86th Meeting of the National Cancer Institute (NCI)
Council of Research Advocates (NCRA)
National Institutes of Health (NIH)

Virtual Meeting

June 29, 2022

Members Present

Ms. Anjelica Davis*, Chair*

Ms. Melinda Bachini

Dr. Victoria Buenger

Ms. Annie Ellis

Ms. Jennifer Pegher

Ms. Kristen Santiago

Ms. Jacqueline Smith

Mr. Kevin Stemberger

Dr. Nicole Willmarth

Speakers

Dr. Philip Castle, Director, Division of Cancer Prevention (DCP), NCI

Ms. Holly Gibbons, Deputy Director, Office of Government and Congressional Relations (OGCR), NCI

Ms. Hope Krebill, Executive Director, Masonic Cancer Alliance, and Associate Director, Outreach, The University of Kansas Cancer Center (KUCC)

Dr. Douglas Lowy, Acting Director, NCI

Dr. Robin Vanderpool, Branch Chief, Health Communication & Informatics Research Branch, Division of Cancer Control and Population Sciences (DCCPS), NCI

Ms. Amy Williams, Acting Director, Office of Advocacy Relations (OAR); Executive Secretary, NCRA, NCI

Ms. Tonia Yelder, Patient and Investigator Voices Organizing Together (PIVOT), Patient Research Advocate, The University of Kansas Cancer Center

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Welcome and Opening Remarks

Ms. Anjelica Davis and Ms. Amy Williams

Ms. Williams opened the meeting at 12:00 p.m., welcomed Council members and attendees, and reviewed the meeting agenda. Ms. Davis called the meeting to order, reviewed the conflict-of-interest rules for the meeting, confirmed that a quorum of members was present, and provided brief opening remarks.

Noting that this is her last meeting as NCRA Chair, Ms. Davis commended Council members for their strong engagement and leadership during her term and offered heartfelt thanks to NCI team members for their diligent work behind the scenes.

Acting NCI Director's Update

Dr. Douglas Lowy

Dr. Lowy acknowledged the contributions of Ms. Davis during her term as NCRA Chair, Ms. Jennifer Pegher as her term on the board expires, and incoming Chair, Ms. Annie Ellis. He presented his perspective on providing continuity of leadership to NCI as a Deputy Director since 2010 and as Acting Director three times: 2015–2017, 2019, and at the present time. During his tenure at NCI, Dr. Lowy has been involved in important NCI initiatives, such as the Precision Medicine Initiative-Oncology and the National Cryo-EM user facility at Frederick National Laboratory (2015), the Cancer Moonshot (2016), a $40 million increase in P30 support grants for NCI-designated cancer centers (2016–2022), and enabling Congress to recognize low NCI funding rates for investigator-initiated research (2019).

Dr. Lowy described recent and upcoming activities that demonstrate NCI engagement with the cancer community. Current and near-future NCI activities include continued funding of the most promising initiatives of the Cancer Moonshot; development of Phase 3 for the P30 Cancer Center support grants; and selection of at least one new signature project at the Frederick National Laboratory. In April, Dr. Lowy provided remarks at the American Association for Cancer Research (AACR) meeting and addressed the National Association of Cancer Center Development Officers Public Affairs and Marketing Network. He presented the plenary speech and met with the Board of Directors at the June meeting of the American Society of Clinical Oncology (ASCO). He will be speaking at the Association of American Cancer Institutes (AACI) meeting in October.

Dr. Lowy announced two critical appointments to the Childhood Cancer Data Initiative (CCDI). Dr. Brigitte Widemann has been named Special Advisor to the Director for Childhood Cancer, and Dr. Gregory Reaman will join the CCDI in September as Scientific Director.

An online conversation entitled "Equity in the Healthcare Workforce: Why It Matters for Patients" was broadcast live across NCI's Facebook and YouTube accounts. Featured discussants included Drs. Lowy, Paulette Gray (NCI), Jeffrey Hall (Centers for Disease Control and Prevention), and Randy Jones (Oncology Nursing Society).

