

- New brochure offers guided tour of Clinical Center art collection
- CC raises more than \$157,000 for charity
- Barber shop on B1 reopens

Burwell visits NIH



Sylvia M. Burwell, secretary of HHS, speaks to NIH staff in Masur Auditorium Jan. 28.

The Secretary of the Department of Health and Human Services (HHS), Sylvia M. Burwell, visited the NIH Jan. 28 and shared her fundamental approach to her work during a Town Hall meeting with staff in the Clinical Center. More than 1,000 people attended the Town Hall in person and online.

"The mission of HHS is to make sure that people have the building blocks they need to lead healthy, productive lives," Burwell said. "You are an anchor of that work. Every day your research and the work you are doing clinically, the whole spectrum of the work being done here, is fundamental. NIH is an essential and core part of the work of HHS."

Stressing the importance of "impact, prioritization and relationships," Burwell told a story about a previous job in the Global Development Program at the Bill and Melinda Gates Foundation. During her time in the program, which aims to harness advances in science and technology to save lives in developing countries, Burwell kept a picture of a two-year-old Senegalese child pinned to her bulletin board, and labeled the photo "the boss." She also gave all new employees a copy of the picture, with a note saying she looked forward to working with them to deliver impact for "the boss."

BURWELL page 4

Patients provide real-time feedback to the CC

Since January, patients have been able to access a new electronic tool that allows them to provide real-time feedback about their experiences at the Clinical Center.

By accessing the tool, patients can inform Clinical Center administrators about everyday issues that could impact the quality of their experience in the research hospital, such as food or housekeeping concerns, a broken ice machine or problems with wireless access. The feedback allows Clinical Center staff and administrators to identify the clinic or unit location where the feedback was provided in order to more rapidly respond to immediate patient questions and concerns.

The tool is anonymous and will not identify a patient's name or room location. All comments — whether positive or negative — are extremely valuable to staff.

"We want patients to let us know how their experience here can be improved. This mechanism gives patients a new way to do that," said Bekah Geiger, special assistant for Clinical Center operations, who helped develop the tool.



The feedback tool allows patients, who are our partners in clinical research, to give real-time feedback.

The feedback tool can be accessed via an icon on the TV/tablets in patient rooms within the inpatient units and on the homepage of desktop computers located in the outpatient clinics. With just one click, the revamped tool now also allows patients to have access to a Spanish-language version.

In addition to the convenient new tool, all inpatients will continue to receive a separate comprehensive patient perception survey by mail after being discharged from the hospital.

Psychologist shares experience as an NIH employee and patient with StoryCorps

In early December, Lisa Horowitz sat down with her brother to talk about her experience as a transplant patient for StoryCorps, a national oral history project. This recording was just one of 18 that took place in the Clinical Center. The NIH will use select recordings to add to the NIH Oral History Project, which helps capture the voices of the NIH community.

Horowitz describes the recording experience as "cathartic and therapeutic." Her transplant was six years ago, but, as she recovered and her busy life resumed, Horowitz realized she had never really talked in depth with her family about what she went through. Having her brother interview her after time had passed and she was no longer sick allowed both her and her brother to truly process the experience.

She was diagnosed with lymphoma in September of 2001, when her daughter

was just 6 months old, and she was told she had less than five years to live. Her greatest concern was not being around to raise her daughter.

"When you hear that you have cancer, there is no comfort," Horowitz explained. "It just takes a lot of time to process."

Over the next several years, she had multiple treatments: finally her cancer went into remission. Horowitz learned to savor life in the moments between the difficulties. This past April, she planned and attended her now 13-year-old daughter's Bat Mitzvah, a day she never expected to see.

The message she hopes to convey by sharing her story is, "Don't let the news and stress of your disease rob you of the preciousness of time. Be engaged in your life in any way that you can."

STORYCORPS page 2

Horowitz's story is unique because while she was a patient, she was also, and still remains, a clinical psychologist within the NIH National Institute of Mental Health Psychiatry Service.

In 2006, just three weeks before her family moved to the D.C. area and she began her career at NIH, she received the news that her lymphoma had returned. She enrolled in an NIH National Cancer Institute protocol that allowed her to receive a bone marrow transplant from an unrelated donor.

"A complete stranger saved my life," she said. "I never stop being appreciative of that. It has been very impactful, and I feel compelled to pay it forward." Since her transplant at the Clinical Center, she has helped co-found a project that aims to increase racial and ethnic diversity in the bone marrow registry.

