February 2002

Clinical Center News

In this issue:

Bennie Wilson jokes with his wife Karen, a kidney transplant recipient, on patient care unit 11East.

'Angel in disguise' gives coworker a new chance at life

Acts of kindness, big and small, occur in unexpected places. Such was the experience for Karen Wilson of San Antonio. She and David Carter had been working in the same office for five years at their jobs as computer specialists when Karen began feeling ill.

Carter had noticed Wilson wasn't her usual zestful self. Their relationship was like that of many coworkers, chatting about family and business matters or having lunch together, going home their separate ways at day's end. But Carter became concerned about Wilson and sent an email to her husband Bennie who confirmed his wife was having health problems—he told Carter she was experiencing kidney failure and needed a transplant.

Not long after he sent the email Carter handed his coworker a note asking her to wait until she got home to open it. In that note, the essence of his message was a living donor's plea, "please let me do this for you." Wilson couldn't believe what Carter was offering. He was offering to give her one of his kidneys. "David is a warm and sensitive person. Neither of us is shy but we are private people

See **Organ**, page three

NIH serves as accreditation practice site

NIH went under the microscope for ten days in December and January, when a team from the Association for the Accreditation of Human Research Protection Programs (AAHRPP), evaluated clinical research programs as part of a pilot to develop an accreditation process for human subjects research.

AAHRPP is a nonprofit organization that offers accreditation to institutions engaged in research involving human participants. It was incorporated in April 2001 to ensure that scientific research can continue to grow and flourish under conditions in which the best interests of research participants will be protected.

"The visit afforded NIH the opportunity to receive a candid, confidential assessment of the effectiveness of our human subjects research program, and it enabled AAHRPP to begin to test out its accreditation and site-visit process," said Dr. Michael Gottesman, deputy director for Intramural Research.

The accreditation process involves two steps: rigorous self-assessment, followed by a site visit from AAHRPP accreditors. The voluntary, peer-driven, and educationally focused accreditation process aims to foster a culture of conscience and responsibility within institutions

See **AAHRPP**, page five

briefs

African American history

The NIH Annual African American History Month Observance will be held on Monday February 25, at 1:30 p.m. in Lipsett Amphitheater, Bldg. 10. Roger Wilkins, LL.B., writer, historian and civil rights activist, will be the keynote speaker. For more information contact Kay Johnson Graham at 301-402-6419.

NIH/PITT training

Applications for training in clinical research from the University of Pittsburgh are available in Bldg. 10, Room B1L403. The program requires that students spend eight weeks in residence at the University of Pittsburgh, beginning in July 2002. The eight-week summer program is then supplemented by additional courses offered at the Clinical Center via videoconferencing. Tuition for the 2002-2003 academic year is $480 per credit, with partial tuition waivers for some courses. The room charge for the eight-week summer session is $800. Prospective participants should consult with their Institute or Center regarding the official training nomination procedure. For more information send an email to crtp@imap.pitt.edu or call 412-692-2686. Deadline for applying is March 1, 2002.

NIH/Duke training

The deadline for applying to the 2002-2003 NIH-Duke Training Program in Clinical Research is March 15, 2002. Designed primarily for clinical fellows training for careers in clinical research, the program offers formal courses in research design, statistical and decision analysis, research ethics and research management. Courses for this program are offered at the CC via videoconferencing from Duke or onsite by adjunct faculty. Academic credit earned by participating in this program may be applied toward satisfying the degree requirement for a Master's of Health Sciences in Clinical Research from Duke University School of Medicine. For additional information regarding course work and tuition costs, refer to the program website at **http://tpcr.mc.duke.edu/**.

Commute to NIH

Beat the Beltway Blues is a bus service that runs from Glenarden, Landover, Riverdale, College Park, and Greenbelt to the NIH Metro Station. The coach buses run every 30 minutes and cost $1 each way. NIH employees can use their Transhare Metropasses to ride. For more information visit the website at **http://www.mtamaryland.com/schedules/beltwayblues/beltwayblues.cfm**.

