LISTEN. UNDERSTAND. ACT.
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Dear Friends and Colleagues,

What should happen when one encounters high-stakes “never-befores” that offer enormous benefits yet could also bring about great harm? Our strategy is a three-fold response: Listen. Understand. Act.

This response is the theme of our 2016 annual report:

• Cheaper and easier genome modification offers unprecedented power and control over ourselves and our environment; we undertook projects to assess and clearly articulate the moral stakes, and we developed recommendations for responsible research.

• Advancing artificial intelligence could lead to valuable new tools and to new dangers; we assembled experts to explain, to each other, where the technology is going and what needs to be done to make sure that AI incorporates—perhaps even “learns”—human values.

• Increased longevity is upending world population demographics, resulting in new levels of older people in need of care and social connection; we are convening experts across disciplines that rarely interact and recommending major reforms in social priorities and reimbursement practices.

In our highly polarized society, challenged by transformative technological and social developments, listening has never been more important. We bring together people who disagree with one another and orchestrate a productive interchange. Our listening is not passive; it is robust engagement and respectful dialogue. It leads to understanding and action. We seek consensus where possible, and when that is not possible, we clarify commonalities as well as differences. Our resulting publications, presentations, and other activities help scientists, scholars, policy-makers, journalists, and the public listen to one another, understand these issues, and act on them.

On the pages of this annual report, you will, for example, read about interviews Sarah McGraw, an anthropologist on our staff, conducted with NFL football players and their families about the health effects of their football careers, as well as the listening Hastings is doing to hear from experts across diverse disciplines—from architecture to gerontology—about how to build a society capable of supporting a huge number of older people. You will read about our scholars’ recommendations for ensuring the wise use of genome modification in humans and in animals and plants in the wild, and about policy recommendations offered to the mayor of New York City to enhance health care for undocumented immigrants.

The Hastings Center’s goals across these contexts are respect, compassion, justice, and promotion of human flourishing. Our way of getting there is—to listen, to seek understanding, and to encourage action. In these times, our society more than ever needs a respectful approach to problem-solving. I am deeply proud of our achievements.

Thank you for being a part of our community, striving so hard to create respectful spaces for authentic dialogue, smart analysis, and action-oriented results.

Yours sincerely,

Mildred Z. Solomon

President and CEO
How might the use of gene editing in humans affect core human values such as love, compassion, acceptance, and respect for those with disability? That question is at the heart of a major international project that The Hastings Center began in 2016 with support from the John Templeton Foundation. It is focusing on the social and ethical implications of using powerful gene editing methods on human germline cells—sperm, eggs, and embryos. Such methods would create permanent changes passed on from one generation to the next. These technologies have raised unprecedented hopes for benefiting human health, but they also pose such profound safety and ethical questions that, in 2015, some of the scientists who developed CRISPR-Cas9 called for a moratorium on its use in humans, providing time to consider whether and how to deploy it.

Leading the Hastings Center’s project are Erik Parens, a senior research scholar, and Josephine Johnston, director of research. Co-investigators are Gregory Kaebnick, a research scholar, and Mildred Solomon, the president.

An early takeaway from the project is that it will require more than genetic technologies alone—no matter how powerful and miraculous—to enable people to flourish. We also need to respect people with whatever genomes they’re born with, have the courage to set limits on uses of human gene editing that could impede human flourishing, and build public health and social policies that support healthy human development.

During 2016, the project developed original research on ethical dilemmas posed by human gene editing and designed education initiatives for journalists and teachers. These include a scholarly book; a symposium we planned for the 2017 annual meeting of the American Association for the Advancement of Science, the world’s largest multidisciplinary scientific society; and major journalism workshops designed for the 2017 annual meeting of the Association of Health Care Journalists and the 2017 World Conference of Science Journalists.

The proliferation of these technologies could exacerbate the already obscene gap between the haves and have nots.
—Erik Parens, senior research scholar, addressing the National Academy of Science, Medicine and Engineering, July 2016
What Will It Take to Ensure that AI is Beneficial to Humanity?

Seeking answers to that question drives The Hastings Center’s project, “Control and Responsible Innovation in the Development of Autonomous Machines,” led by Wendell Wallach, a senior advisor, and supported by the Future of Life Institute funded by Elon Musk.

