

July/August 2017

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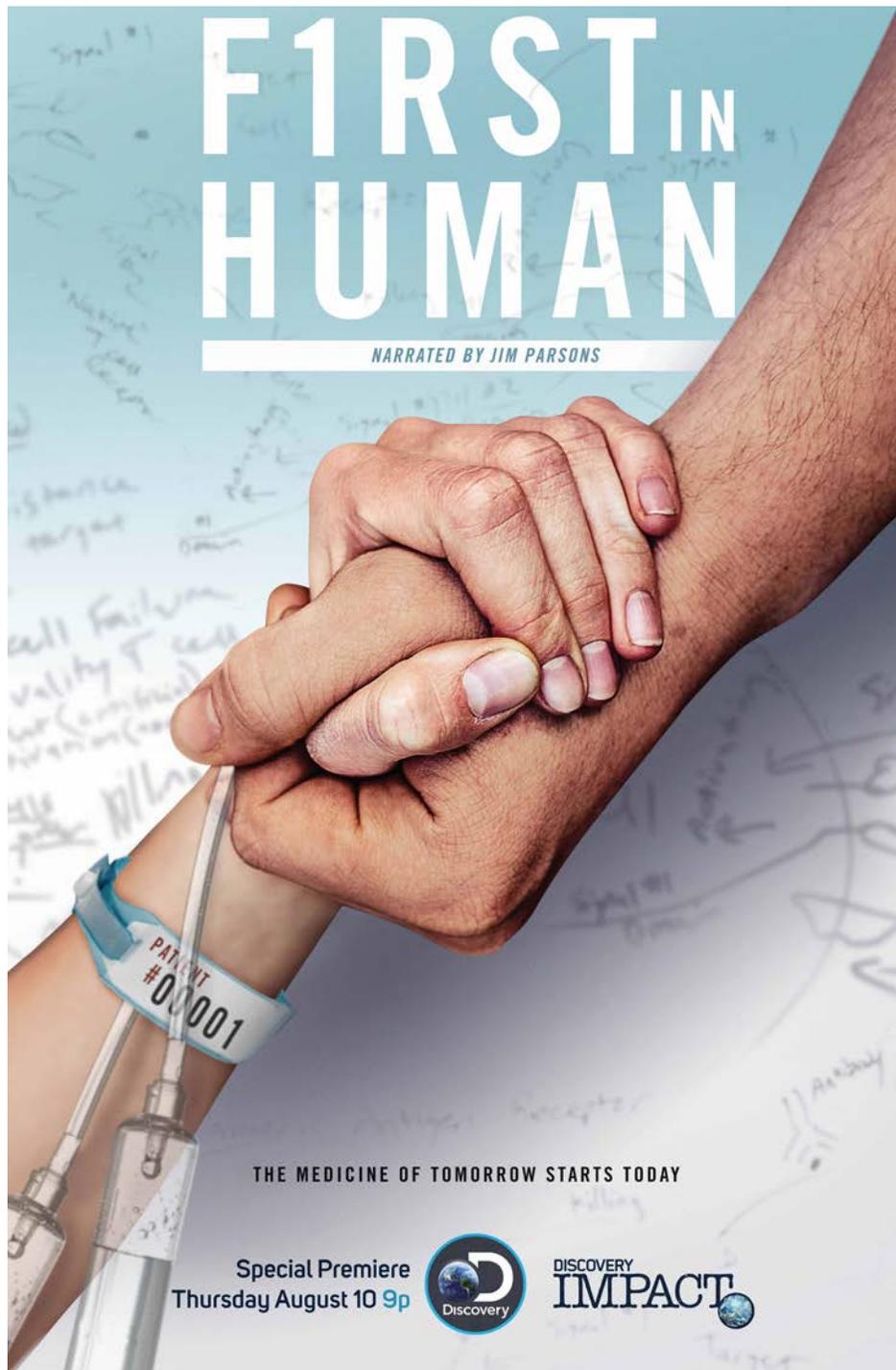
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# Clinical Center

NIH...Turning Discovery Into Health®

## First in Human: Discovery Channel documentary on the NIH Clinical Center airs Aug. 10, 17, 24

*"I know that everyone who watches 'First in Human' will feel the same sense of pride I did when I discovered this incredible institution that our country created." - Jim Parsons, documentary narrator*



On Aug. 10, the Discovery Channel will premiere a three-part documentary series on the NIH Clinical Center Building 10. The program, called "First in Human," highlights the innovation and hard work that takes place in the Clinical Center, depicts how challenging illness are diagnosed and treated, and provides an inside look at the successes and setbacks that are a part of experimental medicine.

