

U.S. Department of Health and Human Services
National Institutes of Health

**Twenty-Seventh Meeting of the
Clinical Center Research Hospital Board
June 21, 2024**

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Clinical Center Research Hospital Board

Monica M. Bertagnolli, M.D., Director, National Institutes of Health (NIH)

Nina F. Schor, M.D., Ph.D., Deputy Director for Intramural Research, NIH, and Designated Official and Executive Secretary, NIH Clinical Center Research Hospital Board (CCRHB)

David M. Baum, PMP, Patient, NIH 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, Chief Executive Officer (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 27th meeting in person and via videoconference on June 21, 2024. The meeting was webcast live and open to the public. A [video recording](#) is available online.

James K. Gilman, M.D., memorialized his colleague and friend, Norvell V. Coots, M.D., the Chair of the CCRHB, who had passed away a few weeks earlier. Dr. Gilman's professional affiliation with Dr. Coots began in 2002, when both held U.S. Department of Defense jobs and Dr. Gilman was Dr. Coots's supervisor. Dr. Gilman recounted Dr. Coots's many professional accomplishments as he pursued a career as a dermatologist in the military.

Nina F. Schor, M.D., Ph.D., offered condolences to Dr. Coots's family and began the meeting officially at 9:11 a.m. ET. She introduced members of the board who were present at the meeting or attending virtually. She indicated members who could not attend.

Geoffrey Ginsburg, M.D., Ph.D., provided an overview of the *All of Us* Research Program and suggested ways that the program and the NIH Clinical Center (CC) could collaborate. *All of Us* can advance understanding of health and disease, especially because of the diversity of the participant cohort. The program aims to recruit more than 80% of its participants from communities that have been historically underrepresented in biomedical research. One of the program's goals related to representation is to have about 45% of participants self-identify as members of racial and ethnic minority groups.

Participants can share data from electronic health records (EHRs), surveys, biospecimens, physical measurements, and wearable devices (e.g., Fitbit devices). These data are curated and released to researchers regularly through the cloud-based Researcher Workbench platform. As of August 1, 2024, more than 12,000 researchers have registered to use the platform, and there are nearly 400 publications that use *All of Us* data.

Participants can also receive two types of DNA results from the program: a "Hereditary Disease Risk" report on 59 genes associated with serious health conditions and a "Medicine and Your DNA" report on how the human body metabolizes common medicines.

All of Us and the CC could collaborate in multiple ways, including: ancillary studies, research into the genetics of undiagnosed diseases, co-enrollment of participants in *All of Us* and CC research, understanding the natural history of disease after participants leave the CC, intramural research training programs, best practices for including participant voices in the program, and refining return-of-results strategies.

Dr. Ginsburg answered questions about planned pediatric enrollment, how the program can motivate questions within the research community, how the data are stored, data safeguards, and whether the data might be linked with other datasets in the future. Antoinette Royster said that she is an *All of Us* participant, and Dr. Ginsburg thanked her for her enthusiasm and for trusting the program with her data.

Dr. Schor announced changes in leadership at NIH: Kathleen M. Neuzil, M.D., became Director of the Fogarty International Center; Joshua Gordon, M.D., Ph.D., became Director Emeritus of the National Institute of Mental Health (NIMH) and was replaced by Shelli Avenevoli, Ph.D., as Acting Director; Deborah E. Citrin, M.D., became Scientific Director for Clinical Research at the National Cancer Institute (NCI) Center for Clinical Research (CCR); Heather Patisaul, Ph.D.,

became Scientific Director of the Division of Translational Toxicology at the National Institute of Environmental Health Sciences (NIEHS); and Georg Aue, M.D., Ph.D., M.B.A, became the Acting Clinical Director of the National Heart, Lung, and Blood Institute (NHLBI). Dr. Schor described Monica M. Bertagnolli, M.D.'s signature activities: the Women's Health Research Initiative (WHRI), the Inter-Agency Rare Disease Research Initiative, and Communities Advancing Research Equity for Health. Dr. Schor shared the names of NIH staff who had been elected to the National Academy of Sciences or received Presidential Rank Awards. Also, W. Marston Linehan, M.D., received the Secretary's Award for Distinguished Service. André Nussenzweig, Ph.D., received the U.S. Department of Health and Human Services (HHS) Career Achievement Award. Brigitte Widemann, M.D., received the Secretary's Award for Meritorious Service.

Dr. Gilman gave the Chief Executive Officer update. He congratulated Ms. Royster on being a CC patient for 25 years; Nicole Farmer, M.D., on being selected as a 2024 NIH Distinguished Scholar; and the NIH Sterile Processing Section Nursing Department team on receiving the HHS 2023 Green Champion Award for Environmental Stewardship. On June 14, 2024, the first CC-wide graduation ceremony was held for NIH graduate medical education fellows. On May 30, 2024, there was a town hall presentation on "Suicide Prevention Reflections: Healthcare Providers With Lived Experiences." Dr. Gilman discussed the current state of searches for key CC leadership positions. The paperwork has been completed for Magnet recognition from the American Nurses Credentialing Center (ANCC), which will visit the CC this summer or early fall. The construction of the Surgery, Radiology, and Laboratory Medicine wing continues. Dr. Gilman showed images of the most recent DNA Day and Take Your Child to Work Day. The hospital's average daily census indicated a comeback from the pandemic years, and the number of telehealth visits has stabilized after a pandemic-related surge. Among the Diversity, Equity, Inclusion, and Accessibility (DEIA) updates were activities for Black History Month (February) and Women's History Month (March), plus a panel discussion on lessons learned from the COVID-19 pandemic. Masks became optional in the CC on May 20, 2024, but masking may be reinstated in the fall when viral diseases return. Most of the discussion after Dr. Gilman's presentation related to the masking issue.

David M. Lang, M.D., M.P.H., reported on The Joint Commission's (TJC's) visit to the CC on April 9–11, 2024, and its recommendations. A 2021 visit had identified the management and storage of sterile instruments as key issues, and the CC worked to fix these problems before the visit, engage a consultant, and participate in a mock visit. The CC has fixed or addressed issues that TJC found at its most recent visit. These include an expired vial of contrast, maintenance of hazardous, sterile medication preparation pressure differentials, infection control, and provision of care to an outpatient under sedation.

