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Twenty-Sixth Meeting of the Clinical Center Research Hospital Board

February 16, 2024

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Clinical Center Research Hospital Board

- Norvell V. Coots, M.D., President and Chief Executive Officer (CEO), Holy Cross Health, and Chair, National Institutes of Health (NIH) Clinical Center Research Hospital Board (CCRHB)
- Lawrence A. Tabak, DDS, PhD, Principal Deputy Director, NIH
- Nina F. Schor, M.D., Ph.D., Deputy Director for Intramural Research, NIH, and Designated Federal Official and Executive Secretary, CCRHB
- David M. Baum, PMP, Patient, Clinical Center (CC) Patient Advisory Group
- David C. Chin, M.D., M.B.A., Distinguished Scholar, Johns Hopkins Bloomberg School of Public Health and Johns Hopkins University School of Medicine
- Regina S. Cunningham, Ph.D., RN, FAAN, CEO, Hospital of the University of Pennsylvania Health System
- Sherin U. Devaskar, M.D., Executive Chair of the Department of Pediatrics at the University of California, Los Angeles (UCLA); Physician-in-Chief, UCLA Mattel Children's Hospital; and Assistant Vice Chancellor of Children's Health, UCLA Health
- Julie A. Freischlag, M.D., Dean, Wake Forest University School of Medicine
- Steven I. Goldstein, M.H.A., President and CEO, Strong Memorial Hospital, University of Rochester Medical Center
- Jack Leslie, Former Chairman, Weber Shandwick, Senior Visiting Fellow, Duke Global Health Institute
- Stephanie Reel, M.B.A., Assistant Professor, Johns Hopkins University School of Medicine, Division of General Internal Medicine
- Antoinette Royster, NIH Research Participant and Patient Advocate
- Craig E. Samitt, M.D., M.B.A., Founder and CEO, ITO Advisors
- *Absent

Executive Summary

The Clinical Center Research Hospital Board (CCRHB) of the National Institutes of Health (NIH) convened its 26th meeting in person and via videoconference on February 16, 2024. The meeting was webcast live and open to the public. A <u>video recording</u> is available online.

Norvell V. Coots, M.D., President and Chief Executive Officer (CEO) of Holy Cross Health and Chair of the CCRHB, called the meeting to order at 9:00 a.m. ET. He welcomed everyone to the meeting and indicated who was attending in person and who was attending virtually.

Lawrence A. Tabak, D.D.S, Ph.D., Principal Deputy Director of NIH, shared that he will step down from his role on the CCRHB and that Nina F. Schor, M.D., Ph.D., the Deputy Director for Intramural Research at NIH, will be the designated federal official and executive secretary of the CCRHB. Dr. Tabak shared other leadership updates at NIH as well as recent awards and accomplishments of NIH staff and NIH-funded researchers. He provided an update on NIH's efforts to support people with disabilities in the biomedical research workforce, including updating NIH's mission statement, designating people with disabilities as a population with health disparities, and supporting research to better understand these disparities. Dr. Tabak recognized the Diversity, Equity, Inclusion, and Accessibility (DEIA) Working Group that is part of the NIH Steering Committee and its efforts to support the disability community by addressing culture, ableism, and research policies and systems.

James K. Gilman, M.D., CEO of the NIH Clinical Center (CC), updated the Board on awards received by CC staff, including the CC's 2023 Clinical Recognition Program, the NIH Director's Awards, and the 7th Annual CEO Awards. Dr. Gilman shared several CC staff updates, including hiring the Chief of the Pharmacy Department after more than 4 years of interim leadership. He reported that for the first time in several years, the average daily census has improved from the previous fiscal year (FY). So far for FY 2024, inpatient admissions have increased by 9%, and the average length of stay (LOS) has decreased by 6%. The CC continues to offer telehealth visits, which help it operate more efficiently.

Dr. Gilman also updated the Board on the CC's progress on its Magnet[®] accreditation application, efforts in DEIA, the redesign of the CC website, and the construction of the Surgery, Radiology, and Laboratory Medicine (SRLM) wing. He then reviewed the results of the CC's 2023 Federal Employee Viewpoint Survey and the Hospital Survey of Patient Safety Culture, which was conducted as part of the 2024 Joint Commission. Finally, Dr. Gilman told the Board about the CC's recent efforts to address mental health and suicide in the health care worker population. The CC hosted a town hall focused on suicide prevention, which he said was very well received, and has established many resources for CC staff to support their well-being.

Colleen Hadigan, M.D., M.P.H., Chief Medical Officer of the NIH CC, shared the CC's efforts to develop its Health Equity in Clinical Care Strategy in response to the Joint Commission's health care equity standards. Aspects of this strategy include the collection of data on inpatient health outcomes and the identification and remediation of potential health disparities. Dr. Hadigan reported on inpatient health outcomes based on FY 2022 data. This analysis looked at a variety of health outcomes based on sex, age, race, ethnicity, preferred or predominant language (either English or non-English), insurance status, and Z-codes, which are codes related to the social determinants of health. One of the findings from this analysis showed that patients who do not speak English were more likely to have longer LOSs, to develop catheter-associated urinary

tract infections, and to die during hospitalization or within 30 days of discharge. This indicates that patients with limited English proficiency may be uniquely vulnerable at the CC, so the CC intends to take steps to better understand and address these disparities.

Diana Bianchi, M.D., Director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, and Brigitte Widemann, M.D., Chief of the Pediatric Oncology Branch at the National Cancer Institute (NCI) Center for Cancer Research and Special Advisor to the NCI Director for Childhood Cancer, outlined the CC pediatric working group's strategic plan. The working group identified the most impactful scientific areas of pediatric research where NIH could substantially improve child health and outlined scientific priorities for pediatric research at NIH and the CC. The working group also identified infrastructure and resource enhancements that the CC could implement to improve and expand pediatric research.

Jennie Lucca, CEO of The Children's Inn, presented an overview of The Children's Inn and its role in supporting pediatric research at the CC. Ms. Lucca also shared the renovation and addition plans for The Children's Inn—known as The Inn of Tomorrow—, which will allow it to continue supporting cutting-edge pediatric research and advance sustainability and well-being.

Dan Wheeland, P.E., Director of the NIH Office of Research Facilities (OD/OM/ORF), updated the Board on the ongoing construction and improvements in support of the Clinical Center. Although the FY 2024 federal appropriations have not been finalized, NIH did receive \$120 million in Nonrecurring Expenses Fund (NEF) resources to support five infrastructure projects that will benefit Building 10. Mr. Wheeland shared updates on the Pharmacy and Permanent Intravenous Admixture Unit renovation, the Radiopharmacy and Cell Labeling Facility, the Sterile Processing upgrades in Building 10, the E-Wing Renovation, the Center for Cellular Engineering Cell Processing Facility, the SRLM wing, the Center for Alzheimer's and Related Dementias Program, the Post Anesthesia Care Unit and Pre-Operation Renovation, and renovation of the electrical switching station, emergency generators, and cogeneration plant. He also shared details about NIH's seismic preparedness efforts.

Dr. Coots adjourned the meeting at 12:22 p.m. The next meeting of the CCRHB is slated for June 21, 2024.

Meeting Summary

February 16, 2024

Welcome and Board Chair's Overview

Norvell V. Coots, M.D., President and Chief Executive Officer (CEO), Holy Cross Health, and Chair, NIH Clinical Center Research Hospital Board (CCRHB)

Dr. Coots welcomed NIH and Clinical Center (CC) leaders, members of the NIH community, and members of the public to the meeting, which was conducted in a hybrid format.* In addition to Dr. Coots, the following Board members attended the meeting in person: David Baum, PMP; David C. Chin, M.D., M.B.A.; Regina S. Cunningham, Ph.D., RN, FAAN; Jack Leslie; Stephanie Reel, M.B.A.; Antoinette Royster; and Craig E. Samitt, M.D., M.B.A. The following members participated via the virtual meeting platform: Sherin U. Devaskar, M.D.; Julie Freischlag, M.D.; and Steve Goldstein, M.H.A.

