

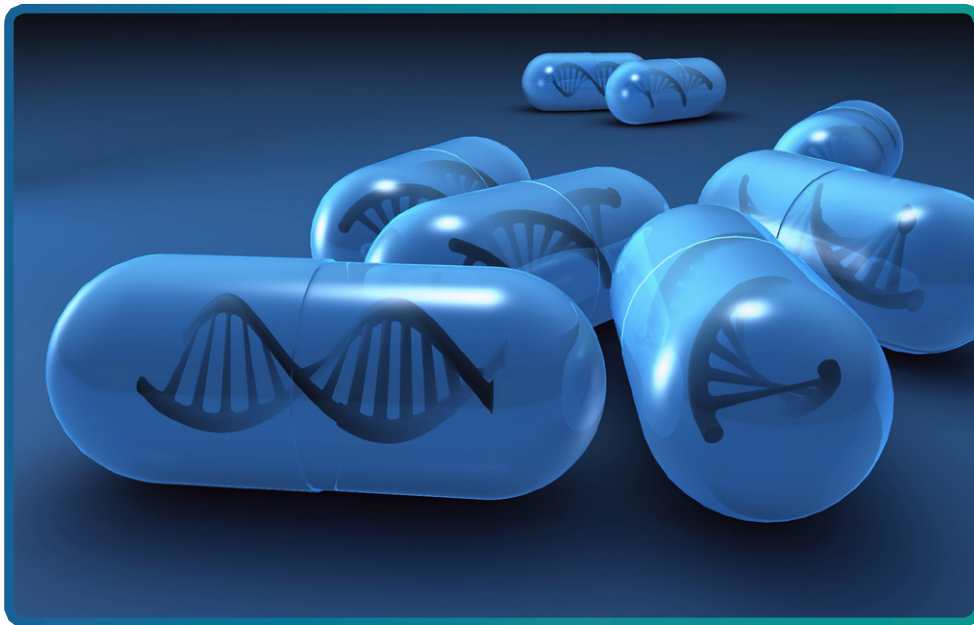


The Pontifical Academy of Sciences

Workshop on

# THE REVOLUTION OF PERSONALIZED MEDICINE

Are We Going to Cure All Diseases  
and at What Price?



8-9 April 2019 | Casina Pio IV | Vatican City



*“ There is no doubt that, in our time, due to scientific and technical advancements, the possibilities for physical healing have significantly increased; and yet, in some respects it seems that the capacity for “taking care” of the person has diminished, especially when one is sick, frail and helpless. In effect, medical and scientific achievements can contribute to improving human life, provided that they are not separated from the ethical root of these disciplines. ”*

Address of His Holiness Pope Francis to participants in the commemorative conference of the Italian Catholic Physicians' Association on the occasion of its 70th Anniversary of Foundation | Paul VI Audience Hall, Saturday, 15 November 2014

## Concept Note

*The Technion Integrated Cancer Center (TICC)  
The Rappaport Faculty of Medicine and Research Institute,  
Technion-Israel Institute of Technology, Haifa, Israel*

One of the decades-old mysteries in medicine has been the observation that apparently similar diseases have a vastly different course in different patients. Similarly puzzling has been the hugely different response of patients with the “same” disease to similar drug treatment. Some patients respond favorably, some moderately, some do not respond at all, and some develop a broad range of side effects – from mild to fatalities – with or without a beneficial effect of the drug for the primary ailment for which it has been prescribed. Physicians and researchers have been lacking tools to predict the disease course or the response to drugs in individual patients, and have relied largely on statistics. While we have realized that these differences stem from the different genetic repertoire people harbor, we lacked access to the code. When the term Personalized Medicine was coined by Leroy Hood and became part of our daily jargon a bit more than a decade ago, the realization of this goal appeared to be an inevitable milestone on the road of future medicine. The journey began with the sequencing of the first human genome that lasted several years, cost several hundred million dollars, and was completed in 2000. With exciting technological developments, time span and cost have been shortened dramatically and still continue to decrease, converting genomic sequencing into an almost routine clinical test. The development of additional omics platforms (e.g. transcriptomics, proteomics, metabolomics) added important missing layers to our ability to obtain a complete profile of the individual patient and reaching a precise diagnosis of the pathogenetic mechanism of his/her ailment. Yet, the main gain of this revolution is still ahead of us – the discovery of novel disease targets with the development of therapeutic modalities to target them. With the mirror of medicine turning from treating a disease to treating a disease in the context of an individual patient – Personalized Medicine is going to be – in the vision of Leroy Hood – more Precise, but also Predictive, and therefore Preventive. Importantly, it is going to be also Participatory, where the patient is going to play a major role in the decision-making process of his/her treatment, and the physician becoming more of a professional consultant rather than an absolute authority. The newly evolving medicine is therefore known also as the 4P’s medicine.

