Secretary of State Hillary Rodham Clinton visits Clinical Center

Secretary of State Hillary Rodham Clinton called for a renewed push for an “AIDS-free generation” in a November speech in the Clinical Center’s Masur Auditorium, marking 30 years of the fight against HIV/AIDS.

“The goal of an AIDS-free generation is ambitious, but it is possible,” Clinton said, emphasizing the use of scientific advances to stem the pandemic.

“We need to let science guide our efforts,” she told the packed crowd of scientists, administrators, and State Department and Department of Health and Human Services officials.

Clinton emphasized using a variety of tools in a “combination prevention” strategy as the most effective way to combat HIV/AIDS nationally and globally, with the focus on three key interventions: ending mother-to-child transmission, expanding voluntary medical male circumcision, and scaling up treatment of people living with HIV/AIDS.

“None of the interventions can create an AIDS-free generation by itself,” she said. “But used in combination with each other and with other powerful prevention methods, they present an extraordinary opportunity.”

NIH Clinical Center celebrates family caregiver day

The Clinical Center hosted its second annual NIH Family Caregiver Day November 8, recognizing the critical role of family caregivers and encouraging them to take care of themselves.

At the CC, family members and friends who provide emotional and physical patient support are essential components of the clinical research team. According to the National Alliance for Caregiving, an estimated 65.7 million people living in about 35.5 million households in the United States serve as unpaid family caregivers. Caregivers often maintain home responsibilities in addition to being at the bedside of their loved one. For outpatients, they may administer medications, drive their loved ones to and from medical appointments, and help coordinate their care.

The Family Caregiver Day guest speaker was Dr. Gary Epstein-Lubow, assistant professor in the Department of Psychiatry and Human Behavior at the Warren Alpert Medical School of Brown University. He is also attending psychiatrist and assistant unit chief at Butler Hospital’s inpatient geriatric psychiatry unit in Providence, RI. Epstein-Lubow spoke about “Strategic Directions for Assisting Family Caregivers in Hospital Settings,” in Lipsett Amphitheater.

“Every day at the Clinical Center we have caregivers who are balancing their own needs with those of their loved one,” said Dr. Margaret Bevans, CC co-organizer of NIH Family Caregiver Day. “We need to understand their experience and help them identify what resources are out there to support them.”

Activities included an informational fair and expo where CC staff and representatives from local and national caregiver organizations reached out to attendees with educational and health oriented resources, including information about maintaining one’s physical, social, and mental health.

Bevans and event co-organizer Leslie Wehrlen said the take-home message for

Massage therapist Nae Pearson gives a seated massage to a family member of a Clinical Center patient during Caregiver Day, an event recognizing family caregivers.
Lecture addresses genes and treatment

The 14th annual Astute Clinician Lecture brought a crowd to Masur Auditorium on November 2 to learn how knowledge about human disease genes can be converted into safe and effective treatment for neuromuscular disorders. Dr. Kenneth Fischbeck delivered the lecture titled “Developing Treatment for Hereditary Neuromuscular Disease.”

Established by the late Dr. Robert W. Miller and his wife, Haruko, the Astute Clinician Lectureship honors a US scientist who has observed an unusual occurrence and, by investigating it, has opened an important new avenue of research.

Fischbeck is an NIH distinguished investigator and chief of the National Institute of Neurological Disorders and Stroke’s neurogenetics branch. His research focuses on converting what is known about the causes and mechanisms of hereditary neurological diseases into safe and effective treatments for these disorders, particularly two pediatric neuromuscular diseases, Duchenne muscular dystrophy and spinal muscular atrophy.

Training program alumni receives NIH staff appointment

Dr. Sarah Kranick is continuing to make an impact as an NIH clinician-scientist after two rounds of training on campus. In July 2011, Kranick became the first Clinical Center Clinical Research Training Program (CRTP) alumna to join the NIH staff when she was named chief of the NINDS neurology consult service. Two months later, she was also appointed NINDS assistant clinical director for medical education.

Kranick’s first NIH training experience was as a 2003-2004 CRTP fellow under the mentorship of Dr. Mark Hallett, chief of the NINDS medical neurology branch and human motor control section. After graduating and completing neurology residency training at the University of Pennsylvania, Kranick returned to Hallett’s laboratory for a clinical research fellowship in movement disorders, studying the phenomena of volition and agency, particularly in patients with psychogenic movement disorders (PMD).