On behalf of the Board members, Dr. Coots thanked Nina F. Schor, M.D., Ph.D., the Deputy Director of Intramural Research at NIH, who will serve as the CCRHB's designated federal official and executive secretary. This role was previously held by Tara Schwetz, Ph.D.

NIH Director's Remarks

Lawrence A. Tabak, D.D.S, Ph.D., Principal Deputy Director, NIH

Dr. Tabak noted that this was a transition meeting because his duties on the CCRHB would soon be taken on by Dr. Schor.

NIH Leadership Changes

Dr. Tabak shared changes in leadership at NIH:

- Monica M. Bertagnolli, M.D., was appointed the NIH Director on November 9, 2023. She is the first surgeon and the second woman named as NIH Director. Dr. Tabak shared Dr. Bertagnolli's regrets for not being able to attend the CCRHB meeting; she had a previous commitment to speak at the 2024 American Association for the Advancement of Science meeting in Denver, Colorado.
- Dr. Tabak moved from the role of Acting Director to Principal Deputy Director. Dr. Schwetz, who was the Acting Principal Deputy, is now the Deputy Director for Program Coordination, Planning, and Strategic Initiatives, leading the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI). DPCPSI is the largest division within the Office of the Director.
- The new Director of National Cancer Institute (NCI), Kimryn Rathmell, M.D., Ph.D., was sworn in on December 18, 2023. Dr. Rathmell comes from Vanderbilt University Medical Center.
- Sean Mooney, Ph.D., was recently named the Director of the Center for Information Technology (CIT) and will officially join NIH in March. Dr. Tabak acknowledged the leadership of CIT's Interim Director, Ivor D'Souza, M.S.

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^{*} This meeting was videorecorded; the recording is available online.

- Lyric Jorgenson, Ph.D., was officially named as the Associate Director for Science Policy after serving as the Acting Director.
- Jane M. Simoni, Ph.D., was selected as the Associate Director for Behavioral and Social Sciences Research, within DPCPSI.
- Diana Finzi, Ph.D., was named the Acting Associate Director for AIDS Research. There is an active search underway for a permanent Director of the Office of AIDS Research.
- John T. Burklow, was the Associate Director for Communications and Public Liaison for many years and then served as Acting Chief of Staff for the NIH Office of the Director. He was recently named to this position permanently.

Awards

Dr. Tabak shared notable honors received by NIH staff and NIH-funded researchers:

- The CC's Steven Rosenberg, M.D., Ph.D., received the National Medal of Technology and Innovation, the nation's highest honor for technological achievement. Dr. Rosenberg received the medal from President Biden at a White House ceremony in October.
- The winners of the 2023 Nobel Prize in Physiology or Medicine were NIH grantees
 Katalin Karikó, Ph.D., and Drew Weissman, M.D., Ph.D. They were recognized for their
 work stabilizing messenger RNA (mRNA), which led to the development of mRNA
 vaccines against COVID-19. Dr. Tabak noted that this recognition shows the importance
 of basic research.
- André Nussenzweig, Ph.D., NCI, and John O'Shea, M.D., National Institutes of Arthritis and Musculoskeletal and Skin Diseases, were elected to the National Academy of Sciences.
- Bruce J. Tromberg, Ph.D., Director of the National Institute of Biomedical Imaging and Bioengineering (NIBIB), was elected to the National Academy of Engineering.
- Michael F. Chiang, M.D., and Eric Green, M.D., Ph.D., Directors of the National Eye Institute (NEI) and the National Human Genome Research Institute, respectively, were elected to the National Academy of Medicine.

Events

Dr. Tabak shared that President Biden signed an executive order on November 13, 2023, to establish the <u>Initiative on Women's Health Research</u>. The signing ceremony was attended by Janine Austin Clayton, M.D., FARVO, Associate Director for Research on Women's Health at NIH; U.S. Secretary of Health and Human Services Xavier Becerra; and Dr. Bertagnolli. NIH will be heavily involved in this initiative, so updates will be shared with the CCRHB as this work takes shape.

On October 25, 2023, First Lady Jill Biden, Ed.D., and Jodie Haydon, partner of the Prime Minister of Australia, visited NIH. Drs. Tabak and Bertagnolli, along with James K. Gilman, M.D., guided the First Lady and Ms. Haydon on tours of the CC and NCI.

Supporting Individuals with Disabilities in the Biomedical Research Workforce

At the previous CCRHB meeting, Dr. Tabak shared NIH's efforts to update its mission statement, which says: "NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." Many people in the disability community have complained

that the statement—particularly "reduce illness and disability"—implies that there is something wrong with people with disabilities, and that they need to be "fixed."

In August 2023, NIH released a <u>request for information</u> (RFI) to collect feedback about the proposed revision to the mission statement: "NIH's mission is to seek fundamental knowledge about the nature and behavior or living systems and *to apply that knowledge to optimize health and prevent or reduce illness for all people.*" The RFI closed on November 24, and analysis of the many responses is ongoing. There has been a variety of responses and feedback, including concerns about removing "lengthen life" from the current statement. Based on the variety of responses, NIH will likely have to hold focus groups, town halls, and roundtable discussions to inform any changes to the statement. These efforts are important to ensure that the NIH mission statement reflects the common viewpoint among the disability community.

In addition to updating the mission statement, NIH is taking steps to enhance the lives of people with disabilities. In September 2023, the National Institute of Minority Health and Health Disparities (NIMHD) Director, in consultation with the Agency for Healthcare Research and Quality (AHRQ) Director, designated people with disabilities as a population with health disparities. In conjunction with this designation, NIMHD issued a funding opportunity for research on approaches and interventions to address the intersections of disability, race, ethnicity, and socioeconomic status on health care access and outcomes.

NIH is also fully committed to its DEIA efforts, which NIH staff actively provide their invaluable input on. The NIH Steering Committee has a DEIA Working Group that is focused on addressing culture, ableism, and research policies and systems at NIH. Dr. Tabak shared an example of how NIH is addressing accessibility. NIBIB developed the coronavirus disease 2019 (COVID-19) at-home diagnostic tests, but it was quickly obvious that these tests were not suitable for people who are blind or have low vision. NIBIB has since developed an appropriate solution in which the test instructions and results are read out loud through a smartphone app.

Dr. Tabak reminded the Board that Dr. Schor will present this update at future CCRHB meetings.

Discussion

Dr. Coots thanked Dr. Tabak for this service for the CCRHB and welcomed him back any time.

NIH CC CEO Update

James K. Gilman, M.D., CEO, NIH CC

Dr. Gilman acknowledged Dr. Rathmell, NCI Director and Chair of the CC Governing Board, who joined the meeting in person. Dr. Gilman also shared his gratitude for Dr. Tabak's service to the CCRHB and welcomed Dr. Schor as the CCRHB's designated federal official and executive secretary.

Recognition and Awards

Dr. Gilman congratulated Dr. Coots on his retirement from Holy Cross Health. Dr. Coots will still serve as Chair for the CCRHB.

Dr. Gilman recognized the winners of the NIH CC's 2023 Clinical Recognition Award Program:

- Richard Chang, M.D., a senior clinician in the Radiology and Imaging Sciences Interventional Radiology section, was named Staff Clinician of the Year.
- Elaine Cochran, M.S.N., CRNP, and Stacey Solin, M.S., CRNP, both nurse practitioners, were named Physician Assistants/Nurse Practitioners of the Year.
- Marcus Means from the CC's Office of Hospitality and Volunteer Services, and Katie Roth Stagliano, Ph.D., Deputy Laboratory Chief of the CC's Department of Laboratory Medicine, both won Administrator of the Year.