The AI project is developing a comprehensive plan to ensure that autonomous systems will be demonstrably beneficial, and that this innovative research progresses in a responsible manner. Wallach is the co-chair of the World Economic Forum’s Global Council on Technology, Values and Policy, and Mildred Solomon is a member. The council focuses on how values that represent the global public interest can be incorporated into AI technologies and into international oversight of emerging technologies.

In December 2016, The Hastings Center organized a public event in New York about the social and ethical implications of AI. Solomon moderated a roundtable discussion, which included Wallach and two working group members who are among the world’s most prominent robotics scientists —Mary (“Missy”) Cummings, of Duke, and Illah R. Nourbakhsh, of Carnegie Mellon. (See page 15)
In 2016, Hastings Center research methodologist Sarah McGraw conducted one-on-one interviews with 25 current and former NFL players and 27 of their relatives about their health and other aspects of their lives. Her research was a key component of the Law and Ethics Initiative of the groundbreaking Football Players Health Study at Harvard University, an independent research study working to understand the medical, legal, and ethical issues that promote and impede player well-being. The law and ethics initiative, led by I. Glenn Cohen of Harvard Law School, who is a Hastings Center Fellow, began in 2014 in part through an award from the National Football League Players Association and with funds allocated for research by the players’ collective bargaining agreement.

“The goal of my work was to better understand how careers in the NFL affect the players and their families and what can be done to improve their lives,” says McGraw. “The players and their families were amazingly frank.” They talked about injuries and pain, experiencing depression, and financial pressures. McGraw’s findings point to the need for players and their families to have access to a variety of professionals, including mental health professionals, that is confidential and as free as possible of conflicts of interest.

Writing in the November 2016 Hastings Center special report, *NFL Player Health: The Role of Club Doctors*, authors I. Glenn Cohen, Holly Fernandez Lynch, and Christopher R. Deubert, all of Harvard University, examined an important theme, first identified in a larger Harvard report they produced. How can players be protected from professional conflicts of interest among club doctors, who care for players but work for team owners? They concluded that conflicts of interest are inherent to the current structure of the relationship between football players and club doctors, and they recommended that ties between the club doctors and the club be largely severed and that the doctor’s role be refashioned “into one of singular loyalty to the player-patient.”


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*Increasing Access to Trustworthy Health Care

Football is America’s game, but the potential health consequences of the sport are increasingly taking center stage. From major media outlets to federal research funding to conversations among concerned spectators and parents, we are at a moment of unprecedented focus on the potential health consequences, and especially the neurological consequences, of playing football.*

—I. Glenn Cohen, Holly Fernandez Lynch, and Christopher R. Deubert, guest editors and authors of the lead article in The Hastings Center’s special report, *NFL Player Health: The Role of Club Doctors, November 2016*
Health Care Access for Undocumented Immigrants

In spring 2016, New York City Mayor Bill de Blasio accepted recommendations made by Hastings Center scholars research Nancy Berlinger and Michael Gusmano and colleagues at the New York Immigration Coalition. They called for a networked primary care medical home system for uninsured immigrants.

Nursing, Ethics, and Health Policy

This Hastings Center special report, published in September 2016, emphasizes the historical and potential role of nurses and nursing in the development of ethical health policy.

Leaders in nursing and nursing education praised the report, calling it “pioneering (and so badly needed)” and referencing it in professional publications.


This book offers extensive recommendations for health care leaders on addressing common ethical challenges.
Precaution in the Implementation of Emerging Technologies

We humans tend to think in binaries: proceed or stop! Advances in biomedical technologies tend to heighten that natural tendency, so that we find ourselves divided between those who are pro and those who are con on a wide range of topics, from genetically modified foods to the development of human-animal chimeras. But wisdom, as Aristotle reminded us, is often about finding a middle way.

In 2016, The Hastings Center was influential in searching for a middle way on many new transformative technologies—advancing the use of those technologies while offering guidance on how to do so carefully.

With support from The Hastings Center’s Boger Initiative for the Wise Use of Emerging Technologies, Greg Kaebnick, who heads our Humans and Nature program area, spent part of 2016 serving on a special committee of the National Academies of Sciences, Engineering and Medicine (NASEM).

