
IMPACT REPORT

Making the Case for Personalized
Medicine through **Education,**
Advocacy, and Research

MISSION

The Personalized Medicine Coalition, a 501(c)3 nonprofit organization, promotes the understanding and adoption of personalized medicine concepts, services, and products to benefit patients and health systems.

President and Chairperson's Letter

Dear Colleague:

One might say that in the world of health care, it is, as Dickens wrote in *The Tale of Two Cities*, “the best of times and the worst of times.”

On one hand, a challenging economic environment has forced many biotechnology and diagnostics companies, whose work underpins personalized medicine, into a period of constriction. Even the world's largest pharmaceutical companies have not been immune to the economic consequences of the rising cost of research and post-pandemic corrections. Clinical care providers are also facing their own crises in providing cost-effective care, forcing many to cut costs and slow their adoption of new technologies and therapies.

But, on the other hand, new scientific breakthroughs are providing unprecedented opportunities to target prevention and treatment strategies to the right patients at the right times. A rapid pace of progress in science and medicine is ushering in a new era of more precise health care that promises better outcomes for patients and more efficiency for health systems. “We may be,” as one columnist wrote, “on the cusp of astonishing innovation — the limits of which aren't even clear yet.”

Recognizing that the gap between the promise of personalized medicine and its reality has never been greater, the Personalized Medicine Coalition is dedicated to accelerating investment in and adoption of personalized medicine. Twenty years ago, President Clinton noted that “human genome research rapidly advances our understanding of the causes of human disease and will serve as the foundation for a new generation of effective treatments, preventive interventions, and cures.”

PMC remains committed to that vision, which, with your help, we can realize.

Sincerely yours,



Edward Abrahams, Ph.D.
President



Lincoln Nadauld, M.D., Ph.D.
Board Chairman

OVERVIEW

PART I: EDUCATION · Page 6

Focusing Executives, Policymakers, and Journalists on Opportunities in Personalized Medicine

PART II: ADVOCACY · Page 8

Notching Bipartisan Public Policy Victories for Personalized Medicine

PART III: RESEARCH · Page 10

Inspiring Health Care Professionals to Address Clinical Practice Gaps in Personalized Medicine

2023 Membership · Page 12

2023 Conference/Research Sponsors · Page 14



PART I

Education

An Established Platform

Business executives, policymakers, and journalists hold PMC's educational platforms in exceptionally high esteem.

The Coalition's opinion essays and editorial letters have been published by outlets including *The Wall Street Journal*, *The Washington Post*, and the *Boston Globe*'s health care affiliate, *STAT*. Its flagship *Annual Personalized Medicine Conference* has won critical acclaim from outlets including *The Boston Globe*, which named the conference a "forward-leaning event to watch" after its last Boston-based showing at Harvard Medical School in 2019. And its *State of Personalized Medicine Luncheon* attracts annual participation from many of the most influential voices in health care and personalized medicine.

In 2023, PMC's educational initiatives turned an expanded number of business executives, policymakers, and patients into believers of both PMC and personalized medicine. Several of its 2023 educational achievements are summarized on the following page.

Focusing Executives, Policymakers, and Journalists on Opportunities in Personalized Medicine

NOV. 30/DEC. 1

Annual Personalized Medicine Conference

With confirmed speakers from every sector of the health care system and media participation from representatives of outlets including *The Washington Post*, *Fortune* magazine, and *Endpoints News*, the 2023 *Annual Personalized Medicine Conference* provided business executives, clinicians, researchers, and

patients with an opportunity to demonstrate how far personalized medicine has come — and how far it has to go — two decades after the first sequencing of a human genome in 2003. Nearly a third of the 300 conference attendees were CEOs, Principals, or Managing Directors at their respective institutions.



MAY 24

State of Personalized Medicine Address

PMC convened an audience of about 150 executives, policymakers, journalists, and patients at the National Press Club in Washington, DC, to hear National Human Genome Research Institute Director Dr. Eric Green give the 2023 *State of Personalized Medicine Address*. Coverage of Dr. Green's remarks in the *Oncology Times* and *Bioprocessing International* magazine encouraged tens of thousands of oncologists and biomanufacturing industry professionals to embrace innovative clinical practices and manufacturing solutions that promise to bring the benefits of personalized medicine to more patients, sooner.

