

- National Nurses Week
- Medical Research Scholars Program
- Take Your Child to Work Day

NIH and the District of Columbia expand HIV/AIDS program



Mike Mack (center), first patient in an NIH protocol to receive his medication at Unity's DC General site, with his health care team. Left to right: Tess Petersen (CCMD IRTA); Annette Ford (Unity MA); Chloe Gross (SAIC-F/support to NIAID); Dr. Brenda Crowder-Gaines (Health Center Director, Unity/DC General); Dr. Anita Kohl (SAIC-F/support to NIAID); Georgia Freeman (Unity RN).

In 2008, NIH initiated a partnership with the District of Columbia Government to reduce the impact of HIV on the District, which has the highest HIV rate of any city in the US. Five years later, according to Dr. Henry Masur, chief of the Clinical Center's Critical Care Medicine Department, who

leads the project with Dr. Carl Dieffenbach of the National Institute of Allergy and Infectious Diseases, "the program is far ahead of schedule in meeting its goals."

The program, called the DC Partnership for HIV/AIDS Progress, or DCPFAP, brings together intramural and extramural researchers

from multiple NIH Institutes, the DC Department of Health, and the George Washington University School of Public Health and Health Policy. Providers and patient groups in the DC HIV community have welcomed the program, which operates at three sites in Southeast and Northeast DC, in partnership with Unity Health Care and Family Medicine and Counseling Services.

"This program has demonstrated that Washington DC has extraordinary medical resources in terms of committed health care providers and outstanding health care organizations that serve all parts of the city," says Masur. "What no city in the US has is a citywide database to allow measurement of health care needs among patients with HIV/AIDS, and a system for evaluating the impact of new programs. In DC, patients with HIV have gotten expert primary care, but for the underinsured, getting access to subspecialty care has been difficult. This program has helped give patients with HIV/AIDS better access to research opportunities."

"The Office of AIDS Research has been pleased to provide core support to this

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Clinical Center staff makes a difference in the life of a sickle cell patient

World Sickle Cell Awareness Day is June 19

When Tyese Womack was about nine years old, she learned that the reason she was having so many health problems was because she had sickle cell disease. She also learned that she was only expected to live until about age 24.

Now she is 45, and while there are many complications from the disease that she must deal with on a daily basis, she is still going strong. "One of the main reasons things have gone so well for me is because I've been coming to NIH," Womack says.

Dr. Gregory Kato, of the Cardiovascular Pulmonary Branch of the National Heart, Lung and Blood Institute, and Dr. Caterina

Minniti, staff clinician in the Hematology Department, are Womack's primary physicians. But one of the main advantages patients

enjoy at the Clinical Center is the ability to benefit from an integrated approach to medicine, and the expertise and care of a multidisciplinary team of health-care professionals. "It really does take a village to heal a patient," Minniti says. "Patients here have access to a team like nowhere else. The patient is looked at as a whole person."

Womack first came to the Clinical Center about 10 years ago, when NIH doctors invited patients at the Sickle Cell Clinic at Howard University to participate in a clinical study. Among other complications, Womack had a chronic leg ulcer that had caused a bone infection (osteomyelitis).

Doctors at another hospital had told her that the leg would



Front row (L to R): Dr. Gregory Kato (NHLBI), Tyese Womack, Dr. Caterina Minniti (Hematology). Second row (L to R): Karen "KC" Chandler Axelrod (RN, Wound Care Specialist); Mark Jones (Tyese's husband); Kathleen "Katie" Rizzo (RN, Wound Care Specialist); Anna K. Conrey, Nurse Practitioner.

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DCPFAP program

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unique collaboration," says Dr. Jack Whittes-carver, NIH Associate Director for AIDS Research. "We view this as an important model to address AIDS and its complications, cofactors, and comorbidities in the nation's capital, and to improve access to cutting-edge research and care. It is also a unique way for NIH to directly engage with patients and caregivers in the local community."

In addition to receiving medical care for HIV-related hepatitis, patients in the program are given the opportunity to participate in studies for new treatments. "There are many new, exciting drugs for hepatitis C that offer the potential for more effective and better tolerated therapy with shorter regimens," Masur says. "We have been gratified to see providers and organizations embrace initiatives that provide improved services for DC residents. All stakeholders have been enthusiastic about contributing."

New phase of program

In April, a new phase of the partnership began, with investigational drugs being delivered to the DC site so patients don't have to come to NIH every time they need their prescriptions filled. "It's a lot of work to get clinical protocols

approved for use in a community setting," says Dr. Anita Kohli, an infectious disease specialist with the program. "Issues of environmental control present special challenges. Unity's Director of Infectious Diseases, Dr. Gebeyehu Teferi, has been very helpful in getting the approvals needed, and in making the program the success it has been."

While patients and DC health care organizations benefit from the program, DC clinics also provide NIH programs with a resource to allow rapid protocol accrual once patient and provider trust are established. This allows researchers to evaluate their scientific questions expeditiously, and demonstrates that intramural research can do cutting edge, translational research as rapidly, or even more rapidly, than other academic centers. For DCPFAP's first interventional program, researchers were able to recruit sixty patients in six weeks.