While some of the promises of this “simple” road map view remain, the path has become more convoluted, and major roadblocks have emerged. The prom-

ise of Personalized Medicine was initially painted with rosy colors, in large part due to naiveté in the scientific and medical communities with respect to the complexity of the problem. In addition, some scientists were eager to convince the public and funding agencies that a defined roadmap toward new therapies for many diseases was around the corner, lacking only adequate funding. While the goals of Personalized Medicine can still be achieved, a more realistic view of the obstacles and pitfalls is needed. Obstacles reside in each and every level of the road to this revolution – from scientific discovery to drug development by pharmaceutical companies, and from legal to administrative concerns to political, religious and ethical issues. For example, the role of non-coding DNA, though shown to be associated with disease pathogenesis, is still largely unknown. The map of proteins interactomes and the pathways that regulate different processes are only partially known. We are still missing technologies to analyze the entire proteome and post-translational proteome with complete coverage, and unravel its dynamics and response to different cues. The same is true for the metabolome – technologies to dynamically analyze small molecules such as sugars and lipids. Above all these shortcomings – it has become clear that many diseases, psychological (e.g. autism), but many others such a metabolic, heart and lung diseases (e.g. COPD) are multi-genic, and the distinction between the primary and secondary drivers – the passengers and hitchhikers – has become a daunting task. We learnt that the phenotypic pathology depends on the penetrance of the different genes involved and their modulation by environmental factors. The elusive behavior of tumors, for example, has elicited a fierce debate on the therapeutic approach to cancer – whether to target the specific mutations, which accumulate and become resistant to therapy, or to target major upper stream “switches” such as evasion of cell death, immune surveillance, growth promoters, and dysregulation of cellular energetics. We learnt the hard way that genetic variation is not equivalent to dysfunction. The mere interaction of 20,000 gene products with 20,000 small molecules provides an array of 400 million potential interactions. Another obstacle resides in “multi-morbidity”. Realizing that 25% of all people and 65% of people who are above 65 years of age, have multiple morbidities challenges our prior single-disease paradigm and leads to further exploration of common pathways for disparate diseases.

From the standpoint of drug development, a major concern is that Personalized Medicine will mark the end of the blockbuster era, where one or a few competing drugs are being used to treat an entire population with a certain disease. For example, the now familiar classification of patients with breast cancer based on expression of HER/Neu2, estrogen receptor mutation, progesterone receptor mutation and the still “mysterious” triple negative malignancy is likely an oversimplification of this complex disease. In the future, an array of genomic, RNA, proteomic and metabolic data will likely be used to identify more types which will divide the patients populations into smaller groups, each requiring a specific treatment. Pharmaceutical companies are already reluctant to develop certain short-lived drugs such as antibiotics, and may not be enthusiastic to develop drugs targeting a smaller number of patients. In this setting, drug development will become prohibitively expensive. To respond to this problem, investment is needed to develop improved preclinical disease models that can be used to predict drug efficacy and toxicity. This process might be facilitated by using Personalized Medicine approaches to identify factors that might make individuals more or less sensitive to certain drugs. This problem of drug pricing resides already in the twilight zone between technology and bioethics – whether the products of this exciting revolution are going to be accessible to different patients populations worldwide.

Most difficult to resolve however are the true bioethical issues emerging from the revolution of Personalized Medicine. For example, genomic analysis of a blood or a tissue sample for clinical research or even personal purposes, might have multiple, unforeseen implications. Some “simple” questions relate to the privacy and confidentiality with respect to the potential use of the information by employers, governments, or insurance companies to make decisions that are not necessarily related to the health care of the patient. More complicated is the problem of how to address incidental information referring to a potential or evolving pathology of which the patient is unaware, and for which he/she might not have consented, particularly, the discovery of a predisposition to a disease that cannot be treated or prevented. This problem is even more complex when the information is discovered as part of prenatal testing or in utero examinations of embryos, and needless to say, bear important implications to the children of the patient. This information has the possibility to affect physician-patient relationship, social networks, family structure, and parenthood in ways that are difficult to predict. These rapidly evolving ethical challenges will require continuously updated guidelines and legislation. The scientific community needs to proactively and transparently communicate recent discoveries generated in laboratories to engage the

political, philosophic, clerical, and judicial members of society to meet the challenges of ethical utilization of data and new technologies.

