann Huff**, Associate Professor of Oncology and Medicine and Director of the Multiple Myeloma Program at the Sidney Kimmel Comprehensive Cancer Center.

**“Each year, we look at people who spend 80 percent of their time doing clinical work, and we judge them for promotion based on what they do in the other 20 percent of their time.” This is changing.**

**“It is not unusual at Hopkins for an excellent, distinguished clinician, even after decades of practice and teaching, to hold the rank of assistant professor or instructor.”**

**Daniel A. Laheru**, Associate Professor of Oncology at the Sidney Kimmel Comprehensive Cancer Center; the Ian T. MacMillan Professor in Clinical Pancreatic Cancer Research; Clinical Director, Division of Gastrointestinal Oncology; Co-Director, Skip Viragh Center for Pancreas Cancer Clinical Research and Patient Care.

**Julie Lange**, Associate Professor of Surgery, Oncology, and Dermatology.

**Linda Lee**, Assistant Professor of Medicine.

**Susan W. Lehmann**, Associate Professor of Psychiatry and Behavioral Sciences; Founding Director and Medical Director of the Geriatric Psychiatry Day Hospital; Director of the Geriatric Psychiatry Outpatient Clinic; Director of the Psychiatry Clerkship; Director of Medical Student Education in Psychiatry.

**Kristen Nelson**, Assistant Professor of Anesthesiology & Critical Care Medicine; Director of Pediatric Cardiac Critical Care.

**Richard J. Redett**, Associate Professor of Plastic and Reconstructive Surgery; Director of the Cleft and Craniofacial Center, Facial Pain Paralysis Center, and Pediatric Plastic Surgery.

**Daniel Sciubba**, Associate Professor of Neurosurgery, Orthopedic Surgery, Oncology, and Radiation Oncology and Molecular Radiation Sciences.

**Deborah Sellmeyer**, Associate Professor of Medicine; Medical Director of the Metabolic Bone Center at Johns Hopkins Bayview. ■

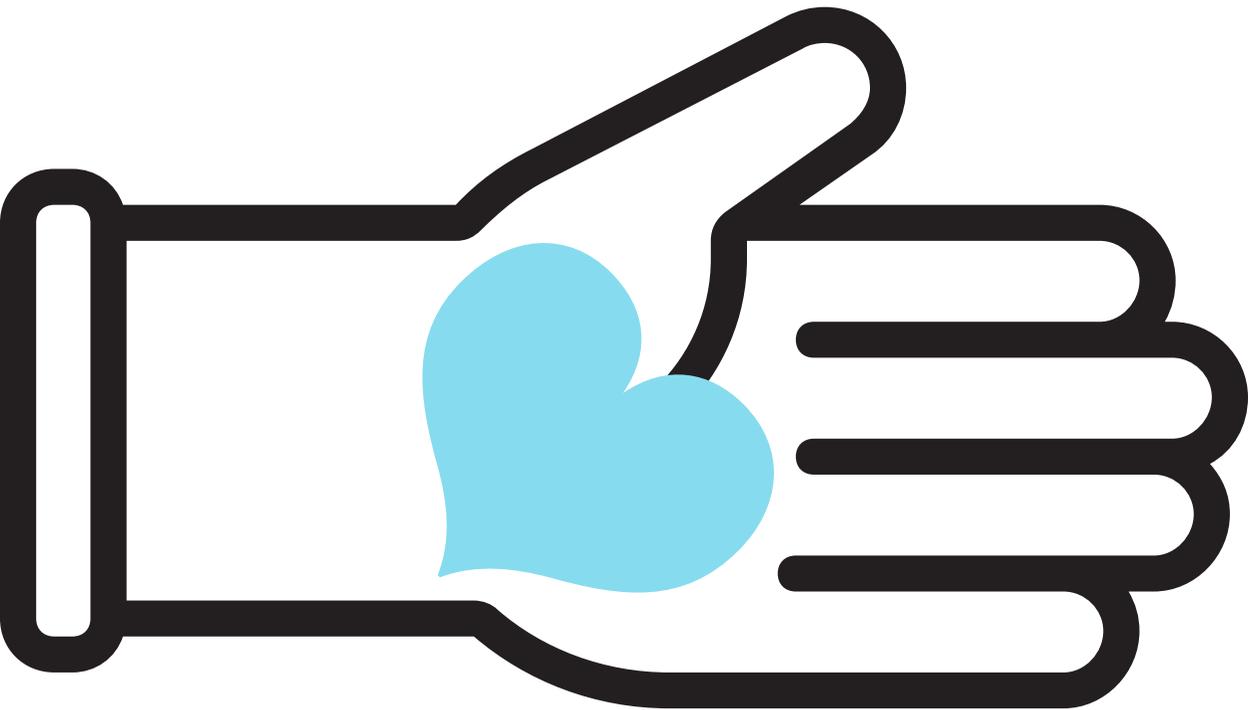
## Grace in the Secular World of Medicine

