Clinical Center 70th Anniversary
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# Hard Cases, Compassionate Care

## A spouse's account of care at the Clinical Center

*By Marcy Mager*

As an NIH Clinical Center ICU nurse, you care for patients who have extreme needs, who require constant care and attention and whose illnesses often take their lives. Because this is NIH—where the most difficult cases are welcomed, the solutions to the puzzles of medicine are sought and the boundaries of knowledge are expanded—your patients are not only among the neediest in the hospital, but in the entire world.

Imagine it is May 2021 again. In addition to the challenges of your regular work routine, the COVID pandemic looms over everything, adding to the complexity of your tasks and to your own anxieties.

As an ICU nurse this is the framework within which you must care for your patients, even before the impact of the virus. Amid this whirlwind of demands and emotions, you meet a 78-year-old male with non-Hodgkin's lymphoma, who is part of a clinical trial and reacting negatively to some of the medications. He was admitted with permanent AFib, congestive heart failure, sleep apnea and now extreme diarrhea, which is impacting his heart and his kidneys. This is his third bout with cancer, and at this stage is likely to cause his death.

For the next 12 hours, he is your patient. For 30 years, he is my husband.

Mager's husband being cared for by Clinical Center staff

You cross the threshold of his room and face him to convey caring and concern. Despite two hearing aids, his severe hearing loss cannot overcome the barrier of your mask, and he cannot hear most of what you say. So, you talk louder, come closer and include me in the conversation, because I can be right at his ear, right at his mouth; I can facilitate the communication.

You learn the details of his needs and implement his treatment, inserting the tubes, drawing the blood, administering the medications. You attend to his well-being, hooking him up to monitors and machines, observing progress and distress, calling for assistance as needed. You make him as comfortable as you can amid the relentless barrage of lights and noise that are endemic to the ICU.

You understand that you cannot cure him, but you seek to establish a connection in these few hours, which will improve his medical and emotional state. You show interest, respect and commitment. And yet, over the course of 10 days and more than two dozen nursing staff at the Clinical Center, there is a wide range in the details of how all of these things are done. Most of you can smile with your eyes and demonstrate a balance of positive energy and gentle touch that clearly show your commitment.

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*Forward by Dr. James Gilman, NIH Clinical Center CEO*

*While no one really knows whether or not we are on the backside of the COVID-19 pandemic, we do seem to have a bit of a hiatus—fewer cases, less severe cases, etc., etc. On the off chance that we will not be talking about coronaviruses for a while, it is important that we learn everything we can about what we do and how we do it before too much time passes.*

*One of the policies put in place for the pandemic allowed and sometimes even encouraged "rooming in" for caregivers for adult patients. The perceptions of these caregivers provide us with a valuable look in the mirror, one that we seldom get.*

*I recently made the acquaintance of one such caregiver, Marcy Mager. Marcy and I have had discussions by phone and email regarding her husband David Lunter's hospital stay and, in particular, his stay in our ICU.*

*I have found Marcy to be intelligent and perceptive. She is a professional educator, and it is apparent in our discourse. In particular, I have been struck by her ability to separate her observations from the specific persons or personalities of those who cared for her husband.*

*Many caregivers might make a complaint about a staff member or small group of staff members. Marcy never has done that. She focuses on what was said and done and not who said or did it. This makes her instructions much more generalizable.*

*In her comments, I can find many, many issues related to care that we do particularly well here in the Clinical Center. However, I can also find important observations that relate to patient care issues that could still need work. I think her observations are worthy of inclusion in this issue of the CC News.*

# The Edmond J. Safra Family Lodge receives a calming and refreshing makeover

The Lodge's re-upholstered furniture in the family room

The Edmond J. Safra Family Lodge serves as a welcoming respite for patients and their family who have spent a long day at the Clinical Center attending appointments.

The Lodge recently completed a series of updates with the goal of making patients feel more comfortable during their stays. These changes include re-upholstering furniture, adding new kitchen fixtures, updating doors and the fireplace, adding new fitness room equipment and refreshing the outside pergolas which provide shade.