She is also grateful for the wonderful care she received from what she refers to as "incredibly dedicated" nurses, physicians and staff at NIH. "The Clinical Center is called the House of Hope, and I really feel like I lived that."

While being treated at the Clinical Center, Horowitz found that her dual



Lisa Horowitz talked to her younger brother David during a StoryCorps recording session.

roles as patient and NIH employee overlapped, sometimes in unforeseen ways. For example, one of the individuals she saw in her new job was a lymphoma patient who was receiving a transplant. And when coming for treatment herself, she found that some nurses would be puzzled to see her show up as a patient – often thinking she was there in her professional role to assist a patient. Eventually, she established a code. If she was wearing her white coat, she was working; if not, she was a patient. This technique helped smooth those moments of surprised recognition.

Her experience has affected how she

interacts with patients. She believes she has become a better listener. "I have a stronger empathetic connection with the patient I wouldn't have had otherwise," she said. She also feels she can share additional insights with her colleagues – a true view from the patient perspective.

Similar to Horowitz, the other NIH StoryCorps participants told of powerful, compelling experiences. Interviews covered a patient's battle against prostate cancer, long-time research partners talking about discoveries made on the human papillomavirus (HPV), a patient's journey with brittle bone disease, nurses' memories on decades of care and a pair of sisters' recollections of losing their father to Parkinson's disease.

The complete recordings of the NIH participants will be archived at the American Folklife Center at the Library of Congress. Select recordings will be edited and featured on NIH's website and elsewhere, to share with the community. Stories will be available to hear online this spring: <http://www.nih.gov/about/voicesofNIH>. For more information, email storycorps@nih.gov.

Clinical Center exceeds Combined Federal Campaign contribution goal

During the 2014 Combined Federal Campaign (CFC), Clinical Center donors contributed more than \$157,000 to non-profit organizations that provide life-enriching and life-saving services across the U.S. and around the world. The Clinical Center shattered the fundraising goal by almost \$10,000 during the annual campaign. Collectively, the Institutes and Centers across the NIH raised a total of \$2.39 million.

In addition to the standard cash, check and payroll deductions, some employees also participated in departmental fundraising events during the CFC open season.

For example, employees had fun baking and tasting delicious treats during the Baking it Possible fundraiser Oct. 29. The bake sale raised \$2,429 for charity in only two hours and 30 minutes – more than \$16 a minute. Also, through friendly competition, the Department of Laboratory Medicine held a Penny War fundraiser and collected a hefty \$663 in coins! Together, the Clinical Center and all of NIH helped "Make it Possible."



Representatives from the Department of Laboratory Medicine proudly display their Penny War contributions to the 2014 Combined Federal Campaign.

Read more online! Scan the barcode or visit www.cc.nih.gov/about/news/newsletter.html



Use a downloaded app on a smartphone or tablet to scan the Quick Response (QR) barcode. You will be directed to the CC News online.

Clinical Center News

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Published monthly by the Office of Communications and Media Relations, Justin Cohen, chief

News, article ideas, calendar events and photos are welcome. Submissions may be edited.

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New brochure offers guided tour of Clinical Center art collection

For more than three decades, Clinical Center patients, visitors and staff have gazed upon artwork in the hospital for comfort, contemplation and inspiration. To further promote the powerful effect the artwork can have, a brochure has been created to allow viewers to take a self-guided walking tour and learn about the pieces of art displayed by the Clinical Center's Fine Arts Program.

The mission of the Fine Arts Program, which has collected and displayed art since 1984, is to pair art with medicine, and to promote healing by creating an aesthetically pleasing environment for patients, caregivers and employees. The Clinical Center art collection includes more than 2,000 pieces of art.

The collection of photography, sculpture, painting, collage, watercolor, textile, folk art, glass and both abstract and representational works is made possible in part through donations from artists, staff, visitors and patients.

Annette Abrams, a patient who received a stem cell transplant at the Clinical Center, was so moved by the artwork during her stay that she created a tile mosaic

after recovery for other patients to enjoy. Her pieces are on display outside the unit where she was treated.

"When I was an inpatient, I would often walk around each floor and look at the art. It was very soothing to me and inspiring as well," said Abrams. "I feel proud to have [my] angel mosaics hanging at the entrance of the two wings that I spent a lot of time in and where I received incredible care. My thought was that these could give hope to those who are going through what I went through when they enter the same wings for care."

With the two-page brochure in hand, a person can locate 130 pieces of art throughout six floors of the Hatfield building. While some artwork remains permanently on display in the building, there are six galleries that offer new exhibits every eight weeks, often showing the work of local artists.

