Why We Can’t Wait: Conference to Eliminate Health Disparities in Genomic Medicine

2013 Theme: The role of industry, foundations, non-profits and government

May 29-31, 2013
Palace Hotel
San Francisco, California

Presented by the John P. Hussman Foundation

Organized by
John P. Hussman Institute for human genomics
University of Miami Leonard M. Miller School of Medicine
and
Stanford Center for Computational, Evolutionary, and Human Genomics
Stanford University School of Medicine
Welcome to the second annual Conference to Eliminate Health Disparities in Genomic Medicine. Last year, the conference was hosted by the University of Miami (UM) and held in Miami, Florida. It was a culmination of the Genetics Awareness Project (GAP), an initiative of UM’s Hussman Institute for Human Genomics (HIHG) to actively promoted awareness, interest, and involvement in genetics research in Hispanic/Latino and Black communities. The conference drew approximately 200 stakeholders, including researchers, physicians, genetic counselors, ethicists, community liaisons, public health specialists, nurses, study coordinators, pharmacists, attorneys, among others from over 20 states and 5 countries. A report of this conference written by Charles Rotimi (current Director of the Center for Research on Genomics and Global Health) is published in the August 2012 edition of the journal *GenomeMedicine*.

This year the conference is being co-hosted by the University of Miami and Stanford University. Once again the conference aims to bring together stakeholders, who would not otherwise have the opportunity to interact, to discuss and address a potentially serious disparity in the provision of state-of-the-art genomic medical care. As you are all aware, health disparities have had an especially profound effect on the overall health of many diverse racial and ethnic groups, but particularly Hispanics, Latinos, African-Americans and Blacks in the United States. These groups have disproportionately higher health-risk factors, limited access to health services, and ultimately poorer health outcomes and life expectancies than non-Hispanic Whites. Genomic medicine has the potential to reform medicine by changing healthcare from a discipline that merely reacts to disease to one that predicts, prevents, and/or tailors treatment, which may serve to greatly mitigate health disparities. However, it relies on the inclusion of diverse populations in both research and clinical applications, as well as access to such advances. Populations who are not included in genomic research will be at a significant disadvantage when research is translated into clinical practice.

As the field of genomic medicine moves from mostly a research endeavor primarily undertaken at government and university labs and research hospitals to health-care practice, we need to engage the private and non-profit sectors. We need to understand how underrepresentation in genomics impacts their businesses as well as the role they can play in reducing health disparities in genomics. Many different for-profit entities in health-care innovation and delivery are stakeholders, ranging from startups developing new sequencing and genome interpretation technologies to payers setting reimbursement policy. Likewise, there are great opportunities for the non-profit sector to help reduce health disparities. What lessons can be learned from their experiences that can help other philanthropic groups?

We hope the information presented and the networking that occurs at this conference will be utilized towards efforts to minimize and eventually eliminate health disparities in genomic research and medicine. We are especially grateful to our sponsors! Without them this conference simply would not be possible.

Conference Co-Chairs

*Margaret A. Pericak-Vance, Ph.D.*
*Carlos Bustamante, Ph.D.*
*Susan Hahn, M.S., C.G.C.*
*Joycelyn M. Lee, Ph.D.*
The John P. Hussman Institute for Human Genomics (hihg.med.miami.edu), a center of excellence within the University of Miami Leonard M. Miller School of Medicine, was established in 2007, under the leadership of two of the world’s leading genetic researchers, Dr. Margaret Pericak-Vance and Dr. Jeffery M. Vance. The Vances’ accomplishments will make a difference in the lives of millions of people.

The Hussman Institute is breaking ground in genetic discoveries. We are taking what we learn from our genetics research and translating that information into the practice of healthcare with personalized medicine. This is no longer simply the search for genes.

The implications of our research will create a paradigm shift in how you are diagnosed with illness. It will guide your treatments to those that make the greatest difference, depending on your personal genetic make-up. Countless individuals will reap the benefits of personalized healthcare and genomic medicine. Individuals at risk for a disease can take preventative steps to delay the onset of the symptoms until late in life.

At the Institute, researchers are working to identify the genetic variants involved in many debilitating diseases, including Alzheimer disease, Parkinson disease, cardiovascular disease, multiple sclerosis and cancer. From there, doctors can better diagnose, treat and even prevent these illnesses.
THE CENTER FOR COMPUTATIONAL, EVOLUTIONARY AND HUMAN GENOMICS WAS LAUNCHED in 2012 by the School of Humanities and Sciences and the School of Medicine at Stanford University. Directed by Marcus Feldman, the Burnet C. and Mildred Finley Wohlford Professor, and Carlos Bustamante, Professor of Genetics, the center works at the forefront of the information age of genomics to improve human well-being.

Faculty and students from Stanford’s seven schools collaborate on interdisciplinary research projects that support the computational analysis of genomic data. Researchers have access to vast amounts of information today but interpreting even the simplest genomes remains a daunting challenge. Ethical and legal questions also come into play. Addressing such issues will allow scientists to translate genomic data into scientific advances that can help promote global health, agriculture and biotechnology.