DEC. 1

Public Awareness Campaign

PMC launched a national personalized medicine public awareness campaign featuring digital content as well as an advertorial insert distributed in copies of *USA Today* newspapers in select metropolitan markets across the country. The campaign gives government and health system policymakers another reason to believe that their constituents and patients will welcome efforts to advance personalized medicine.



PART II

Advocacy

A Deep Legacy

PMC has worked with its members to understand and address public policy obstacles in personalized medicine every year since it was founded in 2003.

To name but a few examples, PMC has played a leading role in advocating for regulatory reforms that have led to the U.S. Food and Drug Administration's approval of more than 40 companion diagnostics and 280 personalized medicines between 2005 and 2020; in helping to shape the passage of the *Genetic Information Nondiscrimination Act of 2008*, which protects patients from genetically based discrimination in health coverage and employment; and in supporting a 2021 Medicare policy change that helped ensure Medicare payment rates high enough to support sustainable patient access to a groundbreaking class of curative cell-based cancer treatments called chimeric antigen receptor (CAR) T-cell therapies.

In its letters to Members of Congress and federal agency officials, PMC advised opposition, support, or refinement of no fewer than 14 Congressional priorities and statutory proposals in 2023. Several of those issues — as well as the Coalition's 2023 Congressional briefing on personalized medicine's benefits for mental health patients — are spotlighted on the following page.

Notching Bipartisan Public Policy Victories for Personalized Medicine

JUL. 20

Personalized Medicine and Mental Health Briefing

PMC and the bipartisan and bicameral Congressional Personalized Medicine Caucus co-hosted a standing-room only briefing for Congressional staffers titled *Personalized Medicine and Mental Health*. The briefing demonstrated how advancements in personalized medicine may help address a mental health crisis affecting more than one of every five Americans. It was the fifth in a series of briefings that have helped double the size of the caucus in the last two years.



OCT. 13

Winning CMS Policy Change

Officials at the Centers for Medicare and Medicaid Services (CMS) finalized a PMC-supported policy change that will make it easier for physicians to personalize Alzheimer's disease diagnosis and treatment by removing once-per-lifetime restrictions and ending Coverage with Evidence Development requirements that limit Medicare beneficiaries' timely and appropriate access to beta amyloid positron emission tomography (PET) imaging tests.



OCT. 18

Building Bipartisan House Support for Personalized Medicine

Following a meeting with PMC executives earlier in the year, Rep. John Moolenaar (R-MI-02) agreed to join Rep. Eric Swalwell (D-CA-14) as a second Co-Chair of the Congressional Personalized Medicine Caucus in the House of Representatives. Rep. Moolenaar's decision shows bipartisan support for personalized medicine and the caucus, which is co-chaired by Kyrsten Sinema (I-AZ) and Tim Scott (R-SC) in the Senate.

NOV. 7

Supporting Bertagnolli Confirmation

The U.S. Senate confirmed Dr. Monica Bertagnolli, whose research on the genetic drivers of gastrointestinal cancers has significantly advanced the frontiers of personalized medicine in oncology, as the new Director of the National Institutes of Health. PMC announced its support for Dr. Bertagnolli's candidacy on October 17.



PART III

Research

A 5x Return for Members Sponsoring Studies

PMC's research delivers exceptionally strong returns for the members who sponsor it.

Research studies in health care cost an average of about \$590,000 each. Yet, between 2022 and 2023, with a total research budget of less than \$600,000, the Coalition published two research reports and four journal articles whose significance is still resonating at professional societies and in media outlets including *The Washington Post* and the *Boston Globe's* health care affiliate, *STAT*. Six months after its publication on October 31, 2022, a PMC/Diaceutics special report on clinical practice gaps in non-small cell lung cancer was still second on the list of the most-read articles in *JCO Precision Oncology*.

The following pages explain how three recent PMC research studies are reshaping thinking about the future of health care and personalized medicine.