Kranick’s consult position keeps her involved in general clinical neurology, providing neurological input on patients with a wide range of underlying conditions. “Patients at the Clinical Center frequently have many simultaneous medical issues. So when a patient here has a headache, it’s never just a headache,” said Kranick. She continues to work with Hallett’s group to better characterize genetic, psychological, and other predisposing factors in PMD.

Her newest medical education position is close to her heart given her previous experiences at the NIH. “I felt like a kid in a candy store when I was in the CRTP in terms of getting to talk to all of these leaders in their fields, and I hope to encourage more students and trainees to take advantage of that,” Kranick said.
Clinical Center Nursing and Patient Care Services co-hosted the third annual International Association of Clinical Research Nurses conference: “Mapping the Future for Clinical Research Nursing,” November 16-18.

This year’s theme emphasized a core agenda item of the group, which is to further define the scope of their professional specialty, said association incoming president Shaunagh Browning, nurse manager at the Georgetown-Howard Universities Center for Clinical and Translational Science. “Even the hospitals we work in don’t understand us. This is really helping organizations outside the CC to understand what a clinical research nurse does and what we bring to the clinical research process,” she said.

Dr. Clare Hastings, CC chief nursing officer, welcomed conference attendees to the NIH Natcher Conference Center, and recognized the clinical nurses who were taking care of patients so that conference attendees could be there. Hastings presented on career pathways for nurses in clinical research, emphasizing the variety of opportunities available and the way that the dimensions within clinical research nursing as a practice shift in different positions. “There is a full career’s potential in being a clinical research nurse, working with clinical research patients,” she said.

Dr. Barbara Turner, doctor of nursing practice program chair at the Duke University School of Nursing, delivered the conference’s keynote titled “Moving Forward as CRN Leaders and Scientists: Are We on the Right Track?” As a principal investigator, Turner explained, “I know that no work can get done without clinical research nurses.” She also addressed her own volunteer experience in a trial, crediting her commitment to the nurses who helped her navigate through the maze of clinical trial participation.

Turner encouraged the group to be proud of their profession, to expose nurses and nursing students to opportunities in clinical research.

Other presentations highlighted clinical and study management issues, addressed the challenges in the training and education of clinical research nurses, and proposed development of intentional and purposeful programs. “One of the things that people recognize when they come to this meeting—nurses in clinical research—is that they have finally found an organization that represents them,” said Hastings.

Study challenges standards for pulmonary hypertension

A study at the Clinical Center led by Dr. Leighton Chan, chief of the Rehabilitation Medicine Department, is challenging the way that physicians perceive and treat patients with a rare disease called pulmonary hypertension.

Pulmonary hypertension occurs when elevated blood pressure in the arteries of the lungs causes the right side of the heart to work harder than normal. Chan explained that scientists often aren’t sure what causes the disorder, but for many years treatment options often included medications and lifestyle changes that limited rigorous exercise.

“The concern was that increasing heart rate and stress elevates pressure in the lungs, which might increase heart failure. Therefore, exercise might put people at more risk,” said Chan. His team has challenged that notion and produced interesting research findings that suggest people with pulmonary hypertension may actually benefit from an intensive exercise program.

The trial, which is conducted in collaboration with Inova Fairfax Hospital and George Mason University, randomized patients to either 10 weeks of an education-only program or 10 weeks of education combined with an exercise program.

The study’s exercise program involved 25-30 minutes of treadmill training at 70-80 percent heart-rate reserve and found that those who received the combination of exercise and education made greater improvements.

“Individuals who got the exercise increased the amount they could walk in six minutes by 60 meters, which is almost double what we would consider an important finding,” said Chan. The study also found that patients in the exercise and education program could exercise

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Nurse chosen for Excellence Award

Nancy Munro, the senior nurse practitioner in the Clinical Center Critical Care Medicine Department and on the Pulmonary Consult Service, is one of 10 recipients of Washingtonian magazine’s 2011 Excellence in Nursing Award.

“It’s really a great honor,” Munro said of the award. “I love being a nurse. It is so satisfying when you can help someone understand or deal with their disease.”

