

Celebrating Aliki at 10

A BOLD MOVEMENT BECOMES A SCIENCE

*Knowing
the Patient
as a Person*

THE JOHNS HOPKINS CENTER FOR INNOVATIVE MEDICINE



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LEARNING THE ART OF HEALING

Excerpt from *Let Me Heal: The Opportunity to Preserve Excellence in American Medicine*, by Kenneth M. Ludmerer (Oxford University Press: 2015)

David B. Hellmann and Roy C. Ziegelstein listened to the concerns of Bayview house officers, who repeatedly pointed out that intense time pressures and high patient workloads did not adequately allow them to learn or heal.

In 2007 Hellmann and Ziegelstein created a new program for internal medical house officers at Bayview, the Aliko Initiative, that aimed to develop "caring doctors who have a genuine and deep appreciation of the importance of knowing each patient's unique personal circumstances and who make patient care recommendations that apply the best evidence to the individual patient." The explicit goal of the program's founders was to enable physicians-in-training not only to master the mechanics of delivering medical care but to learn the art of healing.

To accomplish this, (they) reduced the number of patients assigned to each resident on the Aliko team by one-half. Traditional internal medicine teams at Bayview admitted ten patients every fourth night on "long call" and four patients during an intervening "short call." The Aliko team admitted five patients on long call and two on short call. In addition, the Aliko house officers visited their patients after discharge at home or in institutional facilities, thereby receiving the opportunity to spend more time with patients both during and after hospitalization. With the reduced census, the Aliko team members had more time to read, reflect, participate in teaching sessions, make home visits, and engage in mentored experiences designed to improve their skills at history taking, counseling, and developing individualized treatment plans. The thrust of the Aliko experience was to help house officers develop an understanding of each patient as a unique person within his or her own home and community.

The Aliko rotation, which was required of all Bayview internal medicine house officers, quickly became the program's most popular feature. Initially house officers worried that fewer patients would mean less learning. They quickly discovered that the Aliko service provided sufficient clinical experience and that the additional time for reading, reflection, bedside teaching, conferences, home visits, and clinical discussions resulted in more learning than would be received on the standard rotations. Equally important, house officers on the Aliko service felt more fulfilled in their work. One intern remarked, "It's given me time to be the kind of doctor I've always wanted to be and do the things I should be doing for all my patients." A senior resident at the end of her residency even said that "the Aliko rotation made her love medicine again and reminded her of why she once dreamed of becoming a physician." ■

Celebrating Aliki at 10: *A Bold Movement Becomes a Science*

The trend in medicine is going the other way – toward depersonalization. Toward technology. Toward spending hours looking at a computer screen. Where is the person in this?

Ten years ago, we began a program that was very simple, very straightforward, and also a bold departure from medical trends then and now. It was called the **Aliki Initiative**, and it has been wildly successful – and far more influential than we could have imagined at first.

Aliki is now a permanent part of our DNA here at Johns Hopkins Bayview, where it continues to be led by our Aliki Scholars and Aliki leadership team (*see page 14*). As I hope you will see in these pages, the Aliki Initiative has had a transformative effect on medical education and patient care. Patients love it. Families love it. Doctors and doctors-to-be love it, too, because it places an emphasis on connecting with the patient as a person, on compassion and on aspects of doctoring that other experiences simply do not teach. It reminds us of why we wanted to become doctors in the first place.

It has also saved hundreds of thousands of dollars a year at Johns Hopkins Bayview in hospital readmissions for patients with congestive heart failure. It turns out that just taking a little extra time to make sure patients and their families understand what they need to do – the medications they need to take, when to take them, and some dietary changes that can help – has made a huge difference in the health, recovery, and lives of thousands of people. In fact, the Aliki approach has been so successful that one of its newest adaptations is as a “Hotspotting” program for a high-risk population (*see page 21*).



“Every patient has a story, and every patient’s story is worth listening to. Knowing who the patient is as a person is an essential factor in understanding how best to treat that person’s illness.”

Aliki’s impact on our residents is enduring, which means that as these young doctors leave Hopkins and go out into the community or to other academic medical centers, they are causing their own ripple effects (*see page 10*). We could take up a whole publication with responses to Aliki from patients, residents, faculty, medical educators, and others, but we’ve included just one, an excerpt from Pulitzer Prize-nominated author, Kenneth Ludmerer, M.D. (*see story on opposite page*).

