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

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).

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.

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

On May 15, the 2018 J. Edward Rall Cultural Hallway mural (https://go.usa.gov/xG9Pj) brought vocal artist/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 in care 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 cardiovascular 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 NIH-positive women.

In her speech and subsequent interview with Dr. 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 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, hoes 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 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 and technologies developed at NIH.

**PROJECT SEARCH at NIH graduates eighth class**

Congratulations to the eighth class of graduates from the NIH Project SEARCH program! Project SEARCH is a 6-month program at NIH designed for adult students with intellectual and developmental disabilities who are transitioning from school to work.

SEARCH at NIH began in the fall of 2010 and has provided workplace training and education to adults with intellectual and developmental disabilities who are transitioning from school to work.

CONTRIBUTORS: Deborah Accame, Robert Borchardt, Jana Budge, Lynne Lipton, Cindy McCabe, Drusian Kuehn, Maria Markinowski, Angela Mozaffari, Patricia Neuhauser, Donnie Quigley, Karen Kaczorowski, Jonathan Motzny, 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 and technologies developed at NIH.

**PROJECT SEARCH at NIH graduates eighth class**

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 and technologies developed at NIH.

**PROJECT SEARCH at NIH graduates eighth class**

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 and technologies developed at NIH.

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 and technologies developed at NIH.
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 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 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 Redfeld (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.