“We want everyone to benefit from advances in genomics technology and big data sciences,” Director Bustamante says. “This requires us to push the boundaries of computational, human and evolutionary genomics and to train people in analyzing large-scale genomic data sets in medicine, agriculture and conservation biology.”

Innovative partnerships are already under way. Statisticians use computational analysis to understand gene interaction and identify risk factors for coronary heart disease. Researchers harness big data to analyze how climate change will affect crops and to develop new strains that will be less susceptible to climate change. And since the study of human genomics involves “the genes, the bones and the languages,” says Director Feldman, the history of human behavior will be included in research. Archaeologists, anthropologists and historians are joining mathematicians, statisticians and geneticists to catalyze discovery in the information age of genomics.
PLANNING COMMITTEE

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Director, John P. Hussman Institute for Human Genomics

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Professor, Department of Human Genetics, Stanford School of Medicine
Center for Computational, Evolutionary, and Human Genomics

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Assistant Director, Communications and Compliance, John P. Hussman Institute for Human Genomics
University of Miami Miller School of Medicine

Joycelyn Lee, Ph.D., Co-Chair
Associate Research Scientist, John P. Hussman Institute for Human Genomics
University of Miami Miller School of Medicine

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Stanford University

Kayla Czape, MS, C.G.C.
Genetic Counselor
University of Miami Miller School of Medicine

Jeffery Vance, M.D., Ph.D.
Professor
University of Miami Miller School of Medicine
CONFERENCE AGENDA

Wednesday, May 29, 2013

12:30 p.m.  Registration  
Ralston Ballroom

2:00 p.m.  Welcome/Introduction  
  •  Margaret A. Pericak-Vance, Ph.D.  
    University of Miami  
  •  Carlos Bustamante, Ph.D.  
    Stanford University

2:15 p.m.  Race, Ethnicity, and Challenges of Global Genomic Medicine  
  •  Rick Kittles, Ph.D.  
    University of Illinois, Chicago  
  •  Noah Rosenberg, Ph.D., M.S.  
    Stanford University  
  •  Atul Butte, M.D., Ph.D.  
    Stanford University

4:00 p.m.  Break

4:20 p.m.  Community Engagement  
  •  Connecting the community with practitioners and the research community  
    Toby Citrin, J.D.  
    University of Michigan  
  •  Engaging Alaska Native People in Genomics Research  
    Bert Boyer, Ph.D.  
    Center for Alaska Native Health Research

5:30 p.m.  Keynote Speaker:  Cardiovascular Disease Genomics and Health Disparities  
  Gary Gibbons, M.D., National Heart, Lung, and Blood Institute

6:00 p.m.  Break

6:30 p.m.  Poster Session and Welcome Reception  
Sponsored by SAP  
Gold Ballroom
Thursday, May 30, 2013

7-8:15 a.m.  Breakfast
Sponsored by Oracle Health Sciences
Ralston Ballroom

8:30 a.m.  Platinum Keynote Speaker:  Opportunities to Address Disparities with Big Data
Barbara Stortz, Senior Vice President of SAP HANA Development Team

9:00 a.m.  Industry Perspective
- John West, M.B.A., M.S.
  Personalis
- Elissa Levin, M.S, C.G.C.
  Life Technologies

10:00 a.m.  Break

10:30 a.m.  Presenting Sponsor Session:  The Foundations’ Perspective
- John P. Hussman, Ph.D.
  Hussman Foundation
- Joshua Knowles, M.D., Ph.D.
  The FH Foundation
  Stanford University
- Maria C. Carrillo, Ph.D.
  Alzheimer’s Association

12:00 p.m.  Keynote Luncheon:  New approaches for genomic research in diverse populations
Grand Ballroom  Anne Wojcicki, 23andMe

1:30 p.m.  Perspective of the Payer
- Perspective of the Payer
  Karen Lewis, M.S., M.M., C.G.C.
  Priority Health
- Payer Drive Solution
  Amber Trivedi, M.S., C.G.C.
  InformedDNA
- Centers for Medicare and Medicaid Services
  Barry M. Straube, M.D.
  Marwood Group & Co.
  Former Chief Medical Officer, Centers for Medicare & Medicaid Services

3:00 p.m.  Break

3:30 p.m.  Dealing with Health Disparities in the Genomics Era
- A Collaborative Framework for Eliminating Health Disparities in the Genomic Era
  Muin Khoury, M.D., Ph.D.
  CDC’s Office of Public Health Genomics
- Barriers to Uptake of Genomic Services among Minority Populations
  Tuya Pal, M.D., FABMG (invited)
  Moffitt Cancer Center
- A Public Health Genomic Approach to Lynch Syndrome
  Cecelia Bellcross, Ph.D., M.S., C.G.C.
  Emory University
- Public Health Perspective on Disparities in Implementation of Genomic Medicine
  Debra Duquette, M.S., C.G.C.
  Michigan Department of Community Health
7-7:45 a.m.  Breakfast  
Sponsored by Oracle Health Sciences  
Ralston Ballroom

8:00 a.m.  Health IT, Privacy and Genomics  
Moderated by Kenneth Chahine, Ph.D., J.D.  
• Health IT and Genomics  
  Frederick Lee, M.D., M.P.H.  
  Oracle Health Sciences: Gold Sponsor  
• The Opt Out Approach to Privacy  
  Kyle Brothers, M.D.  
  University of Louisville  
• Attitudes about Genomics and Privacy in Native American Populations  
  Nanibaa’ Garrison, Ph.D.  
  Stanford University