Dr. Gilman said that the CC was well represented at the NIH Director's Awards, which recognize exceptional performance and work that fulfills the mission of NIH. This year 48 CC staff members were recognized through eight awards (seven individual awards and one group award).

On December 15, 2023, the CC held its 7th Annual CEO Awards ceremony and reception, where Dr. Gilman presented 132 awards to 596 staff members. Although the ceremony was virtual, the reception was held in person, at the CC atrium, for the first time in several years. This ceremony also marked the return of two traditions—a gingerbread house contest and vocal music in the atrium—that were paused during the COVID-19 pandemic.

CC Staff Updates

Dr. Gilman shared new hires and retirement at the CC:

- Saly Gabriel, Pharm.D., M.B.A., joined the CC in early February as the new Chief of the Pharmacy Department. Her most recent position was Regional Director of Pharmacy Services for Providence Health in Oregon. The appointment of Dr. Gabriel comes after 4.5 years of interim leadership. Dr. Gilman acknowledged Colleen Hadigan, M.D., M.P.H., who led the search and was a selecting official for this chief position.
- David F. Stroncek, M.D., was recently named Chief of the Department of Transfusion Medicine and Center for Cellular Engineering. He will begin this position at the end of February. Dr. Stroncek has been an NIH employee for 27 years and most recently served as Director of the Center for Cellular Engineering (CCE).
- In December, Ann Berger, M.D., M.S.N., retired after 23 years as Chief of the Pain and Palliative Care Service. M. Jennifer Cheng, M.D., is serving as Acting Service Chief.

Hospital Census

Dr. Gilman reported that for the first time in several years, the average daily census (ADC) has improved from the previous fiscal year (FY). This is an indication that the effects of the COVID-19 pandemic are starting to subside. Although the ADC for FY 2024 remains below the 3-year average, the CC will continue to track these numbers to see if things improve. Between FY 2023 and FY 2024, inpatient admissions increased by 9%, and the average length of stay (LOS) decreased by 6%. This decrease indicates that visits are becoming more efficient and corresponds with no change in the number of inpatient days.

The number of new patients has dropped slightly from FY 2023 but will be monitored throughout the year. Between FY 2022 and FY 2023, outpatient visits increased by 10% to 15%. The increase in outpatient visits led to an increase in the inpatient census. The CC continues to rely on telehealth visits, which may remain part of the CC's practice to help it operate more efficiently.

Barbara Jordan, D.N.P., RN, NEA-BC, CNO, presented at the previous CCRHB meeting about the CC's Magnet[®] accreditation journey. The CC Nursing Department (CCND) is working diligently on its Magnet[®] accreditation application, which is due at the American Nurses Credentialing Center (ANCC) on April 1. The ANCC is expected to schedule a site visit to the CC in the late summer or early fall. Dr. Gilman commended the CCND for its hard work despite many challenges, such as the COVID-19 pandemic.

DEIA Updates

Dr. Gilman said that NIH asked the Institutes and Centers (ICs) to include accessibility as part of its Racial Ethnic Equity Plan; however, the CC has always included accessibility in its plan. One example of the CC's DEIA efforts was hiring Cecelia C. Henry, M.S., RN, Scientific Diversity Advisor for the CC. Ms. Henry works directly with CC leadership and connects CC leaders and staff to DEIA programs and resources. The CC recently reviewed its DEIA plan with the Office of Diversity, Equity, and Inclusion at NIH. Dr. Gilman said the CC has made good progress on its DEIA efforts in recent years, but there is still more work to be done.

CC Website Redesign Project

Dr. Gilman said that the CC is redesigning its website to be more user friendly for staff and patients. In 2023, the website received more than a million views—a 12% increase from 2022. The redesign project will improve the search functions and the overall usability of CC website.

The CC has funded a contractor who will design and develop the updated website. Currently, the CC is working to map how data from the Biomedical Translational Research Information System (BTRIS), the NIH's research data repository, will connect with the CC's electronic health record (EHR) system and be shared on the CC website.

Surgery, Radiology, and Laboratory Medicine (SRLM) Wing

Dr. Gilman showed pictures of the SRLM construction, which he said is making progress and is mostly on schedule, despite some setbacks such as the detection of asbestos in the soil. Dan Wheeland, PE, shared more details about the progress of the SRLM Wing in his presentation later in the meeting.

2023 CC Federal Employee Viewpoint Survey (FEVS) Results

Dr. Gilman said that FEVS is the federal government's annual assessment of the workforce, administered by the Office of Personnel Management (OPM). The 2023 FEVS was distributed via email to all full- and part-time permanent, nonseasonal employees who were onboarded on or before November 30, 2022; contractors do not participate in FEVS. The survey was opened the week of May 15, 2023, and closed the week of June 30, 2023. The FEVS for 2023 included several new items, such as an Employee Experience Index and a Performance Dimensions section.

The 2023 FEVS response rate from the CC was 65.4%—an increase of 0.4% from 2022 and the highest response rate ever for the CC. This is one of the most important metrics to ensure that the CC is receiving useful information. Despite this high rate, however, it did not represent a major increase from 2022, and it falls below NIH's overall response rate of 68.2%.

Dr. Gilman reviewed each of the OPM- and U.S. Department of Health and Human Services—measured indices in the CC's FEVS responses: Belief in Action Indicator, Employee

Engagement Index, Global Satisfaction, Performance Confidence, and DEIA. Overall, there were no major changes to these indices for the CC between 2022 and 2023, and the positive rating percentages from the CC for these indices were below those from NIH.

Seventy-five of the 89 items in FEVS were considered strengths for the CC, with a 65% or higher positive rating. None of the 89 items were considered challenges, which would require a 40% or lower positive rating, or opportunities, which would require a 30% or higher neutral rating. None of the items significantly improved or declined from the 2022 results; the positive rating did not increase or decrease by 5% or more.

These items from the CC's FEVS had the highest positive ratings and were considered the top strengths for the CC:

- "Employees in my work unit meet the needs of our customers."
- "It is important to me that my work contribute to the common good."
- "My organization has prepared me for potential cybersecurity threats."
- "I am held accountable for the quality of work I produce."
- "Employees in my work unit contribute positively to my agency's performance."

Although none of the items from the CC's FEVS met the 30% or higher neutral rating threshold to be classified as an opportunity, several items close to this threshold could be viewed as opportunities for the CC:

- "My organization responds to my accessibility needs in a timely manner."
- "In my work unit, differences in performance are recognized in a meaningful way."
- "Management encourages innovation."
- "How satisfied are you with your involvement in decisions that affect your work?"
- "Senior leaders demonstrate support for work–life programs."

No item from the CC's FEVS was categorized as a challenge (i.e., a 40% or lower positive rating), but the one item that received less than a 50% positive rating was related to employee satisfaction with pay. There were also items in which the positive rating declined between 2022 and 2023, though not by 5% or more:

- "My organization effectively adapts to changing government priorities."
- "I identify with the mission of my organization."
- "Senior leaders demonstrate support for work–life programs."
- "It is important to me that my work contribute to the common good."
- "My organization responds to my accessibility needs in a timely manner."
- "I can easily make a request of my organization to meet my accessibility needs."

Dr. Gilman noted that overall, the results of the 2023 FEVS for the CC were neutral. He said that CC leadership needs to consider how to improve these scores.

2024 Joint Commission and Hospital Survey of Patient Safety Culture

Dr. Gilman said that the Joint Commission is expected to visit the CC later in 2024. David Lang, M.D., M.P.H., and his staff have prepared the Joint Commission Readiness Guide, and the CC staff are reviewing the results of the Hospital Survey on Patient Safety Culture, which was developed by AHRQ. This survey was completed in December 2023. However, only 569 out of 5,000 survey recipients responded. This low response rate likely is due to survey fatigue at NIH.

