

**A Primer on Genetic Testing:  
What Is It? How Does It Work? Why Does It Matter?  
October 28, 2008, 9 – 10:30 a.m.  
National Press Club**

	<b>Topic/Issues</b>	<b>Speaker</b>
9:00 – 9:05	<b>Welcome</b>	Alan Mertz ,President American Clinical Laboratory Association
9:05 – 9:10	<b>The Top Issues in Genetic Testing</b>  John Iglehart will identify the issues that are most important in understanding the science of, and the public policies surrounding, genetic testing.	John Iglehart, Founding Editor <i>Health Affairs</i> National Correspondent, <i>New England Journal of Medicine</i>
9:10 – 9:25	<b>What <u>IS</u> Genetic Testing? And What is its Value?</b>  Dr. Sherri Bale, co-founder of Gene Dx in Rockville, MD, will focus on the basics of the science. How does genetic testing work? How is genetic testing related to mapping the human genome? How is genetic testing used in medical treatment? What are different types of “genetic testing”?	Sherri Bale, PhD, Co-Founder Gene Dx Inc. Rockville, MD
9:25 – 9:55	<b>Genetic Testing in Genomic Medicine</b>  Speaking from the perspective of a physician, Dr. Gail Vance will explore how genetic testing and genomics-based therapies relate to traditional approaches to medical care and health policy challenges. She will also address the economic implications of genetic testing, including costs and affordability.	Gail Vance, MD, Professor Department of Medical and Molecular Genetics, Indiana University School of Medicine Indianapolis, IN
9:55 – 10:10	<b>Answering the Hard Questions</b>  Moderator John Iglehart will pose the following questions to an expert panel and the morning’s speakers:	Sharon Terry, MA President and CEO The Genetic Alliance Washington, DC  Jamie McDonald, M.S. Licensed Genetic Counselor Co-Director, Hereditary Hemorrhagic Telangiectasia Clinic, ARUP Salt Lake City, UT  Vicky Pratt, Ph.D. Chief Director, Molecular Genetics Quest Diagnostics Chantilly, VA
10:10 – 10:30	<b>Q&amp;A/Open Discussion</b>	

## **SPEAKER BIOS**

### **John K. Iglehart**

#### **Founding editor of *Health Affairs* and National Correspondent for *The New England Journal of Medicine***

For the last 26 years, John Iglehart has held two editorial leadership positions in the world of health policymaking. Iglehart was editor of *Health Affairs*, a bimonthly policy journal that he founded in 1981 under the aegis of Project HOPE, a not-for-profit international health education organization. Over this same period, Iglehart also has served as national correspondent of *The New England Journal of Medicine*, for which he has written more than 100 essays called Health Policy Reports. Iglehart stepped down from the editorship of *Health Affairs* in September 2007 with the intent to return to a full-time life of writing. *Health Affairs*, a peer-reviewed, multidisciplinary journal, has made its mark by translating health services research and analysis into content that is more accessible to Members of Congress and other key participants in federal and state health policymaking. *Health Affairs* publishes its journal six times a year but it also posts original, peer-reviewed papers on its Web site every week. *Health Affairs* is the largest circulating health policy journal in the United States and also has subscribers in 25 foreign countries.

Before 1981, Iglehart served for two years as a vice president of the Kaiser Foundation Health Plan and director of its Washington, D.C. office. During the decade 1969 to 1979, Iglehart held a variety of editorial positions, including the editorship, of *National Journal*, a privately published weekly on federal policymaking. Iglehart was elected to membership in the Institute of Medicine (IOM) of the National Academy of Sciences in 1977 and served on its Governing Council for six years (1985-1991). He also is an elected member of the National Academy of Social Insurance and serves on the Advisory Board of the National Institute For Health Care Management. Previously, Iglehart served on the boards of the American Board of Medical Specialties, the Educational Commission for Foreign Medical Graduates and AcademyHealth. He holds a degree in journalism from the University of Wisconsin and has been a journalist-in-residence at Harvard University.