FY23 NCI Budget

Dr. Lowy participated in a May 11 House Committee on Appropriations hearing about the NIH Fiscal Year (FY) 2023 budget request. Due to strong bipartisan support for cancer research, Congress has declined in recent years to reduce funding for cancer research, even in challenging budget cycles. Both the Chair and Ranking Member of the Subcommittee expressed their hope that they could continue to increase funding for NIH in FY 2023.

The House Labor-Health and Human Services (HHS) Appropriations Subcommittee FY 2023 Bill proposes $7.4 billion for NCI, including $216 million for the Cancer Moonshot, and would represent an overall $466 million increase for NCI over FY 2022.

NCI partnered with Cancer Research UK (CR UK) to launch the Cancer Grand Challenges. Over a 5-year period, a total of $100 million will be awarded to four international, interdisciplinary teams from around the world to solve some of the toughest challenges in cancer research. The recently announced 2022 awards will conduct research on cancer cachexia as a tumor-driven syndrome; extrachromosomal DNA that helps tumors evolve and evade treatment; development of engineered T-cell therapies for childhood cancer; and discovery of what triggers normal cells harboring cancer-causing mutations to become tumor cells. About $60 million of the award will support research conducted in the United States.

Dr. Lowy highlighted recent cancer research publications. In June, a paper authored by NCI intramural investigators reported that uterine cancer death rates are rising and are highest among black women in the United States; black women are twice as likely to die of uterine cancer compared with women in other racial and ethnic groups. Most of the mortality increase is attributable to non-endometrioid uterine cancer, which disproportionately affects black and Hispanic women. Between 2010 and 2017, non-endometrioid cancer mortality increased 3.5 percent per year for black women and 6.7 percent for Hispanic women. Although this type of cancer represents about 20 percent of uterine cancer incidence, it accounts for more than 40 percent of mortality. There is an urgent need for new research in the affected populations.

Over the last 20 years, the gap between mortality rates for black men and white men and most race and ethnicity groups has decreased. The exceptions are among American Indian/Alaska Native (AI/AN) and Asian and Pacific Islander (A/PI) men.

The Lung Cancer Research Foundation reports that the rate of U.S. Food and Drug Administration (FDA) approvals of lung cancer treatment has increased over the past 20 years. Although a 2020 study attributed the reduction in lung cancer mortality to decreased tobacco consumption, there also has been substantial benefit from cancer treatment as a result of these FDA approvals.

Dr. Lowy provided examples of opportunities in pancreatic cancer research: a pancreatic cancer prevention vaccine, early detection via multi-cancer detection screening, and treatment that targets *KRAS* G12C and G12D. Until recently, the *KRAS* oncogene was thought to be an undruggable target; last year, FDA approved the first treatment for mutant *KRAS* in lung cancer. Preclinical data suggest that the inhibitors being developed against *KRAS* G12D may be useful; early-phase trials will start next year.

Dr. Lowy presented an overview of the next phase of the Cancer Moonshot, which builds on success of initial investments from the first phase of the Initiative. FY 2023 is the last year of the first phase. Between 2017 and 2021, the Initiative catalyzed more than 2,000 publications, 49 clinical trials, and more than 30 patent filings. It will be important to support the most promising initiatives from the first phase while developing additional activities for the "supercharged" Moonshot phase.

In February 2022, President Biden announced the goals of the Cancer Moonshot's next phase: cut the cancer death rate in half within 25 years; transform the meaning of cancer; and address cancer-associated inequities.

A peer-reviewed publication targeted for release in the next few months will describe how achieving these aspirational goals can be made feasible. Key steps toward accomplishing these goals include:

- Investment in the pipeline of new drugs for prevention, interception, and treatment.
- Expansion of clinical trials to speed evaluation of candidate interventions in diverse populations (racial, ethnic, and geographic).
- Ensuring equitable healthcare delivery of current and new standards of care.
- Increasing diversity of the cancer research and care workforce to more closely resemble the communities served.