The cumulative effect of the Aliki Initiative is growing every day. Soon after its launch, the initial program began to spread beyond the Aliki Service – to the Intensive Care Unit, to the Nursing School, to Johns Hopkins medical student education, and to other academic medical centers. The Aliki Initiative has created that rare thing: an educational laboratory, where we can teach interns and residents how to become better, more empathetic doctors. The Aliki Initiative has led to new academic scholarship. It has also propelled the careers of those who have been curating it; many of our Aliki Scholars and leaders have vaulted up the academic ladder to become leaders in Johns Hopkins Medicine, as well.

And now, a decade out, the Aliki Initiative is blossoming into a new science, called Personomics.

Continued next page »

Roy Ziegelstein, M.D., the Sarah Miller Coulson and Frank L. Coulson, Jr., Professor of Medicine, a Miller Coulson Master Clinician, cardiologist, and now Vice Dean for Education at the Johns Hopkins School of Medicine, coined this term (*see story on page 5*). Personomics is the natural outgrowth of the Aliki Initiative: it is the science of knowing the patient as a person.

We have barely tapped the surface here.

In order for Personomics to succeed, we need to collaborate with ethicists, information technology experts, psychologists, neuroscientists, economists, basic scientists and clinicians involved in precision medicine.

Medicine has never needed the Aliki approach more than it does now; in fact, the need is urgent. A recent study in the *Annals of Internal Medicine* found that medical residents in Switzerland spend a little over 50 percent of their time on the computer, and maybe 15 to 18 percent of their time with patients.

This is wrong. In fact, the medical residency system as we know it began at Johns Hopkins more than a century ago. It was the brainchild of Sir William Osler, who taught Hopkins residents that “It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.” The whole idea of a medical resident was, literally, someone who lives in the hospital – to be close to the patients day and night. Not to spend half of your time entering data into electronic medical records, and not to be more familiar with CT scans and lab reports than with the actual patient down the hall.

How can we add what we have learned from the Aliki Initiative to research, and how can we use this knowledge to make medical care better? We need Aliki-based science: Personomics. Roy Ziegelstein explains the difference between what we can see in patients and the science that explains it: “For hundreds of years, it has been clear that some people can tolerate their alcohol and others can’t. But that was just an observation until recently, when scientists identified a mutation in a gene for an enzyme that metabolizes alcohol. Individuals with this mutation feel

flushed and drunk after consuming just a small amount of alcohol. Whereas this observation is due to differences in individuals’ DNA and proteins, many others are related to individuals’ life circumstances, support systems, and beliefs. That’s Personomics.”

As Johns Hopkins University President Ron Daniels said about Personomics at the 2017 Commencement: The idea is neither to narrow our focus to a single person, nor to reject “the power of troves of data to revolutionize and optimize our ability to discover, to comprehend, and to heal.” Rather, it’s this: “To paint the fullest picture of any circumstance, (we) must find a way to do both – take the expansive view and look at things up close; understand the collective evidence and never lose sight of the incredible richness and complexity of the human story.”

Knowing patients as individuals is not new. It’s as old as DNA, proteins, and differences in how people metabolize alcohol and drugs. What’s new is the science of knowing patients as people. We are on the dawn of the discovery of a new field: personomics. Imagine being able to support that field from its infancy.

We have the unique ability at this time in our history to go beyond observations. Beyond the idea that some people can hold their liquor and others can’t. Some of that will be explained by DNA and proteins, but much of it will be explained by an individual’s personality, social support, culture, religious beliefs, and financial means. We need to know patients as people, and personomics will help determine the best ways of doing that.

Our goal is to transform medicine.

We are off to an excellent start.



DAVID B. HELLMANN, M.D., M.A.C.P.

Aliki Perroti Professor of Medicine

Vice Dean, Johns Hopkins Bayview

Johns Hopkins University School of Medicine

Chairman, Department of Medicine

Johns Hopkins Bayview Medical Center



DAVID HELLMANN: HOW THE ALIKI INITIATIVE GOT STARTED

It was Tuesday, September 13, 2005, and I was at Chief Rounds, with the Department of Medicine's medical house staff and some medical students. This is a time-honored tradition established at Johns Hopkins Hospital more than a century ago by Sir William Osler, and the idea is to teach, and learn, about disease at a patient's bedside.