In conclusion, the road to Personalized Medicine is longer and more tortuous than we imagined a decade ago. We find ourselves in the midst of an exciting era in medicine in which we can see that the promise of individualized prevention, early detection, and efficient treatment of diseases is possible. This revolution of Personalized Medicine has passed the stage of conception and entered reality, with well-documented examples of intervening in human health earlier and more effectively than ever before. Furthermore, the discovery of the CRISPR-Cas9 technology for gene editing has opened to road to “correct” mutations [it has already been used recently to treat Mucopolysaccharidosis II (Hunter’s disease)]. Realizing this goal will require however innovative multidisciplinary approaches to address the scientific, commercial and ethical challenges posed by these new technologies and techniques. Like many endeavors in research, the next milestone in the road may not be around the corner and might come from an unexpected source. Continued investments in high quality research using both traditional and novel approaches in a wide field of study will be required to achieve these goals. As we do this, it is important to remember what our patients might think of when they hear the term “Personalized Medicine”. For example, Carolyn Bucksbaum recently provided a \$42 million gift aimed at improving bedside manners (New York Times, September 22, 2011) by establishing a center to teach doctors “bedside manners” and to “preserve kindness and personalize” the patient-doctor relationship. Providing both the Personalized Medicine described by Dr. Hood and Ms. Bucksbaum represents an exciting challenge in the practice of medicine in the 21st Century.

Thus, the path to Personalized Medicine is not hopelessly long, but will require thoughtful planning, coordinated efforts and continued societal investment.

The speakers only Workshop in the beautiful set up of the almost 400 years old Pontifical Academy of Sciences, that resides in a gorgeous building in the Vatican, will discuss all these issues. It will provide a technical background to the roots and current state-of-art of the revolution of Personalized Medicine, but will devote an equal part to its complexity, the technological one, but most importantly the bioethical one.

AARON CIECHANOVER

This Introduction is partially based on the commentary: Sznajder, J.I., and Ciechanover, A (2012). *Am. J. Respir. Crit. Care Med* 186, 945-947. doi: 10.1164/rccm.201210-1772OE.

# Programme

MONDAY 8 APRIL	
9:00	<i>Opening</i> <b>Prof. Joachim von Braun</b>   PAS President <b>H.E. Msgr. Marcelo Sánchez Sorondo</b>   PAS Chancellor <b>Prof. Aaron Ciechanover</b>   PAS Academician
9:10	<i>Vision of 21st Century Personalized Medicine</i> <b>Prof. Leroy Hood</b>   Providence St. Joseph Health (USA)
9:40	Discussion
9:50	<i>The Historical Background of Personalized Medicine</i> <b>Prof. Diego Gracia-Guillén</b>   Complutense University (Spain)
10:20	Discussion
10:30	Coffee Break
11:00	<i>Personalized Medicine and Disorders of Consciousness: An Alternate Convergence of Knowledge Towards a New Clinical Nosology</i> <b>Prof. Joseph Fins</b>   NY Cornell University (USA)
11:30	Discussion
11:40	<i>The Concept of Relevance of Gender to Personalized Medicine</i> <b>Prof. Marianne Legato</b>   Columbia University (USA)
12:10	Discussion
12:20	General Discussion
13:00	Lunch at the Casina Pio IV
15:00	<i>Personalized and Precision Medicine: What Kind of Society Does It Take?</i> <b>Prof. Barbara Prainsack</b>   University of Vienna (Austria)
15:30	Discussion
15:40	<i>International Governance of Powerful Biomedical Technologies</i> <b>Prof. Eric Lander</b>   Broad Institute of MIT and Harvard (USA)
16:10	Discussion
16:20	Coffee Break
16:50	<i>Regulating CRISPR</i> <b>Prof. Dianne Nicol</b>   University of Tasmania (Australia)
17:20	Discussion
17:30	<i>Personalized Medicine: Can the Assembly of Large Data Sets Enable the Development of More Effective Therapies?</i> <b>Prof. Roger Perlmutter</b>   Merck Pharmaceuticals (USA)
18:00	Discussion
18:10	General Discussion
19:00	Dinner at the Casina Pio IV