The committee was tasked with analyzing whether, and if so, how, to proceed with the testing and development of a technology called gene drives. Gene drives make changes to the genome of an organism in a way that, in principle, can be “driven” through a whole species, radically overriding the rules of Mendelian inheritance. When used in combination with CRISPR-Cas9 and other techniques, gene drives can alter, reduce, and even eliminate whole populations of organisms in the wild.

The benefits could be enormous. Imagine, for example, eradicating or modifying the mosquitoes that transmit malaria, dengue fever, and Zika.

But the risks are also real. How might the alteration of a species in the wild affect other animals or the ecosystem as a whole?

In June 2018 NASEM issued a report, Gene Drives on the Horizon: Advancing Science, Navigating Uncertainty and Aligning Research with Public Values, which calls for moving forward with research on gene drives, but it lays out a controlled and mindful approach that includes carefully constructed field trials in geographically bounded areas, ecological risk assessments, and a phased pathway that allows research to move forward in steps, making it possible to learn about a proposed use and modify plans.

Soon after the report was published, the Bill and Melinda Gates Foundation indicated that it will follow NASEM’s guidance. The foundation is planning field trials that will use gene drives to suppress mosquitoes carrying malaria in selected field sites in Africa.
Critics can hold exaggerated risks and create barriers to scientific advances. Such skeptics are sometimes criticized for stimulating “risk panics” that get in the way of scientific progress. But the thrill of designing biological systems is, well, thrilling, and it too can create another kind of problem, something we called an “innovation thrill” in our article in Science. Precaution is a middle way. It need not lead to moratoria. Indeed, it often goes hand in hand with advancing the science. It just asks that we do it with care and forethought. —Gregory Kaebnick, research scholar and lead author of an article in Science, November 11, 2016
In the Genomic Age, Knowledge is Power. . .or Is It?

American bioethics, and indeed, American culture, values knowledge, not least because it enhances choice and the personal freedoms that come from it. But can there be too much knowledge? Where is the line between knowledge and too much information?

This question becomes salient in the genomic era we have entered. With cheap and easy genome sequencing, we are now able to gather a great deal of information. However, much of it is highly uncertain, even uninterpretable, and gives rise to serious questions about what information should be routinely collected and offered to patients. Nowhere is this issue more critical than in the context of pregnancy care.

Until recently, prenatal genetic tests could look for relatively small number of disorders including Down syndrome. New prenatal genetic tests—some as simple as a maternal blood draw—will soon enable prospective parents to learn far more, far earlier than ever before about their fetuses’ medical conditions and risks, and some nonmedical traits. This information could lead to life-saving treatments for medical conditions. But it also points to a future in which prospective parents are inundated with a large amount of information about their fetuses, including the genetic risk of adult-onset conditions, and nondisease traits possibly associated with intelligence or athletic ability.

In 2016, The Hastings Center began a major three-year project, funded by the National Institutes of Health, to consider how best to deploy these new prenatal tests. Among the questions being explored:

• What should be tested for?
• Are there traits that the tests should not be used to investigate?
• What are the implications for the rights of people with disabilities?
• What policy changes are needed to support ethical use of these tests?

Josephine Johnston, director of research, is heading the project, which includes leaders of major medical societies, researchers, and patient representatives. They are developing recommendations on what should be tested for and how such testing should be offered, integrated into clinical care, and supported by public policy. Johnston also oversees our Children and Families program area.

Advances in genomics, including new gene editing technologies, would offer prospective parents an enormous amount of information about—the genetic make-up of their children. How can prospective parents use these new powers in ways that help them and their families to flourish, without eroding shared commitments to freedom and equality? —Josephine Johnston, director of research and leader of a Hastings Center project on next-generation prenatal genetic tests
The field of prenatal genomic sequencing is rapidly advancing, and much of what is being identified is of uncertain significance given the immaturity of the field and the limited available clinical data. We health care practitioners are wrestling with what information should be given to couples and how certain we should be of the results we share. The Hastings Center’s work in prenatal genomics is providing invaluable input to this discussion. —Wendy Chung, MD, PhD, Herbert Irving Associate Professor of Pediatrics and Medicine, Columbia University College of Physicians and Surgeons and a member of The Hastings Center’s advisory council
Population aging is raising profound questions at every level of American society. They go far beyond the traditional questions of health care ethics—beyond treatment decisions at the bedside—to community decisions in neighborhoods and counties, as well as at state and federal levels. By 2035, one in three households will be led by someone over age 65, often someone living alone and with frailty. By 2050, 16 million Americans will be living with Alzheimer’s disease. How should housing and community services be reconfigured to serve their needs? What supports should a just and compassionate society provide older people and their family caregivers? How should health spending be redesigned?