They told me, almost apologetically, that they had 'only' — they used the word 'only' — a patient with asthma for me to see this week. As if such a patient would be uninteresting and unworthy of the Chair of Medicine visiting. I didn't like that.

I went to see this patient, named Susan.* It soon became very apparent to me that the interns and residents — while they were knowledgeable about her asthma and how to treat it — knew very little about Susan herself.

How do I know this? Because they totally missed the fact that Susan didn't live in Baltimore, but was here to visit her daughter. They knew she worked in an office, but they hadn't picked up that the office in which she worked used to be in the Twin Trade towers in New York City. It isn't there anymore, because it was destroyed on 9/11. She was one of the lucky ones who got out, but she lived through chaos and devastation and the deaths of nearly 3,000 people and the injuries of 6,000 others. Susan was part of the "second wave" of the 9/11 attacks: one of thousands who suffered health effects simply because they happened to be at Ground Zero. About one out of seven people who were directly exposed to the terrible, choking dust clouds, were found to have asthma, and many continue to suffer long-term respiratory symptoms.

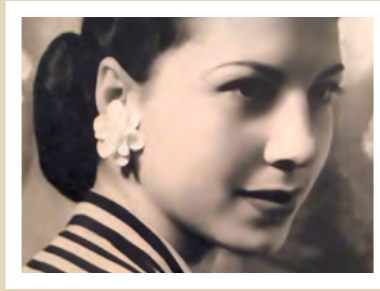
Anxiety makes it worse.

They also had no notion that she might be subject to PTSD. Every year, before and after September 11, Susan's asthma symptoms became more acute — so much so that her daughter had Susan come and stay with her in Baltimore during this time. While she was visiting, she got sick enough that she had to be admitted to the hospital.

Now, we had really wonderful residents then, and we have really wonderful residents now. I realized that this wasn't their fault; it was a fault of the system. At Bayview, I am in charge of that system, so that's when I realized that we had really gone off course, and that we needed to correct.

I realized that this wasn't their fault; it was a fault of the system. We had really gone off course, and that we needed to correct.

I explained this to Mrs. Aliki Perroti, a generous and caring philanthropist visiting from Greece. She gave us a gift to start a program to help young doctors learn to know their patients as people, and in October 2007, we started the Aliko Initiative. As you will see on these pages, that initial program has grown and evolved. We are everlastingly grateful to Mrs. Perroti, and we look forward with excitement to applying what we have learned to science — so that we can include understanding of the person in every setting of medical care, teaching, and research. ■



WHO IS ALIKI?

WE NAMED OUR ALIKI INITIATIVE AFTER THE REMARKABLE GREEK PHILANTHROPIST, MRS. ALIKI PERROTI, WHOSE GENEROSITY MADE IT POSSIBLE. Mrs. Perroti's life of philanthropy can be seen in America as well as her native Greece, and is based on a decision she made as a child.

“Going to and from school as a child in Athens,” she has said, “I saw on the streets the bodies of those who had died of starvation. This touched a nerve and made me feel that I had to share my good fortune with those less fortunate than I. When I grew up, I had the opportunity and means to do this on a large scale.”

Compassion is integral to Mrs. Perroti's character. She is the daughter of Theodoros Koustantopoulos, an internationally renowned civil engineer who helped rebuild Greece after World War II – after his wartime refusal to cooperate with the Nazis during the war resulted in the confiscation of his construction company and exposure to personal danger. In honor of her father and her mother, Maria, Mrs. Perroti established and funded the Konstantopoulou Hospital in Athens; like Johns Hopkins, the hospital is located in an underserved neighborhood and provides world-class health care to patients regardless of their ability to pay. Mrs. Perroti also established and funded the Dimitris

Perrotis College of Agricultural Studies at the American Farm School in Thessoloniki, Greece, in memory of her husband, and the state-of-the-art Aliki and Dimitrius Perrotis Library there.

She has long been a friend of Johns Hopkins, and was particularly impressed with the Center for Innovative Medicine (CIM). In addition to funding the Aliki Initiative, she also established the Aliki Perroti Professorship in Innovative Medicine.

Mrs. Perroti cares about people and has worked to make the world a better place. The idea of knowing the patient as a person is very important to her.

... AND WHAT IS *Personomics*?