Munro earned a bachelor’s in nursing from Villanova University and a master’s in nursing at Emory University. She received her acute care nurse practitioner certificate in 1997 from Georgetown University, just as the specialty was emerging. Munro was the first nurse practitioner on the Surgical Critical Care Service at Washington Hospital Center and then worked at Inova Alexandria Hospital before joining the Clinical Center in 2004.

“Nancy Munro brings to the Washington, DC, medical community leadership in clinical care for our sickest patients, leadership in training a relatively new category of health care provider, and scholarship to the ICU that enhances the quality of our workforce and our patient care,” wrote Dr. Henry Masur, chief of the Critical Care Medicine Department, in Munro’s nomination.

In addition to her full-time position at the CC, Munro is a clinical instructor in the Acute Care Nursing Practitioner/Clinical Nurse Specialist Graduate Program at the University of Maryland School of Nursing in Baltimore.

She has made significant contributions to the American Association of Critical-Care Nurses, serving on the group’s national board of directors and chairing various work groups that wrote standards for care delivery and identified important education topics.

Munro and her fellow recipients were honored at a dinner in Washington, DC, on December 7.

CC celebrates caregivers day

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caregivers is that it is important to make sure they R.E.S.T (relax, eat healthy and stay active, sleep, and take care of yourself). To reinforce that point, the day included a campus nature walk and several stress-reducing activities, including interactive sessions on mind-body techniques, seated massage, walking meditation using a guided labyrinth, and relaxation chair sessions.

“They worry so much. It is their loved one’s life, many times, that is on the line. That takes a lot out of a person. I encourage them to do things that are self-sustaining and self-caring. Relaxation. Make sure you’re eating properly. Make sure you’re getting enough rest and sleep,” said Renee Stubbs of the CC’s recreation therapy section.

Tanya Preble, a family caregiver whose son is receiving care at the CC, can relate. She said when she first came to the research hospital that she had tons of questions. “How can I connect with the chaplain? How can I get this information? Where can I get my email? Everybody has been really superb about that … and even your shuttle drivers are fabulous.”

To learn more about CC’s caregiver resources, visit: clinicalcenter.nih.gov/wecare.

Whitman-Walker Clinic honors Clinical Center’s critical care chief

Dr. Henry Masur, chief of the Clinical Center’s Critical Care Medicine Department and prominent AIDS researcher, was recognized by Whitman-Walker Health, a community health clinic in Washington, DC, for the role he has played in the fight against HIV/AIDS.

“Each year, Whitman-Walker and AIDS Walk recognize individuals and organizations that are doing outstanding work in the fight against HIV/AIDS,” said Don Blanchon, executive director of Whitman-Walker Health, the producer and beneficiary of the Walk. “Since this is the 25th AIDS Walk, we also wanted to reflect on the history of the epidemic here in DC and recognize 25 people who played prominent roles in that history.”

With Carl Dieffenbach of the National Institute of Allergy and Infectious Diseases (NIAID), Masur leads the DC Partnership for AIDS Progress, a unique collaboration between NIH and the DC government, which aims to create an urban model for decreasing the impact of HIV/AIDS on underserved populations. NIAID, the National Institute of Mental Health, CC, and Office of AIDS Research lead this effort.

The program is developing a city-wide database with the 13 largest HIV providers that will make DC the first city to be able to analyze data on all HIV patients in the city and to link with the Department of Health.

“Whitman-Walker and our other collaborators in the DC Partnership have provided impressively professional and compassionate HIV/AIDS care for the DC community since the beginning of the epidemic,” said Masur. “The AIDS Walk is tangible evidence of the dedication of volunteers, providers, patients, and the community to reduce the impact that HIV/AIDS has on our nation’s capital.”

Masur and his collaborators in the CC and the NIAID have led a nationally recognized program in HIV/AIDS since the beginning of the epidemic.
Study addresses pulmonary hypertension

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longer before going into anaerobic metabolism and that almost all quality-of-life measures improved. Little change was reported in the education group.

While diagnostic tests and examinations are conducted at the CC, the collaboration with Inova Fairfax allows for patients south of the DC Metro area to easily participate in the education and exercise components of the study.