The sweetness of Tom Duffy's return to Johns Hopkins, to deliver the 12th Annual Miller Lecture, is something to be savored on many levels. Our Miller Lecture, established at Johns Hopkins Bayview through the generosity of the Miller family, celebrates the qualities that make for an excellent clinician – the humanism and compassion, the diagnostic delicacy and craftsmanship – that haven't traditionally been celebrated at academic medical centers.

Thomas P. Duffy, M.D., is a magnificent clinician. In fact, a longtime Hopkins administrator ranked him as one of the three greatest Hopkins clinicians ever. (The administrator's other two picks for greatest Hopkins clinicians, in case you're wondering, are the late pioneering hematologist, C. Lockhard Conley, and the late consummate diagnostician, Philip Tumulty.)

But wait: Duffy is a Yale man; in fact, he's Professor Emeritus of Internal Medicine and Hematology at Yale University School of Medicine. That's because Yale was lucky enough to snatch him up 40 years ago – after Hopkins let him go “because he was ‘only a clinician,’” says David B. Hellmann, M.D., Aliko Perroti Professor of Medicine, Vice Dean of Johns Hopkins Bayview Medical Center and Director of the CIM. “One of the greatest clinicians in the world. We are absolutely delighted that he agreed to come back for the Miller Lecture and the induction of the 2015 members of the Miller-Coulson Academy of Clinical Excellence, which celebrates master clinicians.”

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**“No one had a hint of real service. They were learning from their patients and generating new knowledge and publishing new textbooks. I’m not condemning; I understand them. But it was a culture that was remarkably late in understanding that physicians lead a life beyond the ordinary.”**

Duffy’s return highlights the sea change in the recognition and valuing of clinical excellence at Johns Hopkins. Now, our Miller-Coulson Academy, an initiative of the Center for Innovative Medicine, is leading the way in academic medicine, inspiring similar initiatives and rigorous portfolio systems by which clinical performance can be evaluated at other institutions.

The topic of Duffy’s lecture? Grace.

Duffy has many fond memories of his training at Hopkins and of the outstanding clinicians he knew – legends such as A. McGehee Harvey, Philip Tumulty, Ben Baker, and Mason Lord, who taught him physical diagnosis at Baltimore City Hospital (now Johns Hopkins Bayview) and whose name adorns the building that houses our Department of Medicine. These doctors epitomize the Hopkins tradition of clinical excellence “that is part of its very fiber.”

But Duffy, who is also a medical historian, notes the divergent legacies of two of the original “Big Four” founding faculty of Johns Hopkins Hospital when it opened back in 1889. One of them is no stranger to readers of *Breakthrough* and friends of the CIM: Sir William Osler, the first Professor of Medicine at Hopkins, whose clinical teachings and observations remain true and profound today. The other was William Welch, a pathologist and brilliant scientist who studied in some of the greatest universities in Europe; he started the first postgraduate program

for physicians in America, and his own notable trainees included Simon Flexner, Walter Reed, and two who would become Nobel Laureates, Peyton Rous and George Whipple.