The NIH has worked with the Discovery Channel (<http://bit.ly/2tJkB1l>) to produce the documentary featuring the amazing research, patient care, spirit and dedication that abounds at the Clinical Center. "First In Human" represents the first time cameras have embedded for over a year in the hospital and followed first in human patients throughout their trial.

The documentary is scheduled to air on the Discovery Channel Aug. 10, 17 and 24 at 9 p.m. ET/PT.

The series will be narrated by actor Jim Parsons ("The Big Bang Theory," "Hidden Figures"). Parsons expressed enthusiasm about the work conducted at the Clinical Center.

"I know that everyone who watches 'First in Human' will feel the same sense of pride I did when I discovered this incredible institution that our country created," Parsons said. "I hope viewers will share the sense of gratitude and awe that I felt when learning about the human beings who bravely put their lives in the hands of some of our most innovative scientists and doctors as they search together for the medicines and cures that give all of us fuller, longer lives. This is truly the story of how we, as human beings, function: both at an elemental level and at our most profound."

The doctors leading first in human trials at the Clinical Center are using treatments that are brand new with outcomes that are unknown. Often, they can only partner with patients who have exhausted all other options current medicine has to offer. This doctor-patient partnership is utterly unique to medicine: whatever the outcome, each of these brave "first in human" volunteers immediately becomes part of medical history.

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Clinical Center Chief Executive Officer Dr. James K. Gilman added, "The unique partnership and respect we have with our patients is key to making the discoveries that improve medicine across the country and around the world. I am especially proud that we have this opportunity to share with the American people how their investment in research provides a benefit to us all."

## Careful Coordination: A Behind The Scenes Look at Production

The concept for the documentary was brought to NIH by John Hoffman, currently the executive vice president of documentaries and specials for Discovery Communications. Part of what gave the Clinical Center confidence to allow the crews access was that Hoffman has a track record of producing quality documentaries with NIH, including "Sleepless in America," "The Weight of the Nation," "The Alzheimer's Project" and "Addictions." Despite the previous working relationship, there was still exhaustive pre-production planning and a Memorandum of Understanding between the NIH, Discovery Communications and the production company, McGee Media.

The Clinical Center leadership closely coordinated with the NIH institutes and centers, the NIH Office of the Director and departments within the research hospital that agreed to filming. Intramural investigators across a handful of institutes and centers were heavily involved.

Under the direction and supervision of the Clinical Center Office of Communications and Media Relations (OCMR), three camera crews videotaped staff and patients throughout the hospital every day. More than 125 patients opened their lives to the cameras to document the reality of clinical trials, including their arrival to NIH, CT/MRI scans, procedures in the operating room, bone marrow biopsies, test results and more. In addition, more than 1,100 staff and guests/family consented to participate.

While providing technical assistance and guidance to the Discovery Channel to aid the show's accuracy and success, the Clinical Center remained firmly committed to protecting the privacy and safety of patients and staff. No one was filmed without their advance, written, informed consent. Further, all Discovery staff working on-site completed a special Clinical Center orientation, safety and privacy training. At the end of the training, they signed an affirmation that they understood what was discussed and the importance of protecting patient privacy.

The OCMR also closely coordinated on a daily basis with senior leaders, nurse managers, care providers, hospital epidemiology and others in regards to requests to film and the date, time, location and description/who was involved with the event or procedure.