Nursing database available

The NIH Library now offers convenient access to the Cumulative Index to Nursing and Allied Health Literature (CINAHL), through any campus computer desktop. CINAHL provides authoritative coverage of all aspects of nursing and allied health disciplines, and indices more than 1,000 publications. To access CINAHL, go to **http://nihlibrary.nih.gov/Elecres/databases.htm**.

Senior Administrative Officers named

A new senior administrative officer will work with the clinical departments that report to CC Deputy Director David Henderson. Colleen McGowan joined the CC staff after completing her final assignment in the Air Force as Director, Regional Joint Venture and Director of Managed Care at the David Grant Medical Center in Fairfield, Calif. McGowan attained the rank of Major while serving in the Air Force from 1991 to 2001. She earned her B.S. degree in Business Administration from the University of North Carolina, Chapel Hill where she received the Chancellor's Award for Leadership. McGowan is a diplomat of the American College of Healthcare Executives (ACHE), and received the ACHE Early Career Regent's Award in 1999 and 2000.

Robert Mekelburg will serve as senior administrative officer with the Operations Department. Mekelburg worked at the University of Maryland Medical System in Baltimore as the Vice President of business development before coming to the Clinical Center. He earned his M.B.A. in health administration from Temple University, managed clinical services at Southern Maryland Hospital Center, Clinton, Md., and served as administrator of Anesthesiology Associates within the University of Maryland Medical System. Mekelburg's accomplishments include the establishment of the Joslin Diabetes Center in Baltimore, implementing new cardiac catheterization labs and revamping a community psychiatry program.

Clinical Center News

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Coller is newest member of Board of Governors

Dr. Barry S. Coller is the newest member of the Clinical Center Board of Governors. He has the distinction of being the first endowed David Rockefeller professor at Rockefeller University in New York City, a position he was appointed to in December 2000. As physician-in-chief, his laboratory is devoted primarily to investigating platelet physiology, vascular biology and adhesion phenomena in sickle cell disease.

A *magna cum laude* graduate of Columbia College, Dr. Coller attended New York University School of Medicine, trained in internal medicine at Bellevue Hospital in New York City, and received additional training in hematology at the NIH.

He was appointed as the Murray M. Rosenberg Professor and Chairman of the Samuel Bronfman Department of Medicine at Mount Sinai School of Medicine in 1993. Previously, he served for 17 years as a faculty member of the State University of New York at Stony Brook on Long Island, N.Y., where he achieved the highest academic rank of Distinguished Service Professor. At that time he was also clinical chief of the Hematology Laboratory at Stony Brook University Hospital and head of the Division of Hematology in the Department of Medicine.

The CC Board of Governors was established in 1996 by former Department of Health and Human Services Secretary Donna Shalala to oversee the management of the hospital at the NIH. The governing body is comprised of physicians, scientists and healthcare managers from some of the nation's top academic medical centers and from across the NIH.

Act of kindness highlights importance of organ donation

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so I was surprised," she said.

Annually, living donors account for about one-third of the kidney transplants performed in the United States. Blood relatives, who offer the best chance of compatible tissues and blood types, are responsible for most of those donations. The United Network for Organ Sharing reports that unrelated donors were responsible for about 950 of the 4,000 living donor kidney transplants that occurred during January-September 2001.

Several of her family members had already offered to be kidney donors but were not suitable matches. Carter was evaluated for his compatibility and discovered he was a match.

That was more than a year ago. By early 2002 both Wilson and Carter were on patient care unit 11East with the actual transplant set for January 8. The procedure went well. Wilson, who is the third of four siblings, now refers to Carter as "her youngest brother."

Doctors think a rare virus may have caused her kidney failure. Wilson is participating in an NIDDK clinical trial that is testing a new treatment protocol designed to reduce the need for anti-rejection drugs among transplant recipients. She and her husband think coming to the NIH Clinical Center was a good idea. "This was absolutely the right thing to do. We feel like Karen is doing her part for future medical scientific protocols. She and David are part of a building process. He gave his kidney to her and she is giving of herself by participating in the medical research process to in turn help the next person. Our only wish is that this chance were more universally available and economically accessible," said Bennie Wilson.