9:30 a.m.  Break

9:45 a.m.  Role of the Healthcare System in Remediing Health Disparities  
• Veteran’s Administration  
  Laurence Meyer, M.D., Ph.D.  
  Veteran’s Health Administration  
• Center for Disease Control – Funded Project to Increase Identification of BRCA1/2 Carriers  
  Cecelia Bellcross, Ph.D., M.S., C.G.C.  
  Emory University  
• Private Healthcare System  
  Andrew Faucett, M.S., C.G.C.  
  Geisinger Health System  
• Novel Approach to Educating Physicians  
  Jeffery M. Vance, M.D., Ph.D.  
  University of Miami Miller School of Medicine

11:30 a.m.  Roundtable Discussion and Wrap-Up  
• Margaret A. Pericak-Vance, Ph.D.  
  University of Miami  
• Carlos Bustamante, Ph.D.  
  Stanford University
Gary H. Gibbons, M.D.
Gary H. Gibbons, M.D., is Director of the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health (NIH), where he oversees the third largest institute at the NIH, with an annual budget of approximately $3 billion and a staff of 1,000 federal employees. The NHLBI provides global leadership for research, training, and education programs to promote the prevention and treatment of heart, lung, and blood diseases and enhance the health of all individuals so that they can live longer and more fulfilling lives. Prior to being named director of the NHLBI, Gibbons served as a member of the National Heart, Lung, and Blood Advisory Council (NHLBAC) from 2009-2012. He was also a member of the NHLBI Board of Extramural Experts (BEE), a working group of the NHLBAC. Before joining the NHLBI, Gibbons served as the founding director of the Cardiovascular Research Institute, chairperson of the Department of Physiology, and professor of physiology and medicine at the Morehouse School of Medicine, in Atlanta. Gibbons earned his undergraduate degree from Princeton University in Princeton, N.J., and graduated magna cum laude from Harvard Medical School in Boston. He completed his residency and cardiology fellowship at the Harvard-affiliated Brigham and Women’s Hospital in Boston. Prior to joining the Morehouse School of Medicine in 1999, Gibbons was a member of the faculty at Stanford University in Stanford, C.A., from 1990-1996, and at Harvard Medical School from 1996-1999. Throughout his career, Gibbons has received numerous honors, including election to the Institute of Medicine of the National Academies of Sciences; selection as a Robert Wood Johnson Foundation Minority Faculty Development Awardee; selection as a Pew Foundation Biomedical Scholar; and recognition as an Established Investigator of the American Heart Association (AHA).

Anne Wojcicki
Anne co-founded 23andMe in 2006 after a decade spent in healthcare investing, focused primarily on biotechnology companies. Her hope was to empower consumers with access to their own genetic information and to create a way to generate more personalized information so that commercial and academic researchers could better understand and develop new drugs and diagnostics. Presently, 23andMe has built one of the world’s largest databases of individual genetic information. Its novel, web-based research approach allows for the rapid recruitment of participants to many genome-wide association studies at once, reducing the time and money needed to make new discoveries, and the company has created a proven and standardized resource for finding new genetic association and confirming genetic loci discovered by others. Under Anne’s leadership 23andMe has made significant advances in bringing personalized medicine directly to the public. Anne graduated from Yale University with a BS in Biology. Getting access to and understanding her own genetic information had always been one of her ambitions.
KEYNOTE SPEAKERS

JOHN P. HUSSMAN, PH.D.

Dr. John P. Hussman is the Director of the Hussman Foundation, which funds one of the largest autism research programs in the U.S., as well as global health and education projects. He has authored and co-authored research in peer-reviewed scientific journals focusing on the neuroscience, molecular biology and genetics of autism. He is also the President of Hussman Strategic Advisors, the investment advisor to the Hussman Funds. He holds a Ph.D. in Economics from Stanford University, as well as a B.A. in Economics, Phi Beta Kappa, and an M.S. in Education and Social Policy from Northwestern University. Prior to launching the Hussman Funds, he was active as both a portfolio manager and a university professor, teaching economics and international finance at the University of Michigan and Michigan Business School. As the parent of a son with autism diagnosed at age 2, Dr. Hussman abandoned academic economic research in the late-1990’s and focused his academic research efforts on the neurobiology and genetics of autism. He has both funded and collaborated in autism research, through a long-standing partnership with Margaret Pericak-Vance, Ph.D. In 2011, Dr. Hussman published research in Molecular Autism, applying statistical tools and noise-reduction methods to genomic data. The data revealed that many genes associated with autism cooperate in a pathway that regulates the outgrowth, guidance and circuit formation of neurons in the brain. In addition to autism research, the Hussman Foundation is active in a broad range of philanthropic projects focused on providing life-changing assistance through medical research, education, and direct aid to vulnerable individuals having urgent needs, particularly those needs that can be addressed at a low cost per person affected.