Roy Ziegelstein, M.D., proposed the term, “Personomics” in an editorial in the *Journal of the American Medical Association* (JAMA)– his response to an editorial that appeared in the New England Journal of Medicine, in which two renowned scientists, Francis Collins and Harold Varmus, had discussed the remarkable possibilities for improving health by determining each person’s individual genotypes, gut microbes, and other uniquely tailored sets of data.

Yes, “the possibilities are almost unimaginable,” agreed Ziegelstein. “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.”

Because physicians now must spend 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 who’s just a few feet away*. “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 wrote.

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;

“People have different personalities, resilience, and resources that influence how they will adapt to illness. The same disease can alter one individual’s personal and family life completely and not affect that of another person much at all.”

This is the heart of the Aliki approach.

“People have different personalities, resilience, and resources that influence how they will adapt to illness,” Ziegelstein continued, “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 – “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 argued.

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,” noted Ziegelstein. “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.”

In fact, we won’t ever have truly personalized medicine if the doctor doesn’t have any idea who the person really is. ■



LANA* DIDN'T BOTHER TO OPEN HER EYES THAT DAY in 2009, as Kavitha Kolappa, the third-year medical student who was trying so hard, asked her questions; she just mumbled, “faint responses laced with irritation,” as Kolappa recalls.

Expect little, offer little. Lana had pretty much given up – on doctors, on medicine (which she didn’t take), on herself. Nearly 50 years old, a scarecrow at 70 pounds, HIV positive, diabetic, plagued by abdominal pain and nausea, addicted to narcotics, urine-positive for cocaine – she denied using it – Lana just lay there in her hospital bed encircled by residents, giving no indication of listening as Kolappa presented her case.

Beyond THE BEDSIDE





On the Aliko team, doctors make house calls. This is where they really learn what life is like for their patients — challenges like a steep staircase, or lack of transportation to the grocery store or pharmacy. Home visits have taught Aliko residents that some patients are spending their time as caregivers, too, for a parent or spouse; and some patients aren't the only ones in the household taking lots of prescription medications every day — but the pills are all stored together, which can be confusing.

Then David Kern, M.D., Kolappa's attending physician on the Aliko Initiative, looked right at Lana and said: "We know that life has not been fair to you. You've been dealt a bad hand of cards. We're just going to try to deal you one good hand."

Says Kolappa: "I think that made all the difference." Lana would go on to "surprise us all," becoming involved in her recovery, and Kolappa, Kern, and the Aliko team would come to understand Lana better: orphaned at age 7, raised in foster homes, about to be evicted from her apartment in a drug-riddled neighborhood. She loved a cat named Samson, and was a huge fan of the "Godfather" trilogy.

"We were supposed to discharge her on a Friday," says Kolappa. But Lana asked if she could stay in the hospital until Monday — and not go back to the dangers of her old neighborhood, but transfer directly to a safe place, a group home for women with HIV. Although the team "faced pressures for discharge," she remembers Kern saying, "'We are going to hold her.' It was so profound to me that

he took this risk to protect the patient and meet her needs. That's always stuck with me."

The next day, the entire team visited Lana at the group home. "When our resident asked what we could have done differently," Kolappa recalls, Lana answered: "Y'all already done everything different."

Two years later, Kolappa and Kern went to visit Lana. She was off narcotics, in her own apartment, regularly attending addiction support meetings, managing her medications, seeing her doctors regularly, and cooking for herself — in her own words "fat as a butterball," and "on cloud nine." She had a new cat named Socks and a boyfriend, with whom she went dancing on Friday nights at a neighborhood church.

That month on the Aliko service changed Kolappa's life, as well, and helped her realize "the kind of clinician I wanted to be. It gave me a 3-D insight into someone's life, into not only her challenges but her triumphs. It trained us



“You’ve been dealt a bad hand of cards. We’re just going to try to deal you one good hand.”

to connect as humans first and then as doctors and patients. But it wasn’t just the extra time;” it was being taught by Kern, David Hellmann, and Roy Ziegelstein. “They were already primed to be humanists in the way they dealt with patients. This just gave them the space to teach medicine the way it should be taught.” Kolappa decided she wanted this kind of relationship with her own patients. “I wanted to have the privilege of spending time with them and hearing their narratives.”