## TUESDAY 9 APRIL

9:00	<i>The Revolution of Personalized Medicine is Already Upon Us</i> <b>Dr. Christopher Austin</b>   NIH (USA)
9:30	Discussion
9:40	<i>The Personalization of Medicine and the Common Good</i> <b>Prof. Donna Dickenson</b>   Oxford University (UK)
10:10	Discussion
10:20	Coffee Break
10:50	<i>Ethics and Precision Medicine Through Another Prism</i> <b>Prof. Farhat Moazam</b>   Sindh Institute (Pakistan)
11:20	Discussion
11:30	<i>Potential Challenges to Doctor-Patient Trust Posed by Personalized Medicine</i> <b>Dr. Shlomo Cohen</b>   Ben Gurion University (Israel)
12:00	Discussion
12:10	General Discussion
13:00	Lunch at the Casina Pio IV
15:00	<i>Why Does Precision Matter? Personalized Medicine From the Perspective of Public Health</i> <b>Dr. James Wilson</b>   UCL (UK)
15:30	Discussion
15:40	<i>Ethical Issues in Personalised Medicine</i> <b>Prof. Giovanni Boniolo</b>   University of Ferrara (Italy)
16:10	Discussion
16:20	Coffee Break
16:50	<i>Genomics – Problem of Meaning</i> <b>Prof. Jenny Reardon</b>   UC Santa Cruz (USA)
17:20	Discussion
17:30	<i>Individuation, Personalization and Moral Proximity</i> <b>Prof. Michael Barilan</b>   Tel Aviv University (Israel)
18:00	Discussion
18:10	General Discussion
19:00	Dinner at the Casina Pio IV

## WEDNESDAY 10 APRIL

9:00-12:00	Guided visit to the Vatican Museum
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# List of Participants

## **Dr. Christopher Austin**

*Director, National Center for Advancing Translational Sciences, NIH*

## **Prof. Yechiel Michael Barilan**

*Expert in Internal Medicine and Professor in Medical Education, Tel Aviv University | Academic Director of the Event*

## **Prof. Giovanni Boniolo**

*University of Ferrara. Dipartimento di Scienze Biomediche e Chirurgico Specialistiche. PhD in Physics and Philosophy. Prof. of Philosophy of Science and Medical Humanities.*

## **Prof. Joachim von Braun**

*President, Pontifical Academy of Sciences*

## **Dr. Margherita Brusa**

*Academic Coordinator of the Event*

## **Prof. Aaron Ciechanover**

*Israel Institute of Technology*

## **Dr. Shlomo Cohen**

*Senior Lecturer in Philosophy, Ben Gurion University, Israel, Practicing Physician, chair IRB Soroka Hospital*

## **Prof. Donna Dickenson**

*Prof. Emeritus, University of London, Research Associate, HeLEX, Oxford University*

## **Prof. Joseph Fins**

*The E. William Davis, Jr., M.D. Professor of Medical Ethics & Prof. of Medicine; Chief, Division of Medical Ethics Weill Cornell Medical College*

## **Prof. Diego Gracia-Guillén**

*Prof. Emeritus of Ethics and History of Medicine, Complutense University, Madrid*

## **Dr. Leroy Hood**

*SVP and Chief Scientific Officer, Providence St. Joseph Health*

## **Prof. Eric Lander**

*Director of the Broad Institute of MIT and Harvard*

## **Prof. Marianne J. Legato**

*Emerita Professor of Clinical Medicine, Columbia University, and Adjunct Professor of Medicine, Johns Hopkins University*

## **Prof. Farhat Moazam**

*Pediatric surgeon, PhD in Religious Studies (University of Virginia). Chair, Center for Biomedical Ethics and Culture, Sindh Institute of Medical Science, Karachi, Pakistan*

## **Prof. Dianne Nicol**

*Professor of Law, Faculty of Law, University of Tasmania*

## **Dr. Roger Perlmutter**

*Executive Vice President of Merck & Co. President of Merck Research Laboratories*

## **Prof. Barbara Prainsack**

*University of Vienna and Kings College of London*

## **Prof. Jenny Reardon**

*Professor of Sociology, Director, Science and Justice Research Center, University of California, Santa Cruz*

## **H.E. Msgr. Marcelo Sánchez Sorondo**

*Chancellor, Pontifical Academy of Sciences*

## **Dr. James Wilson**

*Senior Lecturer in Philosophy Dep. UCL, Vice-Dean Faculty of Arts and Humanities, Member of the National Data Guardian Panel (UK)*

# Biographies



**CHRISTOPHER P. AUSTIN, M.D.** Director, National Center for Advancing Translational Sciences, National Institutes of Health. Christopher Austin is director of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH). NCATS' mission is to enhance the development, testing, and implementation of diagnostics and therapeutics across a wide range of human diseases and conditions. The Center collaborates with other government agencies, industry, academia, and the nonprofit community. Before joining NIH in 2002, Dr. Austin directed research and drug development programs at Merck, with a focus on schizophrenia. From 2016 to 2018, he served as chair of the International Rare Disease Research Consortium (IRDiRC). He earned his M.D. from Harvard Medical School, and completed clinical training at Massachusetts General Hospital and a research fellowship in genetics at Harvard.