At the DC General site of Unity Healthcare in Southeast DC, the enthusiasm for DCPFAP is palpable. "The relationship with NIH is wonderful," says Health Center Director Dr. Brenda Crowder-Gaines. "For our patients to know that NIH is here denotes a relationship and connectedness, that they are being provided with seamless care from here to there, and there to here. That makes them feel more comfortable, and anything we can do to promote their comfort is good for their health."

Did you know...

DC Partnership for HIV/AIDS Progress is supported by the NIH Office of AIDS Research and the National Institute of Allergy and Infectious Diseases.

New partners include: the National Institute of Mental Health, the National Institute of Neurological Disorders and Stroke, and the National Institute on Minority Health Disparities.

Highlights of initial DCPFAP programs:

- A citywide database of all HIV patients seen at 12 partner organizations
- Development of prevention programs
- Launching a pilot of the "test and treat" strategy
- Improving subspecialty access for underinsured patients.

To date, more than 5,000 patients have been enrolled in the DC cohort database, with 5,000 more scheduled to enroll in the next couple of years.



60 YEARS OF
DISCOVERING
TOMORROW'S
CURES

Coming soon! A special July edition of CC News celebrating the Clinical Center's 60th birthday

Sickle cell disease

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need to be amputated. But working with her CC colleagues, Minniti found a way, through a series of surgical procedures and a year of constant antibiotic treatment, to heal first the bone infection and then the ulcer. "Some wounds never heal, and the fact that Tyese has been able to do so is truly remarkable," Minniti says.

When asked what she would like people to know about sickle cell disease, Womack says, "I'd like them to know that sickle cell is not an easy disease to have. Sometimes people don't understand. They'll say, 'How are you sick? I don't see anything wrong with you.' But you have to be on a lot of medications, and that can affect your energy and your productivity.

And sometimes you just don't feel well." But, Kato says, "She just keeps plugging along through all her sickle cell complications, including a stroke in 2004 that has made it difficult for her to continue her work as a paralegal."

Womack's participation in several Clinical Center trials has made her a contributing partner with Kato and Minniti in sickle cell clinical research. What would she like people to know about the care she's received at the Clinical Center? "It's a privilege. I know a lot of people who would be grateful to be taken care of the way I've been cared for here," she says. And Minniti stresses the benefit that clinical research brings to everyone, not just the patients in clinical studies. "When you do clinical research, you improve the standard of care for all," she says.

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Submissions may be edited.



National Nurses Week 2013 recognizes the important work of clinical research nurses

Appreciating the key role of nurses in the work of the Clinical Center should be a constant. But once a year, during National Nurses Week, the everyday work and the special achievements of our nurses are showcased and highlighted.

This year the Grand Rounds lecture during Nurses Week featured Dr. Clare Hastings, Chief Nursing Officer, and Dr. Barbara Jordan, Nursing Service Chief for Neurosciences, Behavioral Health, and Pediatrics at the Clinical Center. Drs. Hastings and Jordan titled their presentation “Blending Clinical Care and Research: A Clinical Research Nursing Model of Care.”

Hastings is internationally known for her leadership in establishing a conceptual framework to describe and evaluate the roles of nurses in clinical research, and to establish clinical research nursing as a specialty. In her remarks, she reminded the audience of the need for nurses to “become healthier, both within the healthcare system, and as individuals.” She also stressed the importance of the formal assessment of outcomes as improvements are made in the delivery of patient care.



The 22nd Annual U.S. Public Health Service Nursing Recognition Day was held on May 3, when featured speaker LCDR Margaret F. Bevans received the RADM Julia Plotnick Award for Nursing/Health Policy. From left to right: RADM (ret.) Julia R. Plotnick; RADM Kerry Paige Nessler, Chief Nurse Officer, USPHS; Borghild “Berkie” Bevans, Dr. Bevans’ mother-in-law and 1st LT, US Army and USPHS Civilian Nurse (retired); Keith Bevans, husband; LCDR Margaret Bevans; Carolyn Bevans, daughter; and CAPT Veronica Gordon, N-PAC Chair FY 2013.

Jordan earned her Doctorate of Nursing Practice in 2012 with a focus on relationship-based care, which she defines as care in which the nurse “engages with the patient and focuses on them rather than on all the tasks that have to be completed.” She and five other Clinical Center nurses—Debbie Kolakowski, Ann-Marie Matlock, Teresa Brockie, Ann Peterson, and Myra

Woolery—who have earned nursing doctorates in the past year were recognized for this professional achievement.

Other recognition celebrations events acknowledged the varied contributions and achievements of nurses in clinical research, including the 22nd Annual U.S. Public Health Service Nursing Recognition Day. (shown above)

“Take Your Child to Work Day” events teach kids about nutrition, the human body and leading a healthy lifestyle

On April 25, NIH employees were invited to bring their kids to work with them for “Take Your Child to Work Day.” Thousands of school-age kids (grades 1-12) came for a day of discovery and fun. Throughout the day, visiting children were invited to explore more than 80 activities, many of them about health education.