In 2016, with generous support from the Robert Wilson Charitable Trust, The Hastings Center took a fresh look at our program area, Aging, Chronic Conditions, and End of Life. We launched a two-year process to build a bigger bioethics, extending the boundaries of our field so it can influence thought, practice, and policy for an aging society, including its social as well as medical needs.

We are involving experts from housing policy, planning, urban design, social gerontology, and other fields and bringing them together to identify how best to enhance the flourishing and welfare of older Americans. Codirected by Nancy Berlinger who heads our Aging, Chronic Conditions, and End of Life program area, and by Mildred Solomon, the project’s goal is to create a blueprint for the next generation of Hastings research and public engagement activities on behalf of older Americans.

Recognizing Physicians for Exemplary Care

The Hastings Center Cunniff-Dixon Physician Awards recognize doctors in the United States who give exemplary care to patients near the end of life. In 2016, awards totaling $95,000 were given to five physicians who advance the practice of palliative care, model outstanding skill and compassion, and promote justice by reducing racial and ethnic disparities in end-of-life care.
Hastings Responds to the Severe Shortage of Palliative Care Physicians

With major funding from the Milbank Foundation and additional support from the Donaghue Foundation, Hastings reached out to the Society of Hospital Medicine (SHM), the membership society of the nation’s hospitalists. Together, we built new clinical strategies to ensure advance care planning for all seriously ill patients and their families.

Hospitalists are the physicians who direct most of the care when someone is admitted to a hospital. They are the fastest growing medical specialty in the nation; currently SHM has 30,000 hospitalist members.

This project created new hospital routines to ensure that hospitalists would recognize patients for whom it would be important to initiate conversations about goals of care and a suite of learning materials, now housed on the SHM website. Harnessing hospitalists in this way builds what many experts are now calling for: primary care palliative care, not dependent strictly on board-certified palliative care physicians whose numbers are sorely restricted.

The Hastings Center-SHM pathway was awarded a blue-ribbon award at the National Seminar of the Center to Advance Palliative Care (CAPC) in October 2016.

Advising Thought Leaders on Big Ideas to Transform End-of-Life Care

Hastings Center President Mildred Solomon was one of four national experts invited to advise the Aspen Health Strategies Group (ASHG), formed by the Aspen Institute, on ways to improve the care of people nearing the end of life. The AHSG was chaired by two former U.S. Secretaries of Health and Human Services, Kathleen Sebelius and Tommy G. Thompson. The group produced five “big ideas” for transforming this care. The report is available at https://assets.aspeninstitute.org/content/uploads/2017/02/AHSG-Report-Improving-Care-at-the-End-of-Life.pdf)
Our Scholars and Projects at a Glance

HEALTH AND HEALTH CARE

- Ethical Issues in Prescription Drug Access Under Restricted Distribution Programs • Sarah McGraw (Greenwall Foundation under subcontract from Brigham and Women’s Hospital)
- Governance of Learning Activities in Learning Health Care Systems • Sarah McGraw and Mildred Solomon (Patient Centered Outcomes Research Institute under subcontract from University of Pennsylvania)
- The Battle Over Evidence: Medicare and the Fight for Evidence-Based Medicine • Karen Maschke and Michael Gusmano (Gaylin Fund)
- The Football Players Health Study at Harvard University, Law and Ethics Initiative • Michael Gusmano, Karen Maschke, and Sarah McGraw (National Football League Players Association under subcontract from Harvard Medical School)
- The Selfhelp Virtual Senior Center Initiative • Michael Gusmano (Selfhelp Community Services, Inc.)