FY 2023 activities to jumpstart the Cancer Moonshot include Funding Opportunity Announcements (FOAs) for a Cancer Moonshot Scholars Program and a feasibility trial for asymptomatic multi-cancer detection screening. Notices of Special Interest (NOSIs) and Requests for Information will be issued on adapting visualization methods to enhance Cancer Moonshot data, harmonizing existing data to Human Tumor Atlas Network standards, and targeting fusion oncoproteins in childhood cancers.

Dr. Lowy closed with a discussion about how the COVID-19 pandemic brought about major changes in cancer clinical trials. The patient became the center of clinical trials activity, which allowed remote consenting, laboratory tests at home or a local facility, delivery of drugs to the home, and remote monitoring and auditing. Some of these changes can be incorporated into future trial conduct toward building a patient-centered clinical trials enterprise.

Discussion

Ms. Davis thanked Dr. Lowy for his report.

- Ms. Pegher noted that the AACI has been collecting information on diversity and clinical trials from cancer centers over the past year, but only 36 cancer centers (about 10%) have responded. Between 2019 and 2020, clinical trial participants at cancer centers were largely female and white. She stressed the importance of diversifying clinical trial participation. Patients want to hear from people who look like them. Staff attrition is another challenge. Dr. Lowy pointed out that NCI is a research organization that supports the research conducted at cancer centers; the centers are care delivery organizations and have the opportunity to put research findings into practice.
- Ms. Santiago asked why uterine cancer mortality has increased. Dr. Lowy responded that the causes are not known; the increased mortality rate among Hispanic women was not called out until recently. He suggested that finding answers would require a program like The Cancer Genome Atlas (TCGA) to characterize molecular abnormalities in women across different communities and epidemiological evaluations to identify molecular signatures from inadvertent environmental exposures.
- Ms. Ellis commented that the Gynecologic Cancer Steering Committee has been asking about disparities in clinical trial enrollment in light of these mortality disparities. It is important to serve people who currently are not benefiting from the research.
- Ms. Ellis also noted that many of the Cancer Moonshot roundtables involved patient advocates and asked about the role of advocates in Moonshot 2.0. Dr. Lowy responded that he would raise this topic at the next meeting with White House Cancer Moonshot Coordinator Dr. Danielle Carnival.
- Mr. Stemberger requested more details about where the Advanced Research Projects Agency for Health (ARPA-H) will be housed, its funding, and when its work will begin. Dr. Lowy explained that, typically, an agency is authorized, followed by an appropriation, but in the case of ARPA-H

the appropriation came first in the form of a $1 billion investment over a 3-year period. It remains to be seen what will happen with the authorizing legislation.

- Dr. Buenger commented on lessons learned during the pandemic and their implementation in pediatric clinical trials; for example, home exams, remote consenting, and reliance on oral options. Dr. Doug Hawkins recently presented on pediatric patient adherence, noncompliant scheduling, and outcomes. Dr. Lowy responded that these data are being collected, and he expects that incoming CCDI Scientific Director Dr. Reaman will be looking at adherence to best practices and beyond to outcomes.
- Ms. Davis asked how changes in clinical trial design requirements will be communicated to research scientists who are submitting clinical trial applications now. Dr. Lowy responded that although NCI is bound by regulatory issues, the FDA recognizes that changes need to be instituted. NCRA members may bring specific issues to NCI's attention through Ms. Williams or by contacting him directly. Ms. Davis added that enabling patients to receive standard of care at home would be a great accomplishment. Dr. Lowy commented on the tension between quality of care and location; that is, whether standard of care at home will be substandard care.
- Ms. Smith described her experience in a clinical trial where she was required to visit the hospital (1.5 hours each way) every day for the first week of every month. A patient next to her was unable to continue in the trial because of transportation costs. She noted that the number of required visits is a factor in trial accrual, access, and attrition. There is evidence that physician bias is a factor affecting which patients are offered the opportunity to participate in trials. She asked whether there are studies looking at physician bias in this context. Dr. Lowy agreed that the impact of explicit or implicit bias and the practical aspects of trial participation are critical issues.