Kolappa is now a psychiatrist at Massachusetts General Hospital. She and Kern wrote about Lana in the journal, *Patient Education and Counseling*. ■

**In this story, patients’ names have been changed to protect their privacy.*

CLOSING THE LOOP

Linda Mobula, M.D., then an intern on the Aliko team, didn’t know that her patient, Wanda,* couldn’t go up the steep stairs of her East Baltimore row home, until she made a house call.

That home visit “really closed the loop and made me understand how important the patients’ home environment is.” Mobula found that all Wanda’s pills were kept in a drawer in her bathroom – at the top of the stairs.

“We had changed some of her medications at the time of discharge, but her caretaker had not been informed. She had two sets of medications in her drawer. I was really struck by the fact that communication is important, not just for the patient, who had a little bit of dementia, but also for caretakers.”

Months later, Mobula met David.* “He came in with abdominal pain, was found to have metastatic cancer.” At first, David was “very suspicious, and it wasn’t clear why,” until Mobula talked to him for a long time. She learned “how race and segregation affected his life and really impacted how he viewed medicine.” Then “it made sense why he was refusing multiple procedures.” David went home. Mobula went to visit him, and met his wife and daughter. “He passed away a couple weeks after that. His wife contacted me, and thanked me and the team for caring for him.”



Ripple Effect

IS THE ALIKI APPROACH MAKING A LASTING DIFFERENCE?

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

In surveys, many of our graduates have told us that their time on the Aliko service has had a significant impact on their medical practice – which means a lot to us.

But what we really want to know – and what we suspect you may be wondering, too – is: Are we making ripples in medical practice that spread far beyond Johns Hopkins?

We are.

It’s been eight years since Marc Larochelle, M.D., M.P.H., was an intern on the Aliko team. Now he’s on the faculty at Boston University School of Medicine and Boston Medical Center. Recently, he was in clinic, accompanied by Jim,* a fourth-year medical student, as they met Claire,* a new patient. Larochelle let Jim “take the steering wheel” for the history and physical. “About 20 seconds into our interaction, Claire said something and kind of laughed it off, but there were tears in her eyes.”

Jim “drove through that quickly and went back to his agenda, which was symptom-driven,” a checkbox list to get through. “I let him go for a little bit.” Then Larochelle came back to Claire’s earlier comment. “We got into a whole depth of stuff about what had been going on with her past. She had a lot of traumatic things that had been bottled up for some time. The context of what we got out of that extra 15 to 20 minutes was so important to me to understand who she is, where she’s coming from, and what she really needs.” In return Claire was “so grateful,” Larochelle says. “She had been to other doctors and felt like she couldn’t talk to anyone; she had never really felt comfortable.”

Just investing those few minutes to find out who Claire is, and to learn about some of the challenges she’s facing, made a huge difference, Larochelle says. “I hope this is the start of a relationship that is going to enable her to get on top of some substantial issues in her life” that affect her health.



The Aliko team, with attending physician David Kern, right. As Aliko alum Linda Mobula says, “If you look at medicine as a job, it’s easy to burn out. But if it’s viewed as a passion, you find it very fulfilling to spend time with your patients, because you’re so dedicated to improving their lives.”

In a typical clinic, Larochelle usually has about 20 minutes to see each patient. That’s not much time to get to know someone as a person and address specific symptoms. Meanwhile, “we’re getting messages every day in our inbox: ‘We really care about our patient experience scores, and the number one thing patients care about is their wait time.’” In turn, when Larochelle is teaching, “the main thing interns and residents want to work on is how to get faster and be more efficient. I work in a safety net hospital (which cares for many uninsured, Medicaid, and low-income patients). We see as many people as we can.

“There are all these pressures in the real world not to do what the Aliko service teaches us. But having had that experience and seeing the power and benefit of it – even in the middle of a busy clinic, I had a teaching opportunity for a fourth-year medical student. There’s a lot of value in that.” The next time he sees Claire, Larochelle adds, he probably won’t need to spend that much time talking, “but we will if we need to.” Conversely, “if I’m 20 minutes late for her, maybe she will understand why.”

Knowing the patient as a person, says David Hellmann, M.D., founder of the CIM, makes doctors feel happier in their jobs. “It’s why we went into medicine in the first place. And doctors who feel personally rewarded are less likely to burn out.”

