



## Clinical Center

NIH...Turning Discovery Into Health®

### New hospice suites provide home-like environment

According to the NIH National Institute on Aging, people who are at the end of life need care in the areas of physical comfort, mental and emotional needs, spiritual issues, and practical tasks. Their families need support as well. In hopes of providing that support to our patients, the NIH Clinical Center opened a Hospice Unit on 3SEN-Medical Oncology July 10.

The unit is comprised of two rooms that have been converted into a home-like environment where families can stay with the adult patients. Each suite has a bedroom and a community area, including a kitchen and family sitting area.

At the opening ceremony, NIH Director Dr. Francis Collins said, "There are noble efforts made to try to save lives that don't always result in that happy outcome but yet we promise those individuals that we're not just interested in doing science. We are interested in them. We care about them. We owe it to them, in those circumstances where our efforts are not succeeding, to care for them in a place like this."

Read the complete story, including photos of the unit: <https://go.usa.gov/xQaew>



Dr. Ann Berger, chief of the Pain and Palliative Care Service, Dr. Francis Collins, director of the NIH, Dr. Jim Gilman, CEO of the Clinical Center and Dr. Gwen Wallen, chief nursing officer, open the Hospice Suites.

### Gender identity now incorporated into medical records

Since late 2017, patients enrolled in clinical trials at NIH have been asked to provide their preferred gender identity during the admissions process. Information about sex and gender identity, similar to documenting a patient's age and ethnicity, help hospital staff provide the appropriate services for the study in which a patient is participating in.

"Asking patients about their gender identity is quickly becoming an industry-standard practice," Tricia Coffey, chief of the Health Information Management Department, said via email to NIH hospital staff. "It is important as we work to continually improve the patient experience here at the NIH Clinical Center and provide a welcoming, all-inclusive environment for those we service."

During admissions, staff enter a patient's sex (male or female), in the medical record and mark gender identity (a person's inner sense of their gender – male, female, transgender male, transgender female, neither or another gender).

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### Patient photography and records dept relocate, cafeteria updates

#### Health Information Management relocated to B1

The hospital's Health Information Management Department (Medical Records) relocated to the B1 level in Room B1L400 — across from the Credit Union and next to the convenience store.

As of April 20, all medical records requests can be obtained at the new location. The office is designed to support NIH Clinical Center Patient Portal (Follow My Health) and to assist patients and staff with medical records information. Business hours remain the same – Monday-Friday, 8:30 a.m. to 5:00 p.m., closed on federal holidays. Contact the Health Information Management Department at 301-496-3331 or toll free 888-790-2133. To submit a medical record form, fax 301-480-9982.



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### Providing medical insurance information for emergency purposes

As of May 31, patients coming to Building 10 are asked to provide their medical insurance information. Having this information readily available helps the hospital staff coordinate any emergent or home care needs for patients who need them. Here are three things you need to know:

- **There's a benefit to providing patients' insurance information.** If care is unexpectedly needed outside of the NIH Clinical Center, this information will expedite the process of ambulance transport, procedures or hospitalization. The information will make it easier to arrange home care needs and/or to make arrangements for any medical equipment needed after discharge.
- **We do not bill for services.** The NIH will not bill for any services.

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• **Unless it's a medical emergency, we will not share patients' insurance information without authorization.** Medical information related to services provided by the NIH Clinical Center will never be shared with patients' insurance companies without patient authorization. Patients will be informed and need to authorize that their insurance information can be shared with an outside facility. There is an exception if there is a medical emergency.

Despite the benefits providing insurance information provides, it is optional. If patients have health insurance and decline to provide it, necessary/emergent services or treatments may be delayed at outside medical facilities with which the NIH Clinical Center may be trying to coordinate a patient's care on her/his behalf.

Admissions staff is collecting patients' insurance information and scanning insurance cards into the patient's medical record. The insurance information is viewable by Admissions, Health Information Management Department (Medical Records) and Social Work staff. NIH staff, view frequently asked questions about the new process: <https://go.usa.gov/xU4P6>

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Providing a gender identity is optional; patients can decline to answer. Neither sex nor gender identity data will be included on patients' wristbands.

A training conducted by The Fenway Institute via videocast on the collection of sex and gender identity for NIH Clinical Center patients is available for staff: <https://go.usa.gov/xQFbh>

### For more information on the gender identity or medical insurance information articles, please contact:

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Karen Kaczorowski, 301-496-2341  
kkaczoro@cc.nih.gov

Health Information Management  
Tricia Coffey, 301-496-2292  
tcoffey@cc.nih.gov

Read more online! Scan the barcode or visit [www.cc.nih.gov/about/news/newsletter.html](http://www.cc.nih.gov/about/news/newsletter.html)

• National Volunteer Week honors volunteers for their support to patients/administration  
• Nurses Week honors 1,000 nurses  
• Fleisher, former Chief of Dept. of Lab Med, receives HHS career achievement award

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.