Welch was the “ringleader,” Duffy notes, of a circle of early Hopkins faculty who were “enchanted by the German biomedical model of education.” What they were so enamoured of is contained in a book by a Prussian-born surgeon, Theodor Billroth. When the book, *The Medical Sciences in the German Universities*, was translated into English in 1924, Welch wrote an introduction. “The book is astonishing,” comments Duffy; among its other qualities, it is highly anti-Semitic. “When it was published in Vienna, there were riots. There are statements to the effect that patients should relate to their doctors the way a servant does to his master. The book is heavy on ideas and knowledge. There is no hint of ideals.” In embracing Billroth and German-style medical education, the medical profession in America “set forth on a journey of garnering knowledge, but never the recognition that a life in medicine is one of service.” More on this in a minute.

Duffy credits the tradition of clinical excellence at Hopkins to the other philosophical branch – the work of Osler, “his extended influence on many people, his words, his writings. I believe that he inhabits the air of Hopkins; he always did for me.” The clinicians who taught Duffy carried on the “sacred responsibility” of Osler’s clinical excellence. “The tradition doesn’t just happen on a Tuesday or Wednesday; it takes a heritage that is capitalized upon and that people continue to be excited by and about. Medicine is an oral tradition. It’s passed on, as emblazoned in the Hippocratic oath.”

At the same time, not sufficiently valuing clinical excellence in and of itself is a problem endemic in academic medicine everywhere. “It’s a very constant refrain.” At a medical meeting several years ago, Ken Ludmerer – Pulitzer Prize-nominated medical historian, professor of history and of biostatistics at Washington University in St. Louis, and longtime friend of the CIM – made a comment that stuck with Duffy. “He said that there were a remarkably large

number, a laudatory number of (faculty) chairs at his institution, and not a single one was occupied by a clinician. And then he said, ‘Not only is that unfair, that is unethical.’”

Duffy points out that the real currency at academic medical centers is the generation of new knowledge, “which in our world is usually lab-based. I think the mistake that institutions make is that clinical excellence does not compete with scientific excellence. My prejudice is that they are synergistic with one another.”

**“People think I’m naïve, that my conception of medicine as the richest life that any human being can live – if they choose it for the right reasons – is naïve.”**

But clinical excellence, Duffy believes, by itself is not enough. And this leads us back to service, and grace, and the focus of Duffy’s talk. “One has to understand where fulfillment is,” he says. “What constitutes grace in the everyday life of a physician? I believe that it is in encountering patients, and caring for them. I’m never going to win a Nobel Prize, but I have repeated moments of grace as a result of my life in caring for other human beings,” in responding to the call of others. “People think I’m naïve, that my conception of medicine as the richest life that any human being can live – if they choose it for the right reasons – is naïve. These days, many of the wrong reasons are leading people to be very unhappy in the profession,” and society is unhappy with medicine, too. “Isn’t it strange that at a time when medicine can do so much, when medicine is at the zenith of its scientific and intellectual knowledge, that things fall apart? That old center is not holding.”

Duffy recently re-read *The Immortal Life of Henrietta Lacks*. Lacks was an impoverished tobacco farmer and patient on the “colored” ward of Johns Hopkins Hospital in the 1950s.

Her cells were taken without her knowledge, cloned and used in developing the polio vaccine, gene mapping, in vitro fertilization (IVF), and many other projects, for which she received not a dime. “I knew all of the players – Richard TeLinde, Georgeanna Seegar Jones and Howard Jones,” pioneers of IVF. “These were the Southern gentlemen and gentleladies that I respected and wanted to grow up as. But no one had a hint of real service. They were learning from their patients and generating new knowledge and publishing new textbooks. I’m not condemning; I understand them. But it was a culture that was remarkably late in understanding that physicians lead a life beyond the ordinary.”