BARBARA STORTZ

Barbara Stortz is the SVP of SAP HANA development team. She is responsible for development and roadmap of SAP HANA Healthcare platform. Before this she held numerous management positions within SAP’s in memory development organization. Barbara has been with SAP for 14 years. In her spare time she enjoys spending time with her two kids and leading an active lifestyle.
CONFERENCE CO-CHAIRS

Margaret A. Pericak-Vance, Ph.D., is the Director of the John P. Hussman Institute for Human Genomics and the Dr. John T. Macdonald Foundation Professor of Human Genomics at the University of Miami Miller School of Medicine. She is a global leader in the genetics of common diseases. Her more than 550 peer-reviewed papers demonstrate outstanding productivity and establish important milestones in diseases. Her research is also breaking ground in other areas as well, including autism and the genetics of the eye diseases such as macular degeneration, glaucoma and retinitis pigmentosa. Newsweek magazine named her in the “Century Club: 100 People to Watch as We Move to the Next Millennium.” She was elected to the Institute of Medicine, a division of the National Academy of Sciences, in 2004. In 2001, she received the international “Louis D” Scientific Prize from the Institut de France Académie des sciences for her Alzheimer’s research. In 2011, she was honored with a Lifetime Achievement Award from the Alzheimer’s Association. In 2012, she was named a fellow of the American Association for the Advancement of Science, for her distinguished contributions to the field of genetics.

Carlos Bustamante, Ph.D., is a professor in the Department of Genetics at Stanford University, co-founding director of the Stanford Center for Computational, Evolutionary, and Human Genomics (CEHG) and director of Informatics, Stanford Center for Genomics and Personalized Medicine. Bustamante is a population geneticist whose research focuses on analyzing genome wide patterns of variation within and between species to address fundamental questions in biology, anthropology, and medicine. His current research focuses on human population genomics and global health including developing statistical, computational, and genomic resources for enabling trans- and multi-ethnic genome-wide association and medical sequencing studies of complex biomedical traits. In 2010, he was named a MacArthur Fellow.

Susan Hahn, M.S., CGC is the Assistant Director of Communications, Compliance, and Ethics at the Hussman Institute for Human Genomics at the University of Miami Miller School of Medicine and a Director of the American Board of Genetic Counseling. Her research interests include translation of genomic medicine discoveries into clinical care, the role of genetic counselors in genetic research and translation, health disparities related to genomic medicine, and community engagement and education regarding genomic medicine. She has extensive experience overseeing large genetic studies, and has first-hand experience addressing the difficulties of ascertaining diverse populations. She also has extensive curriculum and conference development experience, and expertise. She also teaches two graduate courses that address ELSI issues related to genomic medicine and research.

Joycelyn M. Lee, Ph.D., is an Associate Research Scientist at the John P. Hussman Institute for Human Genomics at the University of Miami Miller School of Medicine. She oversees clinical ascertainment in the Autism Genetics Study. Her research interests are: aggression in autism spectrum disorders, broad autism phenotype in multiplex families, and disparities in research participation among diverse populations. Through her outreach within South Florida’s African American communities, she raises awareness about autism spectrum disorders as well as the potential impact of genetics research participation on the improvement of African American health outcomes. Dr. Lee is also a licensed clinical psychologist with specialization in developmental disabilities, assessment, school consultation, and program evaluation. She was recently awarded the Legacy Magazine -25 Most Influential and Prominent Black Women in Business and ICABA 100 Most Accomplished Blacks in Health Care and Law for her contributions to the improvement of health sciences research among diverse populations.
SPEAKERS

Cecelia Bellcross obtained her Master of Science degree in Medical Genetics through the University of Wisconsin-Madison Genetic Counseling program in 1990, and her Ph.D. from the U.W.-Madison Department of Population Health Sciences in 2007. She practiced in WI as a clinical genetics counselor from 1990-2008, and completed an ASHG fellowship with the CDC’s Office of Public Health Genomics in Atlanta in 2010. Dr. Bellcross received her certification from the American Board of Genetic Counseling (ABGC) in 1993, and currently serves on the Accreditation Council for Genetic Counseling. She is an Assistant Professor with the Department of Human Genetics, Emory University School of Medicine, where she developed and is Director of the new Emory Genetic Counseling Training Program. Her areas of interest and expertise include hereditary cancer and translational genomics.

Bert Boyer, Ph.D.

Cecelia Bellcross, Ph.D., M.S., C.G.C.

Dr. Boyer is interested in understanding genetic and environmental risk and protective factors related to obesity and diabetes in Alaska Native Yup’ik people using a community-based participatory research framework. In collaboration with colleagues at the University of Washington, he is also involved in a pharmacogenetics network grant to investigate gene-by-environment interactions related to warfarin drug safety and efficacy. For the past 11 years, Dr. Boyer and colleagues from the Center for Alaska Native Health Research (CANHR) have worked with ~1,600 Yup’ik people in 11 communities in rural southwest Alaska to collaboratively investigate health research priorities of Yup’ik people. He works closely with Yup’ik co-investigators in the cultural adaptation, implementation and evaluation of translational research strategies, including return of the full continuum of research results to participants in a culturally respectful and understandable format.