After a brief recuperation Carter is back on the job at Wilford Hall Medical Center in San Antonio. Wilson hopes to return to work there by late February. In the meantime she feels better about her present quality of life compared to before the transplant when she had to undergo dialysis four hours a day, three times a week and had difficulty climbing stairs.

She will also have the time to reflect on the generosity of her coworker. Perhaps Wilson's mother, Eula Paul, summarized it best. "It's amazing when you think of who you haven't known and then realize that someone reached out like that—an angel in disguise."

Indeed.

–by Dianne Needham

Responding to a need

Cultural brokers bridge diverse patient worlds

The Clinical Center has responded to its international patient population by hiring two multilingual interpreters, a first in Clinical Center history.

"We're like cultural brokers," said José Rosado-Santiago, one of the newly hired interpreters. "The patient comes here and is unfamiliar with how NIH and the Clinical Center work and the staff is unfamiliar with how things work for the patient. It's not that the patient doesn't speak English, but it's that the staff doesn't understand the language and the culture. It works both ways."

Rosado-Santiago came to the CC as an intern through the Hispanic Association of Colleges and Universities. Being fluent in English, Spanish, French, Italian and Creole, Rosado-Santiago volunteered his services as an interpreter at the CC before applying for the new position.

"It's more rewarding to be a part of the process and watch these patients come to the CC not knowing where to go or what to do, and in a matter of weeks, they can find their way around and go to the market by themselves," he said. "It's just good to know that you were a part of that process of a patient becoming independent."

When María Rudulovic's husband told her about interpreters being needed in the CC, she came to volunteer and was put to work immediately. That was in July 2001. Five months later she was hired permanently.

"NIH is a model and strives to be the best at what it does," said Rudulovic, who is fluent in Spanish, English, French, and German. "We are striving to be the best model for international patients."

The move to hire two full-time interpreters stems from a federal executive order passed in August 2000, requiring all federal facilities receiving medical funding to provide adequate service to those with limited English proficiency. Those agencies not providing adequate service are in violation of Title VI of the Civil Rights Act of 1964, that promises equal access to all federally assisted programs and activities. According to the Office for Civil Rights, English is spoken by 95 percent of the people in the United States. However, the remaining five percent represent millions of people who cannot speak, read, write or understand English.

"Patients are being brought in from different countries and we are required to provide good, quality patient care, and that includes interpreters," said Andrea Rander, director of Volunteer Services.

Within the past three years, the demand for interpreters has grown six times, exceeding the capacity of the original program. The interpreter program began as a volunteer-only program. In 1990, only two volunteer interpreters who spoke Spanish were needed. Today, the numbers have grown to more than 100 volunteers and 42 languages.

Yet oftentimes volunteers are not always available. When interpreters are not provided, then service to patients may be delayed or sometimes denied until an interpreter can be found.

According to Adrienne Farrar, chief, Social Work Department, that is not how the CC should present itself to its international patients. In fact, Farrar sees these new hires as just the beginning of a much larger program. "We are continuously building the program," she said. "We are establishing policies and procedures and we are piloting several new systems."

One new system is the

See **Interpreters,** page five

José Rosado-Santiago and María Rudulovic are the first interpreters to be hired at the Clinical Center to help with the increasing population of international patients.

> ***"We want the CC to be seen as an international resource..."***
>
> ***– Adrienne Farrar***

Blood donor couple hits 100 mark

In 1996, Elizabeth Diffley walked into the NIH Blood Bank and gave blood for the 100th time, entitling her to have her photograph placed on the blood bank's Wall of Fame. She was the first woman to receive that recognition.

Now, she and her husband John, both of Bethesda, Md., have the distinction of being the first couple to give blood at the Blood Bank 100 times.

"We are the only couple to have a place on that wall," she said .

Elizabeth and John, both 80, have been blood donors for more than 25 years. She began in 1974 and, despite having donated to the Red Cross, Elizabeth developed a fondness for the NIH Blood Bank.

"We have a daughter who was seriously ill when she was younger and she received marvelous care here," she said. "Everyone was so nice and professional. We've never had a negative experience giving blood at the NIH." She especially praises Glorice Mason, R.N., a Department of Transfusion Medicine staffer who has known the couple for years.