Inspiring Health Care Professionals to Address Clinical Practice Gaps in Personalized Medicine

NOV. 30

Conference Presentation

On the first day of the *Annual Personalized Medicine Conference*, PMC and its partners from Health Advances, a research consulting firm, announced the preliminary findings of a study showing that in the era of personalized medicine, health systems that adopt changes to their administrative policies and clinical practices in eight key areas are able to more consistently select the most appropriate therapies for their patients. The findings promise to accelerate the clinical adoption of personalized medicine by providing United States health care providers with a publicly available blueprint that they can use to assess and improve their clinical practices in this new era.



OCT. 2022 – JAN. 2023

Special Report & Op-Eds

In 2022, PMC and Diaceutics co-published a special report in *JCO Precision Oncology* showing that the diagnostic and therapeutic tools underpinning personalized medicine are reaching less than 40 percent of the advanced non-small cell lung cancer patients who may have benefitted from them. In 2023, PMC op-eds in *The Washington Post* and the *Boston Globe's* health care affiliate, *STAT*, helped make the paper one of the most-read articles in the history of personalized medicine.

MAR. 23

American Cancer Society News Coverage

In a development that underlined the significance of a PMC research article titled “Clinical Utility of Genomic Testing in Cancer Care,” the American Cancer Society published a news article in its peer-reviewed *Cancer* journal to explain how physicians can help improve care for cancer patients by adopting a PMC proposal to revise what it believes is an outdated definition of the concept of clinical utility as it relates to genomic testing in cancer care. By updating the medical community’s understanding of the benefits that genomic testing can provide for both patients and health systems, the article encouraged tens of thousands of oncologists to order key personalized medicine tests more consistently.

PMC Membership

JANUARY 2024

CLINICAL LABORATORY TESTING SERVICES

Blue Genes
Invitae
Laboratory Corporation of America (Labcorp)
Quest Diagnostics
SmartLabs

DIAGNOSTIC COMPANIES

10x Genomics
Agendia NV
Agilent Technologies
Biological Dynamics
Castle Biosciences
Circulogene
Cofactor Genomics
Delfi Diagnostics
Exact Sciences
Exai Bio
Foundation Medicine, Inc.
GeneCentric Therapeutics
GRAIL, Inc.
Guardant Health
Illumina
Myriad Genetics
NanoString Technologies
NeoGenomics Laboratories
Olaris, Inc.
Oncocyte
Quibim
Roche Diagnostics
Singular Genomics
SomaLogic, Inc.
Thermo Fisher Scientific

EMERGING BIOTECH/ PHARMACEUTICAL COMPANIES

1cBio
Actio Biosciences
Adaptive Biotechnologies
Alexion Pharmaceuticals
Day One Bio
Denovo Biopharma
Elevation Oncology, Inc.
Freenome
Helix

ImmunoGen
Jazz Pharmaceuticals
Kyverna Therapeutics
Merus
OneOme
Rapafusyn Pharmaceuticals

HEALTH INSURANCE COMPANIES

Point32Health

INDUSTRY/TRADE ASSOCIATIONS

American Clinical Laboratory Association
Biocom California
National Society of Genetic Counselors
PhRMA

IT/INFORMATICS COMPANIES

Aetion
Aitia
Aranscia
Assurance Health Data
Aster Insights
BC Platforms
Change Healthcare
Concert Genetics
DNAnexus
Flatiron Health
Nucleai
Oxford Nanopore Technologies
PathAI
Syapse
Translational Software
Verily Life Sciences

LARGE BIOTECH/ PHARMACEUTICAL COMPANIES

AbbVie
Amgen, Inc.
Astellas
AstraZeneca Pharmaceuticals
Bausch Health Companies
Biogen
Blueprint Medicines
Bristol Myers Squibb
Eli Lilly and Company
Genentech, Inc.