Kyle Brothers, M.D. is an Assistant Professor in the Department of Pediatrics at the University of Louisville, where he is also affiliated with the Institute for Bioethics, Health Policy, and Law. His work focuses on the ethics of genetic research and the translation of genomic technologies into clinical care. He has worked closely with colleagues at Vanderbilt University on the ethical and regulatory implications of the opt-out biobank BioVU. Dr. Brothers is a pediatrician and practices medicine in both pediatric primary care and pediatric weight management. Dr. Brothers is currently completing a PhD in Ethics and Society in the Graduate Department of Religion at Vanderbilt. His graduate studies have focused on philosophies of medical practice and scientific epistemology, and the implications of these fields of knowledge to medical practice in the “Era of Personalized Medicine.” Dr. Brothers received his Bachelor’s degree from Centre College of Kentucky and his Doctor of Medicine degree from the University Of Louisville School Of Medicine. He completed his residency training and chief residency in Pediatrics at Vanderbilt Children’s Hospital in 2008.

Kyle Brothers, M.D.

Atul Butte, M.D., Ph.D., is Chief of the Division of Systems Medicine and Associate Professor of Pediatrics and Genetics, and by courtesy, Medicine and Computer Science, at Stanford University and Lucile Packard Children’s Hospital. Dr. Butte trained in Computer Science at Brown University, worked as a software engineer at Apple and Microsoft, received his MD at Brown University, trained in Pediatrics and Pediatric Endocrinology at Children’s Hospital Boston, then received his PhD in Health Sciences and Technology from Harvard Medical School and MIT. Dr. Butte is also a founder of Personalis, providing clinical interpretation of whole genome sequences, and NuMedii, finding new uses for drugs. The Butte Laboratory builds and applies tools that convert more than 300 billion points of molecular, clinical, and epidemiological data -- measured by researchers and clinicians over the past decade -- into diagnostics, therapeutics, and new insights into disease. Dr. Butte has authored more than 120 publications in personalized and systems medicine, biomedical informatics, and molecular diabetes. Dr. Butte’s recent awards include the 2011 National Human Genome Research Institute Genomic Advance of the Month, 2010 Society for Pediatric Research Young Investigator Award, and the 2006 Howard Hughes Medical Institute Early Career Award.

Atul Butte, M.D., Ph.D.
Dr. Carrillo is Vice President, Medical and Scientific Affairs, at the Alzheimer’s Association. At the Association, Dr. Carrillo has a wide range of responsibilities, including oversight of the Association’s granting process and communication of scientific findings within and outside of the organization. Dr. Carrillo is responsible for overseeing the International Research Grant Program, the mechanism through which the Association funds research. In addition to ensuring the smooth review of applications and distribution of awards to successful applicants, she is responsible for sharing results and ongoing investigations with a wide range of constituents. Dr. Carrillo also manages several Association initiatives. One of these is the Alzheimer’s Association Research Roundtable, which provides a forum for pharmaceutical companies to discuss trends in Alzheimer research and therapeutic targets. Other Association programs managed by Dr. Carrillo include the management of the World-Wide Alzheimer’s Disease Neuroimaging Initiative (WW-ADNI), which is a multi-country research effort aimed at finding biomarkers for early detection of Alzheimer’s, and the Working Group on Technology (WGT), which aims to promote the use of technologies available today for the support of individuals affected by Alzheimer’s disease to retain their independence as long as possible. Dr. Carrillo is a member of the Genworth Financial Medical Advisory Board.

Toby Citrin is Adjunct Professor of Health Management and Policy at the University of Michigan School of Public Health. Citrin is Founding Director of the Center for Public Health and Community Genomics (www.sph.umich.edu/genomics) whose mission is to integrate genomics in public health practice with emphasis on the reduction of health disparities and the engagement of communities. From 1990-2007 Citrin was Director of the Office of Community-Based Public Health at the U-M School of Public Health, facilitating efforts to develop and maintain partnerships between the School, Community-Based Organizations and Public Health Practice organizations to address community health challenges and further Community-Based Participatory Research. Citrin has been Principal Investigator of several major grants to further community-engagement, community-based policy-making and education in genetics. These include: Genome Technology: Values and Public Policy and the Communities of Color and Genetics Policy Project, implementing community-based dialogues throughout Michigan and Alabama; the Community Genomics Forum project, organizing five community forums in mid-western states; and Education for Community Genomic Awareness, a project bringing a modern genomics curriculum to high schools in Detroit and Flint and furthering joint engagement on genomics between students, parents and other adults.