**YECHIEL MICHAEL BARILAN** is a practicing physician, expert in Internal Medicine and Professor of Medical Education in the Sackler School of Medicine, Tel Aviv University. Barilan's research focuses on moral theory, especially the interaction between human rights and constitutional law, on one hand, and medical ethics on the other. He also focuses on the interactions between ethics and the social history of the body. Among his publications are: *Human Dignity*, *Human Rights and Bioethics* (MIT Press, 2012), *Jewish Bioethics* (Cambridge University Press, 2014).



**GIOVANNI BONIOLO** (doctoral degree in Physics and in Philosophy). Full Professor of Philosophy of Science and Medical Humanities (Dipartimento di Scienze Biomediche e Chirurgico Specialistiche, Università di Ferrara). Honorary Ambassador of the Technische Universität München. President of the Accademia dei Concordi (Rovigo). Scientific Director of the Civitas Vitae Research Centre (Padova). Editor-in-chief of History and Philosophy of the Life Sciences. Series Editor of Springer Briefs on Ethical and Legal Issues in Biomedicine and Technology. His work in the fields of the philosophy of biomedicine and its ethical implications is witnessed by 13 books (plus 12 books edited) and about 230 papers most of which in international peer reviewed journals. <http://docente.unife.it/giovanni.boniolo>



**JOACHIM VON BRAUN | PRESIDENT** is considered an internationally leading expert on the problems of hunger and malnutrition and solutions of these problems. His scientific publications address poverty, international development economics, economics of natural resources, agriculture, and science and technology policy. von Braun was Director General of the International Food Policy Research Institute (IFPRI) based in Washington, DC, USA from 2002 to 2009. Since 2009 von Braun is Director of the Center for Development Research (ZEF) and Professor for Economic and Technological Change at University of Bonn, Germany. ZEF is Germany's leading multi-disciplinary research institute on aspects of development. von Braun serves as chair of the Bio-Economy Council of the German Government, and on various international, and European advisory councils. He has had work experience in the following countries: Egypt, Gambia, Guatemala, Rwanda, Sudan, Ethiopia, India, China, Bangladesh, Russia.



**MARGHERITA BRUSA** earned a Degree in Pedagogy and Philosophy from the University of Padua, Master in Bioethics and Phd in Preventive Medicine and Public Health from the University Complutense, Madrid. She earned a second PhD in Epidemiology and Community Medicine from the Department of Pediatrics, University of Padua. She spent a fellowship in bioethics, at Georgetown University, Washington D.C. Margherita has been a member of diverse hospital ethics committees in Spain, Italy, and USA. She also taught and guided the first bioethics committee in the Palestinian Authority, the Caritas Baby Hospital, Bethlehem. She coordinated two Master programs in bioethics, and taught numerous classes to undergraduate, graduate and continuous education programs in medical ethics in Spain, Italy and Israel. She has authored peer reviewed academic publications in Bioethics.



**AARON CIECHANOVER** was born in Israel in 1947. He is a distinguished Professor in the Technion in Haifa, Israel. He received his M.Sc. (1971) and M.D. (1973) from the Hebrew University in Jerusalem, and his Ph.D. from the Technion (1982). There, as a graduate student with Dr. Avram Hershko and in collaboration with Dr. Irwin Rose from Philadelphia, they discovered that tagging of protein substrates with ubiquitin targets them for degradation. Among the many prizes he received are the 2000 Albert Lasker Award, the 2003 Israel Prize, and the 2004 Nobel Prize (Chemistry; shared with Drs. Hershko and Rose). Among many learnt bodies, he is a member of the Israeli National Academies of Sciences and Humanities, the National Academies of Sciences (NAS) and Medicine (NAM) of the USA (Foreign Member), and Chinese Academy of Sciences (Foreign Member).