DCP Director's Update

Dr. Philip Castle

Dr. Castle described DCP and its priorities and provided an update on the breadth and depth of cancer prevention work across the division. DCP leads, supports, and promotes rigorous, innovative research and training to reduce risks, burdens, and consequences of cancer to improve the health of all people. In the context of the translational research continuum, DCP supports basic research, translation to humans, and translation to populations, and identifies novel strategies that are handed off to other groups (e.g., the NCI DCCPS) for support.

DCP areas of focus are preventive and interception agents designed to reduce cancer incidence; screening and early detection to reduce cancer mortality; and symptom science, prevention, and management to improve quality of life. Cancer prevention offers great promise: one-third to one-half of cancer deaths are attributable to modifiable risk factors in western populations. Effective cancer prevention requires evidence-based personal and population actions.

DCP's approach to symptom management and toxicity mitigation focuses on understanding the mechanisms of action for chronic adverse effects; characterizing the clinical syndrome for the toxicity or symptom; and capturing how the patient functions and feels through patient-reported outcomes. It is important to recognize the interaction between symptom management, survivorship, and therapy efficacy.

An inclusive model for precision cancer prevention (1) employs a targeted, molecular-based approach to intercept carcinogenesis before cancer develops or becomes untreatable and (2) considers for whom, where, and how prevention is delivered to assure health equity for all people. An inclusive model will

improve not only the health of all but also the representativeness of research. The basic science that has fueled prevention and treatment interventions has been subject to biases such that current precision cancer prevention interventions may not be effective in all populations. Several examples are specific to those of African descent: the TCGA was not representative of the population getting colorectal cancer, and HPV35 is not included in current prophylactic human papillomavirus (HPV) vaccines. Precision cancer prevention must take into account nonbiological risk factors such as social determinants of health.

Dr. Castle described studies of intervention delivery modes that may be more applicable and amenable to high-risk or underserved populations. A screening study conducted in the Mississippi Delta Region found that women were 4 times more likely to choose self-collection HPV testing than clinic-based testing; a cluster randomized controlled trial (RCT) of choice versus a clinic-based test found that women were five times more likely to select choice over clinic-based screening, and among those who selected choice, women were 20 times more likely to complete self-collection than go to a clinic.

The Last Mile Initiative is an NCI-led public-private partnership to facilitate regulatory approvals for self-sampling approaches for HPV testing as an alternative to provider-based sampling for cervical cancer screening. Planning is underway for a nationwide multicenter screening trial to examine self-sampling in diverse delivery settings.

Multi-Cancer Early Detection Assays

Dr. Castle presented his views on multi-cancer early detection (MCED) assays that attempt to detect multiple components of a growing cancer in blood or other body fluids. The possibilities are exciting, but their effectiveness is unproven. Each MCED assay measures different things for a different set of cancers. A positive test result is a signal for cancer but not a diagnosis. Some tests suggest tissue of origin, and some require extensive imaging after a positive result.

Dr. Castle reviewed several unknown aspects about MCED cancer screening and the importance of further research. For instance, we need to understand whether screening an asymptomatic population for cancer with MCED tests will result in mortality reduction from cancer; whether a blood test will make screening more accessible or exacerbate disparities; and how clinicians should respond if a cancer is not found following a positive MCED test. He also suggested it is important to study whether MCED assays will lead to overdiagnosis of indolent cancers.

Dr. Castle described a possible platform RCT design for MCED assays. Starting with the most advanced assays, the RCT would have a control arm plus one arm for each assay. All arms would be offered standard-of-care screenings. Following administration of the MCED test, all cancer cases and cancer deaths would be captured. Primary endpoints would include measurement of cancer deaths and death rates from specific cancers compared with the control arm.

NCI plans to invest in understanding the biology of bloodborne biomarkers through large cohort studies to identify when these markers "turn on," validate technologies, and develop a reference set for analytic validation. If any of these biomarkers work, they will drive innovation. Cancers may be detected earlier than ever before (particularly those for which no screenings currently are available), possibly leading to new therapies that prevent progression of disease.