## Barbra Streisand visits NIH; talks about her support, involvement with women's heart health



Left, Dr. Francis Collins, director of the NIH, welcomes Barbra Streisand to talk about her activism in women's heart health. "She's not only an ambassador of our country's culture but she's also an improver of our society and also an icon for leading the cause for better health for women," he said. Right, Streisand met with two Clinical Center patients during her visit.

On May 15, the 2018 J. Edward Rall Cultural lecture (<https://go.usa.gov/xQFzX>) brought vocalist, actress/producer and cultural icon Barbra Streisand to NIH to speak about her interest and activism in women's heart health.

Her attention was initially drawn to this issue after reading a 1991 *New England Journal of Medicine* editorial by former NIH Director Bernadine Healy, "The Yentl Syndrome." The journal article referenced the film that Streisand directed and produced called 'Yentl', in which a young girl has to be disguised as a boy to receive an education. The editorial detailed wide discrepancies and differences in cardiovascular care received by women when compared to the standard of care received by men.

"Women are half the population – we're indispensable to everything that matters most," Streisand said. "We have different equipment, we have different plumbing."

In 2008, Streisand became directly involved by partially funding the Women's Heart Center at Cedar Sinai Medical Center in Los Angeles that was later named for her. In 2014, she co-founded the Women's Heart Alliance, a nonprofit organization advocating for increased and improved research and treatment for women's car-

diovascular health and learning more about sex specific differences. The Women's Heart Alliance has supported NIH research and has also partnered with NIH to improve the heart health of HIV-positive women.

In her speech and subsequent interview with Dr. Francis Collins, NIH director, she described her interest in gender equality, which began with the film industry, but broadened into her presence as a high-profile, active ally in an area affecting all women – heart and cardiovascular health.

"Scientists and artists have much in common," Streisand said. "We're both obsessed with the quest for beauty, understanding and truth. We're both seeking answers to the big questions about causes and consequences, hows and whys, origins and endings, life and death. What links our two communities is the focus on what it means to be human. Our life's work, our passion, our purposes is improving and uplifting humanity."

The annual cultural lecture, part of the Wednesday Afternoon Lecture Series, honors the memory of J. Edward Rall, the first Deputy Director for Intramural Research. He recommended in 1984 that NIH add a cultural lecture to its Director's Lecture series.

## Two history exhibits now on display featuring NIH pioneers, microscopes



The Microscopes, Tools of Science exhibit (right) is located near the entrance to the Bioethics Department on the first floor (past the Pediatric outpatient Clinic). The exhibit will be on display for 3 years. In addition, the twin historical exhibits (left) of the life and work of Drs. Christian Anfinsen and Michael Potter, are on display in the central corridor on the first floor near the FAES bookstore.

Two new history exhibits recently opened in the NIH Clinical Center. Microscopes, Tools of Science from the DeWitt Stetten, Jr., Museum of Medical Research Collection, features several microscopes on display. One dates back to the 1830s - that's older than NIH which traces its roots back to 1887.

The second exhibit features two large displays of artifacts, photos and history of NIH pioneers Drs. Christian Anfinsen and Michael Potter. Potter held a 50-year career at the National Cancer Institute. His research focused on plasma cell tumors and the structure, function and

genetics of antibodies. Potter received a 1984 Albert Lasker Award for Basic Medical Research. Anfinsen worked at what was called the National Heart Institute and what is now the National Institute of Diabetes and Digestive and Kidney Diseases. Anfinsen shared the 1972 Nobel Prize in chemistry for his work on ribonuclease.

The exhibits are presented by the Office of NIH History and the Stetten Museum. The Stetten Museum at NIH collects instruments important to scientific research, especially instruments and technologies developed at NIH.

## Project SEARCH NIH graduates eighth class



Congratulations to the eighth class of graduates from the NIH Project SEARCH program! Project SEARCH at NIH began in the fall of 2010 and has provided workplace training and education to 80 men and women. The 30-week internship program attempts to level the playing field for young adults with intellectual and developmental disabilities who are transitioning from school to work. One of the graduates will soon begin as a part time housekeeper in the Clinical Center and the others are seeking competitive employment in the community.

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### Patient photography studio moves to third floor

The Patient Photography Studio moved to a new location on the third floor of the Clinical Center. The new studio opened in room 3-1608 NW on June 12. To find the new studio location from the first floor, take the elevators located at the north end of the hospital (near the Hospitality desk) to the third floor. The studio is located near the elevators on the west side of the building. The phone numbers of the studio will remain the same - office: 301-496-9994 and cell: 301-440-3335.

Please contact Karen Kaczorowski if you have any questions: 301-496-2341, [kkaczoro@cc.nih.gov](mailto:kkaczoro@cc.nih.gov)

### Weekend food service is on the move

Beginning Saturday June 9, and for all weekends and holidays indefinitely after that, all cafeteria operations in Building 10 will be relocated from the second floor to B-1. Regular services will remain in Balance Kitchen (ACRF café) Monday-Friday for breakfast, lunch and dinner. Call the Food Service Program with questions: 301-827-3248.