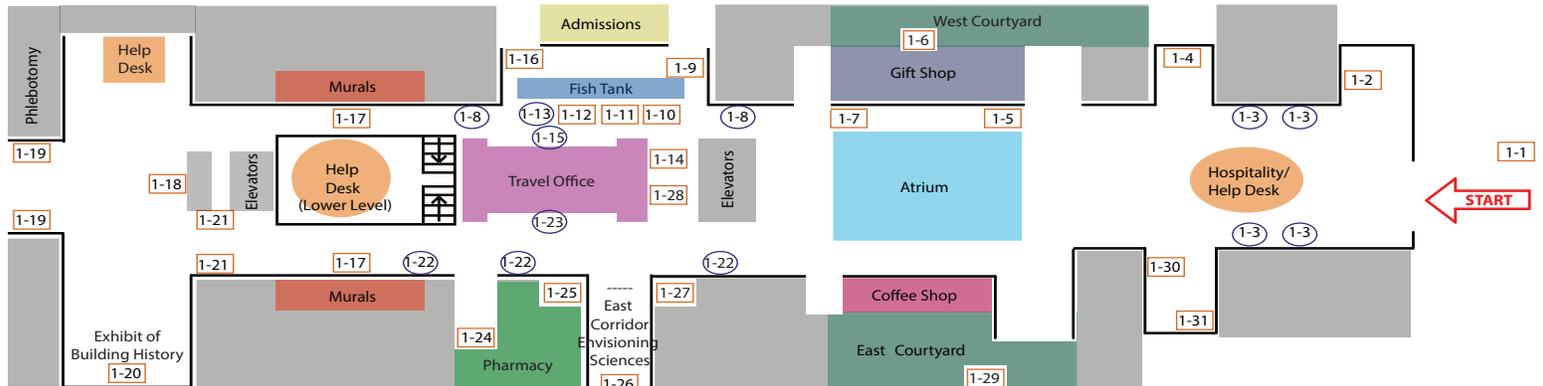
Each piece of artwork is available for purchase, and 20 percent of the sales from the changing art exhibits benefit the Clinical Center Patient Emergency Fund. The fund assists patients and their families with incidental emergency expenses incurred while they are participating in NIH



Annette Abrams, a former Clinical Center patient, created two pieces of art, one of which is displayed near the third floor unit she was treated on. Photo courtesy of Rhoda Baer.

protocols. Since 1989, these galleries have raised over \$75,000.

Copies of the brochure can be found at the hospitality desk near the north entrance, the reception desk near the P1 garage and the patient library on the 7th floor of the Clinical Center as well as at The Children's Inn at NIH and The Edmond J. Safra Family Lodge at NIH.



The two-page art brochure offers a guide to permanent and changing exhibits throughout the Clinical Center, including the first floor seen above.

Barber shop reopens on B1 with fresh new look, additional stylist



In addition to men's hair cuts and facial shaves, the barber shop now also offers women's services such as color, relaxers and rollersets.

The newly-updated barber shop on the B1 level of the Clinical Center reopened its doors Jan. 12 after months of renovation. The space has been improved top to bottom and now has a fresh look, including new flooring, counter-tops and paint.

Two master barbers are now joined by a female stylist, allowing the shop to broaden the scope of services provided. The NIH community, including staff, patients and their families, can walk in to the barber shop 8:30 a.m. – 4:30

p.m. or call 301-496-3019 to schedule an appointment.

The barber or beautician can also come directly to a patient's room if the patient is unable to leave the care unit. Patients without financial means may be eligible for free services after an assessment and referral by a social worker. To reach the Social Work Department, call 301-496-2381 or go to <http://go.usa.gov/uXcJ>.

More information on the Recreation and Welfare Association barber shop: <http://tinyurl.com/l86rcsw>

"The idea of the picture was to help focus on who it is we were trying to serve, and what we were doing every day in our work, to deliver actual impact to those people," Burwell said.

During the Town Hall, she addressed questions from staff that were submitted in advance. One of the questions asked Burwell to touch on the prospect for NIH to grow and thrive in the current political and budget climate.

"NIH is well placed for growth," Burwell said in response. She then explained how she's trying to promote bipartisan support for areas where there is agreement, and that medical and scientific research is one of those areas. "We're going to do everything we can to maximize support," she said.