Dr. Castle highlighted additional DCP priorities, including biological and population risk-informed interventions that are more targeted and offer better benefits, including harm ratio; mitigating the effects of obesity as a contributor to cancer and the burden of cancer; innovations in technologies to bring standard of care or better to underserved populations at higher risk of cancer; symptom science and

precision symptom prevention and management; immunology and preventive vaccination; and new technologies such as synthetic biomarkers.

Discussion

Ms. Davis thanked Dr. Castle for presenting a helpful and thorough summary of DCP work.

- Dr. Willmarth noted that her organization views MCED assays as potential game changers. Currently, there is no screening option for brain tumors, and the only known risk factor is ionizing radiation. Dr. Willmarth thanked Dr. Castle for setting realistic expectations for this unproven screening option. Noting that many patients who have nonmalignant brain tumors experience symptoms and cognitive impacts, she asked whether MCED tests might be able to detect nonmalignant tumors. Dr. Castle noted that detection of a brain tumor does not equal a benefit to patients. He said that distinguishing between malignant and nonmalignant tumors would be a good research question and could be fueled by creation of a biobank.
- Ms. Ellis commented that from a survivor's perspective she would rather not have cancer; prevention is ideal, followed by early detection when an available intervention offers a cure. The ovarian cancer community has seen a lot of direct-to-consumer marketing of products; she asked whether MCED tests would have the same sensitivity and specificity thresholds as specific cancer tests. Dr. Castle responded that many investigators want to use reduction of advanced cancers as an early endpoint, but NCI does not accept that; a mortality benefit must be shown, and then one can validate the surrogate. It is not clear what the MCED tests will be able to detect at this time.
- Ms. Santiago asked how Pap tests passed the benefit/harm ratio, given Dr. Castle's statement that 49 out of 50 women would not get cervical cancer if we did nothing. Dr. Castle explained that cancer is not the endpoint for cervical cancer detection trials because the surrogates—cancer precursors CIN2 and CIN3—are known, and these trials complete much faster than other detection trials. In the case of MCED assays, there is no validated test to which they can be compared.
- Mr. Stemberger asked what units of measure or conditions are used to demonstrate that cancer has been prevented, given that prevention is invisible. Dr. Castle indicated that data from cancer registries and surveillance are used to show decreased incidence on a national level. DCP must do more RCTs than those in the treatment space. The upside is that people never get cancer.
- Ms. Davis commented that she hopes a large trial for MCED tests will include an economic study because she is concerned that some policy proposals are getting ahead of the science. The data must be very clear to the advocacy community so that they will not be swayed to accept them before assays are shown to be effective. She asked whether CMS, FDA, and others are contributing to the analysis of MCED assays. Dr. Castle responded that the cancer advocacy community should disseminate this message.

Budget and Legislative Update

Ms. Holly Gibbons

Ms. Gibbons acknowledged the passing of former Congressman John E. Porter, a champion for biomedical research known as a strong advocate and appropriator for NIH. The John Edward Porter Neuroscience Research Center on the Bethesda campus is named in his honor.

While reviewing the appropriations process by which NCI receives its funding, Ms. Gibbons noted that

the FY 2022 budget was enacted on March 15, 2022, followed 2 weeks later by release of the President's Budget (PB) for FY 2023. The FY 2023 PB provides a $16.1 billion increase for NIH, including $5 billion for ARPA-H. The House proposes a $2.5 billion increase (+5.6%) for NIH and a $466 million increase (+6.7%) for NCI.

The balance of funding across NIH and ARPA-H is a topic of extensive discussion. The FY 2022 budget appropriates $1 billion for ARPA-H, which HHS Secretary Becerra transferred to NIH in April. The House proposes a $2.75 billion allocation for ARPA-H outside of NIH. Authorizing legislation is pending. In the House, the ARPA-H Act passed on June 22, which establishes ARPA-H within HHS but outside of NIH. Additional provisions address structure and operation; the Director would be a Presidential appointment without requiring Senate confirmation. In the Senate, a related Act proposes ARPA-H within NIH. The geographic location of ARPA-H remains to be determined; the House and Senate authorizing bills specify that it could not be located on any NIH campus.