Justin Cohen, M.S., M.A., Chief of the Office of Communications and Media Relations, described the ongoing re-build and re-design of the CC website. These include achieving compliance with the 21st Integrated Digital Experience Act (IDEA), the law passed in 2018 that governs the modernization of federal digital properties to improve the user experience. As part of this effort, Section 508–compliance for accessibility will be strengthened and the number of web pages will be reduced. The new website will be more patient focused while also including improvements for staff usage. The website will be greatly streamlined, and there will be a place for users to provide feedback. The website will have artificial intelligence (AI) capability, not yet implemented. The board supported the improved user experience (UX) from the redesign.

William Gahl, M.D., Ph.D., explained the Undiagnosed Diseases Program (UDP) and the Undiagnosed Diseases Network (UDN). People with undiagnosed disease can apply to spend time at the CC, where they are given a series of tests so that their conditions can be identified and, if possible, provided with treatment options. Dr. Gahl discussed examples of patients treated by the program. Over the years, multiple Institutes and Centers have collaborated with the UDP, and there are opportunities for postbaccalaureate Intramural Research Training Awardees to participate in the program. In 2013, the program expanded to become the UDN. In 2014, the Undiagnosed Diseases Network International was created; it has expanded these activities to countries throughout the world. This research could only have been done at the CC because of its unparalleled expertise in rare diseases. The discussion centered on issues such as the parallels to Dr. Ginsburg's presentation, the role of compelling patient stories in motivating research, the difficulty of doing research if a large number of variants could be the cause, and the possibility of program participation for those who could not come to the CC.

Dr. Schor adjourned the meeting at 12:42 p.m. ET. The next meeting of the CCRHB is scheduled for October 18, 2024.

Meeting Summary

June 21, 2024

Welcome and Memorial Comments for Dr. Coots

Nina F. Schor, M.D., Ph.D., Deputy Director for Intramural Research, National Institutes of Health (NIH), and Designated Official and Executive Secretary, NIH Clinical Center Research Hospital Board (CCRHB)

James K. Gilman, M.D., Chief Executive Officer (CEO), NIH Clinical Center (CC)

Dr. Schor began the meeting at 9:00 a.m. ET by recognizing Dr. Gilman, who memorialized Norvell V. Coots, M.D., the Chair of the CCRHB who passed away a few weeks ago.

Dr. Gilman said that he met Dr. Coots as his supervisor when both held U.S. Department of Defense jobs in 2002. Everyone, including colleagues in Europe, wanted Dr. Coots to be on their team. One of his current colleagues on the CCRHB, David M. Baum, PMP, called him a mensch. Dr. Gilman said that Dr. Coots had difficulty turning people down, but he and Dr. Coots were a team; Dr. Coots referred to Dr. Gilman as his coach. Dr. Coots attended the U.S. Military Academy for a year, then transferred to Howard University; he eventually earned his medical degree from the University of Oklahoma Health Sciences Center. Dr. Coots wanted to become a dermatologist; after a two-year assignment as a general medical officer in South Korea, he was given a training position by the U.S. Army in dermatology.

Dr. Coots was a member of a benevolent order of French knights, for which he supported an orphanage in Moldova. Dr. Coots's mother was devoted to activism, and Dr. Gilman speculated that Dr. Coots's tendency to overcommit may have come from her. His father was a physician in Tulsa, Oklahoma, who helped establish a local chapter of the Urban League. Dr. Coots was a great staff officer with interpersonal skills who could be both a team member and a team leader. He earned a master's degree in strategic studies from the U.S. Army War College and eventually became a general in the Army. Dr. Gilman visited Dr. Coots twice at his home, first to pick up and then to return a saber used in a wedding ceremony. In a podcast, Dr. Coots said that he would like to be remembered as a plodder who always pursued his goals. Dr. Gilman said that Dr. Coots received second chances in life because of his exceptional people skills, and that he would be missed but never forgotten.

Dr. Schor sent condolences to Dr. Coots's family and said that this would be hard on the board as well. She officially began the meeting 9:11 a.m. ET and welcomed those who joined in person: Mr. Baum; David C. Chin, M.D., M.B.A.; and Antoinette Royster. The following members participated via the virtual meeting platform: Sherin U. Devaskar, M.D.; Steve Goldstein, M.H.A.; Stephanie Reel, M.B.A.; and Craig E. Samitt, M.D., M.B.A. The following members were unable to attend: Regina S. Cunningham, Ph.D., RN, FAAN; Jack Leslie; and Julie Freischlag, M.D.

NIH's *All of Us* Research Program

Geoffrey Ginsburg, M.D., Ph.D., Chief Medical and Scientific Officer, All of Us Research Program

Dr. Schor introduced Dr. Ginsburg, the Chief Medical and Scientific Officer for the *All of Us* Research Program. Dr. Ginsburg wished the members of the board peace in the days ahead after Dr. Coots's death.

Dr. Ginsburg said that *All of Us* was a platform on which the CC could stand. Noting the 76th anniversary of the Framingham Heart Study, he pointed out the power of longitudinal studies. In 12 years, the Framingham Study had identified important risk factors for heart disease, such as cigarette smoking and high cholesterol; the study also identified how exercise and diet could reduce a person's risk. When the findings of the Framingham Study were adopted in clinical care, there was a dramatic decrease in cardiovascular disease and stroke.

The program's name, "*All of Us*," signifies the diversity of the country, as reflected among both participants and researchers. Participants are drawn from every state and from some of the territories. The program aims to recruit more than 80% of participants from communities that have been historically underrepresented in biomedical research and about 45% from racial and ethnic minority groups. Currently, about 47% of participants self-identify as members of racial and ethnic minority groups. Nearly 90% of *All of Us* participants have never been involved in a biomedical research study before.

Participants can share data from multiple sources, including EHRs, surveys (there are eight active surveys on a variety of health topics and two closed surveys about COVID-19), biosamples, physical measurements, and wearable devices (e.g., Fitbit devices). The wearable data provides continuous phenotyping between the surveys.

Curated data are released to researchers on a regular cadence with the next data release scheduled for September 2024. The program's dataset contains one of the largest short-read whole genome sequence datasets in the world. Nearly 300 million genetic variants in this dataset have never been seen before in public datasets. Because of the diverse participant cohort, the *All of Us* dataset could help close gaps in genomic research that has historically relied on data from people of European ancestry. The genomic dataset also includes a growing collection of long-read whole genome sequences. In addition, the program's Fitbit dataset is one of the largest wearable datasets in the world. Fitbit data include physical activity, step counts, heart rate, sleep data, and device data.