Gilead
GlaxoSmithKline
Johnson & Johnson
Merck & Co.
Novartis
Pfizer, Inc.
Sanofi

PATIENT ADVOCACY GROUPS

Accelerated Cure Project for Multiple Sclerosis
AiArthritis
Alliance for Aging Research
Alzheimer's Foundation of America
American Association of Kidney Patients (AAKP)
American Cancer Society Cancer Action Network (ACS-CAN)
Bulgarian Association for Personalized Medicine
Cancer Treatment Options & Management Inc. (CTOAM)
Colorectal Cancer Alliance
Emily's Entourage
EveryLife Foundation for Rare Disease
Friends of Cancer Research
Glioblastoma Foundation
Global Liver Institute
GO2 for Lung Cancer
International Cancer Advocacy Network
KRAS Kickers
LUNgevity Foundation
Multiple Myeloma Research Foundation
National Alliance Against Disparities in Patient Health
National Alliance for Hispanic Health
National Health Council
National Pancreas Foundation
Rabble Health
Sepsis Alliance
Support Fibromyalgia Network
SynGAP Research Fund
TargetCancer Foundation
Team Trevor
The Assistance Fund

PERSONALIZED MEDICINE SERVICE PROVIDERS

CareDx
Coriell Life Sciences
InformedDNA
Michael J. Bauer, M.D., &
Associates, Inc.
My Gene Counsel
QURE Healthcare
Tempus

RESEARCH, EDUCATION & CLINICAL CARE INSTITUTIONS

AccelevirDx
AdventHealth
American Association for Cancer
Research (AACR)
American Medical Association (AMA)
American Society of Health System
Pharmacists (ASHP)
Arizona State University
Association for Molecular
Pathology (AMP)
Audubon Bioscience
Business Finland
Cancer Treatment Centers
of America
Cedars-Sinai
Clarified Precision Medicine
Codex4SMEs
Colorado Center for Personalized
Medicine
CommonSpirit Health
Coriell Institute for Medical Research
Culmination Bio
Duke Center for Research
Essentia Institute of Rural Health
European Infrastructure for
Translational Medicine (EATRIS)
Genome Canada
Hamad Medical Corporation
Hospital Albert Einstein
iCAN – Digital Precision Cancer
Medicine at University of Helsinki
Intermountain Healthcare

King Faisal Specialist Hospital and
Research Centre
MaineHealth Accountable Care
Organization
Manchester University School
of Pharmacy
Marshfield Clinic
Mayo Clinic
MD Anderson – Institute for
Personalized Cancer Therapy
Moffitt Cancer Center
Morehouse School of Medicine
National Pharmaceutical Council
Nicklaus Children's Hospital
Research Institute
North Carolina Biotechnology
Center (NCBIO)
NorthShore University
Parkview Health
Qatar Biobank
Sanford Imagenetics, Sanford Health
Teachers' Retirement System
of Kentucky
The Christ Hospital
The Jackson Laboratory
Translational Genomics Research
Institute (Tgen)
UC Davis Mouse Biology Program
University of Alabama, Birmingham
University of California, San Francisco
(UCSF)
University of Chicago
University of Pennsylvania
Health System
University of Pittsburgh Medical
Center (UPMC)
University of South Florida Morsani
College of Medicine

RESEARCH TOOL COMPANIES

Octave Biosciences

STRATEGIC PARTNERS

ADVI
Arnold & Porter
Avalere
Bradford Power

Bruce Quinn Associates
Cambridge Healthtech Institute
Carol Colman
Catalytic Agency
Clinical Transformation Partners
ConText
ConvergeHEALTH by Deloitte
Deverka Consulting
Diaceutics
Foley & Lardner, LLP
Foley Hoag, LLP
Genome Creative
Goldbug Strategies, LLC
Harbor Precision Genomics
Health Advances, LLC
Innovation Horizons
Innovation Policy Solutions
KPMG
L.E.K. Consulting
McDermott Will & Emery
Morrison Foerester
Prasanth Reddy, M.D., M.P.H., F.A.C.P.
Priya Hays, M.D., Ph.D.
Reservoir Communications
Slone Partners
SolarisRTC
The Synergist
Trusted Health Advisors
United States Pharmacopeial
Convention (USP)
Veranex Solutions
W.J. Pignato & Associates, LLC
William P. Stanford, M.D., Ph.D..

VENTURE CAPITAL

Andreessen Horowitz
GreyBird Ventures, LLC
RA Capital Management
Section 32
Third Rock Ventures, LLC

2023 Conference/Research Sponsors

THROUGH DECEMBER 2023





PERSONALIZED
MEDICINE COALITION

1710 Rhode Island Ave., NW
Suite 700
Washington, DC 20036