**SHLOMO COHEN** earned his Medical Doctor degree as well as his PhD in philosophy from the Hebrew University in Jerusalem. He has worked for years as a medical doctor and is now a senior lecturer at the department of philosophy at Ben-Gurion University, specializing in moral philosophy and bioethics. Shlomo's recent publications cover such topics as the limits of moral obligation, the ethics of paternalism and of consent, the ethics of truthfulness and deception, and more. They have appeared in journals such as *European Journal of Philosophy*, *Australasian Journal of Philosophy*, *Bioethics*, and *American Journal of Bioethics*, among others. Shlomo serves as the chairman of the IRB of Ben-Gurion University.



**DONNA DICKENSON** is Emeritus Professor of Medical Ethics and Humanities at the University of London, and Research Associate at the HeLEX Centre, University of Oxford. Previously she was Leverhulme Reader in Medical Ethics and Law at Imperial College School of Medicine, London. For many years she served on the Ethics Committee of the Royal College of Obstetricians and Gynaecologists. She was Principal Investigator of four European Commission projects in such areas as evidence-based medicine and property in human tissue. The author of 25 books and over a hundred academic articles, she has recently published a study of personalized medicine, *Me Medicine vs. We Medicine: Reclaiming Biotechnology for the Common Good* (Columbia University Press, 2013) and a co-edited volume, *Personalised Medicine, Individual Choice and the Common Good* (Cambridge University Press, 2018). In 2006 she became the first woman to win the high-profile International Spinoza Lens Award for her contribution to public debate on ethics.



**JOSEPH J. FINNS**, M.D., M.A.C.P., F.R.C.P. is The E. William Davis, Jr. M.D. Professor of Medical Ethics and Chief of the Division of Medical Ethics at Weill Cornell Medical College where he is a Tenured Professor of Medicine, Professor of Medical Ethics in Neurology, Professor of Health Care Policy and Research, and Professor of Medicine in Psychiatry. He is the founding Chair of the Ethics Committee of New York-Presbyterian Weill Cornell Medical Center where he is an Attending Physician and Director of Medical Ethics. A member of the Adjunct Faculty of Rockefeller University and Senior Attending Physician at The Rockefeller University Hospital, he co-directs the Consortium for the Advanced Study of Brain Injury (CASBI) at Weill Cornell Medicine and Rockefeller. In 2014, he served as the Dwight H. Terry Visiting Scholar in Bioethics and Visiting Professor in the History of Medicine at Yale. In 2015, he was appointed the Solomon Center Distinguished Scholar in Medicine, Bioethics and the Law at Yale Law School. The author of over 350 publications, his most recent book is *Rights Come to Mind: Brain Injury, Ethics and The Struggle for Consciousness* (Cambridge University Press, 2015).



**DIEGO GRACIA-GUILLÉN**, MD, PhD, is a psychiatrist and Emeritus Professor of History of Medicine and Bioethics at the Medical School of the Complutense University of Madrid, Spain. He is Honorary Professor of the School of Medicine of the University of Chile, Lima (Perú) and Cordoba (Argentina). He is also Director of the Department of Public Health and History of Science, and Director of the Masters Degree in Bioethics, Complutense University of Madrid; Director of the Masters Degree in Bioethics, Regional Program of Bioethics for Latin America and Caribbean Countries, Pan American Health Organization, Santiago de Chile; Appointed Member of the Royal National Academy of Medicine of Spain; Fellow of the National Academy of Medicine of Chile; Director of the Zubiri Foundation of Madrid; President of the Board of Trustees of the Foundation for the Health Sciences of Madrid; Director of the Institute of Bioethics of the Foundation for the Health Sciences of Madrid; Fellow of the Hastings Center (New York).



**LEROY HOOD** got his degrees from Johns Hopkins (MD) and Caltech (PhD). He was a faculty member at Caltech (1970-1992) and University of Washington (1992-2000). He founded the first cross-disciplinary department of biology at the UW and in 2000 co-founded the independent Institute for Systems Biology—the first academic systems biology organization. He has pioneered important technologies in genomics, proteomics, and single-molecule analyses. He is a member of all 3 US national academies—science, medicine and engineering. More recently, he has formulated the idea that healthcare should be predictive, preventive, personal and participatory (P4). He conceptualized deep phenotyping to measure the complexity of individual humans and has pioneered scientific wellness—all leading to revolutionary 21<sup>st</sup> century medicine.