Ms. Gibbons also provided an overview of legislation of interest to the NCRA. The House has passed its version of the FDA User Fees Reauthorization (FY 2023–2027), which includes provisions to improve diversity in clinical trials and the Give Kids a Chance Act (new authority for trials in pediatric cancers). In the Senate, the HELP [Health, Education, Labor and Pensions] Committee approved the FDA Safety and Landmark Advancements Act, which does not include provisions for clinical trials or the Give Kids a Chance Act; a final vote is pending. Differences must be resolved before the President receives a bill to consider.

Two recent congressional briefings were highlighted. Dr. Brigitte Widemann addressed a congressional briefing to honor Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Day on May 17. DIPG is the leading cause of childhood brain tumor deaths. Dr. Amy LeBlanc, Director of NCI's Center for Cancer Research Comparative Oncology Program (COP), also participated in a virtual congressional briefing on animal research. The COP helps researchers better understand cancer biology and improve assessment of novel treatments for humans by treating pets with naturally occurring cancers.

Ms. Gibbons closed by noting that the House and Senate will be in session for 23 days before the end of the fiscal year.

Research Advocacy Training Initiatives

Dr. Robin Vanderpool and Ms. Hope Krebill

Dr. Vanderpool provided background on the community outreach and engagement (COE) activities of NCI-designated cancer centers, which were formalized in the 2016 reissuance of the Cancer Center Support Grants for NCI-designated Cancer Centers. In 2019, new guidance expanded COE to include inreach—connecting community perspectives to basic, clinical, and translational research in a bidirectional relationship where the community needs help drive the cancer center research. This should catalyze activities of special relevance to the geographic catchment area and generate examples of research projects where outreach to and engagement with communities and patient advocates inform and result in high-impact science. To support these conversations and build capacity, DCCPS issued an administrative supplement to support these activities. The KUCC team was able to leverage the PIVOT program to successfully compete for the supplement. They developed training about COE with a goal of developing and maintaining relationships among scientists and communities as research partners. The FY 2020 supplement projects are wrapping up; grantees have developed case studies to share best practices.

Dr. Vanderpool noted that these case studies speak to the opportunities that a relatively small amount of

money and capacity building can provide at cancer centers by connecting patient advocates and scientists to make the research more relevant for patients, caregivers, and the entire cancer community.

Ms. Krebill began her remarks by noting that the KUCC catchment area includes 4.5 million people in urban and rural counties in Kansas and Missouri. To understand how to conduct COE across this large land mass, the KUCC team needed to understand the data; identify community strengths; hear from advocates and other stakeholders; stimulate and support research; and drive, disseminate, and implement cancer control activities. Involving patient research advocates in these activities ensures patient focus and relevance; adds a human face and sense of urgency; provides real-life, diverse, insightful expertise; and spurs innovation.

The community advisory board (CAB) meets four times per year and comprises 18 individuals representing diverse cancer experiences, skills, community connections, geography, culture, race, ethnicity, and gender. The CAB is responsible for setting priorities, developing policy, and providing guidance for outreach and engagement. PIVOT patient partners conduct grant reviews, planning, development, implementation, oversight, reporting of results, and dissemination.

The focus on patient research advocacy meant that the advocates needed to be pre-vivors, survivors, and co-survivors with lived cancer experiences; committed to representing patient concerns and perspectives; tied to the broader community of cancer survivors and co-survivors; and able to share a collective patient perspective. A great research advocate has a desire to make things better for patients; strong communication skills; the ability to represent all patients, not just their own stories; a drive for knowledge; and the ability to work collaboratively with others.

The advocates created the PIVOT vision: patients, families, caregivers, and researchers accelerating innovative approaches to redefine cancer research together. There are now over 130 PIVOT members.

PIVOT patient advocate trainings are available in person, virtually, and hybrid and include topics such as Cancer Research 101, how to create an NIH biosketch for an advocate, the translational research timeline, the KUCC response to COVID-19, effective research partnerships, reviewing an informed consent in the Clinical Trial Office, and grant review team training. In addition to trainings, advocate tools are available such as the advocate-researcher toolkit; the Rapid Reactor Team (RRT) toolkit; PIVOT YouTube; bench-to-bedside Facebook Live, a newsletter highlighting KUCC events and advocacy opportunities; KUCC annual research symposium/poster walks; and a private Facebook group.

