

PMC Member Newsletter

Dear PMC Members,

September 2005

We have seen over the past few months an increased awareness within the public sphere of personalized medicine and the impact that genetic-based tests are having on medicine. In the September 5th issue of *Business Week*, the article "Drugs Get Smart" is a prime example, highlighting how new medicines in development are being targeted to improve outcomes for patients.

Earlier this month, the Personalized Medicine Coalition held a seminar on Public Attitudes Toward Genetics, which featured new survey data on the subject of genetic non-discrimination. A summary of the event is featured below. In this issue, we also highlight a recent article on the PMC in the *Personalized Medicine Journal*; a Congressional briefing on Personalized Medicine and the public policies that will accelerate or impede its advancement; and the announcement of our recently-elected Board members. Please also see our PMC Calendar of Events for a listing of upcoming programs, Board and Committee meetings, and PMC-sponsored events.

PMC IN THE PRESS

The *Personalized Medicine Journal* features the Personalized Medicine Coalition in its August 2005 issue. [Click here](#) to download a PDF copy of "The Personalized Medicine Coalition – 8 months on," an interview with Edward Abrahams, PMC Executive Director, in which he discusses the Coalition's goals and strategies.

Biotechnology Healthcare's August 2005 issue also features the PMC. "Seeing Patients Through Genetic Lenses" discusses how the "emergence of molecular medicine and diagnostics is bringing sweeping changes to the delivery of health care." PMC Executive Director, Edward Abrahams, and PMC Board members, Joseph McInerney (NCHPEG) and Gualberto Ruaño (Genomas, Inc.), are quoted. [Click here](#) to download the PDF.

"PUBLIC ATTITUDES TOWARD GENETICS"

Americans are extraordinarily favorable to the idea of using genomics to improve health care, with large majorities saying that they would like to see pharmacogenomic data used to improve drug safety and efficacy. But they are also very fearful of how

PMC Calendar of Events

PMC Programs

September 28th
[Congressional Briefing on Personalized Medicine and Genetic Non-Discrimination](#)

Special Guest Speakers:

Newt Gingrich
Founder, Center for Health Transformation

Dr. Francis Collins
Director, National Human Genome Research Institute

November 29th
PMC Dinner Roundtable on personalized medicine
Menlo Park, CA
(Members-only event)

BOD Meetings

September 22nd
12:00pm - 3:00pm
1401 H Street, NW
Suite 200
Washington, DC 20005

December 7th
Strategic Planning Retreat and Dinner
11:00am
New York, NY

Committee Meetings

September 22nd
Public Policy Committee
10:00am - 12:00pm
1401 H Street, NW
Suite 200
Washington, DC 20005

Sponsored Events

October 7th
[Preparing for Personalized Medicine](#)
Organized by: Genomic Healthcare Strategies and Nixon Peabody LLP

October 18th
[Personalized Medicine Forum](#)
Organized by: Burrill & Company, BIO

November 3rd - 4th
[Personalized Medicine: Promises and Prospects](#)
Organized by: Harvard Medical School-Partners

genetic information may be used, according to Christy White of Cogent Research, who reported the results of her new survey of public attitudes toward genetics at a PMC seminar on the subject on September 7th.

According to White, 68 percent of those polled in a scientific survey say that they are "concerned about how personal genetic information would be stored and who would have access to that information." And almost one third say that their concern would prevent them from having a genetic test. Americans, she found in large numbers, do not trust insurance companies, with 69 percent agreeing with the statement that insurance companies would deny coverage for drugs people need if a genetic profile indicates a low chance of their responding. This poses a potentially serious problem for the introduction of pharmacogenomics into the future of medicine. Almost three quarters of her sample said that the government should protect the privacy of information.

Resting on the assumption that policymakers, business executives, and healthcare providers must pay attention to public opinion when new technologies are introduced, the PMC convened the seminar to begin its consideration of the subject in an effort to better serve those interested in helping advance personalized medicine in the public sphere. Attended by almost 100 people from the diverse sectors that comprise our membership, our panel included Kathy Hudson, Ph.D., of the Genetics and Public Policy Center and Sharon Terry of the Genetic Alliance, who also shared their concerns, based upon earlier surveys they have done, regarding how the public is absorbing the challenges of new genetic information. The panel was moderated by Marcia Kean of Feinstein Kean Healthcare.

GINGRICH AND COLLINS TO SPEAK AT PMC CONGRESSIONAL BRIEFING

The PMC is pleased to announce that it will hold a luncheon for Members of Congress, their staffs and PMC members on September 28th at 12:30 pm in 2261 Rayburn House Office Building with special guest speakers Newt Gingrich, Founder, Center for Health Transformation and Dr. Francis Collins, Director, National Human Genome Research Institute. They will discuss personalized medicine and the public policy issues that will support or impede its advancement. Hosted by Representatives Judy Biggert (R-IL), Anna Eshoo (D-CA), Bob Ney (R-OH), and Louise Slaughter (D-NY), the bi-partisan authors of the Genetic Information Non-Discrimination Act, the briefing will focus in particular on the impact that fear of genetic discrimination is having on medical progress today.

If you are interested in attending the luncheon, [click here](#) to register or rsvp to peter.norman@mpi.com. Seating is limited.