The comprehensive redesign also includes a significant enhancement to the venue's six ADA-accessible rooms. Yasmin Rheubottom, the manager of operations and guest relations at the Lodge, collaborated closely with an architect to ensure these improvements were made with utmost consideration.

"It is my goal to treat each of our guests like they are my family. I want the Lodge to exude a homely ambiance where our guests can feel at ease, as if they are staying in a home away from home. My aim is to create a safe and inviting space for everyone," stated Rheubottom.

In addition to these updates, the accommodations are undergoing a significant aesthetic transformation. All of its 34 guest rooms transitioned from gold-colored accents to a more soothing palette of calming shades of gray. This shift further contributes to the serene and tranquil atmosphere that the Lodge wants to provide for its guests.

- Yvonne Hylton

# Lecture Recap:

*DEIA hosts engaging panel on Sex and Gender*

"When Cece asked me if I would talk for at least a couple of minutes and welcome you, I actually was reasonably uncomfortable - because this is a topic that I know very little about" said Dr. Gilman, Clinical Center CEO, in an uncharacteristically uncertain voice as he opened his Welcome Address to the discussion panel on July 12th.

He continued, "We are trying to discuss how we allow our patients and our family members and our NIH staff... To discuss how each one of them is allowed to be their authentic selves without work prejudices, without any adverse connotations... I think this is very important."

The panel consisted of Dr. Karen Parker, director, Sexual & Gender Minority Research Office; Bali White, strategist, Sexual and Gender Minority Portfolio, Office of Equity, Diversity and Inclusion; Haley Maness, senior clinical research nurse/ safety and quality nurse, 1NW; J. Wade Atkins, supervisor, Quality Assurance and Regulatory Affairs, Department of Transfusion Medicine; and was moderated by David Saeger, chief, Office of Hospital Administrative Support.

Saeger made opening remarks - emphasizing the event was an opportunity for collective learning, acknowledging that none of the participants could possesses complete knowledge on the subject matter.

The panel provided the opportunity for many educational moments, such as information about SafeZone training that White spoke about, or Parker's slide citing a recent Gallup poll that showed that 1/5 Gen Z adults identify as LGBTQ+.

This talk was part of a wave of outreach by Office of Equity, Diversity, and Inclusion (EDI) 's DEIA initiative, which has been bringing up topics that are sometimes complicated or emotionally loaded – such as the two facilitated discussions on Police brutality.

For more information on this topic and link to SafeZone training, visit the EDI website at: https://www.edi.nih.gov/people/sep/lgbti/research/programs

This panel discussion was recorded and can be viewed at https://videocast.nih.gov/watch=49702

- Dan Silber

# Interested in healthy eating and the Mediterranean diet?

Is a Mediterranean-like diet that eliminates many ultra-processed foods healthier than a Western diet?

The CLEAN-MED diet intervention study was designed to test this concept.

Dr. Karen Frank, Chief of the hospital's Department of Laboratory Medicine and the principal investigator of the clinical trial, explained that the role of diet in the modulation of gut microbiota has been widely recognized. Trillions of microorganisms, composed of mostly bacteria, but also viruses, bacteriophages, fungi and others, act together with their host to break-down nutrients, influence immunity and possibly have an active role in disease pathogenesis.

"There are now many scientific studies that have associated diet and health, including mental health and we are excited to dig deeper into the biological pathways responsible, as well as the intricate connection between bacteria and human hosts," said Dr. Frank. The CLEAN-MED diet combines the Mediterranean diet with a diet that utilizes minimally processed foods.

A typical Mediterranean diet includes high intake of vegetables, legumes, fruits, nuts, whole-grain cereals and olive oil; moderate intake of fish and wine; low intake of poultry and dairy; and very low intake of red meat.

This study will follow two groups, a randomized cross-over study design by alternating one month of routine food and one month of food prepared by the NIH metabolic kitchen. The second group of participants will receive education with experienced dieticians, then they cook their own food for a year while receiving guidance from the study team.

