

THE WHITE HOUSE
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White House to Highlight Open Science “Champions of Change”

WASHINGTON, DC – On Thursday, June 20th, the White House will honor 13 leaders and organizations promoting and using open scientific data and publications to accelerate progress and improve our world. As entrepreneurs, academics, and researchers, these Champions of Change have made an impact across disciplines – from archeology to biomedical research, and from the humanities to astronomy. At the event, these Champions will highlight initiatives that are helping make “open” the default in scientific research.

Open sharing of research results is a proven strategy for driving positive change. For example, the rapid and open sharing of genomic data from the Human Genome Project revolutionized biomedical research, and spurred major growth in the biotechnology industry. Additionally, the Federal Government’s liberation of Global Positioning System (GPS) satellite data for use by the private sector led to an explosion of geospatial information systems and the creation of many companies, smartphone apps, and car navigation systems.

The White House Champions of Change program was created as part of President Obama’s Winning the Future initiative. Through this program, the White House highlights individuals, businesses, and organizations whose extraordinary stories and accomplishments positively impact our communities.

To watch this event live, visit www.whitehouse.gov/live at 1:00 pm ET on June 20th. To learn more about the White House Champions of Change program, visit www.whitehouse.gov/champions.

Atul Butte, M.D., Ph.D.
Menlo Park, CA

Atul Butte is a pediatrician, geneticist, computer scientist, and entrepreneur at Stanford University and the Lucile Packard Children's Hospital. Dr. Butte’s lab at Stanford builds and uses computational tools that convert more than 400 trillion points of molecular, clinical, and epidemiological data – measured by researchers and clinicians over the past decade and now increasingly publicly available -- into diagnostics, therapeutics,

and new insights into disease. In addition to creating new diagnostics and drugs for diabetes and cancers and stewarding the release of National Institutes of Health (NIH) immunology data to the public, Dr. Butte is a founder of Personalis, providing clinical interpretation of whole genome sequences, Carmenta, discovering diagnostics for life-threatening conditions in pregnancy from public data, and NuMedii, using public big data to find new uses for drugs.

**David Altshuler, M.D., Ph.D., on behalf of the Global Alliance for Sharing Genomic and Clinical Data
Brookline, MA**

Endocrinologist and human geneticist David Altshuler is one of four founding members of the Broad Institute of Harvard and MIT and serves as the Institute's Deputy Director and Chief Academic Officer. He is a professor of genetics and medicine at Harvard Medical School and at Massachusetts General Hospital, and an adjunct professor of Biology at the Massachusetts Institute of Technology.

Dr. Altshuler studies human genetic variation and its application to disease, using tools and information from the Human Genome Project. He has been a lead investigator in The SNP Consortium, the International HapMap Project, and the 1,000 Genomes Project – public-private partnerships that have created public maps of human genome sequence variation as a foundation for disease research. His work has contributed to the identification of gene variants that are associated with the risk of common conditions, including type 2 diabetes, elevated blood cholesterol, and myocardial infarction.

**David J. Lipman, M.D.
Rockville, MD**

In his 24 years as the founding director of the National Center for Biotechnology Information at the NIH's National Library of Medicine, David Lipman has had a tremendous impact on the amount of biomedical data and health information that are publicly and easily available to drive scientific discovery, help clinicians and patients, and promote development of innovative products and services. Dr. Lipman and his staff have built upon GenBank, the world's largest public database of DNA data, with the development of more than 40 interlinked genomic and bibliographic databases freely available on the Web. Of particular note, in 2000, Dr. Lipman introduced PubMed Central (PMC) to provide free permanent electronic access to the full text of articles from participating journals, with rich links to related scientific data. PMC provided the essential infrastructure for the NIH Public Access Policy, which, since 2008, has made published NIH-funded research freely available to all for the benefit of public health.