After her residency at Bayview, Linda Mobula, M.D., spent a year in Haiti, working for Samaritan’s Purse, where she was medical director of a high-volume women’s clinic. “We saw 100 to 200 patients every day,” she says. “Despite that, based on the experience I had with the Aliko program, I really strived to get to know the patients, to hear their stories.”

When Mobula learned that many of her patients were being physically abused, she set up a focus group for discussion. The women’s stories “prompted us to design a program specifically geared toward addressing issues related to gender-based violence,” she says. “I was surprised at how open they were. They had nobody to talk to. There was a lot of fear, but when we brought them together, they actually found strength in being able to talk amongst themselves and with us.”



One of the most stunning facts that emerged: “All of their children had been conceived by rape. We never would have known that if we hadn’t really invested in trying to get to know them as individuals.”

Next, Mobula went to Liberia and took care of patients at the heart of the Ebola outbreak. Again, individual stories made a difference to public health: A woman rode in the ambulance with her dying husband. “She ended up contracting Ebola. She survived, but she transmitted it to her mother-in-law, who passed away. I thought, ‘Here’s a family who lost two individuals within a matter of days due to a protocol that wasn’t being followed.’” Mobula implemented new rules to prevent this from happening again. She learned that death from Ebola stigmatized the whole family. One woman was forced to leave her village and “had to transport her dead child for miles” to find a burial site. “It was a devastating story that caused us to think of ways to decrease the stigma. Again, this comes back to some of the lessons learned in Aliko – how important it is to listen, to get to know your patient as a person.” ■

**Names changed.*

LESS LIKELY TO BURN OUT

Aliko medicine means so much to Sujay Pathak, M.D., that when he finished his residency, he made it his goal to “Aliko-fy” his Baltimore medical practice.

“I 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.

Just taking that few minutes to show he cares makes a big difference.

“Their faces light up, because they realize, ‘This person knows who I am, and cares about me.’”

As for Pathak, “I find myself incredibly happy in my medical practice. 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.”

Linda Mobula, M.D., concurs. “I think if you look at medicine as a job, it’s easy to burn out. But if it’s viewed as a passion, and if you find it very fulfilling to spend time with your patients, I think it’s less likely that you will burn out, because you’re so dedicated to improving their lives.”



THEY’VE MET EVERY TUESDAY MORNING FOR A DECADE:

Roy Ziegelstein, Cindy Rand, Colleen Christmas, Janet Record, and Laura Hanyok. They are the Aliko leaders. “It’s a robust and energetic group,” says Rand, Ph.D., professor of medicine.

The group’s job and mission have grown over time from designing the initial program funded by Mrs. Aliko Perroti (see page 4), to implementing Personomics in multiple parts of education and patient care at Johns Hopkins and beyond – most recently working with the pediatric residency director at All Children’s Hospital in Florida to design its own version of Aliko.

The Aliko team leaders: From left, Laura Hanyok, Colleen Christmas, Cindy Rand, and Roy Ziegelstein. Not pictured: Janet Record.



Changing

THE CULTURE



The Aliko version of the History and Physical form starts with a description of who the person is. Knowing that, says Aliko leader Colleen Christmas, “then very quickly, I can hone in on important aspects of the medical facts. Thoughts come out so much clearer. Knowing who the patient is: I believe in it so strongly.”

The original Aliko project has expanded to include students from the Johns Hopkins School of Nursing and an Aliko Nurse Attending; an Aliko presence in the Intensive Care Unit at Johns Hopkins Bayview, where the challenge to know the person can be especially poignant and difficult if the patient is unconscious and hooked up to several machines; and an Aliko-type program on the Johns Hopkins Broadway campus. Personomics itself is being adopted throughout Johns Hopkins Medicine.

The leaders have published articles about the Aliko experience, given talks about it at other academic medical centers, and helped medical education leaders at Brown, Yale, Stanford, New York University, Washington University at St. Louis, and the University of Virginia, who are interested in establishing their own versions of the Aliko curriculum.

“It’s hard to know how many programs are using the Aliko curriculum,” says Colleen Christmas, M.D., Director of the Primary Care Leadership Track at the Johns Hopkins School of Medicine. “It is published on Med Ed portal, available for anyone to use it free.”