"They're very dependable," Mason said. "They're a sweet couple who have come here religiously every eight weeks for well over 15 years." Mason, who has been at the Blood Bank since 1970, has personally tended to Elizabeth through those years and has formed a strong bond. "She only comes on days when I'm here," she laughed, "but anyone

can do John's blood draws. He's not particular and has big veins."

Besides donating blood, John volunteers for apheresis, a procedure in which blood is drawn from a donor and separated into its components, some of which are retained, such as plasma or platelets, and the remainder returned by transfusion to the donor.

John and Elizabeth were married in Washington, D.C., in 1949. Elizabeth pointed out John is "strongly motivated" to do things for others, especially when children are involved. "He's pretty good about that," she said.

"We're both impressed by the Children's Inn at NIH and the services it provides for the families of cancer patients." She added that when she sees that level of service provided to those in need, it makes her want to do her part.

–by John Iler

Interpreters help patients adjust

continued from page four

CyraPhone, which is currently in use. The phone is a dual-handset telephone that allows a patient and a physician to be on the line at the same time while speaking to an interpreter. The interpreter on the other line is part of the Language Line, a service providing interpreters on-demand. The service has translators in 142 languages.

Farrar also hopes to incorporate employee training and education into the program. Many employees don't speak a second language and are also unaware of cultural differences, which can hinder a relationship with a patient. "We'd like to see more bilingual employees on staff," said Farrar. "If a nurse is hired and speaks two or three languages, that nurse should be compensated for providing a service."

Overall, Farrar said she would like to see the Clinical Center provide more than just an interpreter to it's international patients. "I see this developing into an international patient center that can follow patients from recruitment through discharge," said Farrar. "We want the CC to be seen as an international resource and we want to have services that support those resources in order to make our international patients feel comfortable and adjust to life not only in the Clinical Center, but also in this country."

–by Tanya Brown

NIH volunteers as test site for AAHRPP accreditation

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seeking its services.

The team sat in on 13 NIH Institutional Review Board sessions and interviewed senior officials, clinical directors, including CC Director Dr. John Gallin, investigators, and research staffs of each Institute. The team also met with CC employees from the Pharmacy Department, Patient Representative Office, and Protocol Coordination Service Center.

Mark Brenner, vice president for research, Indiana University, Bloomington, and vice chancellor for research and graduate studies, Indiana University-Purdue University, chaired the evaluation team. Five other experts in human subjects protection, a clinical investigator and institutional officials who deal with clinical research, completed the team.

Highlights of individual practices within the Clinical Center, such as the standards for clinical research were recognized as being an enhancement to human subjects research.

"The AAHRPP team concluded that NIH has a vigorous and innovative clinical research program with a strong culture of support for human subject research protections to which the NIH leadership and investigators are committed," said Dr. Gottesman.

Murray to lead Microbiology Labs

Patrick R. Murray, Ph.D., was recently named as chief of the Clinical Microbiology Laboratories. Murray earned his Ph.D. in Microbiology and Immunology from UCLA and continued his postgraduate education training as a fellow in Clinical Microbiology at the Mayo Clinic.

After completing his fellowship, Murray became assistant professor and later was named as a professor in the Departments of Medicine and Pathology at Washington University, St. Louis, Mo. Because of the relatively large volume of clinical specimens produced from Murray's lab, he was instrumental in fostering a relationship with diagnostic companies involved in the development of new test procedures.

Prior to coming to the CC, Murray served as a professor in the Department of Pathology at the University of Maryland, Baltimore, where he currently is adjunct professor in the Departments of Pathology and Pediatrics.

"I plan to build on the foundation of excellence that the clinical microbiology laboratory has enjoyed through the years," said Murray.

He will focus on two primary areas that include expanding the molecular diagnostic techniques into the areas of epidemiology and routine detection and identification of microorganisms, and expanding the postdoctoral training programs because "these Fellows represent the future of microbiology," he said.

Murray is editor-in-chief of the Manual of Clinical Microbiology, which is the most commonly used reference text in the U.S. He is also the author of Medical Microbiology, a clinical textbook used in medical schools around the U.S.