Molly Freimuth, media lead for the OCMR and a key manager of the project, said "As the biggest television project the NIH has hosted, we have worked hard to showcase the amazing medical

advances conducted at the Clinical Center. Our greatest reward will be helping more people learn about the work we do and help more patients who have nowhere else to turn to find a place that may be able to help."

## Take Action: Engage with NIH

To celebrate the forthcoming broadcast, all NIH staff are invited to a special one-hour preview of the documentary on Aug. 3, 1:00-3:00 p.m. in Masur Auditorium, followed by a panel discussion. The screening will also be streamed and archived on videocast (NIH Only): <https://go.usa.gov/xRQu2>

Prior to the air date, the NIH will be hosting a twitter chat on Aug. 9 from 1-2 p.m. ET with NIH Director Dr. Francis Collins and Gilman. In addition, the NIH will be live tweeting each of the three episodes using #FirstInHuman to help educate the public about how biomedical discoveries make it from the lab to the bedside.

In addition to participating in a clinical trial, viewers inspired by the series can take action to support the NIH Clinical Center effort by:

- applying for a job/training opportunity;
- volunteering at the NIH Clinical Center;
- donating to the NIH Blood Bank;
- collaborating on a research study.

Learn more about the "First in Human" documentary and additional resources at the Clinical Center webpage (<https://go.usa.gov/xRQZA>) and the NIH webpage (<https://go.usa.gov/xRQZ6>).



Above, (left) videographers capture NIH staff in the Department of Laboratory Medicine in March 2016 and (right) Dr. Alexandra Freeman, NIAID, meets narrator Jim Parsons at the Clinical Center. On May 2, an exclusive preview (center) of the series and a panel discussion with patients, scientists and the documentary producer, took place at the Ronald Reagan Building in Washington, D.C. Among the attendees were members of Congress.

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)



- New child care facility, NIH Northwest Child Care Center, opens across from the CC
- CC employees put their sneakers on for NIH Take a Hike Day
- Redesigned Intranet for staff now available

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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# Hospital celebrates first anniversary of CC TakeMeThere app

With more than 20,000 rooms, 13 miles of corridors, 15 outpatient clinics and 93 day hospital stations the NIH Clinical Center can be a confusing place to get around.

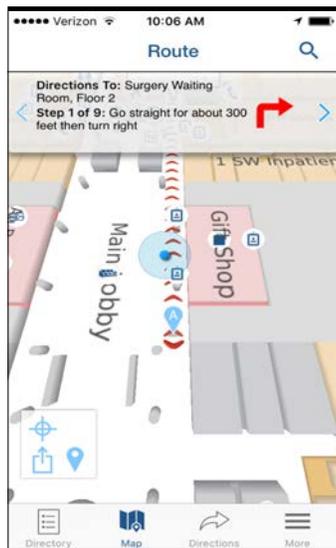
Focused on improving the patient experience, a team of CC innovators began exploring the potential of a virtual map that could help patients find their way around the hospital. This came to fruition in 2016 with the development of an easy-to-use app that patients could download to their smartphones to help them navigate the building. The NIHCC TakeMeThere app was launched to the NIH community in July 2016 and is available as a free download. Employees who joined NIH after January 2017 automatically have the app downloaded on their NIH mobile device.

Hospitals are built with a focus on the care of their patients and not on creating a space that's easy to navigate. Ironically, however, that can unintentionally result in spaces that aren't so easy to navigate. The CC's unique history is also a factor. The hospital opened its doors in 1953 and added the Ambulatory Care Research Facility in 1983 and the Clinical Research Center in 2004. These spaces number their rooms differently, creating the potential for confusion among visitors and staff. The development of NIHCC TakeMeThere helps patients, visitors and staff bridge these challenges.

"Our goal is to get the patient where they want to be when they want to be there," said Eric Cole, chief of the CC Administrative Management Department and lead on the implementation of the app. "In doing so we saw an opportunity to make the hospital safer. With NIHCC TakeMeThere, emergency personnel and first responders can now easily find any room in the facility no matter where it is or if they've ever been there."

The app is available in both English and Spanish. In addition, it has a "talk to" feature that allows anyone with visual impairments to receive spoken commands to get them to their location.