Ms. Duquette is the genomics coordinator at the Michigan Department of Community Health. She has served as the project manager on two Centers for Disease Control and Prevention (CDC) Office of Public Health Genomics cooperative agreements and two CDC Division of Cancer Prevention and Control cooperative agreements for public health genomics. She is also the Founder of the Lynch Syndrome Screening Network (LSSN) which is a consortium of 90 institutions who are working to promote universal screening for Lynch syndrome on all newly diagnosed colorectal cancers. She is also the project manager for the Michigan Sudden Cardiac Death of the Young Surveillance and Prevention. She represents public health genomics on several state advisory committees (i.e., infertility, maternal mortality, asthma, diabetes, cancer and cardiovascular disease). Ms. Duquette is also a board-certified genetic counselor with over 12 years of clinical experience.
Andy Faucett trained as a genetic counselor and currently works as a research scientist. He received his masters in human genetics from Sarah Lawrence College, Bronxville, NY and certification from the American Board of Genetic Counseling. His work focuses on research and community engagement to improve the use of genetic testing as a Clinical Investigator and the Director of Policy and Education at the Genomic Medicine Institute of Geisinger Health System in Danville, PA. He was affiliated with the Centers for Disease Control and Prevention (CDC) in Atlanta from 2000 until 2012. He has a special interest in working with patient advocacy organizations to provide patient submitted information for research and created the online communities www.duchenneconnect.org, www.simonsvipconnect.org and www.prenatalarray.org. He currently participates in NIH funded projects including eMERGE, ISCA, and ICCG; a local funded project for community education about the importance of family history; and a population genetic testing and genetic education project funded by the state of Pennsylvania. He currently serves as Chair of the Board of Directors for the National Coalition for Health Professional Education in Genetics (NCHPEG), and as Chair of the American Society of Human Genetics Information and Education Committee. Previously he has served on the Board of Directors of the National Society of Genetic Counselors and the American Board of Genetic Counseling.

Muin Khoury, M.D., Ph.D. is the founding director of the CDC’s Office of Public Health Genomics. He has developed a number of successful ongoing national and international initiatives to translate advances in genomics and related technologies to recommendations and actions that improve health and prevent disease throughout the life stages. Since 2007, he has also served the National Cancer Institute as senior advisor in public health genomics in the Division of Cancer Control and Population Sciences. Since 2011, he leads the Epidemiology and Genomics Research Program in the same Division. Dr. Khoury received his B.S. degree in Biology/Chemistry from the American University of Beirut, Lebanon and his medical degree and Pediatrics training from the same institution. He received a Ph.D. in Human Genetics/Genetic Epidemiology and training in Medical Genetics from Johns Hopkins University. Dr. Khoury is board certified in Medical Genetics. Dr. Khoury has published extensively in the fields of genetic epidemiology and public health genetics. He has over 450 scientific publications including articles, books and book chapters. Dr. Khoury is a member of many professional societies and serves on the editorial boards of several journals. He is a frequent keynote speaker at many academic institutions, professional organization meetings, as well as state, regional, national and international conferences. He also serves on several scientific, public health, and health policy national and international committees. He is an adjunct professor in the Departments of Epidemiology and Environmental and Occupational Health at Emory University Rollins School of Public Health and an associate in the Department of Epidemiology at Johns Hopkins University Bloomberg School of Public Health.
Rick Kittles received a Ph.D. in Biological Sciences from George Washington University in 1998. His first faculty appointment was at Howard University where he helped establish the National Human Genome Center at Howard University. From 1997 to 2004, Dr. Kittles helped establish and coordinate a national cooperative network to study the genetics of hereditary prostate cancer in the African American community. Dr. Kittles is well known for his research on prostate cancer and health disparities among African Americans. He has also been at the forefront of the development of ancestry-informative genetic markers, and the use of genetic ancestry to map genes for common traits and disease. His work on tracing the genetic ancestry of African Americans has brought light to many issues, new and old, which relate to race, ancestry, identity, and group membership. Dr. Kittles has published over 100 research articles on prostate cancer genetics, Race and Genetics, and health disparities. Currently, Dr. Kittles is an Associate Professor of Medicine and Epidemiology and Biostatistics, Associate Director of the Cancer Center, and Director of the Institute of Human Genetics at the University of Illinois at Chicago.

Dr. Joshua W. Knowles is an Attending Physician in the Stanford Center for Inherited Cardiovascular Disease where he treats patients with Familial Hypercholesterolemia (FH). He has had a longstanding interest in the genetic (inherited) basis of cardiovascular disease and in particular the use modern genetic techniques to improve our ability to diagnose and treat patients at risk of heart disease. Josh completed his MD-PhD at the University of North Carolina at Chapel Hill where he worked in the lab of Prof. Nobuyo Maeda and Nobel Laureate Oliver Smithies studying models of atherosclerosis and lipid metabolism. He completed his Internal Medicine residency and Cardiovascular Medicine fellowship training at Stanford University working in the lab of Dr. Thomas Quertermous. He has published over 35 papers focused on heart disease with research projects currently funded by the National Institutes of Health and the American Heart Association. He is particularly excited to be involved with the FH Foundation in their mission to increase awareness of this condition, identify patients and encourage screening of family members of those with FH and facilitate treatment of FH patients. He views FH as a “winnable battle” because once FH is identified, it can be usually be treated quite effectively.