Comparing the overall patient safety rating between the CC and AHRQ, the CC received a higher percentage of "very good" responses but a lower percentage of "excellent" responses. The survey has 10 composite measures; overall, the CC and ARHQ had very similar positive ratings in these measures. The CC had lower positive ratings than AHRQ in a few of these measures, such as the Handoffs and Information Exchange measure. The CC scored higher than AHRQ in the Staffing and Work Pace measure and the Supervisor, Manager, or Clinical Leader Support for Patient Safety measure. Dr. Gilman noted that the CC can work toward improving these scores—especially given that it plans everything for its patient population, unlike other hospitals or health care centers that have emergency or unanticipated patient admissions.

Staff Wellness

Dr. Gilman said that in response to increasing mental health burdens and rates of suicide, the Special CC Wellness Initiative hosted a town hall on December 7, 2023, called "Managing Depression, Anxiety, and Suicide Prevention." This workshop provided actionable tips on recognizing the warning signs of suicide and how to help oneself, co-workers, family, and friends.

Dr. Gilman said that he was very supportive of the town hall and pleasantly surprised by its positive impact on the CC staff. Many staff members said that the event had a major impact on them, and that they had never before worked for an organization that talked openly about suicide. Based on this response, the CC is scheduling follow-up events on the topic, including small group discussions with families of people who died by suicide and with people who survived a suicide attempt.

What to Expect in 2024

Dr. Gilman said that the CC will focus on the following issues in the coming year:

- Filling key leadership and staff positions
- Continued focus on DEIA
- Acquiring Magnet® accreditation
- Continuing to assess the requirements of care for more pediatric patients
- Focusing on staff well-being
- Continuing the dialogue about future of work

Clinical and Safety Performance Metrics

The quarterly executive dashboard, which was distributed to the CCRHB in advance of the meeting, is on the Board's website. Any questions should be directed to Dr. Lang, Chief of the CC Office of Patient Safety and Clinical Quality (OPSCQ).

Discussion

- In response to a question from David M. Baum, PMP, Dr. Gilman said that Justin Cohen, M.S., M.A., Chief of the Office of Communications and Media Relations and Patient Recruitment, and his office are leading the CC website updates.
- Mr. Baum and Dr. Gilman discussed how the project involving the CC's EHR system for the website is in the early stages; the actual work establishing these data flows has not been funded yet. This project is moving at a slower pace because of the CC's staff focus on the Magnet® accreditation.

- Regarding FEVS, Regina S. Cunningham, Ph.D., RN, FAAN, asked about the percentage of CC staff who are contracted. Dr. Gilman estimated 15% to 20%. Some CC departments have many contracted employees because the market rate for those positions is higher than what the General Schedule pay scale could compensate. On the other hand, some duties in specific positions can be performed only by federal employees.
- Ms. Reel asked about the timing of the Joint Commission visit and whether it was affected by the pandemic. Dr. Gilman said that the Joint Commission visited the CC in August 2021 and identified issues with sterile processing. The CC has put in work to improve its sterile processing—including building the new sterile processing center—so hopefully this will not be an issue during the Joint Commission's upcoming visit.
- David C. Chin, M.D., M.B.A., appreciated the CC's efforts to discuss suicide prevention and asked whether suicide rates are up at NIH. Dr. Gilman said that NIH does not track this information. At the CC, four staff members died by suicide in the past 2 years. These staff members were recognized during the town hall on suicide prevention town hall; attendees said they appreciated the tribute.
- In response to Dr. Cunningham's request, Dr. Gilman said that he would share the recording of the town hall on suicide prevention with the CCRHB members.
- Antoinette Royster and Dr. Gilman discussed the details of the Hospital Survey of Patient Safety Culture and its low response rate. The survey, which was shared via email with anyone who has any type of clinical responsibility at the CC, was designed to take 10 to 20 minutes to complete. But given how many surveys NIH releases, there is some survey fatigue at the Institutes.
- Jack Leslie asked how NIH's FEVS scores compare with other federal agencies. Dr.
 Gilman said that NIH scores relatively high. The highest satisfaction rates, however, are
 at the National Aeronautics and Space Administration (NASA). Leaders across NIH
 share the belief that NIH can do better and should strive to ultimately surpass NASA's
 FEVS satisfaction scores.
- Dr. Coots asked about fatigue and resilience among CC staff. Dr. Gilman said that the CC is taking several steps to support staff well-being, including establishing the CC Wellness Committee; releasing a survey about burnout; creating a bereavement group, which is led by the Spiritual Care Department; and creating Code Lavender, which can be used by employees or departments to access high-touch support from trained CC staff.
- **ACTION ITEM:** Dr. Gilman agreed to share a recording of the "Managing Depression, Anxiety, and Suicide Prevention" town hall with the CCRHB.

CC Health Disparities Data

Colleen Hadigan, M.D., M.P.H., Chief Medical Officer, NIH CC

Dr. Hadigan said that in response to the Joint Commission's health care equity standards, the CC developed its Health Equity in Clinical Care Strategy. This strategy outlines how the CC will identify health care disparities in the patient population and stratify quality and safety data by using sociodemographic characteristics of the CC. This work is being led by Dr. Hadigan and supported by Dr. Lang; Ms. Henry; Tricia Coffey, M.S.; and a Presidential Management Fellow.

The planned activities for this Health Equity in Clinical Care Strategy include establishing an annual data report on inpatient health outcomes (beginning with FY 2022), identifying focus areas for addressing health care disparities that are noted in the annual data report, monitoring and evaluating subsequent annual reports to document and measure progress, and evaluating and stratifying patient satisfaction survey data acquired through a Press Ganey survey in addition to the annual data report.

Dr. Hadigan shared the first planned activity for this strategy: a report on inpatient health outcomes for FY 2022. This analysis identified specific sociodemographic characteristics and/or social determinants of health (SDOH) among the CC's inpatient population, including sex, age, race, ethnicity, preferred or predominant language (either English or non-English), insurance status, and Z-codes. The CC's Health Information Management Division (HIMD) adds Z-codes to a patient's EHR after reviewing and identifying any note or documentation in a patient's file that qualifies as an SDOH (e.g., unemployment, housing insecurity).

Dr. Hadigan highlighted two important aspects about the sociodemographic and SDOH data in this patient population. First, the analysis of the FY 2022 inpatient population showed a small number of patients with Z-codes. The absence of Z-codes in the CC's dataset does not mean that there are fewer patients who qualify to have a Z-code; rather, there was no record found by HIMD to assign a Z-code. Because there were so few patients with Z-codes, the analysis compared patients with any Z-code with those without a Z-code. Second, patients who are admitted to the CC are often asked whether they are insured or uninsured, but sometimes this information is missing in patients' records. However, that does not indicate whether the patient was asked about their insurance status or whether they declined to answer. Therefore, insurance status was analyzed as "insured," "uninsured," or "no insurance data."