Grace is usually talked of in a theological context. So, “where is the secular equivalent?” It is in the act of reaching outside oneself. In his lecture, Duffy moves into the profound thoughts of philosophers, including the French mystic, Simone Weil, who described grace as occurring when one human being looks with loving tenderness upon another. He talks about another French philosopher, the Jewish scholar, Emmanuel Levinas, who said that nowhere is this grace more evident than when a human being looks upon the other who is suffering and dying. “In every patient encounter, there is a reciprocity that results in the gracing of the physician in fulfilling the call of the other.”

Clinical excellence – and scientific achievement, for that matter – are the means to a greater end, Duffy says. Not the end in themselves. “I think we don’t educate our young people properly. We educate them to believe that their fulfillment in medicine is purely intellectual. They do not capitalize on the richness, the joy that comes with acknowledging this solar battery that is available to them. They are looking for fulfillment in the wrong place.”

But fulfillment can be found in the gift of grace, and this comes in “responding to the call of others and giving ourselves and our knowledge.” It happens, or it ought to happen, when the physician reaches outside the self toward another. The simple act of raising the stethoscope is just the beginning. ■

## Aliki in the Real World

Maybe it's happened to you, or to someone you know: You go to see the doctor. You sit there, in a gown on the examining table, doing your best to describe your symptoms and confide your worries to...the top of someone's head! Or a profile! Because the doctor is typing away at your electronic medical record on a computer, not looking up before firing the next question at you. There is no eye contact. You leave the office with a prescription, or maybe an order for a lab test, and also kind of a sad suspicion that the doctor doesn't really care much at all.

It shouldn't be that way, but it is – for a lot of people, all over the country. Which is why Sujay Pathak, M.D., who just finished his medical residency at Johns Hopkins Bayview, has made it his goal to “Aliki-fy” his practice with Johns Hopkins Community Physicians at Wyman Park Medical Center in Baltimore.

“I don't get more than 15 or 20 minutes with each person,” he says, “and I don't try to handle everything in each visit. I just try to work from the standpoint that we're going to start by knowing each other as people.” He spends the first few minutes of each visit just talking with his patients, finding out who they are, asking about their families, what they like to do for fun, where they grew up, how long they've been married. “If they've been married more than 20 years, I ask them what's the secret. I tell them I just got married a couple of months ago, and I want to learn from them.” He also asks his patients what they prefer to be called; nicknames are important in his inner-city urban population. “A lot of people don't go by the first name that is in their chart.” For example, one man named James goes by Jelly; a man named Byron is Buddy to his friends; another man's nickname is Cougar.

**“I find myself incredibly happy in my medical practice.”**

Then, Pathak writes it all down in the chart. “I think I end up painting a pretty vivid picture. I learn about their kids, their grandkids, where they work. I have a really bad memory, but before I walk into the room with a patient, I look at the chart and remind myself who they are. I remember who this person is, and what their face looks like. And then, when I ask them how their wife is, their faces light up, because they realize, ‘This person knows who I am, and cares about me.’ Just because I took the time to jot it down. That makes a really big difference.”

**“I learn all sorts of things that directly influence their health care. Most guys just won’t tell you that their wives are dying of cancer unless you ask.”**

Pathak believes that by developing a relationship with his patients, he can have a greater influence on their health. “I work a lot on behavior change,” he says. “I tell people what the guidelines say, how much you should be exercising, what you’re supposed to be eating and not eating”—but none of it comes as news to most of his patients; they already know it. So, Pathak gets his patients to set small goals that are reasonable – nothing earthshaking, just little changes that can add up over time.

“I will say, ‘In three months, Cougar, I’m going to ask you, are you still doing X, and I want you to say yes. What X is, is completely up to you. You know yourself, you know your life, how much time you have available to you. Tell me what you can do for exercise, or eating, or whatever goal we’re working on. Tell me what’s realistic.’ And I put it in their chart. Then I shake their hand, and I put a little note in the chart that says, ‘His goal today is X, and we have shaken on this.’ And then I show them the note and that we shook on it.”