Find out how to participate in the study here: bit.ly/3KE7ZPQ

Read more online: cc.nih.gov/ccnews

# Leaning In or Leaning Out

## The third in a series on the future of work at the NIH Clinical Center

*By Dr. James Gilman, NIH Clinical Center CEO*

I am grateful that we have finally reached the point in our battle with COVID-19 that I can work in my Clinical Center office unmasked and with the door open. I understand that sometimes doors need to be closed for reasons of security and privacy. I will also work behind a closed door when working on something that requires my full attention. While those occasions do occur, the need for me to avoid interruptions and focus fully on an important issue is not an everyday thing. A closed door suggests the room occupant is either not present or the occupant would prefer not to be interrupted. Closing the door and leaving the lights off—don't get me started. That's leaning too far back!

My current open door has little to do with an official open-door policy. Open-door policies are to ensure staff members, patients, family members or other caregivers have an avenue for redress of a grievance, especially if the usual measures have failed. I support addressing a problem at the lowest level that the issue can be resolved, but if a staff member and their supervisor cannot agree on the nature of the problem or a solution, then the staff member needs to have a way to raise the issue above the supervisor's level. Almost every leader I know in every organization I know is required to have an open-door policy to address problems that cannot be resolved by the usual means.

However, most issues can be solved by other means and my open door is useful in that regard. An open door is an indication to anyone passing by that I am willing to be interrupted if needed. The interruption may be to get a piece of information that I might have that they may need to make progress on an issue. Obtaining that information quickly is a time-saver.

Sometimes the interruption is driven by a rumor. Dispelling erroneous information quickly—before it spreads—is a really important function and also a time-saver in the long run. Occasionally, the interruption is for a true emergency. Quickly mobilizing all the resources of the CC to respond once again saves a lot of time. The open door often allows little problems to be solved before they become bigger.

There are pitfalls to keeping my office door open. Sometimes people may take advantage of the open door just to talk. They generally find I am not a great conversationalist. Sometimes staff members want to talk about an issue that might not be a problem yet. If not cautious, leaders can lean so far in they act prematurely. (Lean too far in and you may just fall on your face.) Timing is very important. With modest amounts of experience, leaders are able to recognize when an issue is still being developed and can avoid wading in too early. Similarly, leaders learn how to confirm the accuracy of information quickly and, thus, avoid acting on uncorroborated rumors. The open door also means that more problems will come my way. That is a problem if I think I am supposed to solve them all myself. I stopped doing that a long time ago, instead relying on other members of the CC staff to find solutions. Except in unusual circumstances, their solutions are as good as mine or even better.

In spite of the pitfalls, I remain a fan of leaning in and keeping the door open. The question today is, how to lean in virtually?

My premise is that leaning in while teleworking takes more thought and more disciplined activity, not less, than it doeswhile in the office with the lights on and the door open. CC staff members have to be better problem seekers while working remotely than when physically present in the workplace. Looking starts with the most frequent sources of usual difficulties, but that alone will not be sufficient. Big problems occasionally come from very unusual sources. So just making virtual rounds with habitual contacts, including supervisors and direct reports, will not get the job done. Furthermore, passivity—expecting the person with the problem to find you just—will not be enough. Not only will problems not be solved, they won't even be identified until they are so large that everyone knows about them.

Only if we can figure out the answers to these following questions, can we be as effective teleworking as when we are all in the workplace.

**Questions to consider: How can we lean in virtually?**

How do your supervisors and your direct reports know that you want to lean in, even when teleworking, and be receptive to issues when they are small problems, before they become big ones?

How about your peers and the problems that enter your purview horizontally and not from your supervisors or direct reports?

How do you ensure you are as accessible when teleworking as when in the office, particularly to people you have seldom seen face-to-face?

For those teleworking staff whose duties are public-facing, especially involving patients and families, how do you convey compassion and empathy for their issues without face-to-face contact?

In the virtual workplace, what is the correlate of the open door? And the closed door with the lights turned off?

To see previous installments of the future of work series, visit: cc.nih.gov/ccnews

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You are able to step out of the shadow of loss, which always hovers around your relationships with patients, and operate in the moment with kindness and focus on this person right here. Many of you have sensitive solutions to the challenges of constant intrusions, disruptions to sleep and the disorientation and delirium they cause.