There is now an Aliko version of the electronic History and Physical Form available to all Johns Hopkins physicians. “The Aliko format starts with a description of who the person is,” says Christmas. “When I’m taking morning report and the residents from a non-Aliko team are presenting in the standard medical format, I feel like I can’t generate my thoughts about the patient until I get all the way through to the bottom of the presentation and learn about the patient’s life. Then very quickly, I can hone in on important aspects of the medical facts; thoughts come out so much clearer. Knowing who the patient is: I believe in it so strongly. It actually helps me doctor better.”

The Extra Time Myth

David Hellmann, M.D., Chairman of Medicine and Vice Dean at Johns Hopkins Bayview, and Roy Ziegelstein, M.D., Vice Dean for Education at the School of Medicine, flat-out do not believe that the Aliko approach slows down an experienced doctor.

“Like many skills,” says Hellmann, “learning to know the patient as a person does take time to master and does require continued practice.”

Imagine having to take care of a patient “without knowing anything at all about him or her. Really imagine doing that. What would happen? The diagnosis and treatment would likely be wrong, the patient would feel unimportant, and the doctor wouldn’t feel rewarded.”

But I’m skeptical that, once learned, these skills require significantly more time. Indeed, knowing the patient as a person may save a lot of time, particularly for unnecessary testing.”

Just imagine, says Ziegelstein, having to take care of a patient “without knowing anything at all about him or her. Really imagine doing that. What would happen? Under most circumstances, the interaction would be so inefficient and ineffective that it would take longer, or there would be more time spent in the long run correcting mistakes. The diagnosis and treatment would likely be wrong, the patient would feel unimportant, and the doctor wouldn’t feel rewarded.”

The key, says Christmas, is “getting to the right diagnosis and treatment for the individual, and that’s why this is a better, more efficient way to think about patients. Most of the chronic diseases we see now in internal medicine – diabetes, heart disease, hypertension, stroke – are related to behavior.” That hasn’t always been the case, she adds. A few decades ago, “we cared for people with acute infections, and maybe knowing the patient as an individual wasn’t as important as knowing the acute medical symptoms. Now, so much of what we take care of in medicine is related to how people are living their lives. Without understanding the person and the environment, you can’t just focus on the pure, straight-up physiology. It’s time for the Aliko approach, because patients have changed. So much is behavior.” ■

“WE NEED TO MAKE THIS A SCIENCE”

The next step, says Colleen Christmas, M.D., is to prove scientifically what the Aliko physicians know anecdotally. “We know we can make faster diagnoses and come up with more pragmatic treatment plans. We know this improves patient satisfaction and also prevents physician burnout.” Now: “How can we study these things further? There are plenty of opportunities for new scholarship.”

A number of studies support the idea that “knowing patients as people translates into better care,” says David Hellmann, M.D. “But it’s not yet at a scientific level of credibility that would justify commanding the nation to spend money on this — say, the way there is for evidence of childhood vaccinations.”

Also: “We know that one-third of what doctors order apparently is a waste. Will Personomics reduce that waste? We don’t know economics of this; we don’t understand on a broader scale whether this impacts choosing wisely. We don’t know how much of what we are teaching young doctors about Personomics will stay with them. We need to make this a science.”



Personomics

IN A COMPLICATED WORLD

“Disease is not just ... biology, and healing still requires a very strong focus on the spirit. That doesn’t go away just because we now have technology to understand the disease process at the molecular level.”

Back in 1889, the founders of Johns Hopkins Hospital recognized that there were “two integral parts of medicine: science, and the spirit,” says Antony Rosen, M.D., Vice Dean for Research and Director of the Division of Rheumatology: “Those two components were inseparable, and that remains true today,” in our increasingly high-tech and busy medical environment.

“Disease is not just the aggregate of biology, and healing still requires a very strong focus on the spirit. People still get presented with something that is life-altering, and that doesn’t go away just because we now have technology to understand the disease process at the molecular level.”

Rosen, an integral part of the Johns Hopkins Center for Innovative Medicine (CIM) from its start more than a decade ago, pioneered “Precision Medicine” in Rheumatology. This is precision diagnosis and treatment tailored to someone’s *specific* illness, as opposed to a “cookie-cutter” drug or procedure that might help most – but

not all – of the people who have that same disease. With funding from Hopkins Dean and CEO Paul Rothman, M.D., and Johns Hopkins Health System President Ron Peterson, Johns Hopkins Medicine is now establishing Precision Medicine Centers of Excellence throughout the institution.