**Drew Endy, Ph.D.
Menlo Park, CA**

A bioengineer at Stanford, Drew Endy is also co-founder and President of BioBricks.org, a charity advancing biotechnology to benefit all people and the planet. Over the past decade, Dr. Endy has provided early leadership and support for many open biotechnology programs including iGEM.org, a competition enabling over 10,000 students to explore biotechnology, OpenWetWare.org, a resource for sharing lab methods and results used by thousands of researchers, and BIOFAB.org, a public-domain factory for engineering high-quality standard biological parts. Dr. Endy and the BioBricks team underwrite an open technical standards-setting process for synthetic biology and, most recently, have developed the BioBrick Public Agreement (BPA) as a legal contract for making genetic materials free to share and use. His research teams have made many initial BPA contributions and encourage everyone to work together in growing a public domain "operating system" for engineering biology.

Eric Kansa, Ph.D.
Alameda, CA

Eric Kansa is an archaeologist and a computer geek, with a passion for making knowledge of the human experience and shared cultural heritage available for everyone to explore and debate. Frustrated with the pervasive lack of access to quality research data in the humanities and social sciences, Dr. Kansa spearheaded the development of Open Context (<http://opencontext.org>), an open access publishing venue for data in archaeology and related fields. Dr. Kansa is an active and vocal member of a growing community in the US and abroad dedicated to better ethics and practices in sharing and preserving knowledge of the past.

Jack Andraka
Crownsville, MD

Jack Andraka is a Maryland high-school student who at age 15 created a novel paper sensor that detects pancreatic, ovarian, and lung cancer in 5 minutes for as little as 3 cents. He conducted his research at Johns Hopkins University and was the winner of the 2012 Gordon E. Moore award at the Intel International Science and Engineering Fair and the 2012 Smithsonian American Ingenuity Award, and was among Mrs. Obama's guests at the 2013 State of the Union Address.

He has spoken at TED Long Beach, over 11 TEDx events including House of Parliament, is the youngest speaker at the Royal Society of Medicine and has been featured on 60 Minutes, World News Tonight with Diane Sawyer, NPR Marketplace, Popular Science, BBC, and Al Jazeera, as well as in award winning documentaries including "You Don't know Jack" by Morgan Spurlock. Jack is currently working with a team of teens (Gen Z) on the Qualcomm Foundation Tricorder X Prize and speaks about open access, STEM education, and universal Internet availability. He is also on the national junior

wildwater kayaking team, and has won awards at multiple national and international math competitions.

**Jeremiah P. Ostriker, on behalf of the Sloan Digital Sky Survey
Princeton, NJ**

Jeremiah P. Ostriker has been an influential researcher in one of the most exciting areas of modern science, theoretical astrophysics, with primary work in the area of the interstellar medium, galaxies, quasars and cosmology, particularly the aspects that can be approached best by large-scale numerical calculations. He has also played a significant role in formulating and administering scientific projects and policy. He served for six years as Provost of Princeton University and is now serving a second term as Treasurer of the National Academy of Science.

Dr. Ostriker, with P.J.E. Peebles, was among the first to show the importance and prevalence of dark matter in the universe and, with Paul Steinhardt, among the first to propose the current model for cosmology in which dark energy has caused the late time acceleration of cosmological expansion. Working with J.E. Gunn and D.G. York, he helped initiate the Sloan Digital Sky Survey, which, surveying the sky with a relatively small telescope, produced an enormous and diverse set of astronomical discoveries and provided the data openly to the scientific community. He played leadership roles in several of the influential national decadal reports in astronomy that helped guide this discipline to great advances in the last half century.

**John Quackenbush, Ph.D.
Dover, MA**

John Quackenbush is Professor of Biostatistics and Computational Biology at the Dana-Farber Cancer Institute and the Harvard School of Public Health. Since the Human Genome Project began in the 1990s, new technologies, producing previously unimaginable quantities of data on human health and disease, have been driving a revolution in medicine and biomedical research. Dr. Quackenbush has been a pioneer in ensuring that these data, and the tools needed to access them, are available, accessible, and useful. In 2011, he and colleague Mick Correll founded GenoSpace, a company that develops advanced software tools for collecting, interpreting, and sharing clinical and genomic data to further biomedical research and facilitate personalized medicine. To support the Multiple Myeloma Research Foundation's groundbreaking CoMMpass study, GenoSpace has created software portals that both engage patients as partners in defeating the disease and provide advanced analytical tools to make the invaluable study data open to scientists everywhere who are interested in finding cures.