**ERIC LANDER** is president and founding director of the Broad Institute of MIT and Harvard. A geneticist, molecular biologist, and mathematician, he has played a pioneering role in the reading, understanding, and biomedical application of the human genome. He was a principal leader of the Human Genome Project. Lander is professor of biology at MIT and professor of systems biology at Harvard Medical School. From 2009 to 2017, he served as co-chair of the President's Council of Advisors on Science and Technology. Lander's honors include the MacArthur Fellowship, Gairdner Foundation Award, Dan David Prize, and Breakthrough Prize in Life Sciences.



**MARIANNE J. LEGATO**, M.D., Ph.D. (hon c), F.A.C.P., is an internationally known academic physician, author, lecturer, and specialist in gender-specific medicine. She is an Emerita Professor of Clinical Medicine at Columbia University and an Adjunct Professor of Medicine at Johns Hopkins Medical School. She received an honorary PhD in 2015. Doctor Legato has established the not-for profit Foundation for Gender-Specific Medicine, which is dedicated to the support of gender-specific biomedical investigation and educational outreach to both the lay and scientific communities. She is the editor of the first textbook on gender medicine, *Principles of Gender-Specific Medicine*, published for the scientific community by Elsevier in 2004. The second edition appeared in 2010. The third edition of the textbook, *Principles of Gender-Specific Medicine: Gender in the Genomic Era*, won an international competition (The Prose Award 2018) with over 15,000 entries for the best book in clinical medicine published in 2017. She is the founder and editor in chief of *Gender and the Genome*. The journal launched in 2017 and is published by SAGE. Dr. Legato spent her research career doing cardiovascular research on the structure and function of the cardiac cell. The American Heart Association and the National Institutes of Health supported her work. She won the Murray Steele Award, the Martha Lyon Slater Fellowship, and a four-year Senior Investigator Award from the American Heart Association, New York Affiliate. She won a coveted Research Career Development Award from the National Institutes of Health and has been a member both of the National Heart Lung and Blood Institute's study section on cardiovascular disease as well as the Basic Science Council of the American Heart Association. Dr. Legato served as a charter member of the Advisory Committee to the National Institute of Health's Office of Research on Women's Health from 1995 to 1998, and was the co-author of their Task Force Report on Women's Health.



**FARHAT MOAZAM**, M.D., FACS, PhD is currently Professor and Founding Chairperson of the Centre of Biomedical Ethics and Culture (CBEC), SIUT in Karachi, Pakistan. She is a pediatric surgeon with an MA in Bioethics and a Doctorate in Religious Studies from the University of Virginia, USA. Previously, Dr. Moazam was Professor and Founding Chairperson of the Department of Surgery and the first Associate Dean of Postgraduate Medical Education, Aga Khan University (AKU), Karachi. Dr. Moazam is Fellow of the Institute of Practical Ethics and Visiting Professor, Centre for Humanism in Medicine, UVA, and International Fellow of The Hastings Center, New York. She has an Honorary Doctorate from the University of Zurich, Switzerland, in 2012 for her contributions towards ethics and organ transplantation. She has served on the Board of Directors (2009-2014) of the International Association of Bioethics, and collaborates with WHO on ethics related projects. Dr. Moazam has authored multiple articles related to surgery, medical education, and bioethics in international journals that include *The Cambridge Quarterly of Healthcare Ethics*, *Journal of Clinical Ethics*, *The Hastings Center Report*, *Asian Bioethics Review*, *Journal of Middle Eastern and South Asian Studies*, *Bioethics*, and *Journal of Medical Health and Philosophy*.



**DIANNE NICOL** is a professor of law at the University of Tasmania in Australia and director of the Centre for Law and Genetics (CLG), which is housed in the Law Faculty. The broad theme of the CLG's research is the regulation and governance of biotechnology, human genetics and genomics and stem cell technology. Dianne's current research focuses primarily on the regulation and governance of personalized medicine, biobanking, genome editing and other emerging technologies, together with commercialisation of biotechnology and patenting of biotechnological inventions.



**ROGER M. PERLMUTTER**, M.D., Ph.D. (Executive Vice President and President, MRL, Merck & Co., Inc., Kenilworth, N.J., USA) has led Research and Development at Merck & Co. since 2013. He is an MD/PhD graduate of Washington University in St. Louis, pursued clinical training at the Massachusetts General Hospital and the University of California, San Francisco, and was a Lecturer in Biology at Caltech before joining the University of Washington, where he was Professor of Medicine and Biochemistry, Chairman of the Department of Immunology, and an Investigator of the Howard Hughes Medical Institute. He previously served as Executive Vice President R&D at Amgen, Inc, and is currently Chairman of the Board of Trustees of Reed College (BA, '73).