How do the Aliko Initiative and Personomics fit into Precision Medicine? They are essential to it. Cindy Rand, Ph.D., Professor of Medicine, a member of the CIM and the Aliko Initiative from the beginning, puts it this way: “The Aliko program began as a way of teaching young physicians how to deliver patient-centered care, to know the patient as a person. That’s the type of care we want all of our patients to experience – every patient in every setting. Now Johns Hopkins Medicine, as part of its strategic plan, has embraced patient- and family-centered care. Personomics is very much aligned with that, and is trying to extend those Aliko principles across teaching, patient care, and research.”



How do you get to know the person sitting in front of you? “There are certain questions that help you get there, but you can’t just go through an algorithm.” Like any skill, Personomics takes time, experience, and lots of practice.

Bringing in the Family

Perhaps nowhere in medicine is the family more important in helping a doctor know who the patient is than in the ICU – where people are seriously ill, hooked up to sophisticated machines, and maybe not even conscious. Janet Record, M.D., one of the key Aliko leaders, says that in the ICU, many important conversations doctors have are not with the patient, but the patient’s family. How do you teach a young doctor that this person lying in the bed is more than just a set of organ systems that are trying to crash? “Yes, you need to stabilize the patient,” says Record. “But it’s also important to find out what’s in keeping with that person’s values and goals.”

Starting Younger

Because of her work as an Aliko leader, Record has been asked to run a new program for third- and fourth-year medical students focused on patient-centered care in the clinic. She encourages them to think about the person sitting there on the examining table, and not just the symptoms. “Empathy declines the longer someone’s in training,” she says. “People often enter medical school

with ideals that they are going to make important connections on a human level with their patients.” But then “they get mired in the overwhelming amount of work and stress that comes from learning, being evaluated, and being immersed in a culture that’s perhaps not always patient-centered, being pulled in all sorts of directions.”

Learning When to Pull Back

Perhaps the most respect a doctor can show a patient is to know, as Laura Hanyok, M.D., says, “when not to push it.” Hanyok, one of the core Aliko leaders and now Assistant Dean for Graduate Medical Education, says, “There are different ways to get to know a person; some are more straightforward; for some people, I take another approach. Here’s a brand new person sitting in front of you. How do you get to know him or her, and find out what’s important in that person’s life? There are certain questions that help you get there, but you can’t just go through an algorithm.”

David Hellmann, M.D., was describing the Aliko Initiative several years ago. “One resident said, ‘My mother would love this. But my father just



likes to go to the eye doctor and get his glasses straightened and fixed. He doesn't want anybody to know him." In other words, some people just want the medical equivalent of the self-checkout lane at the grocery store, and that's okay.

"Hotspotting" for Patients at Greatest Risk

Steve Kravet, M.D., President of the Johns Hopkins Community Physicians, used to have a bad attitude about "concierge" medicine – where doctors limit the size of their practice and charge a retainer fee. "I really abhorred it. But through my experiences with Aliko, I've come recognize that my biases might be somewhat misdirected: I think there are some physicians who do concierge medicine because they want the gift of time. They want to get to know their patients better and provide the kind of care we all want to provide."

Kravet would like to find a way create smaller patient groups for all the JHCP doctors one day. In the meantime, he has found a way to provide concierge-type medicine to some patients who need it the very most: by "Hotspotting."

"In our Medicaid population in East Baltimore, for a very high-risk set of patients who are sick and challenging in many ways – medically, socioeconomically, and culturally – we created a Hotspotting panel. For 100 of our sickest patients, we have a doctor, nurse practitioner, social worker and medical assistant. We've demonstrated a three-to-one return on our investment in savings of health care costs through this model. That is a type of Aliko medicine, and it's being funded by an insurance company. The concept is alive and well." ■

"I can easily and honestly say that I have not met a person in my life who has the pure and deep and unlimited love for her fellow human beings more than Aliko, and who has translated that love generously, and unselfishly and incredibly into acts of tangible worth and meaning."

— SETH FRANK

Thanks to Mrs. Aliko Perroti, we are transforming the way medicine is taught and practiced. Where will the science based on Aliko medicine take us? The possibilities are exciting and limitless, as we bring knowledge of the patient as a person into every aspect of medical teaching, research, and care.

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