A unique feature of *All of Us* involves return of value to participants in the form of genetic information, survey data, EHR and claims data, ongoing study updates, aggregate results, scientific findings, and the opportunities to be contacted for other research studies.

There are two types of genetic results: the Hereditary Disease Risk (HDR) report on 59 genes associated with serious health conditions and the Medicine and Your DNA report, which analyzes seven genes that affect how a person's body metabolizes more than 50 medicines likely to be taken during one's lifetime. More than 260,000 participants have been offered genetic health-related DNA results as of July 2024, and more than 110,000 have viewed their results; of these, about 3% will have actionable results on how to manage their health. About the same number of participants have requested the "Medicine and Your DNA" report; more than 90% of these will have actionable results for the drugs that they take or will take later. Genetic

counselors are available in both English and Spanish. The program also provides genetic ancestry and trait reports, which are now being provided at a rate of 5,000 per week.

There is a growing scientific impact in terms of publications. The first publication was in 2019; there are now nearly 400 publications. Among the findings are protective variants for chronic kidney disease in African Americans and how the number of step counts may reduce the risk for chronic disease.

In the future, *All of Us* could be used as a platform for clinical trial enrollment in areas such as mental health and chronic pain, which could accelerate enrollment at NIH and elsewhere.

Dr. Ginsburg concluded the presentation with next steps for *All of Us* and how the CC could become involved:

- Ancillary studies generate data that could be used by the research community. Examples included a COVID-19 study that showed antibodies for the virus were present in 2019, before the pandemic was officially declared.
- Exploring the Mind is a study that involves recontacting participants for additional surveys.
- *All of Us* and the Nutrition for Precision Health (NPH) ancillary study were featured on *Good Morning America*. NPH is one of the largest dietary studies ever undertaken.
- In 2025, an environmental exposure survey on the link between environmental data and social determinants of health will be released. The study will analyze geospatial data, exposomics, and health to see how the environment and climate affect disease.
- A genotype–phenotype study at the CC evaluates loss of function variants (e.g., *ABHD15* gene) to see what phenotypes are possible or understand genetic disease resilience. The CC could provide nuanced insights.
- The CC could collaborate with *All of Us* on ancillary studies, genetics of undiagnosed disease (rare diseases), co-enrollment with CC clinical studies (joint recruitment in both), and understanding the natural history of disease after participants leave the CC. The CC and *All of Us* could also collaborate on intramural research training for early investigators, share best practices on including the voice of participants, and refine return-of-results/value strategies.

Discussion

- Dr. Devaskar said that *All of Us* was an important study and asked about the 100,000 children that she thought would be enrolled.
- Dr. Ginsburg said that the pediatric protocol has been developed, and 16 participants have been enrolled. Sara Van Driest, M.D., Ph.D., from Vanderbilt University Medical Center, has been recruited to run the pediatric program. The goal is to enroll 150,000 participants up through age 17. However, the biggest challenge now is the budget: *All of Us* received a 34% budget cut earlier this year. The program is ready, Dr. Ginsburg said, but does not want to initiate a protocol that would have to be stopped. Sites have been engaged to recruit when ready. Studying early childhood is important because it will affect adulthood. Since the meeting, pediatric enrollment has started.
- Ms. Reel said that Dr. Ginsburg’s presentation was incredible and asked about the Christchurch variant, which Dr. Ginsburg mentioned in his presentation. Ms. Reel asked how *All of Us* responded to new discoveries like this.

- Dr. Ginsburg said that the program does not carry out research, but the data are publicly accessible to researchers; currently, there are close to 12,000 researchers from six continents. The issue now is how to mobilize the community. The program has a Scientific Priorities Roadmap, which contains strategies on how to do research that is communicated to the research community through a newsletter and a website. The program also works with other NIH Institutes and Centers to include *All of Us* language in their requests for applications (e.g., can you replicate this study and show more by using *All of Us* data?). The researcher community responds rapidly on its own, but there can be “pushes” from the program itself. There is a portfolio of strategies to motivate research, but researchers outside the program do the actual studies.
- Mr. Baum asked about the CC becoming involved—specifically whether there had been attempts to use data already being generated by the CC.
- Dr. Ginsburg said that there have been discussions with all of the NIH Scientific Directors, but he was not aware of any follow-up on integrating already extant CC activities. There needs to be more social engineering for researchers to understand the value of the data. The data have been used by National Human Genome Research Institute (NHGRI) researchers; the program has worked with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the CC on disability surveys. The future work on pediatrics will be important as well. To develop additional ways to do this, Dr. Ginsburg would like insights from the board.
- Mr. Baum asked where the data are stored. Dr. Ginsburg said that there is a Data and Research Center (DRC) responsible for storing the data; the award for the DRC went to Vanderbilt University Medical Center, the Broad Institute, and Verily (a private company). The servers are at Vanderbilt University Medical Center. The data are stored in a cloud-based system that will be expanding to Amazon Web Services within a year.
- Dr. Devaskar asked how the program treats pregnancies and birth among participants.
- Dr. Ginsburg said that pregnancies are included in the surveys and from EHRs. Health aspects of pregnancy can be examined, but there is no targeted survey on maternal health (it will be part of pediatrics when launched). Births are recorded through family history surveys as well as follow-up. Initial pediatric enrollment will be from participants who are already enrolled, which will give dyads (parent and child) and potentially even trios a chance to be a part of the dataset.
- Dr. Chin asked about the safeguards for the data.
- Dr. Ginsburg said that dates and personal health information can be made unclear for security reasons. Some of the data are available on a public website (<https://researchallofus.org>), but researchers need to go through additional training, including codes of conduct, to access the Registered and Controlled Tiers in the Researcher Workbench. The Controlled Tier—where genetic information is contained—requires the highest level of security. The data are being constantly surveyed, and workspaces (where researchers use the data) can be closed down based if the program discovers policy violations. Although perfect security is impossible, that is what the program is striving for. The program is transparent with participants on how the data are being used.
- Dr. Chin said that the databases get more powerful exponentially as the numbers increase, and he asked whether this database could be linked to others being created.