Additionally, Murray sits on the editorial boards of the Diagnostic Microbiology and Infectious Disease and the European Journal of Clinical Microbiology and Infectious Disease.

Murray has a wife, Judith, one daughter, Julie and two sons, Tim and David.

Managers attend customer service meeting, hear employee feedback

"We are committed to ensuring that customer service is a priority and is at the core of all we do," Clinical Center Director Dr. John Gallin said in opening remarks to senior managers who gathered January 15 for the leadership installment of the Center's customer service initiative. In the half-day session, "Contact: You Make the Difference—Management's Role," department heads and office chiefs heard presentations on a customer service model for managers, collaborative communication, bridging the gaps in customer service, and leading teams.

An intense dialogue ensued throughout the session as members of senior management discussed various topics such as patient expectations. As a unique hospital-based setting involved in biomedical research the Clinical Center faces many challenges in satisfying its diverse patient populations. Referencing plans to conduct a patient survey, managers agreed that it would be a good idea to hold focus groups that will further clarify patient responses in the survey.

Attendees talked about leadership and its relationship to customer service—that leadership's role in customer service is to inspire with competence, courtesy, and compassion and that a leader is someone who sets a positive example with these traits, not just the individual holding a management position. Dr. King Li, associate director, Radiology and Imaging Sciences, gave an example of how one receptionist in his office purchases candy to make it easier for patients to drink contrast agents for imaging tests. "These are the kinds of actions that point out how important we are to each other," he said.

Managers learned that if employees feel valued by their supervisors and are treated thoughtfully, they would pass this type of relationship on to their customers. Meeting facilitators emphasized that 80 percent of problems arise from systems and processes while 20 percent of problems stem from people.

Employee Feedback

The full second half of the agenda was spent on employee perceptions of barriers to excellent customer service in the Clinical Center. Feedback collected from 1,258 individuals, clinical and non-clinical front-line employees, and supervisors, during 68 customer service-training sessions was shared with management. Meeting facilitators noted that the employee comments were "delivered in heartfelt conversations during customer training."

The purpose of the feedback is to understand what employees see as hurdles to delivering the very best customer service and to enable Clinical Center leadership to respond to employees' input. Feedback in the form of the highest to lowest perceived barriers, was categorized as follows:

1) Interpersonal/Teamwork: focuses on people with both intradepartmental and interdepartmental issues represented;

2) Intradepartmental Standard Operating Procedures: identifies the

See **Service**, page eight

Deputy Fire Chiefs Michael Kelley, Sandy Spring, and Jim Wilson, Kensington, at Kensington Fire and Rescue Station Number Five.

Wilson saves child's life

CC employee lives by a dutiful creed

First emergency dispatch call: "child unconscious." Second emergency dispatch call: "child has stopped breathing."

Clinical Center Facilities Management Chief Jim Wilson heard those words over the Montgomery County fire radio communication system while driving to a meeting after work in December. "When the second vocal call came out for all units—advanced medical support with paramedics, ambulance, and fire engine—to respond I was about a block and a half from the incident," he said. Wilson turned on his vehicle's siren and emergency lights, went straight to the house, and was on the scene at about the same time as another fire department's deputy chief, Michael Kelley.

Kelley grabbed a resuscitator, Wilson the first aid bag and radio and they ran inside the small house. About 10 people were nervously huddled around a young boy approximately three years of age. The boy was lying down, face to floor, no pulse, no breathing. Located closest to the child was his grandfather. Wilson asked the man if the child had been sick. Yes. Wilson asked if the child had had the flu with a fever and vomiting. Yes. Wilson immediately concluded the child had suffocated.

He and Kelley turned the boy over, swiped his mouth and put his tongue in position to perform CPR. After three breaths and chest compression the boy coughed and his eyes blinked. The grandfather let out an audible sigh of relief. Wilson then got on the emergency radio to inform dispatch that the child was breathing and turned the scene over to the emergency medical technicians who had by then arrived.

Wilson turned to his co-rescuer and said, "Well Mike that's one save for us." The family thanked Wilson and Kelley. "They felt the fire department saved the boy's life. One person told me, "as soon as we called, you were there. It doesn't always happen like that," added Wilson.