**BARBARA PRAINSACK** is a Professor at the Department of Political Science at the University of Vienna, and at the Department of Social Science, Health & Medicine at King's College London. Her work explores the social, regulatory and ethical dimensions of biomedicine and bioscience. Her current research projects focus on personalised and "precision" medicine, on citizen participation in science and medicine, and the role of solidarity in medicine and healthcare. Her latest books include: *Personalized Medicine: Empowered Patients in the 21st Century?* (NYU University Press, 2017); *Solidarity in Biomedicine and Beyond* (with Alena Buyx, Cambridge University Press, 2017), and *Genetics as Social Practice* (ed. with Silke Schicktanz and Gabriele Werner-Felmayer, Routledge, 2014). Barbara Prainsack is a member of the Austrian National Bioethics Committee advising the federal government in Vienna, the European Group on Ethics in Science and New Technologies advising the European Commission, and she chaired the European Science Foundation's (ESF) *Forward Look on Personalised Medicine for the European Citizen* (2011-2012, with Stephen Holgate and Aarno Palotie). She is also a member of the British Royal Society of Arts, and an elected foreign member of the Danish Royal Academy of Sciences and Letters. She can be reached at [barbara.prainsack@univie.ac.at](mailto:barbara.prainsack@univie.ac.at).



**JENNY REARDON** is Professor of Sociology and the Founding Director of the Science and Justice Research Center at University of California, Santa Cruz. Her training spans molecular biology, the history of biology, science studies, feminist and critical race studies, and the sociology of science. She is the author of *Race to the Finish: Identity and Governance in an Age of Genomics* (Princeton University Press, 2005) and *The Postgenomic Condition: Ethics, Justice, Knowledge After the Genome* (Chicago University Press, 2017).



**MARCELO SÁNCHEZ SORONDO | CHANCELLOR** was born in Buenos Aires and was ordained a priest in 1968. He was lecturer in the history of philosophy at the Lateran University in Rome where he became full professor. He was dean of the Faculty of Philosophy at the same university and full professor of the history of philosophy at the Libera Università Maria SS. Assunta, Rome. In 1998 he was appointed Chancellor of the Pontifical Academies of Sciences and Social Sciences by St John Paul II, who then consecrated him titular Bishop of Vescovio. Awards: Cavaliere di Gran Croce (Italy); official of honour of the Légion d'Honneur (France); Grão Mestre da Ordem de Rio Branco (Brazil), Official of the Republic of Austria, Knight of the Republic of Chile, Member of Accademia dei Gergofili, Member of the Accademia Italiana del Vino; Corresponding Member of the Academia de Ciencias de Cuba; Orden del Aguila Azteca (Mexico); Innovation Award of the Gregor Mendel Foundation.



**JAMES WILSON** has been based at UCL since 2008, first as Lecturer in Philosophy and Health, and then as Senior Lecturer in Philosophy. He is Vice-Dean (Interdisciplinarity) for the Faculty of Arts and Humanities, and co-director of the UCL Health Humanities Centre. Much of Wilson's most recent research has focused on problems which arise from the intersection of his work on health and autonomy, with the ethics and governance of confidential information. This is a growing area of concern, as there is wide agreement that (1) future of medicine requires much greater access to patient data, and (2) this needs to be arranged in a way that does not violate the expectations of patients and broader citizens. The principles by which this should be done are still up for grabs. His roles outside of UCL include: Associate editor of Public Health Ethics (since 2015), Independent member of the NHS Digital Data Access Advisory Group (2015-18), and Member of the National Data Guardian's Panel (2016--).

## Memorandum

- ▶ Pickup schedule from your hotels to the Casina Pio IV on 8 and 9 April 2019:
  - A bus will leave the Casa Bonus Pastor at 8.30 a.m. to accompany participants to the Academy's Headquarters, the Casina Pio IV;
  - Another bus will leave the Domus Sanctae Marthae at 8.45 a.m.
- ▶ On 8 and 9 April the same buses will take you back to your hotels after dinner (at about 8:00 p.m.)
- ▶ Lunch and dinner for the participants will be served at the Academy every day. If you are a vegetarian or have any dietary restrictions (food allergies, and/or religious restrictions), please let us know as soon as possible.
- ▶ Wifi credentials:  
Network: **WLAN\_PADS (WPA2)**  
Password: **!!WIFI\_2017\_PADS!!**



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