Although CC patient and northern Virginia resident Anne Lewis remembers thinking that she “will never be able to do this,” since participating in the study, she is a different person.

“Before I started at NIH I couldn’t walk down the hall in my office without stopping to catch my breath,” she said. Lewis not only lost weight but also found confidence in both her ability to exercise and control her disease using the tools and skills she learned in the educational component of the study.

She has continued the regimen and exercise habits established by Chan’s team, walking for 45 minutes, three days a week at a local gym. “At first I thought I was going to die of this disease,” she said, “but now I know I can live a life of quality. But I have to take some responsibility for my own improvement, and I had the support and encouragement to do that at the NIH.”

Chan and his team recently earned the 2011 Alfred Soffer Research Award in the category of outstanding original research from the American College of Chest Physicians for their work on this study.

ResearchPACS stores, organizes, and allows access to radiologic scans for research.

Levin explained that though the content is similar, there is the need for different control mechanisms when it comes to research-oriented data. “In the research PACS, images are only available to the principal investigator or lab that created the data,” he said. Currently, more than 10 million images are in the NIH ResearchPACS.

Six NIH institutes and more than 80 labs currently use ResearchPACS and the system is growing daily. Each investigator has the option to determine who among their team can view the data and whether or not the data needs to be anonymized depending on the project. The ResearchPACS also backs up the data on secure servers and allows users to attach relevant documents to data or scans within the system, which forces more integration and organization.

“It facilitates collaboration, allows users to share data, view it simultaneously, make and share markings, and communicate more effectively,” said Levin.

In the future, Levin hopes to see the ResearchPACS system coordinate with BTRIS, facilitating even more collaboration and organization for researchers. “We pushed the envelope in terms of data,” he said.

Changing art show features NIH scientist

The Clinical Center's November-January changing art show features a series of watercolors created by NIH community member Dr. Jack Harding, a health scientist administrator in the division of comparative medicine at the National Center for Research Resources. The series, which is inspired by flowers and landscapes of the southwestern US, is in the CC’s east gallery on the first floor of the Hatfield Building.

Harding explained that he has had a passion for both art and science from a very young age, “They are both very creative enterprises,” he said. “Your brain is always working when you are doing science, physically, or thinking about science ... the same as when you are thinking about art or physically making it.”

Recruiting trial

A study for individuals 18 and older will explore the physical and emotional health of individuals serving as caregivers for a family member or friend undergoing an allogenic hematopoietic stem cell transplant. Healthy volunteers will be matched to the caregiver participants by age, gender, and race/ethnicity. The results of this study may help in the development of programs that support caregivers in coping with the demands of caring for someone undergoing a transplant. Compensation may be provided.

For more information, please call 1-866-444-221 (TTY: 1-866-411-1010) or visit clinicacenternih.gov/recruit.
BTRIS integrates new resources

Since its launch in 2009, the Biomedical Translational Research Information System (BTRIS) has grown into an extensive resource—giving clinical investigators access to identified data for the subjects on their own active protocols, while providing the intramural NIH community with access to de-identified data across all protocols.

Dr. Jim Cimino, chief of the Clinical Center Laboratory for Informatics Development, reported at the 2011 BTRIS town hall meeting that enhancements to the system will help investigators streamline the research process and assist with mandatory reporting of clinical trials to institutional review boards.

A new data visualization tool called LifeLines, created by the University of Maryland, allows users to dynamically visualize sets of patient data for easier viewing of anomalies and trends. The program itemizes data sets, such as patient records, medical problems, and medications—capturing people, events, and time. “It allows users to look at all of their patient’s data together, and sometimes a human looking at a visual representation is better than turning on a computer mouse to look for statistical correlations. We are good at seeing certain patterns in the data,” Cimino said.

He also explained that BTRIS can now assist investigators in reporting trial results to ClinicalTrials.gov, the registry and results database of federally and privately supported clinical trials. Investigators are required to post results within a year of final data collection, but the process for reporting can be cumbersome. Because BTRIS has enrollment data from the CC’s clinical research information system, if investigators add the treatment and adverse events data, BTRIS can assist in reporting to ClinicalTrials.gov.

