67th Meeting of the National Cancer Institute (NCI)
NCI Council of Research Advocates (NCRA)
National Institutes of Health (NIH)

Updates on NCI Programs, Cancer Genomics Data Commons Program, and Working Groups

Webinar
Hosted from Building 31, A Wing, 10th Floor, Conference Room 10A06
NIH Campus
Bethesda, Maryland

Thursday, March 4, 2015

Members Present

Mr. Max Wallace, Chair
Mr. David Arons
Dr. Gregory J. Aune
Ms. Susan G. Braun
Dr. Adam Clark
Ms. Andrea Stern Ferris
Ms. Martha Gaines
Ms. Joya Delgado Harris
Mr. Jeffrey A. Kaufman
Ms. Shelley Fuld Nasso
Dr. Senaida Poole
Mr. Jon Retzlaff
Dr. Regina Vidaver

Speakers

Mr. David Arons, Senior Director of Public Policy, National Brain Tumor Society
Ms. Joya Delgado Harris, Director, Office of Research Integration, American Cancer Society
Dr. Warren A. Kibbe, Director, Center for Biomedical Informatics and Information Technology, NCI
Ms. Kelley Landy, Acting Director, Office of Advocacy Relations (OAR,) Office of the Director, NCI
Dr. Douglas R. Lowy, Deputy Director, NCI; Mr. Max Wallace, Chief Executive Officer, Accelerate Brain Cancer Cure

Contents

Welcome and Opening Remarks
Ms. Kelley Landy, Mr. Max Wallace

- Ms. Landy and Mr. Wallace welcomed NCRA members, speakers, and guests.
- The program featured presentations from Dr. Lowy and Dr. Kibbe.

NCI Update
Dr. Douglas Lowy

NCI Update

- Details about the NCI budget and its implications for cancer research are available at http://www.cancer.gov/aboutnci/budget_planning_leg/plan-2016.
- From 2001 to 2010, mortality rates have decreased for many cancers (e.g., stomach, prostate, and colorectal for men; non-Hodgkin lymphoma, colorectal, and stomach for women). Overall, the reduction is a bit higher for males (18 percent) than females (14 percent), which is largely attributable to changes in smoking rates.
- Mortality rates have not decreased for some cancers; including liver and pancreatic.
- The number of cancer survivors in the U.S. has increased substantially in recent decades, from less than 4 percent of cancer patients in 1977 to nearly 14 percent in 2012, with a predicted 18 percent surviving in 2022. Many cancer survivors resume productive lives.
- For the past 10 years, the NCI budget has been flat, with progressively decreasing purchasing power. Grant success rates are lower than they have ever been. Industry

support of biomedical research and development decreased by approximately $10 billion between 2007 and 2012.

- The low success rate for research grant applications translates to difficulty in recruiting and retaining the best minds in science and undertaking new large-scale projects.

- Funding is also lacking to support infrastructure.

Precision Medicine Initiative

- Cancer research is moving toward genomics, but genomically oriented clinical trials are more expensive per patient than other trials. President Obama has proposed $70 million in his FY16 budget for the Precision Medicine Initiative, which will expand NCI-supported cancer genomics-based clinical and preclinical studies. The advocate community will have ample opportunity for input into the initiative.

- A key take-home message from The Cancer Genome Atlas (TCGA) is that cancer is very heterogeneous. Even within the same tumor type, there can be many variations of mutated genes. Some variations might be more amenable to treatment than others.

- NCI's Molecular Analysis for Therapy Choice (MATCH) trial, which emphasizes molecular abnormality in a tumor rather than the site of the tumor, will examine experimental drugs that have shown activity against a known molecular target and test each drug in a range of tumors containing the relevant molecular abnormality.

- The National Clinical Trials Network (NCTN) conducts trials at approximately 2,400 institutions with 14,000 investigators and more than 21,000 patients per year enrolled.

- The NCI Community Research Program (NCORP) provides an important connection to community-based cancer care, ensuring that patients have access to the benefits of the latest research regardless of where they live.

- Molecular findings in one cancer can have implications for other cancers.

HPV Vaccine

- The FDA approved a 9-valent vaccine (Gardasil 9) against human papillomavirus (HPV) in December 2014 and recommended it for females aged 9 to 26 and males aged 9 to 15. The 9-valent vaccine adds protection against HPV types 31, 33, 45, 52, and 58, in addition to HPV 6, 11, 16, and 18. It brings the effectiveness of the vaccine to more than 90 percent of cervical cancers.