The “Bod Pod” event gave children and their parents an opportunity to visit the metabolic unit at the Clinical Center. According to Terri Wakefield, NIDDK, who was leading the activity, being overweight can lead to diabetes, kidney disease, heart disease, and can also damage your liver.

Nine-year-old Les Thompson, learned about the importance of healthy lifestyle choices. He was very interested in learning about the Bod Pod, a device that measures body composition, which together with weight is used to study

the fat composition of the body by air displacement in a subject. Wakefield also showed the group a bone density scanner.

At “The Mysteries of Pathology” kids were able to examine normal human lung, kidney, and brain tissues, as well as their

diseased counterparts. Dr. Avi Rosenberg and Dr. Jason Hipp demonstrated how tissues are removed during surgery or at autopsy, and how they are processed so that the proper diagnosis is made.

At “Shake It Up,” kids learned why dairy

products are important, played a trivia game about healthy food choices, and then divided into teams to make healthy shakes with the help of chef Robert Hedetniemi, certified executive chef for the Clinical Center’s Nutrition Department. “It’s tough to get kids to eat stuff they aren’t accustomed to,” says Hedetniemi. “You can either hide it in things that they like, or you can get them involved in the cooking process.”

TYCTW Day gives kids a chance to learn about science, see their parents’ work environment and imagine a career in science for themselves. “Whatever you love, you can do in science,” says Wakefield.



Drs. Avi Rosenberg (left) and Jason Hipp show a human brain to (from L to R) Gabriella Barranta, Jairus Young, and Josiah Young in the Clinical Center’s Pathology Lab.



2012-2013 NIH Medical Research Scholars Program (MRSP) Fellows

Inaugural MRSP fellows present work in May

The inaugural class of the National Institutes of Health Medical Research Scholars Program delivered the final results of their research projects during the MRSP Scientific Presentations, held May 13-14, 2013 in Lipsett Amphitheatre. After nearly a year of conducting research on the NIH intramural campus, the 45 scholars presented their work to the NIH community and invited guests.

Adrienne Taylor, a student at Duke University School of Medicine, presented on the relationship between migraines, depression and cardiovascular disease in a community-based family study. Taylor, who is interested in the connection between mental illness and physical illness, says, "this year has helped me focus on what I want my future career path to be," adding that she is considering enrolling in a joint program in psychiatry and internal medicine.

In addition to conducting and presenting research over the course of the year, MRSP

scholars took part in a curriculum designed to expose them to a broad range of leadership, professional development, and innovation opportunities and workshops.

"This program helped me understand what kind of clinician, and what kind of scientist I want to be," says Jake Cawley, a student at the Virginia-Maryland College of Veterinary Medicine, Virginia Tech. Participants also attended bi-monthly journal clubs, clinical patient rounds, and process of discovery lectures.

Last summer, NIH welcomed this inaugural class of 45 scholars from 34 accredited U.S. universities from across the country. The year-long enrichment program offers talented medical, dental, and veterinary students mentored training and the opportunity to conduct basic, clinical, or translational research in areas matched to their personal interests and research goals.

For complete details on the MRSP please visit <http://cc.nih.gov/training/mrsp>.



Justin Cohen

CC welcomes new communications chief Justin Cohen

This month, the Office of Communications and Media Relations has its own announcement to make: Justin Cohen has joined the department as chief. His vast experience and expertise in health communications will serve the Clinical Center well.

Over the past nine years, Cohen served as a communications director at the U.S. Environmental Protection Agency for a high-profile office responsible for all vehicles and fuels. The office was the first ever to successfully launch federal greenhouse gas regulations.

Cohen has also spearheaded communications as an executive at healthcare nonprofits around Washington, D.C. His interest in healthcare communications began early in his career while working for Senator Harry Reid (D-NV).

Hailing from North Carolina, Cohen's educational highlights include an MS from the Harvard University School of Public Health and an MA in political science from University of Nevada at Las Vegas.

Among Cohen's early goals: "Teaming up with the Clinical Center's amazing staff to more proactively share the good news about their important work in a thoughtful, responsible way."



Samuel J. Heyman

SERVICE to AMERICA MEDALS

by the Partnership for Public Service

Finalists *left to right*,
Dr. Evan Snitkin, Dr. Julie Segre, Dr. David Henderson, Dr. Tara Palmore



For more information: <http://servicetoamericamedals.org/SAM/finalists/index.shtml>

6th Annual NIH "Take a Hike" Day

June 6, 2013

11:30 am – 1:30 pm

All employees are encouraged to participate in the 6th annual "Take a Hike" day, designed to promote a healthier workforce. Enjoy this fun 2.8 mile-walk around the perimeter of the NIH campus. Water stations will be located along various points of the walk. To register, visit: <http://www.ors.od.nih.gov/pes/dats/wellness/hike/pages/hike.aspx>.