In response to a question about President Barack Obama, Burwell said that in addition to his genuine interest in and support for scientific innovation and research, he is also deeply interested and invested in quality management



Sylvia M. Burwell, HHS secretary, speaks with patient Don Dean in the Clinical Center after a presentation from Dr. W. Marston Linehan, chief of the urologic oncology branch in the National Cancer Institute.

of government.

"He believes so strongly in making sure that we are carrying out the mission, doing it as well as it can be done. He believes that we can all function better in our day to day work," she said.

Burwell met with NIH Director Dr. Francis S. Collins and senior leadership but also took the time to host a roundtable meeting in the NIH Library with

12 selected staff members from across campus for a candid exchange.

In the Clinical Center, she visited the surgical oncology outpatient clinic, where she was briefed on NIH work exploring precision medicine -- the use of genetic information about a disease to diagnose or treat disease.

"Precision medicine is a presidential priority," Burwell

said. "The President has a personal interest in this. He believes it's about scientific innovation, about the economy, about the health and welfare of our people."

Burwell was able to witness the beneficial outcomes of precision medicine firsthand when she met Don Dean, a patient in the National Cancer Institute who said the greatest reward of his time spend at the NIH Clinical Center has been "survival."

"It [was] an honor... to be involved in [the] presentation [for the Secretary]," Dean said. "I consider myself as part of a team. My role has been to bring durability, levity, and a unique germ-line to a long journey of discovery. [Burwell] displayed the intelligence, incisiveness, and leadership qualities we expect to find in those in critical positions. She also revealed a personal warmth and sharp sense of humor."

HHS staff, view the videocast: <http://go.usa.gov/3qkkF>

Upcoming Events *View most lectures at <http://videocast.nih.gov>*

The 2015 Clinical and Translational Research Course for PhD Students is Accepting Applications

Admission now through March 30, 2015
Clinical Center Building 10

The program will take place July 6 — 17, 2015 from 9 a.m. — 5 p.m. More details:
<http://cc.nih.gov/training/phdcourse>

Contemporary Clinical Medicine Great Teachers Lecture; NIH Clinical Center's 2015 Distinguished Clinical Research Scholar and Educator in Residence Lecture; Haploinsufficiency Causing Human Inflammatory Disease: When One Gene is Not Enough

Feb. 11, 2015, Noon — 1:00 p.m.

Lipsett Amphitheater

Presented by John P. Atkinson, MD, Washington University School of Medicine.

Deputy Director for Management Seminar Series: Normal is Overrated - Aim Higher

Feb. 12, 2015, 11:00 a.m. — 12:30 p.m.

Masur Auditorium

Presented by Bonnie St. John, leadership consultant and author of *Live Your Joy*.

Clinicopathologic Grand Rounds Lecture; Clinical Cases from the NIH Clinical Center: Recombinant Anti-CD22 Immunotoxin Therapy of Drug-Resistant Hairy Cell Leukemia; Eradication of Minimal Residual Disease Without Chemotherapy Toxicity

Feb. 18, 2015, Noon — 1:00 p.m.

Lipsett Amphitheater

Presented by Ira Pastan, MD, NCI and Robert J. Kreitman, MD, NCI.

NIH Director's Wednesday Afternoon Lecture Series; Autism: New Mutations, Genes, and Pathways

Feb. 18, 2015, 3:00 p.m. — 4:00 p.m.

Masur Auditorium

Presented by Evan Eichler, PhD, University of Washington.

Clinical Center Grand Rounds Lecture; Progressive Multifocal Leukoencephalopathy: Clinical Manifestations and Therapeutic Approaches; The Biological and Molecular Link between Natalizumab Therapy and Risk of Progressive

Multifocal Leukoencephalopathy

Feb. 25, 2015, Noon — 1:00 p.m.

Lipsett Amphitheater

Presented by Avindra Nath, MD, NINDS and Eugene O. Major, PhD, NINDS.

NIH Director's Wednesday Afternoon Lecture Series; The Immune System in Childhood Cancer: Mobilizing the Troops

Feb. 25, 2015 (Rescheduled from Jan. 7)
3:00 p.m. — 4:00 p.m.

Masur Auditorium

Presented by Crystal Mackall, MD, NCI.

NIH Rare Disease Day

Feb. 27, 2015, 8:30 a.m. — 5:00 p.m.

Masur Auditorium

Attendance is free and open to public. Registration: <http://tinyurl.com/l8vrh75>. If you want to display a poster or exhibit, please include in your registration form. Tours of the CC will be available. In association with the Global Genes Project, which uses "jeans and genes" to raise awareness, attendees are encouraged to wear jeans.