Pathak has been doing this for about nine months now, and while some of his patients don’t keep to the goal they set, many of them do – because it was their goal, not the doctor’s.

“This is a fantastic setting in which to practice Aliko medicine,” he says. Knowing his patients as people has been essential: “I learn all sorts of things that directly influence their health care. Most guys just won’t tell you that their wives are dying of cancer unless you ask, and it’s going to be a hollow, empty experience for them unless I ask, ‘How’s your wife, what stage of treatment is she going through?’ But people don’t volunteer this information.” You have to ask.

“I find myself incredibly happy in my medical practice,” says Pathak. “It’s gratifying to call patients about their lab test, and have them tell me that I’m the first doctor that’s ever called them. And they’re 70. Considering that many of my patients are veterans, or widows of veterans, and given the sacrifices they have made for all of us, I find this both heartwarming and sad. But at least they can tell I’m doing something different.”

For the vast majority of his patients, Pathak says, taking this little bit of extra time each visit just to talk “creates an almost immediate bond between me and them that helps us get somewhere,” and helps him find the best way to help his patients improve their health. For example, “if I know they are active in church, we discuss exercise plans that involve walking around the sanctuary a few times a week. If they tell me they are afraid of crowds, we discuss home workouts.” If a patient doesn’t adhere to a plan, “I know to start asking about their mood, or their family stresses, or what other roles they play that force them to put their own health last.”

**“Their faces light up, because they realize, ‘This person knows who I am and cares about me.’ Just because I took the time to jot it down. That makes a really big difference.”**

Best of all: “I’m bonding with this lovely group of patients. I can see myself staying here for the rest of my career, aging alongside my patients, maybe caring for their children. It’s a thought that brings me a lot of joy.” ■

# The Art of Personomics

Roy Ziegelstein, M.D., a Miller-Coulson Master Clinician, cardiologist, and now Vice Dean for Education at the Johns Hopkins School of Medicine, was part of the Aliko Initiative from the ground up. He was there, talking for countless hours in those very early meetings a decade ago with David Hellmann, Colleen Christmas, and Cindy Rand, and later with Janet Record and Laura Hanyok, about what medical students and residents really need to know so that they can care for their patients.

He was there when they figured out how to implement a curriculum of caring – teaching young doctors, down to a handy list of questions they could keep in their pockets, exactly how to glean the nuggets of *who* was lying in that hospital bed. How to learn just who that person was: What was her life like; how many medications was he supposed to take (and how many could he actually afford); did he have a way to get to the drugstore or buy groceries; was she taking care of an ailing spouse as well as herself?

Always, they told each other and taught their students, *it was the person who mattered most*. They quoted the great Sir William Osler, the first professor of medicine at Johns Hopkins, who said more than a century ago, “It is much more important to know *what sort of a patient* has a disease than what sort of a disease a patient has.”

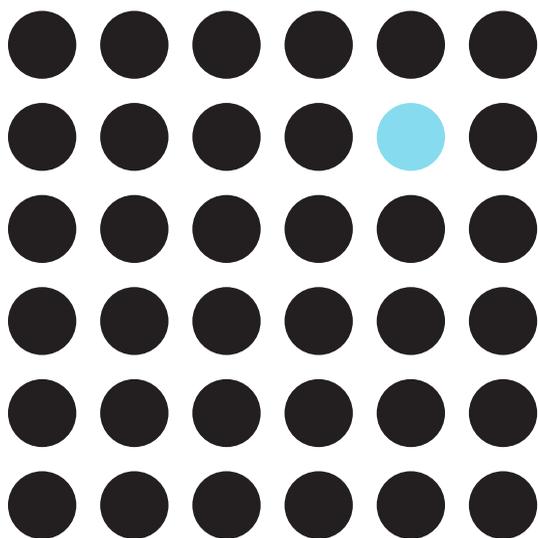
**“People have different personalities, resilience, and resources that influence how they will adapt to illness.”**  
**So basically, a disease that can turn one person's personal and family life upside down may not affect another person the same way at all.”**