The free app can be downloaded on iOS (Apple) (<http://tinyurl.com/jp7gf3e>) and Android devices (<http://tinyurl.com/jva6tqa>) and allows patients and staff to text message or email directions to others who may not have the app. The NIHCC TakeMeThere website ([www.takemethere.cc.nih.gov](http://www.takemethere.cc.nih.gov)) allows individuals to share directions with others via email or print, an important feature for patients without smartphone devices. Questions? Contact [eric.cole@nih.gov](mailto:eric.cole@nih.gov)



## "Say Yes to Everything"

Writer and health leader outlines the future of research

The NIH Clinical Center hosted Dr. Atul Gawande in June at the NIH Director's Wednesday Afternoon Lecture Series. Gawande, a surgeon, writer and public health researcher has written extensively on medicine and public health.

In a conversation with NIH Director Dr. Francis Collins, and answering questions submitted by participants on social media, Gawande embarked in a wide ranging discussion on the importance of research, how incremental scientific advances will save lives in the future and career advice for young scientists.

Gawande has written four New York Times bestsellers: *Complications*, *Better*, *The Checklist Manifesto* and *Being Mortal: Medicine and What Matters in the End*. He practices general and endocrine surgery at Brigham and Women's Hospital in Boston, is a professor in the Department of Health Policy and Management at the Harvard T.H. Chan School of Public Health and a Samuel O. Thier Professor of Surgery at Harvard Medical School.

Selected excerpts from their discussion are below. Questions have been edited for clarity. View the lecture: <https://go.usa.gov/xNfCb>

**Francis Collins (FC):** One of the big questions is the long gap between when research is carried out on the prevention or treatment of disease and then the wait, sometimes for decades, until the research gets implemented. What do you think is the solution to this?

**Atul Gawande (AG):** One of the approaches that we've taken is to probe not just to describe the pattern, but to zero in on the positive outliers, try to understand what they are doing differently and then turn that into a testable



Dr. Atul Gawande (center) met with Surgery branch fellows during his visit to NIH. Fellows, from left to right: Winifred Lo, Christine Kariya, Parisa Malekzadeh, Atul Gawande, Mohammad Jafferji, Ornela Dervishaj and Stacey Doran.

hypothesis, a delivery component. It's also constantly learning from the testing side...it's putting your discoveries from precision medicine together with precision delivery. And believing we can apply the science just as fruitfully to the way your knowledge moves out in the world as we did to the discovery of that knowledge. In fact, it will save as many lives - and arguably more - as our next discoveries, given how much we've discovered that's not getting to people in the first place.

**FC:** There are many young scientists in the room. Any advice for them?

**AG:** I think we're switching from what one of my colleagues called the century of the molecule to the century of the system. And it's becoming the scientist of the interconnections, whether it's at the molecular, physiologic or population level, that is going to be where the biggest insights and the biggest gains in health and understanding are going to come from. That's where I would be spending my time.

**FC:** As a Rhodes Scholar, a surgeon, a powerful writer and a significant commentator on healthcare in the U.S. and the world, how did you get down that road to this path?

**AG:** One of the best pieces of advice I ever got was that before the age of forty, say yes to everything.

# 2017 marks a decade without disease for stem cell transplant survivor

"When I arrived at the Clinical Center [in 2007], I was very weak and nervous," Nelly Vinueza recalls. Now, as she walks through the rotating doors of Building 10, Vinueza feels quite differently. This year marks the 10th anniversary of her stem cell transplant conducted at the Clinical Center which cured her leukemia.

Like so many patients at the CC, Vinueza has a heroic journey that brought her to NIH.

"Around the end of July 2005, I started to feel really sick," said Vinueza, who is from South America. "I had fevers every night and a flu that lasted for almost four weeks. I talked to my OBGYN and he said that I needed to get blood tests completed as soon as possible. When I arrived at his office to hear about the test results, he took me immediately to the office of a hematologist to discuss the results."