Healthcare Center for
Genetics and Genomics

December 8th
[Scientific American Targeted
Medicine 2005:
From Concept To Clinic](#)
Organized by: BioEdge.Net
Inc.

Industry Events

IBM Healthcare and Life
Sciences Seminar
[Information Based Medicine:
A New Era in Patient Care](#)
October 11th - Palo Alto, CA
October 13th - Cambridge, MA

For a complete listing of
upcoming events:



The PMC is pleased to announce our recently-elected Board members:



Mara G. Aspinall
President
Genzyme Genetics

Aspinall joined Genzyme in 1997 and in addition to her current role, has also served as president of Genzyme Pharmaceuticals and as Genzyme's vice president of corporate development. Under Aspinall's leadership, Genzyme Genetics, a leading provider of testing and consultative services, has expanded its range and reach in the marketplace. The division has successfully completed and integrated four acquisitions, expanded research and development programs, and initiated new programs for community outreach and education. Aspinall is also actively involved in the Boston community, with a focus on the fight against cancer, and expanding educational opportunities for young children.



Brett J. Davis
Global Solutions Executive, Healthcare
IBM Healthcare and Life Sciences

Davis is involved in helping shape the marketing, sales and solutions strategy for clinical transformation, clinical genomics, high performance computing, biobanking and translational medicine. In addition to his role at IBM, Davis is on HRSA's Genetic Services Advisory Panel and has been an invited speaker/panelist at industry meetings on information technology's transformative role in the health sciences.



Johanna Allston Griffin, Ph.D.
Executive Officer, Procognia Ltd.
President, Procognia Inc.

Griffin has over 10 years of experience in the biotechnology and pharmaceutical industries. In her role at Procognia, Griffin is helping guide the company in its mission to develop a fuller understanding of proteins as targets and as therapeutics. Previously, Griffin founded ViroPharma, Inc., a Pennsylvania-based biotechnology company which developed antiviral drugs, one of which is used on a compassionate use basis to treat neonatal sepsis. During her tenure at Boehringer Ingelheim Pharmaceutical Company, Griffin led a team that developed one of the first drugs to treat AIDS. She is actively involved with several charities, serves on the executive board of Camphill Soltane which supports the needs and development of children and young adults with special needs, and is also active in environmental protection.



Kathy Hudson, Ph.D.
Director, Genetics and Public Policy Center
Associate Professor, Berman Bioethics Institute, Institute of
Genetic Medicine, Department of Pediatrics, Johns Hopkins
University

Hudson, a molecular biologist by training, founded the Center in April 2002 to fill an important niche in the science policy landscape. By creating the Center, she has introduced an organization solely dedicated to the analysis of public policy issues raised by advances in human genetics. Before founding the Genetics and Public Policy Center, Hudson was the Assistant Director of the National Human Genome Research Institute (NHGRI) responsible for communications, legislation, planning and education activities. She provided focus and leadership in public policy, genetic technology and public affairs issues for NHGRI programs including the Human Genome Project, and spearheaded efforts to develop policies to prevent genetic discrimination.



Joseph D. McInerney, MA, MS
Executive Director
National Coalition for Health Professional Education in Genetics
(NCHPEG)

McInerney has over 25 years experience in genetics education. He joined NCHPEG in September 2000 as executive director. He is currently the principal investigator on a NCHPEG project to develop a television-based CME program on race, genetics, and health care, and has directed development of several BSCS programs based on genetics which were distributed free of charge to 50,000 high school biology teachers in the United States. McInerney has published more than 90 articles, reviews, and chapters in the scientific and science-education literature. He is also a member of the editorial boards of the *Quarterly Review of Biology* and *Community Genetics*.



Sharon F. Terry
President & CEO
Genetic Alliance

Terry's work with the Genetic Alliance over the past few years has included working on international and national committees, particularly focused on genetic literacy, research protections, biosample repositories, technology translation, accessible services and youth issues. Terry is committed to facilitating technical assistance to lay advocacy groups, so that each group benefits from the wisdom of the other. Terry is the founding president of the Genetic Alliance BioBank, a cooperative biological samples and data repository that allows lay advocacy and community organizations to bank and manage samples and data. She is also the founding Executive Director of PXE International, a lay advocacy group for the genetic condition pseudoxanthoma elasticum (PXE). She has co-authored numerous papers including two papers on the discovery of the PXE gene, published back-to-back in *Nature Genetics*, June 2000.



Phyllis Whiteley, Ph.D.
Senior Vice President, Business Development and Licensing
Perlegen Sciences, Inc

Whiteley oversees all commercial partnerships, in-licensing, and portfolio strategy at Perlegen Sciences, Inc. She has over sixteen years experience in pharmaceutical research, development and business development. Her tenure at F. Hoffman La Roche as a Therapeutic Area Head of Arthritis resulted in the advancement of multiple new chemical entities into clinical development. She has comprehensive experience in leading academic and pharmaceutical drug discovery research in many disease areas including rheumatoid arthritis, osteoarthritis, Alzheimer's disease, and diabetes.

Sincerely,

Edward Abrahams
Executive Director
Personalized Medicine Coalition