### **Alan Mertz**

#### **President, American Clinical Laboratory Association**

Alan Mertz became President of the American Clinical Laboratory Association in 2003. During his tenure as President, he has tripled ACLA's membership, broadened its staff and advocacy agenda, increased the visibility and influence of the laboratory industry, and has led two major advocacy battles with the defeat of the Medicare copay legislation in 2003, and the enactment of legislation repealing the Medicare competitive bidding demonstration project in July 2008.

Other advocacy successes for ACLA include the withdrawal of the OIG “excessive charges” rule, the promulgation of regulatory language curbing “POD” laboratories, stopping a single-winner competitive bidding proposal in Florida Medicaid; slowing and modifying the CMS “Medically Unbelievable Edits” project; and successfully seeking the inclusion of laboratories in CMS/OIG regulations on electronic health records.

ACLA also launched an unprecedented educational campaign to promote the value of laboratory services, “Results for Life.”

Prior to taking the reigns at ACLA, Mertz was Executive Vice President of the Healthcare Leadership Council (HLC) from 1998 to 2003. From 1980 to 1998, he served in three senior staff positions in Congress, including professional staff member to the Senate Governmental Committee and for 13 years as Chief of Staff to Congressman Harris W. Fawell (R-IL). Mertz was named a Stennis Fellow in 1996.

Mertz has his Masters Degree in American Government from American University (Washington, DC), and Bachelors degree (with honors) from Monmouth College (Monmouth, IL).

**Sherri Bale Ph.D., F.A.C.M.G.**

**Co-Founder, Gene Dx**

Sherri Bale received her M.S. and Ph.D. degrees from the University of Pittsburgh, and her post-doctoral training in medical genetics at the National Institutes of Health. She is an ABMG Board-Certified Ph.D. - Medical Geneticist and Founding Member of the American College of Medical Genetics. She started GeneDx, Inc. after 16 years at the National Institutes of Health with Dr. John Compton, also a long-time NIH scientist. For over the past 8-1/2 years, she has served as president and Clinical Director of GeneDx, which specializes in developing and providing molecular diagnostics tests for over 150 rare hereditary disorders. She has authored 125 peer-reviewed papers, book chapters, and books in the field. She holds a second degree black belt in judo.

**Gail Vance , MD**

**Department of Medical and Molecular Genetics, Indiana University School of Medicine**

Dr. Gail Habegger Vance is Professor in the Department of Medical and Molecular Genetics and the Department of Pathology and Laboratory Medicine at Indiana University School of Medicine in Indianapolis, Indiana. At the university, she oversees all the genetic testing labs and is the Director of the Cytogenetics Division and the Clinical Genetics residency program and post-doctoral training programs in Molecular Genetics, Cytogenetics, and Medical Genetics.

Dr. Vance is board certified in Clinical Pathology from the American Board of Pathology (1989) and in Pediatrics through the American Board of Pediatrics (1990). In 1993, she obtained certification in Clinical Genetics and Clinical Cytogenetics from the American Board of Genetics with renewal of certification in 2002. She is actively engaged nationally as an advisor to the Secretary's Advisory Committee on genetics health and Society and the Centers for Disease Control and Prevention Best Practice for Molecular Genetic Testing for Heritable Disease.

In 1998, Dr. Vance became a member of the College of American Pathologists (CAP)/American College of Medical Genetics (ACMG) Cytogenetics Resource Committee, becoming chair in 2002. She is currently a member of the College's Board of Governors, Council on Accreditation, and Council on Scientific Affairs. She has performed numerous laboratory inspections since 2001.

### **Sharon Terry, MA**

#### **President and CEO, Genetic Alliance**

Sharon is President and CEO of the Genetic Alliance, a network transforming health by promoting an environment of openness centered on the health of individuals, families and communities. She is the founding Executive Director of PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with pseudoxanthoma elasticum (PXE) in 1994, Sharon, a former college chaplain, and her husband, Patrick, founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and the public.