Another new function of BTRIS is a connection to the CC Radiology and Imaging Sciences’ clinical picture archive viewing system, allowing users to link to a large database of radiology images. “As we add more data, we add more reports and enhancements to the reports,” Cimino explained.

Cassie Seamon, a clinical research nurse in the National Heart, Lung, and Blood’s hematology branch has been a BTRIS user for two years. She and her team use BTRIS to build databases and identify patients who might be interested in other active clinical trials. “BTRIS streamlines data collection and management and makes it easier to find things,” she said. “We typically pull lab reports, reports for imaging, pulmonary function tests, and information about adverse events.”

In the future Cimino will upgrade BTRIS’s ClinicalTrials.gov reporting to package and automate the process. He is also working to integrate new modalities like genetic data into the system. Users have also expressed a desire for clinical research data capture and management functions within BTRIS and the ability to access data from outside research sites.

BTRIS currently has more than 3.5 billion rows of data and results from user satisfaction surveys have been positive. “The original business case said that this was going to take 10 years, but it really only took one year to get it up and running, and we are way ahead of where we were supposed to be in five years,” said Cimino.

Editor’s note: see related story on page 5.

Researcher honored for contributions

Dr. Harvey Alter, associate director for research in the Clinical Center Department of Transfusion Medicine and NIH Distinguished Investigator, was honored with two achievement awards in November.

He received a Distinguished Achievement Award from the American Association for the Study of Liver Diseases, the highest scientific honor given by the society.

The award recognizes Alter’s sustained scientific contributions to the field of liver disease and the scientific foundations of hepatology.

Alter also earned the Tibor Greenwalt Award from the American Association of Blood Banks for major scientific and clinical contributions to hematology and transfusion medicine.

The award notes Alter’s contribution to understanding of viral infectious risk for recipients of blood transfusions and organ transplants and cites his role in the research teams responsible for identification of two viruses—hepatitis B and hepatitis C—that formerly plagued transfusion recipients.
CC patients and staff plant hope

On a late fall afternoon, just before the first snowflakes of upcoming winter fell, dozens of volunteers patiently planted thousands of spring bulbs in the atrium courtyards of the Clinical Center.

The good-hearted gardeners included CC patients, staff and their families, and students from the Stone Ridge School of the Sacred Heart and the Thomas W. Pyle Middle School in Bethesda.

Together they lay the ground work for the vision of a restful space in a vibrant garden with lots of flower varieties created by Elaine Gallin, wife of CC Director Dr. John I. Gallin, and designed by Lynn Mueller, NIH Office of Facilities Research landscape architect.

“I love to garden, and so it’s a treat to work with the patients, staff, and other CC volunteers to make these already lovely outdoor spaces even prettier,” said Elaine Gallin, who also co-planned the event. “I look forward to visiting the CC in springtime, and, hopefully, seeing lots of patients and staff sitting among the gardens bursting with spring flowers.”

Debbie Byram, chief of CC Office of Space and Facility Management, added, “I can’t wait for the spring. To have our patients feel like there are areas in the hospital on one of their days that just don’t feel right that they can come out and see some beautiful gardens that might hopefully make their day a little better … is really an honor to do.”

All of the bulbs were donated to the CC through the Foundation for the NIH. Finding folks willing to get a little dirty wasn’t too difficult either because the courtyards are a shared, treasured resource.

“I have benefited the last several years from being able to eat lunch out here,” said staff member Courtney Bell, who helped with the bulb planting. “It’s nice to know that when they come up in the spring that I got to help out.”

Soon, the ground will be covered with snow. But then, said Byram, a sea of flowers will emerge with spring – and with them will come a feeling of newness and optimism. “The whole mission of this hospital is to provide hope,” said Byram. “And to me, having beautiful flowers is one way to help do that. So that’s what I’m looking at. I’m planting hope.”