- Dr. Ginsburg said that there is no formal linkage to other longitudinal datasets, but there is cross-validation with UK Biobank (i.e., findings discovered in one dataset are confirmed in the other). The program is also working with the Genomic Data Science Analysis, Visualization, and Informatics Lab-Space that NHGRI has developed and the TOPMed consortium from the National Heart, Lung, and Blood Institute (NHLBI). There are not formal linkages now. Down the road, the goal is to develop the capability for researchers to work with their own local datasets next to *All of Us* data in the workspaces.
- Ms. Royster, who has participated in *All of Us* since 2022, lives in rural Maryland. She said that it is hard to get rural and African American participants in the program. She wanted to participate in the program because of the DNA results, but she is particular about who knows about her genetics. She appreciates learning more about herself and her family through the program's surveys. She thanked Dr. Ginsburg for the program.
- Dr. Ginsburg thanked her for sharing that she was a participant. To expand recruitment, there are several vehicles that go around the country to recruit participants. Dr. Ginsburg thanked Ms. Royster for her enthusiasm and for trusting the researchers with her data.
- Ms. Royster got one of her friends to sign up for the program and posted information about it on Facebook. She liked that the number of participants has increased since she signed up when there were 500,000 participants.
- Dr. Schor said that there was a high level of enthusiasm for this program among members of the board. Reaching out to communities not represented in research is long overdue.
- Dr. Ginsburg said that he is open for input from the board and would happily come back for a later visit if desired.

NIH Director's Remarks

Nina F. Schor, M.D., Ph.D., Deputy Director for Intramural Research, NIH, and Designated Official and Executive Secretary, CCRHB

NIH Leadership Changes

Dr. Schor shared changes in leadership at NIH:

- Kathleen M. Neuzil, M.D., became Director of the Fogarty International Center. She is a global health expert and comes to NIH from the University of Maryland.
- Joshua Gordon, M.D., Ph.D., became Director Emeritus of the National Institute of Mental Health (NIMH). He left NIH after almost 10 years in this capacity. In mid-August, he will become Chair of the Department of Psychiatry at Columbia University.
- Shelli Avenevoli, Ph.D., became the Acting Director of NIMH. A national search for a permanent Director of NIMH will begin.
- Deborah E. Citrin, M.D., became Scientific Director for Clinical Research at the National Cancer Institute (NCI) Center for Cancer Research (CCR). Dr. Citrin studies radiation in patients with cancer.
- Heather Patisaul, Ph.D., became Scientific Director of the Division of Translational Toxicology of the National Institute of Environmental Health Sciences (NIEHS). She had previously been a member of the NIEHS board.

- Georg Aue, M.D., Ph.D., M.B.A., became Acting Clinical Director of NHLBI. Dr. Richard Childs, M.D., was the Clinical Director but recently moved to the position of Scientific Director at NHLBI. Dr. Aue was the Deputy Clinical Director but has become Acting Clinical Director while a search for a permanent replacement is ongoing.

Some New Initiatives

Although Dr. Schor is the designated federal official at this meeting, these initiatives are signature activities of Monica M. Bertagnolli, M.D.

Executive Order, Women’s Health Research Initiative

This was created by President Biden through executive order. For decades, how diseases present in women were seen as atypical; in fact, however, these are the typical presentations for individuals who happened to be women. The president has asked NIH to be at the forefront of this effort, in which the CC will play a major role.

Inter-Agency Rare Disease Research Initiative

This is an effort to democratize gene therapy trials in the country. Most such trials for rare diseases are being conducted in a few large academic institutions, and participants have to travel to where the studies are located. NIH can become a national core facility to enable more centers to provide these studies closer to home. This meeting was an interagency meeting with NIH, the U.S. Food and Drug Administration (FDA), and the Centers for Medicare & Medicaid Services (CMS) all participating.

Communities Advancing Research Equity for Health

Primary care practices throughout the country can contribute data that’s already being collected for common diseases, so that these diseases can be looked at in a systematic way through NIH’s data managing and data mining resources. NIH can provide standard data gathering sets to enable primary care practices to participate in a national research effort. This initiative began a few weeks ago.

Awards

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

- The following members of the NIH community were elected to the National Academy of Sciences (NAS): Thomas Kunkel, Ph.D., from NIEHS; Kyung J. Kwon-Chung, Ph.D., from the National Institute of Allergy and Infectious Diseases (NIAID); Steven A. Rosenberg, M.D., Ph.D., from NCI; Giorgio Trinchieri, M.D., from NCI; and Sandra L. Wolin, Ph.D., from NCI. Dr. Wolin is a world expert on RNA.
- The following members of the NIH community received Presidential Rank Awards: Keith Lamirande, M.B.A., from the National Center for Advancing Translational Sciences (NCATS); Colleen McGowan, M.H.A., from the Office of Research Services (ORS); Camille Hoover, M.S.W., from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); and Jerry Sheehan, M.S., from the National Library of Medicine (NLM). This is the premier award for a career government staff member.
- W. Marston Linehan, M.D. received the Secretary’s Award for Distinguished Service. Dr. Linehan, a surgeon, works in the CC on cancer in the urologic system.
- Andre Nussenzweig, Ph.D., received the HHS Career Achievement Award. Dr. Nussenzweig works on DNA damage and its role in cancer predisposition.

- Brigitte Widemann, M.D., received the Secretary’s Award for Meritorious Service. Dr. Widemann is the head of the Pediatric Oncology Group at the CC and works on neurofibromatosis, a predisposition for cancer of the nervous system.

Dr. Schor is proud of all the developments that have occurred since the last meeting.

CC CEO Update

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

Recognition and Awards

Dr. Gilman began by congratulating Ms. Royster, who has been a patient at CC for 25 years.

Nicole Farmer, M.D., the Acting Section Chief for Dietary Behavior and Biopsychosocial Health Section of the Translational Biobehavioral and Health Disparities Branch, was applauded for being selected as a 2024 NIH Distinguished Scholar. The award provides resources for scholars to expand their research efforts.

The NIH Sterile Processing Section Nursing Department was congratulated for receiving the HHS 2023 Green Champion Award for Environmental Stewardship, for reducing the environmental impact of sterilization packaging of surgical devices in the operating room. This innovation reduces the carbon footprint along with reductions in the workload and budget costs.

On June 14, 2024, the first CC-wide graduation ceremony was held for NIH fellows from the graduate medical education (GME) program. There were 74 graduates from 30 programs, and many of the graduates were joined by their children at the ceremony. The idea for the ceremony came from Joyce W. Chung, M.D., Executive Director of the GME CC Office of Clinical Research Training and Medical Education. Dr. Bertagnolli provided recorded remarks for the event.