Specific outcomes in the inpatient population were evaluated based on information from the CC's EHR system, the Office of Patient Safety & Clinical Quality (OPSCQ), and the Hospital Epidemiology Service. The outcomes evaluated included length of stay (LOS), death during hospitalization, death within 30 days of discharge, unplanned intensive care unit (ICU) admission, central line—associated bloodstream infections (CLABSI), catheter-associated urinary tract infections (CAUTI), surgical site infection, and falls. Dr. Hadigan reviewed the specific outcomes for each sociodemographic characteristic and/or SDOH in the FY 2022 inpatient population:

- Sex: There were no significant differences between men and women in LOS, death in hospital, death 30 days after discharge, unplanned ICU, CLABSI, CAUTI, or falls. There was a slight increase in the frequency of surgical site infections in men compared with women, even though men and women were equally likely to have a surgical procedure. The relative risk of surgical site infection between men and women was not statistically significant. The limitation of this analysis is that there are very few cases of surgical site infection at the CC, but it should still be considered a potential health disparity that could be driven by the type of surgery or other sex-specific vulnerabilities.
- **Age:** There were no significant differences in any of the outcomes between the various age groups (0–18 years, 19–34 years, 35–49 years, 50–64 years, 65–79 years, and 80+ years).
- Race: For this analysis, race was reported as White, Asian, Black/African American, or "Other," which includes Hawaiian/Pacific Islander, American Indian/Alaska Native, and mixed race. LOSs were longer in Black/African American and Other patients than in White and Asian patients. There were no significant differences by race for any of the other

- outcomes, but there may have been too few CLABSI, CAUTI, or surgical site infection cases to detect any differences across multiple race categories.
- **Ethnicity:** There were no significant differences in any of the outcomes between Latin/Hispanic and non-Latin/Hispanic patients.
- English vs. non-English language: Non-English-speaking patients had significantly longer LOSs and higher rates of death during hospitalization, death within 30 days of discharge, and CAUTI. There were no significant differences for the other outcomes. A relative risk analysis showed that death during hospitalization and death within 30 days of discharge were statistically significant among non-English-speaking patients. The relative risk for CAUTI was not statistically significant, likely because of the small number of CAUTI cases.
- Insurance status: There were significantly higher rates of unplanned ICU admissions, death during hospitalization, and CLASBI for patients who were insured than for those who were uninsured or had no insurance data. The LOSs were significantly longer for insured patients than for those with no insurance data. The relative risk analysis showed that unplanned ICU admissions, death during hospitalization, and CLABSI were more common in insured patients than in uninsured patients or those without insurance data.
- **Z-code:** Patients with Z-codes had statistically significant longer LOSs and higher rates of death during hospitalization; there were no significant differences between patients who did or did not have a Z-code for the other outcomes. The relative risk for death during hospitalization was statistically significant for patients with any Z-code. This analysis may not completely reflect the inpatient population, because not all patients who qualify for a Z-code are recorded in the database.

Dr. Hadigan reflected on the results for non-English-speaking patients, who were more likely to have longer LOSs, to have CAUTI, and to die during hospitalization or within 30 days of discharge. Patients with limited English proficiency are uniquely vulnerable at the CC because of language barriers. To address this issue, the CC developed a language access policy, which requires staff to provide language services (e.g., oral, written, electronic) to patients and their caregivers with limited English proficiency. This policy also established proficiency requirements for bilingual health care staff. This proficiency is measured through a bilingual fluency test; so far, 149 CC staff members have volunteered to take this test, with a 70% success rate. This indicates that there may be staff members providing language support to patients who are not sufficiently fluent. Another effort to address the language disparity will be to develop catheter care instructions in different languages.

The next steps are to review these results with the Health Equity Working Group and identify specific projects that can address these disparities. These analyses will be repeated using FY 2023 data and will continue in the future.

Discussion

• Craig E. Samitt, M.D., M.B.A., asked about the drivers of extended LOSs. Dr. Hadigan said that the analysis showed that patients who do not speak English or do have any Z-code are more likely to have an extended LOS. These results make sense, because the CC has many patients from around the world who are unlikely to have the appropriate resources to live locally or receive health care outside the CC, leading to a longer LOS. For these patients, the CC should consider opportunities for alternate non-inpatient care.

- In response to Dr. Chin's question, Dr. Hadigan said that her team has considered using ZIP codes or Area Deprivation Indices (ADIs) for U.S.-based patients for its analyses, but many CC patients are international, and it will be difficult to analyze non-U.S. ZIP codes. The team decided to use Z-codes for its analysis, but there were few Z-code records; ADIs may be a better metric for future analyses.
- Sherin U. Devaskar, M.D., asked whether the team captures patient satisfaction and uses these data along with the Social Vulnerability Index to measure patient experience. Dr. Hadigan said that patient satisfaction is captured through a Press Ganey survey, which is offered in multiple languages and translated back to English. The initial results showed no significant differences in patient satisfaction among ethnic groups or preferred language; however, these data are limited, because fewer demographic and SDOH variables are captured in the patient satisfaction survey. Also, for privacy reasons, these survey results are not linked to a patient's EHR.
- Dr. Devaskar asked whether the CC uses simultaneous translation for patients with limited English proficiency during rounds and other times when medical information is being disseminated. Dr. Hadigan said that a few translators do simultaneous translation, but this is not a standard practice at the CC.
- Dr. Cunningham and Dr. Hadigan discussed how Z-codes in patient data are first identified through artificial intelligence and then manually verified by reviewing the chart and confirming documentation to assign the Z-code.
- Dr. Cunningham said that the disparities for non-English-speaking patients are evident, but it is difficult to measure the benefits and effectiveness of language interpretation services—especially given the complexity of the information being translated. Dr. Hadigan said that the U.S. Food and Drug Administration (FDA) recently updated its requirements for translating research consent forms. In response, the CC's central Institutional Review Board (IRB) has initiated a policy requiring full translation of the written, long-form consent rather than using a short-form consent with an oral translator. This will improve access to complex non-English information for these patients. Dr. Schor said that some protocol consents are complex enough that even when the consent is provided in the patient's native language, an ongoing relationship between CC staff and the patient is necessary to keep the patient fully informed. The NIH Library has provided resources to CC investigators to support these translation efforts. Mr. Baum added that electronic consent forms could also help with complex translation issues.
- Mr. Baum asked whether the team could conduct the same analysis on patients who were rejected during the pre-admission protocol screening process. This analysis could help reveal whether there are health disparities in this patient population. Dr. Hadigan said that several NCI investigators have looked to see if their studies reflect the demographics in the national cancer registries. The CC might be able to adopt a similar approach but it would be challenging given the diverse nature of all the studies it supports. Dr. Schor said that the CC's IRB carefully reviews protocol enrollment criteria to ensure they are not excluding certain populations and promoting disparities.
- Mr. Baum said that some clinical trials encourage patients to provide insurance information in case they need to be transferred to a local hospital. Dr. Hadigan agreed and that this practice introduces bias because the CC tends to collect insurance information from sicker patients or those who may require a higher level of care. This may be why patients who have insurance had higher rates of unplanned ICU admissions.

- Mr. Baum noted that translation and language support are needed at the CC call center led by Mr. Cohen's team. The call center provides information about protocols at the CC.
- Ms. Royster asked whether there were instances where a translator or language resources cannot be provided to CC patients. Dr. Hadigan said that on rare occasions the CC has recommended that certain patients should not come to the CC, because the translation services available cannot support certain languages—especially those from remote areas with unique dialects. The CC strives to make sure translators are available to non-English-speaking patients during care and especially for various procedures, such as imaging or blood draws.

CC Pediatric Strategic Plan Working Group Report

Diana Bianchi, M.D., Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development; and Brigitte Widemann, M.D., Chief, Pediatric Oncology Branch at the Center for Cancer Research and Special Advisor to the Director for Childhood Cancer, NCI

Dr. Bianchi acknowledged the working group members and their contributions to this strategic plan over the past 2 years. These members represent the ICs that have pediatric studies at the CC. This working group was charged with identifying the most impactful scientific areas of pediatric research where NIH could substantially improve child health. Its members used horizon scanning to perform long-term, strategic planning for intramural trans-NIH clinical pediatric research that will occur over the next decade and beyond. The overall objective for the working group was to think about the science rather than the cost or logistics of these scientific priorities that allow NIH to be a house of hope for patients of all ages.