## Join a study at NIH!

For information on trials below, or to learn about other opportunities, contact the NIH Clinical Center Office of Patient Recruitment at 1- 866-444-2214, TTY for the deaf or hard of hearing: 1-866-411-1010, email [prpl@mail.cc.nih.gov](mailto:prpl@mail.cc.nih.gov) or visit <https://cc.nih.gov/recruit/index.html>.

The **National Center for Complementary and Integrative Health** is seeking healthy volunteers 12 and older to participate in pain perception research study. Compensation provided. Refer to study 16-AT-0077. <https://go.usa.gov/xQZkr>

**National Heart, Lung, and Blood Institute** researchers need volunteers at least 18 years old with lung disease to participate in a study looking at how to better measure the effects of lung disease. Study-related tests are provided at no cost and results are shared with you and your doctor. Compensation for travel is provided. Refer to study 96-H-0100. <https://go.usa.gov/xN7NN>

## Use your power to save lives —promote safe patient care

While national Patient Safety Awareness Week was formally celebrated in March, staff are working to create a culture of patient safety all year-long at the NIH Clinical Center.



To support patient safety, the Hospital Epidemiology Service recently launched a hand hygiene campaign called 'All Hands on Deck'. The goal of the initiative is to engage and improve hand hygiene compliance amongst health care staff, patients and visitors. The initiative was adapted from a successful pilot program at the Hospital Epidemiology Service at the University of North Carolina Health Care in Chapel Hill, N.C. Frontline health care personnel were involved in conducting hand hygiene compliance measurements among themselves.

Hand hygiene has the power to save lives and stop the spread of infections. Given the prevalence and degree of immunosuppression of the patient population, achieving high hand hygiene compliance is a priority. Proper hand hygiene not only protects patients, but also protects staff.

Upon admission, patients have received a hand fan that says 'I love clean hands' and have been encouraged to speak up, or hold it up, if they feel staff should do a better job at hand washing.

Staff play an important role too! Employees, just say "Top 10" to anyone who is not doing the proper hand hygiene in the clinic or on the unit. This code word may help with the social obstacles of reminding a peer or caregiver to hand-wash.

To request a hand hygiene hand fan, sticker or additional information, contact the Hospital Epidemiology Service at [CCCommunications@mail.nih.gov](mailto:CCCommunications@mail.nih.gov) or 301-496-2209. Staff, report a safety or quality concern: <https://go.usa.gov/xUxkR>. Staff, learn more about hand hygiene: <https://go.usa.gov/xUrKy>. View the campaign video: <https://youtu.be/kuXVNku1CuI>



## Clinical Center patient experiences enrich International Degos Disease Symposium

A group of clinicians and researchers in vascular medicine, dermatology, hematology and other specialties gathered in the NIH Clinical Center April 27 for the 2018 International Degos Disease Symposium, hosted by the National Heart, Lung, and Blood Institute. Also known as atrophic malignant papulosis, Degos disease is a perplexing, ultra-rare disease affecting the skin and digestive system with just a few hundred known cases.

Between presentations on epidemiology, genetics, pathology and treatment, two Clinical Center patients spoke about their experience with an exceedingly rare and potentially fatal disease.

The longest known survivor of Degos disease, a gentleman named Roger, spoke about his symptoms, path to diagnosis and worsening condition put him in a coma. Roger discussed how he was able to be treated with a drug on a 'compassionate use' basis. The drug is approved for another rare disease but not yet for those with Degos disease.

Roger concluded his talk by encouraging others to "learn more about the disease. Share your ideas today and carry those thoughts into action tomorrow and in the years to come."

Later in the day, Theresa Slayton



Theresa Slayton speaks at the 2018 International Degos Disease Symposium April 27.

spoke poignantly about her alarming skin lesions and abdominal discomfort, and her own research leading her to suspect Degos disease.

"There was almost no information and seemingly no treatment," she said.

Slayton had to search to find specialists and to discover that dietary adjustments could help the digestive discomfort. She spoke of the importance of keeping hope alive while fighting to understand and overcome the poorly understood disease.

Together, the comments from each presenter were a vivid reminder of the challenges rare disease patients face in getting answers, finding support and holding on to hope.

## Director of Centers for Disease Control and Prevention visits NIH Clinical Center



On June 12, Dr. Robert Redfield (center), director of the Centers for Disease Control and Prevention (CDC), visited NIH. Redfield learned about NIH efforts on developing a universal vaccine against the influenza virus - one which you wouldn't need to get every year. Dr. James Gilman (third from left), CEO of the Clinical Center, escorted Redfield through the Clinical Center Special Clinical Studies Unit (SCSU), which hosts healthy volunteer clinical trials to advance the research on influenza vaccines. Also pictured is Amanda Campbell (left), deputy chief of staff at CDC, Dr. Anthony Fauci (second from left), director of the National Institute of Allergy and Infectious Diseases, John Burklow (second from right), associate director for communications and public liaison and Dr. Richard Davey (far right), medical director of the SCSU.