On May 30, 2024, there was a town hall presentation on “Suicide Prevention Reflections: Healthcare Providers with Lived Experiences.” The speakers were Erin Harlow-Parker, APRN, PMHCNS-BC, and Janet West, M.D., FAAFP. Dr. Gilman said that the personal reflections provided were very impactful; there were two stories of resilience on the “lived” experience of suicide. Dr. Gilman said that this was a good event to make people think about these issues differently, adding that the CC does not avoid discussing difficult subjects.

CC Staff Updates

Dr. Gilman said that the CC is rebuilding its leadership team. The following CC leadership vacancies are current:

- Executive Officer
- Chief Scientific Officer
- Chief for the Office of Hospital Administrative Support
- Chief for Pain and Palliative Care Service
- Chief for Social Work Department

The CC Executive Officer search will be launched soon, and the searches for all the other positions are well underway.

An Update on the Magnet Journey

Dr. Gilman showed the timeline of where the CC is in its journey toward Magnet recognition. The American Nurses Credentialing Center (ANCC) is currently reviewing the documents submitted by the CC. All the necessary paperwork has been completed. The documents are designed to confirm that the CC does what it claims to do. A site visit from the ANCC will occur later this summer or early in the fall.

Surgery, Radiology, and Laboratory Medicine Wing Continues to Take Shape

Dr. Gilman showed a picture of the construction site taken on May 23, 2024.

Take Your Child to Work Day, Earth Day, and DNA Day

April 25, 2024, was Take Your Child to Work Day, Earth Day, and DNA Day combined. NIH had the formal unveiling and dedication of a DNA statue called the “Ladder.” Dr. Gilman showed a picture of the statue, noting the four children on the statue depict the four messengers, or nucleic acids, of DNA.

Dr. Gilman also included a picture of children who had come to NIH to participate in a gene therapy trial. They arrived from Europe just before the start of the pandemic, showing the ongoing commitment of NIH to research.

For Take Your Child to Work Day, between 3,000 and 3,500 children visited the NIH campus. Dr. Gilman was pictured with the two sons of Juris Mohseni, Chief of the Office of Financial Research Management and CC Budget Officer.

2024 Joint Commission Preparations Completed

Dr. Gilman deferred comments on this to David M. Lang, M.D., Ph.D.’s later presentation.

Hospital Census

Dr. Gilman said that the average daily census indicated a comeback from the pandemic years. There is a 7% to 10% increase over last year.

The year-to-date patient activities for fiscal year 2024 showed increases in some areas (e.g., inpatient admissions, inpatient days, average daily census) relative to last year. Whereas other areas (e.g., average length of stay, outpatient total visits, outpatient clinic visits, outpatient day hospital visits, new patients) were relatively unchanged.

The number of telehealth visits has stabilized now after a surge during the pandemic.

Diversity, Equity, Inclusion, and Accessibility (DEIA) Updates

February was Black History Month, which included a music presentation in the CC from Howard University on “A Journey Through Song of the Underground Railroad.”

March was Women’s History Month, which included a presentation in the CC on “The Wash and Spin to Health (WASH),” a community-based participatory research initiative with Roxanne Mirabal-Beltran, Ph.D., from Georgetown University.

New DEIA initiatives include a Spanish–English exchange circle, a presentation on humanizing health care disparities to improve health for all, and a panel discussion on lessons learned from the COVID-19 pandemic.

Masks Were Made Optional on May 20, 2024

On May 20, 2024, masks became optional. But patients who request that masks be worn by their care team will have their requests honored. Masking may be reinstated in the when viral diseases return with increasing viral activity in the community.

What To Expect in Summer/Fall 2024

The CC's focus will be on continuing to fill staff and key leadership positions, DEIA activities, care for pediatric patients, staff well-being, completing the Magnet journey, and following up on recommendations from The Joint Commission's (TJC's) survey.

Clinical and Safety Performance Metrics

CCRHB members received the June 2024 Clinical & Safety Performance Metrics Report for review in advance of the meeting provided by Dr. Lang. Members were encouraged to ask any questions about the report during Dr. Lang's forthcoming presentation at the meeting.

Meeting Agenda

The agenda for the rest of the day was summarized.

Washingtonian Story on NIH Undiagnosed Diseases Program

Dr. Gilman showed a picture of William Gahl, M.D., Ph.D., as he appeared in *Washingtonian* magazine.

Discussion

- Dr. Chin praised Dr. Gilman on his leadership and on ensuring that the staff are resilient.
- Ms. Royster asked whether the graduation ceremony was recorded. Dr. Gilman said that it had been broadcast but may not have been recorded.
- Dr. Samitt congratulated Dr. Gilman on his leadership. Dr. Samitt asked about masking, whether there has been a review of pre-pandemic levels of non-COVID-19 infection, and how those levels compared with post-pandemic levels; he speculated that masking may have removed secondary infection. Dr. Gilman said that for masking to be effective, enforced compliance, to ensure that everyone is masked, is necessary. There are data comparing when everyone was masking with earlier historical periods, and respiratory isolates were reduced when everyone was wearing masks. When prevalence is high, masks will be required. Some data generated in the CC have been analyzed by epidemiologists and published. Dr. Gilman said that voluntary masking does not work. Dr. Samitt thanked Dr. Gilman for his helpful comments.
- Mr. Baum asked whether masking procedures in place before COVID-19 would still be in force. Dr. Gilman said that if someone is infected, the hospital epidemiology service has the final say on when making would be required.
- Dr. Schor mentioned anecdotal reports that people may have lost immunity during masking, because they were no longer being exposed to some diseases. However, Dr. Schor knows of no reliable data to back up this type of claim.

Report: TJC Survey, April 9–11, 2024

David M. Lang, M.D., M.P.H., Director, Office of Patient Safety and Clinical Quality, CC

Dr. Lang reported on TJC, which they were expecting to occur later in the summer, but TJC came for a visit on April 9–11, 2024.

The 2021 survey had some concerning findings; fixing those problems was a group effort. The problems were with sterile instrument management and storage, as well as the need for greater staff training. There were also high-level findings related to screening for abuse and neglect among outpatients.

After the 2021 survey, the sterile instruments program was overhauled to make sure that the sterile processing department had adequate resources. There was a greater emphasis on uniformity, with only needed units supplied and greater collaborations with institute partners. The training model for staff was revised in 2023 and is now part of the annual training requirement. Sterile instrument management is emphasized at all levels of the organization.