The following new clinical research protocols were approved in October:

- Phase I Trial of AZD7451, A Topomyosin-Receptor Kinase (TRK) Inhibitor, For Adults with Recurrent Gliomas; 12-C-0005; Dr. Howard A. Fine; NCI
- Pilot Phase I/II Study of the Treatment of Classic Centernal Serous Chorioretinopathy with Topical Inerferon Gamma-1b; 12-EI-0013; Dr. Catherine Meyerle; NEI
- Bone Marrow Cell Engraftment of the Uterus; 12-CH-0016; Dr. Erin F. Wolff; NICHD
- Prospective Evaluation of the Effect of Corticotropin-Releasing Hormone Stimulation on 18F-Fludeoxyglucose High-Resolution Positron-Emission Tomography in Cushing’s Disease; 12-N-0007; Dr. Russell R. Lonser; NINDS
- Dose Escalation Study of Oral Octanoic Acid in Patients with Essential Tremor; 12-N-0024; Dr. Mark Hallett; NINDS
- Phase Ib Study of the Combination of Pazopanib, an Oral VEGFR Inhibitor, and ARQ 197 (Tivantinib), an Oral MET Inhibitor, in Patients with Refractory Advanced Solid Tumors; 12-C-0009; Dr. Shivaani Kummar; NCI
**Upcoming lectures**

Lipsett Amphitheater, 12 noon
Lectures will be videocast at videocast.nih.gov.

**December 7**

**Ethics Rounds**
Is it Ethical to Give Presents to Patients?

Philip M. Rosoff, MD, MA
Director, Clinical Ethics Program,
Duke University Hospital
Professor of Pediatrics (Hematology and Oncology) and Professor of Medicine, Duke University Medical Center

Case Presenter:
Ann Marie Matlock, RN, MSN
Nurse Manager, 5 SE and 5 NES-SCSU

**December 14**

**Contemporary Clinical Medicine**
Great Teachers
Communicating Vaccine Science to the Public

Paul A. Offit, MD
Chief, Division of Infectious Diseases and Director, Vaccine Education Center, Children's Hospital of Philadelphia
Maurice R. Hilleman Professor of Virology and Professor of Pediatrics, University of Pennsylvania School of Medicine

**December 21**

**Advances in Tuberculosis Diagnostics and Therapy: The Next Decade**

Henry Masur, MD
Chief, Critical Care Medicine Department, CC

Fred M. Gordin, MD
Chief, Infectious Diseases, Veterans Affairs Medical Center Professor of Medicine, The George Washington University

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**Chinese nursing leaders visit CC**

Two senior faculty from the Fourth Military Medical University School of Nursing in Xi'an, Shaanxi, China, visited the Clinical Center on November 9. Dr. Clare Hastings, Dr. Gwynyth Wallen, and Dr. Cheryl Fisher of CC Nursing and Patient Care Services visited the university last spring to present a nursing research workshop on evidence-based practice.

Dean Dr. Shasha Xu and associate professor Dr. Baohua Cao toured the CC and the NIH Library of Medicine and met with CC nursing leadership in professional development and translational research. They were in the United States for meetings at several academic institutions. “It is an honor to be here learning and visiting,” Xu told Dr. John I. Gallin, CC director.

Connecting during the international meeting were (back row) Maureen Gormley, chief operating officer; Maria Joyce, chief financial officer; Dr. Frederick P. Ognibene, deputy director for educational affairs and strategic partnerships; Dr. David Henderson, deputy director for clinical care; and (front row) Cao; Hastings, chief nursing officer; Gallin; and Xu.

**Principles and Practice of Clinical Research Lecture presented in Russia**

The Clinical Center’s “Introduction to the Principles and Practice of Clinical Research” course was offered in Russia for the first time November 14-18 when Dr. John I. Gallin, CC director, lead the course at the Kulakov Federal Research Center for Obstetrics, Gynecology, and Perinatology in Moscow.

The course was offered to 220 students as part of the CC’s global efforts in clinical research training and focused on clinical trial best practices, biostatistics and data analysis, orphan and rare diseases, ethics in clinical research, review boards and integrity in research, data safety monitoring, and treatments for addiction and tuberculosis.

Pictured at right are several course faculty near the red square in Moscow (from left) Dr. Clifton Barry, chief of the NIAID tuberculosis research section; Gallin; Dr. Laura Lee Johnson, a statistician in the NCCAM Office of Clinical and Regulatory Affairs; and Dr. Jerry A. Menikoff, director of the Department of Health and Human Services Office for Human Research Protections. Not pictured are Dr. David Eckstein, a senior health scientist administrator in the NIH Office of Rare Disease Research and Dr. Markus Heilig, NIAAA clinical director.