The working group identified the following scientific priorities:

- 1. Expanding the scope of natural-history studies to support research on the continuum from diagnosis to treatment throughout disease trajectory
- 2. Building a foundational clinical and scientific infrastructure to support gene therapy, chimeric antigen receptor T-cell (CAR-T) therapy, and other cell and precision therapy studies in young children with inherited or acquired rare, serious, and refractory diseases of unmet need
- 3. Evaluating the efficacy of precision medicine interventions in rare, non-malignant childhood diseases
- 4. Increasing the number of pharmacokinetic and pharmacodynamic (PK/PD) studies to improve rational medication use and proper dosing in children
- 5. Performing metabolic phenotyping across a variety of pediatric conditions, as well as linking metabolic phenotyping on nutrition studies and assessing the impact of diet on immune phenotypes and metabolism
- 6. Developing a cohort of all pediatric patients at the CC to measure physical and mental health and disease across disorders, along with a deeply phenotyped pediatric cohort of healthy volunteer children to establish a standard control group that can be used across studies
- 7. Increasing support for research studies in pregnant and lactating people

Dr. Widemann said that the working group also provided recommendations on how NIH can enhance its infrastructure and resources to support these scientific priorities. Recommended

enhancements included workforce training (e.g., Grand Rounds, a directory of pediatricians), a pediatric section of the IRB, a core focused on protocol development for pediatric clinical research studies, a pediatric natural-history concierge, modular case report forms, common data elements, pediatric-friendly imaging resources and environment, and data management and sharing.

Dr. Widemann outlined the investments that would be required to support these scientific priorities and infrastructure and resource recommendations:

- The priorities and recommendations that would require minimal financial investment include adding a specific pediatric section to the IRB, developing a directory of CC pediatric research and investigators, and establishing a Grand Rounds series focused on child health.
- A low-to-moderate financial investment would be required to support pediatric PK/PD, lactation, and infant and pediatric metabolic studies; to phenotype *All of Us* pediatric participants who are identified as having genomic variants; to create a core for pediatric protocol development; to develop a unified clinical research form, pediatric common data elements, and pediatric-friendly imaging and scanning protocols and facilities; and to establish a natural-history study.
- Major financial investments would be needed to create a clinical infrastructure to support gene therapy, CAR-T, and other cell and precision therapy studies in young children; to deeply phenotype a pediatric-specific health control cohort; and to create a cohort study that included all pediatric patients at the CC across multiple disorders.

Dr. Bianchi said that the working group presented the priorities and recommendations identified as major financial investments to the CC Governing Board. The Board was very enthusiastic about these ideas, but was concerned about whether these investments would increase the school tax that each IC pays to support the CC. The working group agreed to find other sources of funding rather than raise the school tax and applied for funding through the NIH Common Fund. The working group's strategic plan went through several rounds of review and was eventually identified as the second-most-prioritized initiative for the Common Fund. That shows that this strategic plan has broad support across ICs, but it likely will not be funded due to budget constraints for FY 2024. The working group will continue to apply for funding and explore other opportunities to support this work.

Discussion

- Dr. Bianchi said that unless the cell and precision therapies are given to children with inherited disorders at a very young age, these children will suffer devastating consequences throughout their lives. There are also equity issues with cell and precision therapies because of treatment costs and access, as well as the expertise needed to administer these treatments. The working group is committed to addressing these disparities and finding funding to support cell and precision therapies for pediatric patients.
- Dr. Chin asked about the school tax. Dr. Gilman explained that unlike the other NIH ICs, the CC does not get a direct appropriation from Congress. For many years, the CC was funded by user fees from ICs, but this approach started to fail as IC directors had to balance funding investigators and participating in clinical research trial at the CC. For the past 20 years, the CC Governing Board has used the school tax, which is a portion of

- each IC's appropriation. Of note, only 11% to 15% of congressional appropriations stay within NIH, but much of this money funds the CC's school tax.
- Dr. Devaskar asked about the infant-sedation abilities available at the CC. Dr. Gilman said that the CC is following recommendations outlined by William A. Gahl, M.D., Ph.D., and the Pediatric Planning Group for better coverage for pediatric anesthesia. The CC does imaging with pediatric patients through its outpatient and Undiagnosed Diseases Program (UDP) and has at least three pediatric anesthesiologists on staff. Dr. Gilman added that the CC has age restrictions on inpatient pediatrics: Only patients 3 years old or older can be admitted to the CC. But the CC is looking to relax these restrictions to serve pediatric patients as young as 2 years old.
- Dr. Devaskar agreed with Dr. Bianchi's point about providing cellular and precision therapy interventions earlier for pediatric patients. But she warned that cellular therapies could have significant safety issues. Dr. Bianchi said that as part of the funding request to the Common Fund, the CC would create a small pediatric ICU able to care for young children and contract with a local institution that has the expertise to care for children who became critically ill because of a cellular or precision therapy. The CC also has a contract with Children's National Hospital to have pediatric critical care specialists on site at the CC.
- In response to a question from Ms. Reel, Dr. Widemann said that natural-history studies are observational studies of a patient's disease course where there is no intervention. A natural-history study could follow patients who are receiving treatment as part of their clinical care, but it would not be a primary intervention study. NIH is one of the best places to conduct natural-history studies because of its many resources. Being able to conduct natural-history studies in young patients would be very impactful.
- Dr. Cunningham suggested that the resources and infrastructure needed for pediatric
 cellular therapeutics and CAR-T could be shared with similar adult studies at the CC. Dr.
 Widemann agreed, saying that there are many instances when the same target is present
 in pediatric and adult tumors. Regardless, the pediatric and adult tumor research teams
 can collaborate on these efforts.
- In response to a question from Mr. Leslie, Dr. Bianchi said that the working group requested \$12 million per year from the Common Fund. Dr. Devaskar commented that this cost seems reasonable if NIH wants to properly support these pediatric research priorities. In response to a follow-up question from Dr. Chin, Dr. Gilman said that the Common Fund supports new projects for its first few years. Overall, it provides venture capital for a project to grow; after that, ICs can continue to fund the project.
- Dr. Devaskar said that phenotyping normal children as a control population will greatly benefit intramural and extramural research—something that only NIH could accomplish.
- Dr. Bianchi noted that the CC has 250 pediatricians—significantly more than many academic pediatric departments in the country. Even the priorities that require minimal financial investment (e.g., pediatric Grand Rounds) would greatly benefit child health research at the CC and at NIH. The focus on these pediatric research priorities also coincides with the expansion of The Children's Inn, making this is an opportunity for NIH to capitalize on growth and advance pediatric research.
- Dr. Gilman said that the CC recently released job postings for child life specialists.

The Inn of Tomorrow to Propel Pediatric Research at NIH

Jennie Lucca, CEO, The Children's Inn

Ms. Lucca said that The Children's Inn, one of five nonprofit partners at NIH, is located on the NIH campus. The Inn provides lodging and support services for children, teens, and young adults and their families who come from around the world to participate in intramural clinical research studies at the CC.

The vision for The Children's Inn began in the 1980s when Philip A. Pizzo, M.D.—then the chief of the Pediatric Oncology Branch at NCI—saw challenges for families with children who were participating in research studies at the CC. These families were looking for support networks, eating out of vending machines—even sleeping in the waiting rooms. Dr. Pizzo wanted to establish a place that would allow families to stay together while their child was at the CC and help researchers complete their studies. To execute Dr. Pizzo's vision, NIH donated 2.5 acres of land on campus to house what is now known as The Children's Inn. Merck & Co., Inc. donated the original \$3.7 million to build The Inn, and spouses of members of Congress raised the initial funds to furnish it. The Children's Inn opened its doors in 1990.