Dr. Lee leads business development strategies in clinical & translational informatics and personalized healthcare for Oracle’s Health Sciences Global Business Unit. He has helped establish and grow the burgeoning field of personalized healthcare through his ability to merge perspectives from the life sciences, healthcare delivery, clinical informatics, and public health. Prior to Oracle, Dr. Lee was the Founding Executive Director & Chief Medical Officer of the P4 Medicine Institute, a translational innovation consortium dedicated to creating a predictive, preventive, personalized, & participatory future of healthcare. In this role, he helped establish Lee Hood’s vision of P4 Medicine by developing partnerships between systems biology & major academic health centers. He continues to play a key role in P4 Medicine, as the first official fellow of the P4 Medicine Institute. Dr. Lee brings a unique and broad range of professional experiences to the task of creating healthcare of the future, having spent time as a practicing clinician, as a healthcare executive, and as an industry technologist. From the industry perspective, Dr. Lee led product strategy efforts for McKesson Corporation in its Provider Technologies division, focusing on enhancing electronic health records to support genomic & molecular medicine. He has also held leadership roles in General Electric Healthcare, leading product strategy for GE Healthcare Information Technologies in the United Kingdom while working on the UK’s National Health Service Connecting for Health program. Dr. Lee has held executive leadership roles in health systems in the New York / Long Island area, as a Chief Operating Officer and as a Chief Medical Information Officer of a large ambulatory care network in New York. His clinical background is in general surgery and preventive medicine.
Ms. Levin is a nationally recognized leader in developing innovative, responsible approaches to the delivery of genomic medicine. She currently leads the Clinical Support Services department at Life Technologies, providing clinical genomics expertise to a broad range of stakeholders. Ms. Levin was most recently the Vice President of Genomic Services at Navigenics where she managed the company’s clinical services, science, and operations departments and was a key leader of the company’s strategic initiatives. Before joining Navigenics, she served as the Director of Clinical Services at DNA Direct, where she helped pioneer the first direct-to-consumer genetic counseling service, providing testing, education and counseling services for specific medical conditions. Ms. Levin began her career focused on the genetics of congenital heart disease, providing genetic counseling and education to families and staff in the cardiology division of the Children’s Hospital of Philadelphia. At the University of California, San Francisco Medical Center, she counseled clients of all ages about general and metabolic genetics and coordinated clinical trials for enzyme replacement therapy. As a board-certified Genetic Counselor, she is nationally known for developing novel approaches to responsibly realize the promise of personalized medicine as genetic and genomic technologies enter clinical practice. Her expertise has led her to participate in a diverse range of nationwide lectures, workshops, and media appearances.

Karen received her undergraduate degree in biology and Master’s degree in Genetic Counseling from the University of Pittsburgh and has also received a Masters of Management degree from Aquinas College. Karen has worked in a variety of areas in the field of Genetics including laboratory genetics as a cytogeneticist as well as clinical genetics as a prenatal and cancer genetic counselor. Karen’s current position is as the Medical Policy and Technology Administrator at Priority Health, a Michigan based health insurer, where she oversees medical policy development and works with the Medical directors for medical necessity review and grievance and appeals cases. Karen has been involved in many grant projects including sudden cardiovascular death in the young, genetics education for health care providers and is currently the insurance champion for a collaborative agreement between the CDC and the Michigan Department of Community Health evaluating cancer genomics best practices. In addition to her genetics activities Karen is also an adjunct professor at the Michigan State College of Human Medicine in ethics and humanities.

Dr. Larry Meyer is the National Director of the new VA Genomic Medicine Service. This office is centralized and located in Salt Lake City, UT, and consults are performed by telemedicine. He is also the director of Research at the Salt Lake City VA where his research focuses on genomics and immunodermatology. His Ph.D. is in genetics, from the University of California at Davis, and his M.D. is from the University of Miami, FL. He is Board certified in Internal Medicine, Dermatology and Clinical Genetics.
Dr. Pal is a board-certified clinical geneticist based at the Moffitt Cancer Center with a clinical practice focused on evaluation of inherited cancer predisposition. Her research program is focused on epidemiologically-based studies focused on the genetic causes of cancer including the identification and outcomes of high risk individuals, as well as factors associated with access to and delivery of genetic services in these individuals. She has completed a number of studies to investigate the etiology of early onset breast cancer (including genetic and hormonal factors) in young African American women and is currently conducting a 5 year study to recruit an additional 600 young African American women to investigate the etiology and outcomes of early onset aggressive breast cancer. As an offshoot of her research interests, she has also been involved in several educational and outreach activities pertaining to inherited cancer risk at the patient and practitioner level, including initiatives to raise awareness about inherited breast cancer in the African American community.

Noah Rosenberg, Ph.D., M.S., is an associate professor of biology at Stanford University. Dr. Rosenberg’s lab performs mathematical and statistical research in human genetics and evolutionary biology, with an emphasis on the study of human genetic variation and its history. His 2002 study of the genetic structure of human populations was recognized by the Lancet with its inaugural Biomedical Research Paper of the Year Award. Rosenberg has been the recipient of a Burroughs Wellcome Fund Career Award in the Biomedical Sciences and an Alfred P. Sloan Fellowship in Computational & Evolutionary Molecular Biology, and he currently serves on the editorial boards of BMC Bioinformatics, Genetics, Human Biology, Molecular Biology and Evolution, and Theoretical Population Biology. He received his B.A. in mathematics from Rice University and his M.S. in mathematics and Ph.D. in biology from Stanford University, and he completed his postdoctoral training at the University of Southern California.