The doctors told Vinueza that she had acute myeloid leukemia (AML), a fast growing cancer of the blood that can destroy bone marrow and all blood production. In AML, the bone marrow fills with leukemia blasts which squeeze out the normal marrow leading to marrow failure, anemia, bleeding and infection. Having over 20% blasts in the bone marrow or blood points to a diagnosis of AML. Eighty-five percent of the cells in Vinueza's bone marrow were leukemia blasts.

"At first, I was surprised and a little sad. Then, I said, I have a husband, my parents and two little boys to take care of at home. I also have to get back to work," she said. "The doctor looked very seriously at me and said, 'You are not going home from here. You are going right now to the hospital.' This was the beginning of my long journey with AML."

Vinueza's treatment included intense high-dose chemotherapy to destroy as many of the leukemia cells possible. The treatment also reduced her white blood cell count and weakened her immune system, which lead to bronchitis, pneumonia



After battling acute myeloid leukemia at the NIH Clinical Center, Nelly Vinueza (second from right) is now able to enjoy quality time with her kids.

and infections on her skin and body.

After six months in a local hospital, her leukemia was in remission and she went home to re-start her life. Within five months, she was pregnant. During a check-up, her doctor called and said her leukemia had returned. The doctor recommended intensive chemotherapy followed by a stem cell transplant and said the CC was her "best chance."

"I applied for a clinical study and followed up with a phone call to get more information," she said. Her call was answered by Dr. John Barrett, Senior Investigator in the Stem Cell Allogeneic Transplantation Section at the National Heart Lung and Blood Institute.

Remembering that call, Barrett said, "Nelly was very lucky. She met all of the requirements for our study. She understood the risks and the difficult road ahead of her, and had strong support from her family and community. The special difficulty with her case was that she would need to have a stem cell transplant shortly after giving birth. There is little experience

anywhere in the world of giving a stem cell transplant to a new mother."

Vinueza delivered her baby girl by cesarean section at just 27 weeks. When her baby was just 10-days-old, Vinueza traveled to the CC to prepare for the transplant.

"This was the hardest moment. I did not know if I was going to see my daughter again," she said. "It took a few weeks to get prepared for the stem cell transplant donated from my relative. But after the transplant, the side effects from the low white blood cells and a weak immune system were much worse than I had at home after my first chemotherapy."

Within three months she started to get better and her doctors allowed her to go home for a short visit. The moment she reached South America her white cell count began to drop and it became clear that she had rejected the stem cell transplant. This complication is rare but sometimes happens when a transplant is done soon after pregnancy. After just three days with her family, Vinueza's doctors ordered her to return immediately to the CC for a second stem cell transplant to rebuild her bone marrow.

"We had Nelly return immediately to undergo a second stem cell transplant," Barrett said. "This time, we used a better immune suppressing mix that worked. A key learning point for us was the need to more effectively suppress the immune system in new mothers."

In 2007, after spending seven months at the CC, Vinueza's health was recovering and she remained completely free of leukemia. She went back home to restart her life with her family. Since then, she has returned annually to the CC for follow-up tests for the first three years, then less frequently. Now, in 2017, her leukemia appears cured and she is leading a healthy life. She now participates in the NIH long-term follow-up study which tracks transplant survivors every five years for their entire life.



Graduate Annabel Hunter (center) is joined by supporters of the program at NIH: Steve Blanks with SEEC and Lu Merrick with the Ivymount School.

## Eight young adults graduate NIH Project SEARCH with enhanced workplace, community skills

Surrounded by NIH employees, parents and friends, eight young adults received a standing ovation as they graduated the NIH Project SEARCH program June 13.

Project SEARCH at NIH provides education and training to those with intellectual and developmental disabilities. The program involves a 30-week internship for participants to strengthen their workforce and career skills. More than 70 graduates have completed the

program at NIH and over 75% of graduates find employment either at NIH or in the community within six months of graduation.

The program is supported by the Ivymount School's Post High School Program which prepares students for a successful transition from school to employment and adult life; and SEEC, a local nonprofit that provides community-based employment support to transitioning youth and adults. Learn more: <https://www.cc.nih.gov/projectsearch/>