She is at the forefront of consumer participation in genetics research, services and policy and serves as a member of many of the major governmental advisory committees on medical research, including liaison to the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children and the National Advisory Council for Human Genome Research, NHGRI, NIH. She serves on the boards of the Biotechnology Institute, DNA Direct, National Coalition of Health Professional Education in Genetics, and the Coalition for 21st Century Medicine. She is on the steering committees of Genetic Association Information Network of NHGRI, the CETT program, the EGAPP Stakeholders Group and the Google Health Advisory Board. She is the chair of the Coalition for Genetic Fairness that was instrumental in the passage of the Genetic Information Nondiscrimination Act. She is a member of the IOM Roundtable on Translating Genomic-Based Research for Health. She is chair of the Social Issues Committee of American Society of Human Genetics. In 2005, she received an honorary doctorate from Iona College for her work in community engagement and haplotype mapping, and in 2007 received the first Patient Service Award from the UNC Institute for Pharmacogenomics and Individualized Therapy.

Ms. Terry is a co-founder of the Genetic Alliance Biobank. It is a centralized biological and data [consent/clinical/environmental] repository catalyzing translational genomic research on rare genetic diseases. The BioBank works in partnership with academic and industrial collaborators to develop novel diagnostics and therapeutics to better understand and treat these diseases. Along with the other co-inventors of the gene associated with PXE (ABCC6), she holds the patent for the invention. She co-directs a 33-lab research consortium and manages 52 offices worldwide for PXE International.

Terry is committed to bringing together diverse stakeholders that create novel partnerships in advocacy; integrating individual, family, and community perspectives to improve health systems; and revolutionizing access to information to enable translation of research into services and individualized decision making. She lives with her husband Patrick and their two children in Maryland.

**Victoria M. Pratt, Ph.D.,**

**Chief Director, Molecular Genetics, Quest Diagnostics Incorporated**

Dr. Pratt is a Medical and Clinical Molecular Geneticist board-certified by the American College of Medical Genetics. She is currently Chief Director, Molecular Genetics, for Quest Diagnostics, the world's leading diagnostic testing company.

In addition to her work for Quest Diagnostics, Dr. Pratt serves on the U.S. Secretary of Health and Human Services Advisory Committee on Genetics, Health and Society. She also is currently working on the Morbidity and Mortality Weekly Report for Genetic Testing for the Centers for Disease Control and Prevention.

Dr. Pratt is the current chair of clinical practice for the Association of Molecular Pathology and an advisory member of EurogenTest for genetic test validation. She also is a member of the Quest Diagnostics Best Practice Team for Quality Control.

Dr. Pratt has written over 30 papers and book chapters. She continues to be involved in genetics training with a faculty appointment at National Institutes of Health (NIH). Dr. Pratt graduated with a Ph.D. in Medical and Molecular Genetics from Indiana University School of Medicine, Indianapolis, IN. Her fellowship training was in Ph.D. Medical and Clinical Molecular Genetics at Henry Ford Hospital, Detroit MI.

**Jamie McDonald MS,**

**Licensed Genetic Counselor, Co-Director, Hereditary Hemorrhagic Telangiectasia Center,  
University of Utah and ARUP Laboratories**

Jamie McDonald received an undergraduate degree from Carleton College in biology, and a master's degree in Genetic Counseling at the University of California at Berkeley. She is certified by the American Board of Medical Genetics and American Board of Genetic Counseling.

Jamie began work at the University of Utah Medical Center in 1988 and has worked in the Departments of Pediatrics, Obstetrics and Gynecology and the Huntsman Cancer Institute's Hereditary Cancer Clinics as a managing genetic counselor. In 1995 she co-founded and now co-directs a multi-disciplinary Center of Excellence for Hereditary Hemorrhagic Telangiectasia (HHT) at the University of Utah. Jamie is the Vice-Chair of the HHT Foundation International Medical and Scientific Advisory Board. She also works as a consultant to the molecular genetics section at ARUP Laboratories. She has authored multiple articles involving genetic testing and its use in diagnosing and managing a genetic disorder.