- Vaccination rates for HPV lag far behind vaccination rates for Tdap (tetanus, diphtheria, acellular pertussis vaccine) and MenACWY (meningococcal conjugate vaccine). This is true for girls and boys and for one or three doses. Acceptance of the vaccine has been somewhat ambivalent in some medical circles.

- Positive results from an immunogenicity trial should lead to two-dose approval by the FDA and recommendation by ACIP in 2016.

Cancer Genomics Data Commons and NCI Cloud Pilots Program
Dr. Kibbe

- Cancer research is in an era of precision medicine. A health care system that learns from every patient is needed, as well as better understandings of the basic biology of cancer and genomic changes related to cancer.

- Human genetic sequencing pilot projects began in the late 1990s and full-scale human genome sequencing in 2000, with rapid progress that has increased understanding of what the genome is and how to capture the information.

- The Human Genome Project has turned a $5.6 billion investment (in 2010 dollars) to economic development worth $800 billion. It has enabled many basic discoveries, clinical therapies and diagnostics, and applied technologies.

- TCGA and Therapeutically Applicable Research to Generate Effective Treatments (TARGET, the pediatrics part of the program) began in 2005. TCGA, a collaboration of the National Human Genome Research Institute and NCI to examine glioblastoma, lung, and ovarian cancers using genomics, has expanded to more than 20 tumor types.

- The focus of genomics research has shifted from broad analyses to analyses based on single cells. Because of growing realizations of how heterogeneous cancer is, analyses from a single cell are important for cancer.

- An important finding from TCGA is the increasing genomic complexity and increasing burden of mutation. For example, molecular subgroups have been used to refine histological diagnoses of endometrial carcinoma. Molecular diagnosis allows additional correlates for a proper diagnosis and more innovative approaches to treatment.

- The extension of TCGA and TARGET leads to the Cancer Genomics Data Commons and the NCI Cloud Pilots. The Genomics Data Commons will restandardize data and make them consistent, more comparable, and publicly acceptable.

- The Genomics Data Commons also incorporates the idea of the citizen/scientist/patient, data altruists who want to be able to directly contribute their information into the database.

- The NCI Cloud Pilots are designed to be complementary to the Genomic Data Commons. They will put analysis resources in the cloud, along with the data. Researchers can use the Cloud Pilots to ask novel questions and use the computational ability of the cloud to answer questions.
-

- Issues of privacy and confidentiality are offset by voluntary contribution of personal information.

- While socioeconomic backgrounds might affect the ability of individuals to participate in the national cohort study, this will be offset by comprehensive information from NCI's Surveillance, Epidemiology, and End Results (SEER) Program registries.

Updates from NCRA Working Groups

Advocate Engagement
Ms. Joya Delgado Harris

- The Advocate Engagement Working Group is exploring how NCI and the advocate community can work together. The group will discuss how to identify appropriate advocates, engage advocates and identify opportunities, and train advocates.

- The group is planning a webinar in April 2014, an in-person meeting for June 2015, continued discussions on priority areas and strategies through 2015, and a presentation of a summary of activities and suggestions to NCRA in early 2016.

Organizational Engagement Working Group
Ms. Landy

- The group is seeking ways that cancer groups can work together to promote and advance cancer research.

- The group has developed several info-graphics to illustrate the significance of the investment in the future of cancer research and the importance of genetics in cancer research.

Informed Consent and Genomics Research Working Group
Mr. Wallace

- The group aims to find some level of harmonization at the convergence of genomic science and informed consent.

NCI Advisory Board Updates

- NCRA representatives report to the full panel on proceedings of the National Cancer Advisory Board and the Clinical Trials Advisory Committee.

Closing Remarks and Future Meeting Dates
Ms. Landy

- The next NCRA meeting will be June 10, 2015. Other upcoming meeting dates are October 19, 2015; February 24–25, 2016; May 3–4, 2016; and November 3–4, 2016.

Certification
I hereby certify that the foregoing minutes are accurate and complete.

06-10-2015
Date

Chair
NCI Council of Research Advocates

05-06-2015
Date

Executive Secretary
NCI Council of Research Advocates