Barry M. Straube, M.D., is a Director at The Marwood Group, a healthcare advisory/research firm serving institutional and private investors. With offices in New York, Washington, DC, London and Kuwait, Marwood provides expertise to its clients on all aspects of healthcare, focusing on how federal and state law, regulations, and policy affect healthcare services and products. Just prior to joining Marwood in September, 2011, he spent 11 years at the Centers for Medicare and Medicaid Services (CMS), including 6 years as the national Chief Medical Officer. He was Director of the CMS Office of Clinical Standards and Quality, overseeing CMS quality improvement initiatives, coverage decision making, determining conditions of participation and oversight for all U.S. healthcare facilities, clinical IT operations and initiatives, and value based purchasing model design. Educated at Princeton University and the University of Michigan Medical School, he is a Board-certified internist and nephrologist, training at Tufts-New England Medical Center in Boston. He was a clinical/academic nephrologist at California Pacific Medical Center in San Francisco, serving as Chief of Nephrology there from 1987-2004. He was Vice-President of Health Net from 1995-2000, then the fourth largest publicly traded HMO in the U.S. The recipient of numerous healthcare executive awards, he sits on a number of governance, scientific and payment advisory boards for corporations and foundations.
Amber Trivedi is the Senior Vice President, Provider & Client Services at InformedDNA, a nationwide network of board-certified genetic counselors that expands access to genetic counseling by offering services via telephone or web. She manages InformedDNA’s client relationship programs, expert genomics consulting services, and genetics educational initiatives for physicians and patients. Ms. Trivedi received a Bachelor of Arts in Behavioral Biology from the Johns Hopkins University, and she earned her Master of Science in Genetic Counseling from Northwestern University. Prior to her genetic counseling career, Ms. Trivedi coordinated breast cancer clinical trials at UCLA and Northwestern University. She previously performed cancer and reproductive genetic counseling for the Northwestern Ovarian Cancer Early Detection and Prevention Program and Division of Reproductive Genetics. She also served on the faculty of the Northwestern University Feinberg School of Medicine and Graduate Program in Genetic Counseling. She serves on the Expert Panel for Bright Pink, a national non-profit organization that provides support to young women who are at high risk for breast and ovarian cancer.

Jeffery M. Vance, M.D., Ph.D. is a Professor of the Dr. John T. Macdonald Foundation Department of Human Genetics and was the founding Chairman. He is also a Professor of the Department of Neurology; Director of the John P. Hussman Institute for Human Genomics Center for Genomic Education and Outreach at the University of Miami Miller School of Medicine. Dr. Vance is boarded by both the American Board of Psychiatry and Neurology and the American College of Medical Genetics. Dr. Vance’s primary areas of expertise and national recognition are in Neurogenetics, specifically in Parkinson disease and Charcot-Marie-Tooth disease (CMT). His research has focused on the application of clinical, molecular, and mathematical genetic techniques to identify genes leading to human disease. He has identified multiple gene defects for CMT and other neurologic and inherited disorders. Dr. Vance has also been a leader in applying genetics to common medical diseases to identify susceptibility genes. He is the primary principle investigator of the University of Miami, NIH Morris K. Udall Parkinson Disease (PD) Research Center of Excellence. He and his colleagues have established the first masters in genomic medicine program, earned concurrently by University of Miami medical students. He has published over 225 peer-reviewed publications. His work has been cited more than 10,000 times.

Personalis’ CEO, John West, has worked for over 30 years in DNA sequencing. Starting in 2004, he served as CEO of DNA sequencing platform company Solexa, sold it to Illumina, and then managed the initial growth of the business within Illumina. After Mr. West left Illumina, his family became the first healthy family of four to be sequenced. Their experience working with a Stanford team on genome interpretation led to the foundation of Personalis, Inc, where he is now CEO. Personalis is focused on accurate human genome sequencing and interpretation, for research and ultimately, clinical applications.
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CONTINUING EDUCATION CREDITS

“Why We Can’t Wait: Conference to Eliminate Health Disparities in Genomic Medicine” is available for continuing education credits for genetic counselors and nurses.

CREDIT DESIGNATION

**Nursing:** This seminar has been planned and implemented in accordance with the Essential Areas and policies of the Florida Board of Nursing for Continuing Education Provider # 50-2105 Credit Designation: The University of Miami School of Nursing & Health Studies designates this seminar for a maximum of 13 credits.

**Genetic Counselors:** The National Society of Genetic Counselors (NSGC) has authorized the University of Miami John P. Hussman Institute for Human Genomics to offer up to 1.35 CEUs or 13.5 contact hours (Category 1) for Why We Can’t Wait: Conference to Eliminate Health Disparities in Genomic Medicine. The American Board of Genetic Counseling (ABGC) will accept CEUs earned at this program for the purposes of certification and recertification.

DISCLOSURE AND CONFLICT OF INTEREST RESOLUTION

All conflicts of interest of any individuals in a position to control the content of this CME activity will be identified and resolved prior to this educational activity being provided. Disclosure about provider and faculty relationships, or the lack thereof will be provided to the learners.

EVALUATIONS

Evaluations are a valuable tool in assisting us to better serve you. Please remember to complete the evaluation forms and submit them at the registration desk. We welcome your comments and suggestions. Please complete a session evaluation for each session in which credit is desired (provided at welcome desk at conference). Please turn these in at the welcome desk when completed.

An outcome evaluation will be conducted 2 to 3 months following the course to measure the impact this activity has had in changing performance and patient outcomes. We encourage and appreciate your participation.

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