The creed that command-level fire and rescue officers such as Wilson and Kelley follow—if you are closer to an emergency than the first available responding units, you go!—is one that Wilson intimately knows. He has 40 years of fire and rescue training and work experience. During the majority of that time he served as deputy chief of the Kensington Volunteer Fire and Rescue Department along with four years as department chief. With 200 volunteer and 100 career status employees, 40 pieces of apparatus, four stations, and a coverage area of 35 square miles, Kensington Fire and Rescue is the largest in Montgomery County and the State of Maryland.

Wilson is matter of fact when he talks about his strong ties to fire and rescue work. "You do what's necessary. There's a call, not always of this magnitude, about once a week. It could be an auto accident, a building fire or an injured person. If I'm close, I go," he said. Noting the motivation for doing this work he added, "It's a good feeling that you get when you return something to people—their life, their dog, bring a child their burnt up doll. It's the closest type of human relations."

Needham new deputy of communications

Dianne L. Needham is the new deputy director in the Office of Communications. She comes to the NIH Clinical Center from the National Cancer Institute, where she served as a program official in health communication and informatics research. Needham holds a Master's degree in Political Economy with a health sector research emphasis from the University of Texas at Dallas' School of Social Sciences and a Bachelor of Science in Journalism and Life Sciences from Ohio University. The NIH recruited her from the prestigious Presidential Management Intern program. Prior to joining the NIH, Needham was a professional journalist, working in radio news as a reporter and producer. The recipient of numerous writing awards, she has extensive experience as a communications practitioner in both the health and medical fields and the financial and computer services industries.

Managers discuss importance of customer service

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impact of individual department processes on patients and internal customers;
3) Systems/Policy: focuses on requirements and structures that are organizational in nature; and
4) Material Resources: relates to how resources are managed and provided.

Senior managers were clearly impressed by the fundamental barrier statements provided by rank and file employees. They will use the employee data as the basis for the first step in identifying areas that require attention from either a management or process redesign standpoint.

Leadership Response

At the leadership customer service training session management acknowledged and clarified the employee perceptions of barriers to delivering customer service. Clinical Center Director Dr. Gallin has charged each department with formulating a customer service plan this year. Next steps in the customer service initiative focus on processes that need redesigning to improve outcome measures. At their retreat in early March managers should be prepared to present department-level customer service plans. Managers must also make customer service a part of each employee performance plan.

"Customer service is an endeavor that leadership takes very seriously," said Dr. Gallin. "Our efforts in managing an organization as complex as the Clinical Center are thoroughly enhanced by this initiative."

Senior managers listen as Dr. King Li (second from left) emphasizes the important role all employees play in customer service.

february

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater
Reasonable Availability: When Should Researchers Working in Developing Countries Have to Guarantee the Reasonable Availability of Any Interventions that are Proven Effective?
Reidar Lie, M.D., University of Norway, Discussant

Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium
Molecular Basis of Addictive States
Eric J. Nestler, M.D., Ph.D., Texas Southwestern Medical Center, Dallas

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater
Type 2 Diabetes: The Good, the Bad and the Ugly
Robert Kreisberg, M.D.
Univesity of South Alabama

Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium
Papillomavirus Virus-Like Particles: For Vaccines Against HPV and Other Diseases.
Douglas R. Lowy, M.D., NCI

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater
The Effect of Phytochemicals and Cancer Prevention: Wine, Locorice and Carcinogen Activation
Grace Chao Yeh, Ph.D., NCI

Molecular Characteristics of Non-Small Cell Lung Cancer
Xin Wang, Ph.D. NCI

Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium
Biomedical Significance of DNA Polymorphisms
Georgia M. Dunston, Ph.D., Howard University,

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Grand Rounds
noon-1 p.m.
Lipsett Amphitheater
Molecular Characteristics of Non-Small Cell Lung Cancer
Jin Jen M.D., Ph.D., NCI

Wednesday Afternoon Lecture
3 p.m.
Masur Auditorium
Genetic Architecture of Complex Disease: Simple or Complex?
Aravinda Chakravarti, Ph.D., Johns Hopkins University School of Medicine, Baltimore