Today The Children's Inn has a very successful and unique public—private partnership. Though it is located on a federally funded campus, it is a private, nonprofit organization. The Inn is responsible for raising its \$12 million annual budget, which is primarily funded through private philanthropy. Overall, the goal of The Children's Inn is to reduce the burdens that affect families with a sick family member, provide children the opportunity to have normal childhood experiences, and advance the medical research mission of NIH. The Inn supports families in many ways, including delivering recreational, educational, and therapeutic programs to families; and supporting a network of families who have been affected by rare diseases or conditions.

The Inn has 45 staff members and more than 200 volunteers, many of whom are NIH staff. One of the most important and recognizable staff members is Zilly, a therapy dog affectionately known as the Chief of Emotional Support and Engagement. Zilly supports kids at The Inn and makes visits to the CC. A core of individuals and corporations also volunteer their time, advice, and resources to help The Inn achieve its mission.

NIH relies on The Inn to provide a supportive infrastructure for families to participate in clinical research. Since it opened, more than 16,000 families from all 50 states and more than 106 countries have stayed there. Currently, The Inn—which also has three apartments in Bethesda—can support 60 families at a time. Approximately 10% of families stay at The Children's Inn for at least 80 days, and in some cases for 6 months or more. Families that stay there participate in some 480 intramural clinical research studies at the CC run by 15 of the 27 ICs.

Patients and their families are critical partners of medical research, helping to advance cutting-edge treatments. Ms. Lucca shared several examples of how families from The Children's Inn made an impact on understanding and treating a variety of conditions such as leukemia, sickle cell disease, schizophrenia, depression, HIV/AIDS, and many rare and serious genetic conditions. She shared a video of a patient at The Children's Inn named Autumn, who has

neurofibromatosis type 1 (NF-1) and is participating in clinical research led by Dr. Widemann. In the video, Autumn and her family described how The Inn has helped them during their time at NIH.

To keep pace with the cutting-edge research led by NIH, The Children's Inn needs to continue to support the invaluable contributions of patients and their families. The Inn is currently in the planning phases of its renovations, which will make it "The Inn of Tomorrow." In alignment with the CC's strategy to diagnose and treat children much earlier and based on input from clinicians, families, patients, and donors, The Inn of Tomorrow project has three priorities: to transform the building, to continue supporting cutting-edge pediatric research, and to advance sustainability and well-being.

The Children's Inn recently launched a \$50 million capital campaign to support The Inn of Tomorrow. The project involves renovating the existing space and building a 15,000-square-foot addition that includes a lobby, apartment-style rooms that can support patients on respiratory isolation, and a covered bridge from the Inn to the street in front of the CC that follows Americans with Disabilities Act (ADA) design guidelines. This addition and renovation will advance sustainability and well-being by improving ADA accessibility, using state-of-the-art air handling, and having a Leadership in Energy and Environmental Design Silver certification. The Children's Inn also recently broke grounds on its young adult residence, which will be able to house six more families. This residence, on NIH's campus and across the street from The Inn, will utilize a home previously inhabited by NIH IC directors.

In closing, Ms. Lucca shared The Children's Inn health-equity promise, which was developed by The Inn's Board of Directors: "We continually gain knowledge about and actively eliminate barriers to pediatric clinical care at NIH, and we provide culturally competent and inclusive care to our families at The Children's Inn at NIH."

Discussion

- In response to Ms. Reel's question, Ms. Lucca said that the funds for The Inn's addition and renovation are coming from philanthropic donations. Merck Pharmaceuticals, the original donor in 1990, has committed \$14 million for The Inn of Tomorrow. Merck's donation and with others have helped The Inn of Tomorrow reach half of its \$50 million goal.
- Mr. Baum asked about the principal source for annual operating funds. Ms. Lucca said that operating funds are supported through donations from individuals, foundations, and corporations. Also, though The Children's Inn is not a federally operated institution, it does receive a small stipend from ICs for each family that stays there.
- Dr. Devaskar and Ms. Lucca discussed how, as with the Ronald McDonald House, the services provided by The Children's Inn are free to families.
- Dr. Devaskar asked about pet therapy at The Children's Inn. Ms. Lucca said that in addition to Zilly, pet therapy groups visit The Inn and the CC. Pet therapy is extremely beneficial for the children and their families—especially for those who are missing their own pets while away from home. Zilly is the most beloved member of The Inn. Ms. Royster said that pet therapy adds life and hope to a pediatric patient's experience.
- Ms. Royster asked how many families can be accommodated by The Inn now, and how that number will grow after the renovations and additions. Ms. Lucca said that The Children's Inn—including its three apartments in Bethesda for families with children

- who need to be isolated and cannot stay at The Inn—is currently able to support 63 families. When the renovations and addition are done, 71 families will be able to stay there
- In response to Dr. Coots' question, Ms. Lucca said that The Inn of Tomorrow should be completed by summer 2027. The renovation will happen first, followed by the expansion.
- Dr. Widemann said that for the patient named Autumn, an FDA-approved mitogenactivated extracellular signal-regulated kinase (MEK) inhibitor is being used to shrink tumors and prevent them from growing. Dr. Widemann's group will soon launch a new study with patients whose tumors are asymptomatic and determine whether the MEK inhibitor prevents the development of a disfiguring morbidity associated with NF-1. Dr. Widemann acknowledged that The Children's Inn has been instrumental in supporting her research and many of her patients.

Facilities Presentation to the CCRHB

Dan Wheeland, PE, Director, NIH Office of Research Facilities (ORF)

Mr. Wheeland said that as a result of the continued efforts of quarterly meetings with staff of the Senate and House Appropriation subcommittees, NIH has seen a steady increase in the annual appropriations for buildings and facilities; ORF received \$200 million in FY 2021, \$250 million in FY 2022, and \$350 million in FY 2023. Though the government is currently funded under a Continuing Resolution, the hope is that the appropriations for NIH buildings and facilities will be sustained or increased once a budget is passed. The appropriation for FY 2024 affects current projects and serves as a benchmark for FY 2025 funding and beyond.

While NIH is waiting for its FY 2024 appropriations, ORF received \$120 million in Nonrecurring Expenses Fund (NEF) resources to support five projects: (1) electrical power reliability for Building 10, (2) central utility plant chiller and cooling tower replacements, (3) sprinkler system updates for Building 11, (4) steam and chilled water line repairs, and (5) repairs to the parking garages.

Mr. Wheeland shared updates on various renovations and building projects affecting the Clinical Center:

- Pharmacy and Permanent Intravenous Admixture Unit (P-IVAU) Renovation: This suffered a setback when it was discovered that the 24 pass-through units needed for the P-IVAU were not compliant. These units have been replaced and tested. If the renovation and approvals remain on track, the P-IVAU should be activated by November 2024.
- Radiopharmacy and Cell Labeling Facility: The construction mobilization aspect of this \$30 million project just began in December 2023. The goal is to complete the facility by May 2025.
- Sterile Processing Upgrades: These upgrades involve a phased approach; the sterile processing center will be relocated to the basement of Building 10, which will allow the renovations to occur on the second floor. The estimated completion of this project is November 2024.
- E-Wing Renovation including Cell Processing: Renovations to the E-Wing—the primary home for the Department of Transfusion Medicine—involve updates to more than 15 floors. By March, all floors of the E-Wing should be occupied except the Current