To prepare for the 2024 survey, Kim Nelson took the lead. By looking at each standard in the TJC hospital accreditation manual, the CC focused on standards assessment to see how well they complied. In February 2023, an outside consultant was brought in to do a mock survey. The CC also focused on organizing the team so that everyone can respond when asked to describe activities. There was a focused survey on infection control in March 2024, which was about two weeks before the actual 2024 survey occurred. In an internal mock survey, staff role-played. There were also leadership safety rounds in which groups would go throughout the hospital to engage with staff (e.g., ask staff about their safety concerns); this became an interactive conversation. Tracers refer to what happens as entities move through the organization, such as what happens to a blood unit from blood bank to patient.

New requirements to be implemented involved preventing violence in the workplace and performing analyses of health care disparities and social determinants of health. TJC is concerned with workplace violence, including psychological safety. Relating to health disparities, there is a national patient safety goal. Improving health care equity is a quality and safety priority, which involves assessing six elements of performance. The Chief Medical Officer gave a presentation on this at the February CCRHB meeting.

The mock surveys led to several changes. The updated training is now a part of annual practice. There need to be improvements in how people inspect instruments and their work environment. For example, even though rooms may look clean, the tops of cabinets need to be dusted. Maintaining cleanliness is difficult with limited space; clean items should be labeled as such and differentiated from used items. There were also sit-down sessions to discuss issues.

TJC arrived on April 9–11. A physician, a nurse, and a life safety official inspected the hospital. They conducted sit-down sessions on the types of data collected to meet quality goals and the culture of patient safety.

TJC asked the CC to share its priorities, principal investigator projects, and issues of common concern. These are posted on the CC's website quarterly.

TJC shared its general observations. Commission members were impressed with the hospital and its staff and inspired by the CC's mission. Staff are engaged and prepared to speak about their units, and interdisciplinary teamwork is on display.

TJC created a safety matrix with 18 observations targeted to environmental care and life safety. For example, rooms adjacent to patient care need to meet healthcare occupancy standards.

TJC found issues related to clinical care, such as an expired vial of medication. This issue will be solved by moving this storage to the automated dispensing cabinet (Omnnicell). Another issue was that hazardous and sterile medication preparation pressure differentials cannot be maintained in the required range all the time, but the CC has put other controls in place to compensate, and staff safety and medication integrity are maintained. Another issue that needs to be addressed is when a medication titration order is not followed.

TJC identified infection control as another issue. The CC responded by conferring with the instrument washer test strip vendor and adjusting how the strip is loaded. In response to a problem with washing dishes in the rehab medicine kitchen, the CC is investigating whether to acquire a higher-grade dishwasher, and in the interim is limiting the consumption of food prepared by patients in for therapeutic activities.

Also identified was provision of care for an invasive procedure for an outpatient under sedation. The CC is responding with a revised sedation worksheet to document that the patient's history and physical condition are reviewed and updated if needed.

The CC had to respond to each issue and TJC has accepted all of these responses, so these issues are now listed as compliant.

Dr. Lang pointed out that accreditation is validation of outstanding work, but this activity involves ongoing effort rather than something done at a single point in time. The ultimate goal is to give patients the best care possible.

Discussion

- Mr. Baum asked how the pharmacy would know that no medication has expired.
- Dr. Lang said that the pharmacy has an inventory management process to address this issue.

NIH Clinical Center Website Redesign Initiative

Justin Cohen, M.S., M.A., Chief, Office of Communications and Media Relations, CC

Mr. Cohen is the Chief in the Office of Communications and Media Relations (OCMR) for the CC. He began by thanking the board for the opportunity to share the redesign work on the CC website. He said that his OCMR colleagues Cindy Fisher and Donovan Kuehn would contribute if he misspoke during the presentation, and they deserve the most credit for day-to-day work on the project.

Mr. Cohen focused on the framework behind the new website design and offered a demonstration of what it would look like.

The work started in October of 2023 through a contract awarded to the Arch company. There are new government policies on web design and Section 508 compliance. The 21st-century Integrated Digital Experience Act (IDEA) is intended to make federal websites work together to improve mobile experiences, integrate with one another, and improve the user experience. It requires the use of uniform code known as the United States Web Design System (USWDS). The existing design, which dates back to 2014, was not built with USWDS. In parallel, all federal

electronic content must be accessible to those with disabilities, per longstanding Section 508–compliance regulations. The new website will have greater agility to stay up to date with evolving 508-compliance innovations and technologies.

Although the current website was retrofitted to be responsive – meaning that it adjusts to any screen size, the responsiveness of the new site will be far better since it will be built from the ground up and technology has advanced over the past decade. This is important because an increasing number of visitors view the CC website via smart phones and tablets, not just on desktop computers.

Another goal is to improve search results. The current search function is robust, but some URLs are not up to date, which results in sub-optimal search results. Also, the current CC website contains 2,3,00 webpages, which will be reduced by 500 (or 21%) to reduce clutter and improve the quality of search results. The number of PDFs will be reduced, since text within PDFs are not always search-friendly nor responsive. (Print options other than PDFs are being explored.)

The end result will not only strengthen compliance and branding, but it will make the overall user experience on the CC website comparable to that of large academic medical centers (AMCs); visitors want the same experience as they would have in going to an AMC. Because the CC is a world-renowned research hospital, its home page gets about a million visits a year. The website should convey this sense of importance, which is another goal of the rebuild.

Mr. Cohen proceeded to demonstrate examples of what the new site will look like, starting with the homepage. He pointed out that the website will now be permitted to include the insignia of an official government website, because it will be in compliance with IDEA.

“America’s Research Hospital” is a tagline which is being considered for prominent placement on the homepage to explain to people what the CC does; the CC is hoping to trademark the tagline. The space for emergency alert messages on the homepage will be aesthetically enhanced. There will be easier access links to key patient information; these are not available on the existing homepage.

Also, the redesigned homepage will contain mega-menus – drop-down menus going across the screen. There is a hero image in contrast with rotating images that have been used previously. (The CC is researching whether it can animate these images while remaining Section 508–compliant.). The lead pages of departmental webpages will also feature hero images.

The top half of the homepage is patient-focused. There will be a floating “back-to-top” button so that users do not have to scroll all the way up; this feature should improve the overall webpage experience. The homepage will soon also be elongated, which is more common in the commercial sector; this means there will be less need to click through to find information. Materials for staff and researchers will be “below the fold,” on the second half of the page.