Your nighttime behaviors are thoughtful. You limit room visits by combining tasks. You control light by facing your laptops and instruments away from the patient. You reduce noise by not talking near the patient, by shutting the door, by whispering when communication is needed.

Some of you have creative ideas about how to build the patient's spirit and hope. You show humor, share personal stories and insights, arrange to take him outside into the fresh air, back into the world.

And there are those of you who have the ability to see your patient as a whole person. You listen closely to the questions he asks. Your answers are supportive but clear. You understand how what you are doing now fits into his entire treatment. You know that sometimes reassurance and connection might be more helpful than sedation.

I marvel at your ability to find that level of empathy and perseverance. I am struck by how you celebrate small improvements, even as you recognize he won't survive. You applaud his efforts to stand and walk, make a moment to look at pictures of his grandchildren, become my partner in his care.

It is two years later, and I can still see your faces, still feel your warmth. And, I wonder if we can talk honestly about what helps, what works? Can we share and replicate these skills and talents? Can we lift each other up?

Marcy Mager is a member of the NIH Clinical Center's Patient Advisory Group. (https://www.cc.nih.gov/about/welcome/governance1.html)

# Dr. Francis Collins on 70 years of Clinical Center research

Pioneering researcher and former NIH Director Dr. Francis Collins addressed the Clinical Center community in a recent Grand Rounds talk in honor of the center's 70th anniversary.

During his June 28 presentation, entitled "Seven Decades at the Forefront of Medical Research: The NIH Clinical Center," the physician–geneticist barnstormed the center's history of groundbreaking research and shared his insights into its future challenges and opportunities.

Looking back, Collins celebrated a long list of major Clinical Center research advances, which transformed the understanding and treatment of cancer, sickle cell anemia, infectious diseases such as HIV and Ebola, vaccines, mental illness, and rare diseases.

The first cure of a solid cancer tumor with a chemotherapy drug, the very first human gene therapy, and the use of ketamine to treat severe depression and suicidality, were just some of the many milestones Collins cited. The Presidential Medal of Freedom recipient said he hoped his "romp" through 70 years of remarkable Clinical Center research left listeners in awe.

"To see this track record, this number of major advances that have really changed the course of medicine all coming from this Clinical Center ... is pretty darn phenomenal," he said. "There's no place else on Earth that comes close to that kind of level of achievements."

Collins noted, for example, the vision of Steve Rosenberg, who joined the Clinical Center in 1974 and embarked on a decades-long quest to discover how to activate the immune system to fight cancer.

"I think Steve would tell you this is the kind of facility that made it possible over this stretch of time, with many high-risk ... protocols that did not succeed, to keep pushing forward those boundaries," Collins said. "[That] might have been very difficult to do in any other place and now [his research] has unleashed an entire field of cancer immunotherapy."

Collins used the second half of his presentation to spotlight the key opportunities and challenges that he believes the Clinical Center will face in the years ahead. "We're in this exponential phase of progress in biomedical research, much of it driven by technology," he said.

The physician-geneticist highlighted the importance of cell therapy, gene therapy, vaccine research, Alzheimer's research, and precision medicine and emphasized the need to maintain cutting-edge facilities, focus on patient safety, and support the NIH-wide UNITE initiative to address structural racism in biomedical research.

He also shared his hope that the Clinical Center can grow its capacity to treat pediatric patients younger than two years old, particularly when it comes to gene therapies.

Reflecting on the Clinical Center's role as a "House of Hope" for patients who serve as fellow partners in research, Collins said, "The people that we are most grateful to are the patients, who have come here and put their trust in us."

He professed his faith that the Clinical Center will continue to evolve in ways that will save many lives and reduce much suffering. "But it's going to take every bit of energy and creativity and risk-taking that has characterized this Clinical Center from the very beginning back in 1953."

Known for his landmark research into disease genes, Collins led the International Human Genome Project and later worked as NIH Director under three presidents, becoming the longest-serving director in modern NIH history. He currently serves as a senior researcher for the Center for Precision Health Research, where he investigates the role genes play in a range of human diseases with the aim of discovering new treatments.

- Sean Markey

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