- Good Manufacturing Practice facility for the Center for Cellular Engineering (CCE), which will occupy the entire 12th floor. This facility, known as 12E, will eventually be the largest aseptic processing facility at NIH, with state-of-the-art cell processing rooms.
- CCE Cell Processing Facility (AKA T10B): Issues maintaining electrical power during monthly generator tests arose in this CCE facility. In order to ensure that the facility remains in a state of control during power quality scenarios and during generator tests, NIH invested in an uninterruptable power system. The most recent generator test proved that the system is functioning properly.
- SRLM Building, including the NHLBI Catheterization Lab, Interventional Radiology, and NCI Labs: This is the largest project in the history of NIH, with an award amount of \$630 million. NIH is appreciative of the support that the CCRHB provided in obtaining these funds. Since last year's facilities update, substantial progress has been made on the SRLM. Phase 0, which included site logistics and rerouting of traffic, was completed. The project is currently in Phase 1, which involves construction of the site utilities, excavation, and construction of the foundation for the building addition. During excavation, unforeseen conditions, including asbestos and fuel, were discovered and have been remediated. In parallel, the design-build firm has submitted the design for the structural, architectural, mechanical, electrical, plumbing, and fire protection systems. The NIH review of those design documents generated numerous comments, which resulted in a disapproval of the design submission, requiring resubmission. The SRLM project has also led to a new protocol in which Department of Perioperative Medicine staff can call a hotline if noise or vibrations from the construction are inhibiting their work. This protocol has worked well to ensure that CC operations are not interrupted. Targeted completion of the SRLM project is July 2028.
- **Miscellaneous Environment of Care Projects:** Several smaller renovation projects are underway, including refreshing the outpatient exam rooms on Floors 7 and 9, updating public restrooms in patient rooms, and upgrading the nurses' stations.
- Center for Alzheimer's and Related Dementias Program: This \$20 million investment will convert an underutilized cafeteria on the second floor to the Center for Alzheimer's and Related Dementias for the National Institute on Aging (NIA), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Eye Institute (NEI). This outpatient clinic will complement a basic research laboratory that was constructed a few years ago for Alzheimer's and Related Dementias. In addition, the renovated space will provide administrative space for the clinical programs of the National Institute of Minority Health Disparities (NIMHD) and the National Heart, Lung, and Blood Institute (NHLBI).
- Post-Anesthesia Care Unit and Pre-Operation Renovation: This renovation project encountered some unforeseen issues, but the anticipated completion date is March 2024.
- Electrical Switching Station and Emergency Generators: This \$80 million investment involves creating a new, robust electrical facility with new emergency generators, fuel tanks, and switchgear.
- **Black Start of Cogeneration Plant:** Currently, NIH has a cogeneration plant that combusts natural gas to generate electricity and steam. However, this plant is not designed to operate autonomously and would be inoperable without commercial power. The updates to this plant would render it autonomous and facilitate the generation of 23

megawatts of electricity, which would be sufficient to generate chilled water and steam for the most critical facilities, including the Building 10 Complex.

Mr. Wheeland shared NIH's efforts to prepare for earthquakes after a magnitude 5.8 earthquake in August 2011 was felt in Bethesda. Given the lessons learned from that experience, in 2015, NIH worked with the U.S. Geological Survey (USGS) to install two strong motion sensors in the vicinity of Building 10. In parallel, ORF conducted a structural analysis of Building 10. Using motion-sensor data, NIH will now be able to measure the peak ground acceleration, compare it to the structural capacity of the Building 10 Complex after assessing any earthquake damage, and make a much more informed decision about whether to evacuate patients from the building. These preparedness efforts are timely after a recent earthquake in Rockville, Maryland, and after the USGS shared noteworthy changes to its National Seismic Hazard Model for the Atlantic coastal corridor. This model showed that earthquakes would be more damaging on the East Coast of the United States than on the West Coast, because of the nature of the subsurface geology.

Mr. Wheeland noted that NIH leadership has shown their support of buildings and facilities. Specifically, the November 1, 2023 NIH Leadership Forum included a lengthy discussion about addressing NIH's facilities and infrastructure needs. And when Dr. Bertagnolli and Dr. Rathmell recently toured the NIH campus, they expressed their support for improving campus facilities—particularly the areas of Building 10 that are in poor condition. Mr. Wheeland thanked the CCRHB for its continued support.

Discussion

- Several CCRHB members commended the hard work of Mr. Wheeland and ORF. Mr.
 Wheeland said that there are approximately \$900 million worth of active infrastructure
 projects at the CC, some of which were not highlighted during the presentation. None of
 these projects would be possible without strong support from NIH, the Office of
 Management and Budget, Congress, and the CCRHB, which bolstered ORF's credibility
 and articulated the infrastructure needs.
- Ms. Royster asked how asbestos was discovered in soil at SRLM construction site. Mr.
 Wheeland said that the construction team saw a layer of white material within the soil
 and recommended it be tested for asbestos.
- In response to Mr. Baum's question, Mr. Wheeland said that the strong motion sensors are owned by the USGS and are regularly maintained by a specialty firm, so this preparedness investment will be sustained. Most of the strong motion sensors in the United States are on the West Coast, so the USGS was very happy to install these sensors at NIH. These sensors, which are monitored by the USGS, are programmed to notify certain NIH staff when certain values are exceeded.
- Dr. Devaskar indicated that the costs in California to construct an emergency generator have become exorbitant due to the seismic risks. She asked if we had experienced the same. Mr. Wheeland said he would follow up with Dr. Devaskar. He added that the SRLM addition is designed for a higher level of seismic preparedness than the CRC building as a result of evolving seismic criteria.

ACTION ITEM: Mr. Wheeland will provide an answer to Dr. Devaskar regarding the impacts of seismic criteria on the construction of emergency generator infrastructure.

Open Discussion

Dr. Coots asked CCRHB members whether they had any additional questions. Ms. Royster asked about the Initiative on Women's Health Research. Dr. Gilman said that it is in the very early stages, but NIH is collecting information about its ongoing women's health research efforts and determining whether there are gaps in this research that need to be addressed. This initiative will involve many federal agencies, including NIH.

Adjournment

Dr. Coots thanked the presenters for the many great updates and adjourned the meeting at 12:22 p.m. ET.

/Nina F. Schor/
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for Norvell Coots, M.D.
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Lawrence A. Tabak, D.D.S., Ph.D.

Executive Director, NIH Clinical Center Research Hospital Board

Acting Director, NIH

Abbreviations and Acronyms

ADA Americans with Disabilities Act

ADC average daily census

ADI Area Deprivation Index

AHRQ Agency for Healthcare Research and Quality

ANCC American Nurses Credentialing Center

BTRIS Biomedical Translational Research Information System

CAR-T chimeric antigen receptor T-cell

CAUTI catheter-associated urinary tract infections

CC Clinical Center

CCE Center for Cellular Engineering

CEO chief executive officer

CCND Clinical Center Nursing Department

CCRHB Clinical Center Research Hospital Board

CIT Center for Information Technology

COVID-19 coronavirus disease 2019

CLABSI central line–associated blood stream infections

DEIA diversity, equity, inclusion, and accessibility

DPCPSI Division of Program Coordination, Planning, and Strategic Initiatives

EHR electronic health record

FEVS Federal Employee Viewpoint Survey

FDA U.S. Food and Drug Administration

FY fiscal year

HIMD Health Information Management Division

ICs Institutes and Centers

ICU intensive care unit

IRB Institutional Review Board

LOS length of stay

MEK mitogen-activated extracellular signal-regulated kinase

mRNA messenger RNA

NASA National Aeronautics and Space Administration

NCI National Cancer Institute

NEI National Eye Institute

NF-1 neurofibromatosis type 1

NIBIB National Institute of Biomedical Imaging and Bioengineering

NIH National Institutes of Health

NIMHD National Institute of Minority Health and Health Disparities

OPM Office of Personnel Management

OPSCQ Office of Patient Safety and Clinical Quality

P-IVAU Pharmacy and Permanent Intravenous Admixture Unit

PK/PD pharmacokinetic/pharmacodynamic

RFI request for information

SDOH social determinants of health

SRLM Surgery, Radiology, and Laboratory Medicine (wing)

UCLA University of California, Los Angeles

USGS United States Geological Survey