CHILDREN AND FAMILIES

- Goals and Practices for Next-Generation Prenatal Testing • Josephine Johnston (National Institutes of Health/National Human Genome Research Institute)
- Sequencing of Newborn Blood Spot DNA to Improve and Expand Newborn Screening • Josephine Johnston and Erik Parens (National Institutes of Health under subcontract from University of California, San Francisco)

AGING, CHRONIC CONDITIONS, AND END OF LIFE

- Improving End-of-Life Care in the Hospital • Nancy Berlinger (Milbank Foundation)
- Making Difficult Decisions with Patients and Families: A Singapore Casebook 2nd Edition • Nancy Berlinger and Michael Gusmano (Lien Foundation under subcontract from National University of Singapore)
- Reaching Non-Self-Identifiers in End-of-Life Care: Resolving Uncertainty and Improving Practice Among Hospital Clinicians Across Teams and Shifts • Nancy Berlinger (Donaghue Foundation)
- The Last Stage of Life: A Planning Process for The Hastings Center’s Program Area on Aging, Chronic Conditions, and End of Life • Mildred Solomon and Nancy Berlinger (Robert Wilson Charitable Trust, and the Boger, Callahan, and Gaylin Funds)
- The Use of Whole-Exome Sequencing to Guide the Care of Cancer Patients • Sarah McGraw (National Institutes of Health under subcontract from University of Pennsylvania)

SCIENCE AND THE SELF

- Advancing Collaborative Genetic Research: Ethical and Policy Challenges • Karen Maschke (National Institutes of Health under subcontract from Case Western University)
- Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral (PNB) Genetics • Erik Parens and Josephine Johnston (National Institutes of Health under subcontract from Columbia University Medical Center)
- Control and Responsible Innovation in the Development of Autonomous Machines • Wendell Wallach (Future of Life Institute)
- Gene Editing and Human Flourishing • Erik Parens and Josephine Johnston (John Templeton Foundation)
- Le Bonheur Children’s Hospital Biorepository and Integrative Genomics (BIG) Initiative • Karen Maschke (University of Tennessee Health Science Center)
- The Boger Initiative for the Wise Use of Emerging Technologies • Mildred Solomon (Joshua Boger)
- The Moral Psychology of Moral Disagreement: Can Science Help Bioethicists Better Understand and Manage Our Disagreements? • Erik Parens (Chuck Kahn and Nancy Maruyama)

HUMANS AND NATURE

- Values in Impact Assessment • Gregory Kaebnick, Michael Gusmano, and Karen Maschke (National Science Foundation)

EDUCATION

- The Bioethics Project: A Bioethics Research Program for High School Students • Josephine Johnston (Kent Place School)
- The Hastings Center Bioethics Briefings • Susan Gilbert (private donor)
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Each year The Hastings Center welcomes dozens of students, postgraduates, doctors, and scholars from around the world who seek to deepen their understanding of bioethics. Some come as guests to attend lunch talks. Others apply to our visiting scholars program to pursue independent research in bioethics. In 2016, our visiting scholars program accepted 27 people from across the United States, as well as Norway, Japan, Sweden, the U.K., Chile, and Singapore. In addition, we hosted our annual summer bioethics institute for Yale students as part of the Yale-Hastings Program in Ethics and Health Policy.
High school students attended a summer program on bioethics at The Hastings Center as part of an ongoing high school bioethics research program organized by Hastings and the Ethics Institute at Kent Place School in Summit, N.J. The theme for 2016 was medical decision-making and the human lifespan. The program, led by Hastings Center director of research Josephine Johnston, was open to students from all local New Jersey high schools.
Moral Psychology and Bioethics

Cognitive neuroscientist Martha Farah presents an overview of the subject.

Left: Hastings cofounder Daniel Callahan asks a question; below: Hastings senior research scholar Erik Parens speaks on the moral psychology of moral psychologists.

Above: Philosopher Natalia Washington presents while Hastings president Mildred Solomon looks on.

Hastings director of research Josephine Johnston and keynote speaker Jonathan Haidt.

The title of Hilde Lindemann’s talk poses an intriguing question.

Ethicist James Childress on what bioethics can learn from moral psychology.
How should bioethicists use insights from moral psychology? That question animated a daylong public symposium organized by The Hastings Center in New York on May 19, with the generous support of Charles Cahn and Dr. Nancy Maruyama to honor Hastings cofounder Willard Gaylin. Bioethicists have traditionally assumed that reason drives their conclusions and that, when presented with those reasoned conclusions, others will change their behavior, practices, and policies. Findings from moral psychology suggest that those assumptions exaggerate the power of reason and underestimate the power of intuition.