Mr. Cohen then contrasted the current “About Us” page with the new streamlined version. Likewise, the current blood bank page, which is currently very text-heavy, also has a streamlined look in the new version. Notably it will also dynamically highlight what blood types the CC especially needs.

Additional examples of improvements for the new web site include consolidating calendars of events to one place instead of the present approach which scatters the information across multiple sections of the website. Likewise, all senior leaders can be searched for from one page

location rather than having to go to multiple pages. The new site will also include more intuitive ways to search for these individuals.

Finally, users will be able to leave feedback about the website. The redesigned version will have AI capability, but this feature will not be introduced now.

Discussion

- Mr. Baum liked that the redesigned website eliminates the need to go on a “scavenger hunt” to find information. He asked whether the search function would be limited to the CC website or be more wide ranging. Mr. Cohen said that it would be limited to the CC website, but that the CC is researching other functions. The next project will focus on intranet capability, which staff will use with a more robust search function.
- Ms. Royster said that the website looks less crowded, and she appreciated that the selection of images included people from Black, Indigenous, and people-of-color communities. She has been trying to get people to take advantage of NIH resources, and some of her acquaintances—including her doctor—did not know all that NIH is engaged in. For instance, they did not know that there is a hospital at NIH and that more than research on rats and monkeys is done at the NIH.
- Dr. Schor congratulated Mr. Cohen on the redesigned website, because it is now uncluttered and accessible.

The Undiagnosed Diseases Program (UDP) and Network (UDN)

William Gahl, M.D., Ph.D., Senior Investigator, Medical Genetics Branch, and Co-Director, Undiagnosed Diseases Program, NHGRI

Dr. Gahl spoke about the UDP. He acknowledged all the people who have contributed. The program is a product of the entire intramural program, but it has expanded to the extramural program.

In the United States, some 25 million people have a rare disease. In 2008, 6% of all calls to the Office of Rare Diseases Research were from people who were undiagnosed. They can contact the UDP to see whether they can be studied at NIH. Through participation, people can be diagnosed, and the UDP gets to discover new diseases that tell researchers about physiology and genetics.

Applicants will submit their medical records, and there is a place to register online. Dr. Gahl triages these records to appropriate researchers for adults, and Cynthia Tiffit, M.D., Ph.D., triages the records for children. About a third of those who apply are accepted. The patients are brought into the CC for a week. Between 2008 and 2024, approximately 6,000 medical records were reviewed, more than 1,600 patients—40% of whom were children—were admitted and evaluated, and more than 50% of records were related to neurology. Composed largely of geneticists, the UDP has analyzed more than 2,500 exomes/genomes, though all types of diseases are studied. The UDP has diagnosed about 400 patients and has more than 200 publications in journals such as the *New England Journal of Medicine*, the *Journal of the American Medical Association*, *Nature journals*, the *American Journal of Human Genetics*, and *Genetics in Medicine*.

Dr. Gahl gave examples of diseases diagnosed in the program. The first example involved five adult siblings in their 50s with ischemic pain in their feet and joint pain in their hands. He showed pictures of their femoral and popliteal artery calcification. The UDP performed single-nucleotide polymorphism array analysis, because the parents of these siblings were third cousins, which means that they shared 1/128 of their genes. The researchers looked for a region of homozygosity among the siblings, meaning a place where they had inherited the same version of a genomic region from each parent; a variant in that region would be the same on both copies of the gene and could be the cause of a recessive disease. The researchers focused on the 92 genes in the region of homozygosity shared by all of the affected siblings. One good candidate to explain the disease was the gene *NT5E*, encoding CD73, an ecto-5'-nucleotidase. Sequencing analysis revealed homozygous, potentially disease-causing variants in *NT5E*. They also found that fibroblasts expressed a phenotype, i.e., increased alkaline phosphatase activity. The alkaline phosphatase activity could be reduced by treating the cells with adenosine, i.e., the missing product of CD73. There was also increased calcification in the cells that were examined, and the researchers found that the cells could be rescued by administering CD73-producing lentivirus, adenosine, or levamisole (an alkaline phosphatase inhibitor). Dr. Gahl explained that there is a pathway on the surface of the cells that contains CD73, which converts adenosine monophosphate into adenosine and inorganic phosphate. Normally, adenosine receptors on the cell surface produce intracellular signals that inhibit tissue-nonspecific alkaline phosphatase; without adenosine, the increased alkaline phosphates stimulate calcification. Dr. Gahl called this new disease *Arterial Calcification due to Deficiency of CD73*.

By identifying unique phenotypes and then finding associated gene variants in more than one family, the UDP made about 30 new disease discoveries. The diseases were listed, as were the journals where the findings were published or under review.

Dr. Gahl listed multiple rare diagnoses that the UDP has made.

The UDP helps people in multiple ways. If there is a diagnosis, then the patient may learn about prognosis and treatment. Also, the diagnosis gives credence to the patient actually experiencing a disease. Dr. Gahl discussed the example of a 14-year-old girl from Nigeria who was diagnosed with rickets. She spent a large portion of her life wearing casts for her bone fractures. Among her symptoms were low serum bicarbonate and low serum potassium. The UDP found a pathogenic variant in *SLC4A1*, which is a known cause of distal renal tubular acidosis that causes rickets. The patient is now being treated with alkali (bicarbonate or citrate) and potassium.

Dr. Gahl's third example was a 27-year-old woman with dystonia (uncontrollable muscle contractions), involuntary tongue movements, and gait abnormalities. Because of the tongue movements, she could not eat enough. Researchers found a heterozygous *KMT2B* variant as a potential diagnosis. This variant was not associated with a known disease. The UDP had been putting variants possibly associated with new diseases on a website, and Dr. Gahl got a call from Manju Kurian, M.D., the director of a dystonia clinic in London. Dr. Kurian had three patients with *KMT2B* variants; all three responded well to deep brain stimulation (DBS). Dr. Kurian and the UDP then became collaborators.

A UDP neurologist, Ariane Soldatos, M.D., M.P.H., examined another 20-year-old dystonia patient with gait issues, motor-speech problems, and eventually non-ambulatory status. The patient also had a *KMT2B* variant, was treated with DBS, and is now walking. Before, she could move only her fingers. Her dad sent a picture of her fishing with her family.

The UDP training program had more than 60 postbaccalaureate intramural trainees and 13 postdocs. There are weekly patient rounds, and Dr. Gahl finds this work inspiring. The trainees are first authors of about 30 UDP publications.