The Aliko Initiative's philosophy and methods are disseminating throughout Johns Hopkins and, in our graduates, beyond our walls into the community and beyond. Recently, in an editorial in the *Journal of the American Medical Association (JAMA)*, Ziegelstein talked about these principles using a new word: Personomics. “The suffix, ‘-ome,’ or ‘omics’ is often added to an area of human biology, conveying the impression that the field is supported by hard science,” Ziegelstein says. “Given the importance of the psychological, social, cultural, behavioral, and economic factors of each person, it seems only fitting that ‘personomics’ be added to the precision medicine toolkit, and that it be used to refer to an individual's unique life circumstances.”

He wrote the article in response to another editorial that appeared in the *New England Journal of Medicine*. In the *NEJM* piece, Francis Collins, M.D., Ph.D., director of the National Institutes of Health, and Harold Varmus, M.D., Director of the National Cancer Institute, had commented on President Barack Obama's new Precision Medicine Initiative. They discussed the remarkable possibilities for improving health by determining each person's individual genotypes, gut microbes, and other uniquely tailored sets of data.

Indeed, “the possibilities are almost unimaginable,” agrees Ziegelstein, who is also the Miller Scholar. “However, an important element has been left out of the discussion. Individuals are not only distinguished by their biological variability; they also differ greatly in terms of how disease affects their lives.” And this is where the Aliko approach has proven so valuable. “People have different personalities, resilience, and resources that influence how they will adapt to illness,” Ziegelstein continues, “so that the same disease can alter one individual’s personal and family life completely and not affect that of another person much at all.”

Also – a point the CIM has been making for years with its Pyramid model of academic medicine, which puts the patient and the community at the apex – “diseases do not just affect individuals; they affect their families and friends, and their communities.” All of these factors can help or hinder someone’s resistance to disease and response to treatment. “The influence of the unique circumstances of the person – the “personome” – is just as powerful as the impact of that individual’s genome, proteome, pharmacogenome, metabolome, and epigenome,” Ziegelstein argues.



Because residents as well as community physicians now must log so much time at the computer, working on government-mandated electronic medical records, they often get to know the virtual patient – the one whose lab values and CT scans they’re reading on the screen – better than the actual, flesh-and-blood man or woman sitting just a few feet away in the clinic or hospital room. “The paucity of time spent with the patient, coupled with an overreliance on imaging and laboratory tests, has eroded history-taking and physical examination skills,” Ziegelstein writes.

Also, most medical schools don’t really teach students about real-life variables such as behavioral, cultural, or financial issues. These might include a patient’s ability to pay for prescription drugs or physical therapy; the availability of fresh groceries for a better diet, and cultural impetus to choose healthy foods over soda and chips; a safe place to exercise and the opportunity, and desire, to do it.

“The importance of understanding each patient as a person is as critical...as anything else in medical school or residency training,” notes Ziegelstein. “It is not simply that it improves patient satisfaction or contributes to the joy of medical practice, it actually contributes importantly to identifying the correct diagnosis and optimal treatment for the individual patient.”

Knowing the person is just as essential as understanding the patient’s molecular biology and genetics. “The potential of pharmacogenomics to allow health care providers to prescribe the right drug at the right dose to the right patient matters *only* if this treatment is available at the right pharmacy at the right price so that it will actually be taken in the right amount on the right day at the right time.”

The take-home message, in an age where medical technology grows more sophisticated than anything we could have imagined a few decades ago, is that it won’t ever be truly personalized medicine if the doctor doesn’t have any idea who the person really is. ■

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5200 Eastern Avenue  
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**“No one had a hint of real service. They were learning from their patients and generating new knowledge and publishing new textbooks. I’m not condemning; I understand them. But it was a culture that was remarkably late in understanding that physicians lead a life beyond the ordinary.”**

Tom Duffy, Professor Emeritus of Internal Medicine and Hematology at Yale University School of Medicine, who delivered our 12th Annual Miller Lecture, on grace in the secular world of medicine.

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