The Hastings Center’s symposium included leaders in bioethics, neuroscience, and medicine and featured a talk by Jonathan Haidt, a social psychologist who is a professor at New York University and author of the bestselling book The Righteous Mind: Why Good People are Divided by Politics and Religion.
The Hastings Center’s advisory council provides guidance about how best to ensure the impact of our work, particularly our impact in the public square. The council’s meetings are held twice a year often in tandem with meetings of our board of directors to foster communication between these groups. The topic of the event in April 2016 was “How to Protect Yourself and Your Loved Ones When Death Is Near. Hint: It’s Not Death Panels.” The event in October was “When Values Collide: Making Public Policy in a Diverse Society.”
Above: President Mildred Solomon, board member Bradford Gray, advisory council member James Corbett, and research scholar Nancy Berlinger

Left: The April advisory council meeting featured a presentation by Corinne Carey of Compassion & Choices.

Right: Board member Frank Trainer

Below: Board member Gil Omenn

Left: Director of research Josephine Johnston and board member Peter Canellos

Board member Michael Roth

Board member Liza Bailey

Left: President Mildred Solomon with advisory council members Jean Reid and Sissela Bok

Advisory council member John Usdan

Right: Board member Andy Adelson

2016 HASTINGS CENTER EVENTS

- April 21
  How to Protect Yourself and your Loved Ones When Death Is Near. Hint: It’s not Death Panels

- May 19
  Bioethics Meets Moral Psychology

- September 26
  Enhancing End-of-Life Care: Where Do We Go from Here?

- October 13
  When Values Collide: Making Public Policy in a Diverse Society

- October 19
  Human Genetic Engineering: What Can We Do? What Should We Do?

- December 9
  Can We Keep Artificial Intelligence Safe, Controllable, and Beneficial?
STATEMENT OF FINANCIAL POSITION

As of December 31, 2016  Audited

Assets
Cash and Equivalents  760,828
Investments, at fair value  6,707,427
Receivables (grants and other)  964,165
Other Assets  57,867
Furniture and Equipment (net of accumulated dep)  32,404
Leasehold Improvements (net of accumulated amort)  987,383
Total Assets  9,510,074

Liabilities and Net Assets
Payables and Accruals  94,429
Deferred Compensation Payable  253,492
Deferred Revenue  29,991
Total Liabilities  377,912
Net Assets  9,132,162
Total Liabilities and Net Assets  9,510,074

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

Operating revenues and other support:
Grants, Gifts, and Contributions  2,287,211
Government Grants  780,174
Publication Revenue  399,832
Other income  101,702
Total Unrestricted Operating Support and Revenue  3,568,919

Operating Expenses
Program Services  2,777,373
Management and General  460,664
Fund Raising  254,597
Total Operating Expense  3,492,634

Changes in Net Assets from Operations  76,285
Non-operating Income  264,407
Change in Net Assets  340,692
Net Assets, Beginning of year (as restated)  8,791,470
Net Assets, End of year  9,132,162

Operating Revenue and Support
For the year ended 12/31/16 = $3,568,919

Investments & Other Income $101,702
Grants $1,460,777
Unrestricted Contributions $1,606,608
Publications $399,832

Operating Expenses
For the year ended 12/31/16 = $3,492,634

Fundraising $254,597
Management & General $460,664
Program Services $2,777,373

As of December 31, 2016           Audited
The Hastings Center addresses fundamental ethical and social issues in health care, science, and technology. Through our scholars’ writing and speaking, and through the work of the many other people who participate in our projects or submit articles to our publications, we shape ideas that influence key opinion leaders, including health policy-makers, regulators, lawyers, legislators, and judges. Our analyses also deeply influence professional practice: from end-of-life care to psychiatry to immigrant health care, we have helped to shape the standards of practice adopted by physicians, nurses, and lawyers. Founded in 1969 by philosopher Daniel Callahan and psychiatrist Willard Gaylin, The Hastings Center is the oldest independent, nonpartisan, interdisciplinary research institute of its kind in the world.

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