AACR Project GENIE Publicly Releases Large Cancer Genomic Data Set

International consortium makes nearly 19,000 de-identified genomic and limited clinical records public to catalyze and benefit clinical cancer research and precision oncology

PHILADELPHIA — The American Association for Cancer Research (AACR) today announced the first public release of cancer genomic data aggregated through its initiative known as AACR Project Genomics Evidence Neoplasia Information Exchange (GENIE). The data set includes nearly 19,000 de-identified genomic records collected from patients who were treated at eight international institutions, making it among the largest fully public cancer genomic data sets released to date.

The release includes data for 59 major cancer types, including data on nearly 3,000 patients with lung cancer, more than 2,000 patients with breast cancer, and more than 2,000 patients with colorectal cancer. The genomic data and a limited amount of linked clinical data for each patient can be accessed via the AACR website or downloaded directly from Sage Bionetworks.

“We are excited to make publicly available this very large set of clinical-grade, next-generation sequencing data obtained during routine patient care,” said Charles L. Sawyers, MD, FAACR, AACR Project GENIE Steering Committee chairperson, chairperson of the Human Oncology and Pathogenesis Program at Memorial Sloan Kettering Cancer Center in New York, and a Howard Hughes Medical Institute investigator. “These data were generated as part of routine patient care and without AACR Project GENIE they would likely never have been shared with the global cancer research community. We are committed to sharing not only the real-world data within the AACR Project GENIE registry but also our best practices, from tips about assembling an international consortium to the best variant analysis pipeline, because only by working together will information flow freely and patients benefit rapidly.”

The newly released data are fully de-identified in compliance with the Health Insurance Portability and Accountability Act (HIPAA). They are derived from patients whose tumors were genetically sequenced as part of their care at one of the eight international institutions that participated in the first phase of AACR Project GENIE. Therefore, the genomic data are clinical grade, which means they are the highest quality possible.

By releasing the data to the global cancer research community, the consortium aims to catalyze new clinical research that will accelerate the pace of progress against cancer. There are many ways in which the data can be exploited to benefit patients in the future, including through the following: the validation of gene signatures of drug response or prognosis; the ability to identify new patient populations for drugs previously approved by the U.S. Food and Drug
Administration (FDA); the expansion of patient populations that will benefit from existing drugs; and the identification of new drug targets and biomarkers.

“I am extremely proud that the American Association for Cancer Research, as the Coordinating Center for AACR Project GENIE, is delivering on its promise to make these important data publicly available just over a year after unveiling the initiative,” said Margaret Foti, PhD, MD (hc), chief executive officer of the AACR. “I would like to thank like to thank Dr. Sawyers for his vision in conceptualizing this exciting project and also the eight international institutions that have contributed these valuable data to AACR Project GENIE. By actively collaborating to create this extensive, freely available data set, they are leading a revolution in cancer genomics research that holds the promise for significantly enhancing the future utility of precision medicine in the treatment of cancer and for the benefit of patients around the world.”

The eight institutions participating in AACR Project GENIE phase 1 are:

- Dana-Farber Cancer Institute, Boston;
- Gustave Roussy Cancer Campus, Paris-Villejuif-France;
- The Netherlands Cancer Institute, Amsterdam, on behalf of the Center for Personalized Cancer Treatment, Utrecht, The Netherlands;
- Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, Baltimore;
- Memorial Sloan Kettering Cancer Center, New York;
- Princess Margaret Cancer Centre, Toronto;
- University of Texas MD Anderson Cancer Center, Houston; and,
- Vanderbilt-Ingram Cancer Center, Nashville, Tennessee.

To expand the AACR Project GENIE registry, the consortium is accepting applications for new participating centers starting today, which is a year sooner than originally anticipated. Any nonprofit institution that meets certain criteria should submit an application to become a project participant.

For more information on AACR Project GENIE click here or email info@aacrgenie.org.

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About the American Association for Cancer Research
Founded in 1907, the American Association for Cancer Research (AACR) is the world’s first and largest professional organization dedicated to advancing cancer research and its mission to prevent and cure cancer. AACR membership includes more than 37,000 laboratory, translational, and clinical researchers; population scientists; other health care professionals; and patient advocates residing in 108 countries. The AACR marshals the full spectrum of expertise of the cancer community to accelerate progress in the prevention, biology, diagnosis, and treatment of cancer by annually convening more than 30 conferences and educational workshops, the largest of which is the AACR Annual Meeting with nearly 19,500
attendees. In addition, the AACR publishes eight prestigious, peer-reviewed scientific journals and a magazine for cancer survivors, patients, and their caregivers. The AACR funds meritorious research directly as well as in cooperation with numerous cancer organizations. As the Scientific Partner of Stand Up To Cancer, the AACR provides expert peer review, grants administration, and scientific oversight of team science and individual investigator grants in cancer research that have the potential for near-term patient benefit. The AACR actively communicates with legislators and other policymakers about the value of cancer research and related biomedical science in saving lives from cancer. For more information about the AACR, visit www.AACR.org.