In 2018, more than 100 IC and CC physicians from 12 Institutes were involved in the UDP. As of 2019, of the UDP patients, 572 were enrolled in 139 non-UDP NIH protocols, and 159 applicants were referred directly to other intramural studies. The UDP produced publications and CC admissions higher than those of other intramural programs, based on dollars spent; in 2018, there were 37 publications and 600 patient days. Publications from this research include non-UDP co-authors who contributed their expertise or led the investigations. Finally, the UDP helped 14 ICs by providing 28 database searches for gene variants.

In 2013, the UDP expanded to become the UDN, which contained 11 extramural sites in 2018. Within the UDN, personally identifiable information could be shared, and de-identified data could be shared with other investigators. Dr. Gahl cited the statistics for the UDN from August 2015 to March 2024 on the number of applications received, accepted, evaluated, diagnosed, and exomes/genomes examined.

In October 2022, the UDP had \$7.7 million support from the NIH Common Fund. Common Fund support ended at that time, and this amount was then provided by the ICs via a school tax mechanism. The UDP remains part of the UDN.

In 2014, the Undiagnosed Diseases Network International (UDNI) was established with support from the Wilhelm Foundation, an organization founded by [Mikk and Helene Cederroth](#); Helene's three youngest children died of undiagnosed diseases. There have been 12 international meetings. Participants pay their own way to attend, in order to share diagnoses. There is a UDNI working group for Low and Middle-Income Countries, with members throughout the world.

The UDNI Champions Program began by identifying physicians to establish local UDPs in the Democratic Republic of the Congo, Ghana, Pakistan, Mali, and India. Through philanthropy and information-sharing, researchers can collaborate on cases and found clinics. The Champion's Initiative Consortium uses clinical ambassadors in lower- and middle-income countries. Undiagnosed diseases programs are now spread throughout the world, but they all derived from work begun at NIH.

Individuals can work with the NIH UDP in multiple ways: They can refer undiagnosed patients from anywhere in the world, ask the UDP to search its database for variants of interest, or collaborate on research into new diseases. Dr. Gahl has provided his protocol, consent, and manual of operations to physicians wishing to start a UDP.

Dr. Gahl said that this work could be done only at the CC. The resources are free for patients and investigators. There is expertise here in rare diseases that is unparalleled anywhere in the world. The CC has provided the UDP with office and conference space, communications assistance, and excellent patient care. Most of the patients come from major medical centers, but they do not have an explanation for their conditions or a community to support them; this is what the CC helps the UDP to provide.

Discussion

- Dr. Chin praised Dr. Gahl for the work of his team at the frontier of medicine and asked whether there is a parallel between Dr. Ginsburg's presentation and Dr. Gahl's. They

might be seen as bookends in terms of genotype–phenotype linkage (i.e., whether the genotypes are found first).

- Dr. Gahl said that finding the gene or variant first could demonstrate a new disease, which could then be phenotyped at the CC. However, he appreciates philosophically the other approach of identifying first phenotypes that can then be associated with particular genetic variants.
- Ms. Reel said that it is compelling to tell a story about a person, but EHRs preclude the ability to do so, because the content that goes into EHRs is highly prescribed.
- Dr. Gahl said that the records are repetitive, but there was a huge amount of publicity about this program in the early days. The publicity is what allowed NIH to continue the program. The publicity was derived from telling the stories of people who had benefited from receiving diagnoses.
- Dr. Devaskar acknowledged that a diagnosis brings closure, if not treatment, for many families. She said exome and GWS are being used widely in neonatal populations to make diagnoses, which creates a dynamic that is different than families going from institution to institution with undiagnosed disorders. She asked whether Dr. Gahl had any insights into how to locate multiple variants of unknown significance, because it is not possible to study every variant.
- Dr. Gahl agreed that this is a problem; if researchers are lucky, they can limit potential disease-causing variants to 5 or 10. But they have to be selective. Advanced genetic techniques are available, such as RNAseq (which will tell about expression or splicing defects) or long-read sequencing (for smaller deletions), as well as epigenetics. Collaboration is vitally important. With more resources, Dr. Gahl would like to look at old cases and identify potential collaborators based on their expertise with disease-causing variants.
- Ms. Royster asked whether patients could be accepted at a distance if doctors have blood samples to send (e.g., from an infant born with some abnormal condition), or whether the patient would have to be on-site.
- Dr. Gahl said that the patient would first have to apply and be accepted into the program. If accepted, consent could be given over the telephone, and sent DNA could be analyzed (though the person who drew the blood would charge a fee for that service). If it is not feasible, patients will not have to travel; the program is often able to do the work-up from a distance.

Closing Remarks and Adjournment

Dr. Schor thanked everyone for a wonderful meeting and the questions that provoked thought. She said that the final meeting this year will be Friday, October 18, 2024, and 2025 meeting dates will be announced shortly. The Committee Management Team will join virtually after the close of this meeting to report on membership reporting requirements and answer questions. Mandy Stoneberger and Ezelle Wooden are the presenters.

Dr. Schor asked whether there were any further questions on topics not discussed. Hearing none, she adjourned the meeting at 12:42 p.m. ET.

/s/

Nina F. Schor, M.D., Ph.D.

Executive Secretary and Designated Federal Official (DFO),

NIH Clinical Center Research Hospital Board

Deputy Director for Intramural Research, NIH

/s/

James K. Gilman, M.D.

Chief Executive Officer, NIH Clinical Center

Abbreviations and Acronyms

AMC	academic medical center
ANCC	American Nurses Credentialing Center
CC	Clinical Center
CEO	chief executive officer
CCRHB	Clinical Center Research Hospital Board
DBS	deep brain stimulation
DEIA	diversity, equity, inclusion, and accessibility
DRC	Data and Research Center
EHR	electronic health record
GME	graduate medical education
HDR	Hereditary Disease Risk report
HHS	U.S. Department of Health and Human Services
ICs	Institutes and Centers
IDEA	Integrated Digital Experience Act
NCI	National Cancer Institute
NCI-CCR	National Cancer Institute Center for Cancer Research
NHGRI	National Human Genome Research Institute
NHLBI	National Heart Lung and Blood Institute
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health

NIMH	National Institute of Mental Health
TJC	The Joint Commission
UCLA	University of California, Los Angeles
UDN	Undiagnosed Diseases Network
UDNI	Undiagnosed Diseases Network International
UDP	Undiagnosed Diseases Program