The RRT was created to encourage more researchers to partner with patient research advocates. Each 60-minute RRT session includes a 10- to 15-minute researcher presentation, followed by a 45-minute facilitated discussion with 8 to 10 advocates. Sessions offer immediate, relevant, patient-honed feedback to the researchers. Researchers prioritize topics such as research strategies, eligibility criteria, participant burden, or strengthening of recruitment and retention. Researchers and advocates evaluate the experience. We have found that researchers report the sessions help them understand the patient voice, increase sensitivity, provide feedback on feasibility, and clarify project appropriateness.

The Advocate-Research Working Together toolkit was developed to help researchers understand how to interact with advocates. In addition, one-on-one coaching was provided. However, interaction with basic scientists was not at the same level as with other researchers. As Dr. Vanderpool noted, The University of Kansas Medical Center received a supplement to create a COE training program for basic scientists to improve communication skills, incorporate advocates into funded proposals, and form lasting partnerships. The training includes modules on principles of COE, enhancing communication skills, and

individual team-building meetings where they practiced negotiating partnerships. The training concludes with presentations at the KUCC Research Symposium. The response has been very positive, with researchers wanting to continue to partner with advocates and encouraging other scientists to participate in the PIVOT program.

Overall, more than 80 researchers have been engaged, 65 proposals have been supported (e.g., pilot grants, a Department of Defense grant, an NCI R01), and 47 RRT sessions have been conducted.

Lessons learned from PIVOT include the importance of partnerships and intentional interactions; how some research topics can be re-traumatizing for advocates; and research careers are fluid and involve changing institutions.

Discussion

Ms. Davis thanked Dr. Vanderpool for her introduction and Ms. Krebill for an excellent presentation about the amazing work going on in Kansas.

- Ms. Ellis asked whether patient research partners go through an intake process as volunteers at KUCC, and if that system created a barrier to participation in PIVOT. Ms. Krebill responded that advocates come directly through PIVOT and receive hourly consultation fees. This has not been a barrier to participation. They do get requests from researchers for specific cancers, which cannot always be fulfilled; often, the advocates have an overarching experience. Ms. Ellis expressed the hope that a PIVOT research partner would be a member of the NCRA.
- Ms. Yelder noted that the researchers present five slides during an RRT session, and the discussion is led by the advocates who ask questions that the researchers often have not considered. Many of these researchers work in the lab and have little or no contact with patients. The RRT session offers an opportunity for them to engage with advocates and they are very appreciative. There are wins on both sides.
- Ms. Pegher noted that Ms. Krebill is speaking on patient engagement at the AACI annual meeting in October. The PIVOT project is an excellent example of the great work the cancer centers are doing now. When these new COE guidelines were released, cancer center teams asked for a listserv to serve as a forum for sharing with others; nearly 200 individuals from 55 cancer centers now are collaborating through that listserv.

Closing Remarks and Board Administration

Ms. Anjelica Davis and Ms. Amy Williams

Ms. Ellis made a motion to approve the minutes of the 85th NCRA meeting. Ms. Pegher seconded the motion, and the motion passed unanimously.

Ms. Williams thanked speakers for their presentations and participation in the lively discussions that followed. She noted that it is gratifying to see the work taking place at the intersection of science and patient input. She acknowledged Ms. Davis for her contributions to shaping NCRA meetings during her years as Chair and thanked the staff of the NCI Office of Advocacy Relations who speak with advocates daily.

Ms. Williams noted that the next Council meeting will be held in September. Ms. Davis thanked Council members for their active participation throughout the meeting and past meetings.

The meeting adjourned at 3:15 p.m. EDT.

Certification

I hereby certify that foregoing minutes are accurate and complete.

September 30, 2022
Date

/s/
Anjelica Davis
Chair
NCI Council of Research Advocates

September 30, 2022
Date

/s/
Amy Williams
Executive Secretary
NCI Council of Research Advocates