**Kathy Giusti
New Canaan, CT**

Kathy Giusti is the Founder and Chief Executive Officer of the Multiple Myeloma Research Foundation (MMRF) and a multiple myeloma patient. Under Ms. Giusti's leadership, the MMRF, working in close partnership with academic and industry partners, has made unprecedented progress against multiple myeloma. Over the last decade, six new treatments have been approved by the FDA, the myeloma genome sequenced, and patients' survival has doubled. Most recently, the MMRF launched the CoMMpass study, a landmark study to define the molecular subtypes of the disease to drive toward precision medicine. The study will follow 1,000 newly diagnosed multiple myeloma patients longitudinally over at least five years, collecting comprehensive clinical data and tissue samples which will be extensively analyzed using cutting-edge sequencing technology. CoMMpass data will be placed into an open-access data platform, together with data from other MMRF-driven initiatives as well as from other sources entirely, to create the most robust set of clinical and genomic data in any cancer that is openly available to researchers worldwide. In 2011, Ms. Giusti was named to the TIME 100 List of the world's most influential people and has received numerous awards and honors for her work, the Harvard Business School Leadership Award and an Honorary Doctorate from the University of Vermont.

Paul Ginsparg, Ph.D.
Ithaca, NY

A theoretical physicist by training, Paul Ginsparg created an open access system in 1991 for his research community to share its cutting-edge results. Now called arXiv.org, and moved from Los Alamos National Laboratory to Cornell University, it serves as the primary daily information feed for global communities of researchers in physics, mathematics, computer science, and related fields.

Today, arXiv.org supports hundreds of millions of full-text downloads per year by researchers and the general public, and continues to grow. Its proof-of-concept also served as the prototype for many other modern open access systems for scientific research.

Rebecca Moore
Los Gatos, CA

Rebecca Moore is an Engineering Manager at Google, where she initiated and leads the development of [Google Earth Engine](#), a new technology platform that puts an unprecedented amount of satellite imagery online for the first time and enables scientists to conduct global-scale monitoring and measurement of changes in the Earth's environment. Ms. Moore also conceived and leads the [Google Earth Outreach](#) program, which supports nonprofits, communities, and indigenous peoples around the world in applying Google's mapping tools to the world's pressing problems in areas such as

environmental conservation, human rights, and cultural preservation. Ms. Moore received a Bachelor's degree with honors from Brown University in Artificial Intelligence and a Master's degree from Stanford University. Her personal work using Google Earth was instrumental in stopping the logging of more than 1,000 acres of redwoods in her Santa Cruz Mountain community.

Stephen Friend, M.D., Ph.D.
Seattle, WA

Stephen Friend is a world leader in efforts to make large-scale, data-intensive biology more openly accessible to citizens and the entire research community in order to accelerate scientific progress. He began using large datasets and integrative system biology approaches to understanding complex diseases in the mid-1990s, and has taken his efforts from medicine to academia to biotechnology to big pharmaceutical companies. Dr. Friend is currently the President of Sage Bionetworks whose mission is to redefine how complex biological data are gathered, shared, and used, by redefining it through open systems, incentives, and norms.

William Noel, Ph.D.
Baltimore, MD

An advocate for generation of open data by museums and rare book repositories, William Noel directed a twelve-year project that successfully retrieved the erased texts of a thirteenth century prayer book. These erased texts included treatises by Archimedes, speeches by Hyperides, and a lost commentary on Aristotle's Categories. He also pioneered the presentation of machine-readable, openly licensed datasets of digitized illuminated medieval manuscripts on the web.