

## “Without research, there is no hope”

*Medical researchers have a moral responsibility to communicate their findings to the public*

There is no greater commitment than a government's investment in the healthcare of its citizens. If we, as medical researchers and practitioners, are to preserve public trust and support for our scientific enterprise, we need to pay more attention to translating the benefits and grandeur of science into the common language of the general community.<sup>1</sup> Although educators and journalists also communicate the achievements of medical science, doctors and scientists have a greater responsibility to increase the availability and salience of science to the public. I believe we can move further towards realising this goal by keeping several key questions in our minds.

***How have and how can biomedical breakthroughs benefit humanity?*** The development of vaccines and immunotherapies is at the top of my list of major medical advances that have changed humanity's lot for the better. During the past year, the medical crises created by epidemics of Ebola virus and SARS have demanded the creation of new vaccines, which are now poised for clinical trials.<sup>2</sup>

Other developments in medicine include antibiotics to combat infection, organ transplantation to extend life, high resolution imaging that has reduced the number of invasive surgical procedures and, most recently, the global Human Genome Project, which is revealing secrets about the basis of life.

In April 2003, the world simultaneously celebrated the 50th anniversary of Watson and Crick's description of the DNA double helix and the International Human Genome Sequencing Consortium's completion of the human genome sequence. However, the completion of the human genome sequence represented only the

beginning in genomics research; it has led to the unveiling of a bold new vision for its future.<sup>3</sup>

Translating genome-based knowledge into health benefits will be a major focus of future genomics research. Virtually all diseases, with the exception of trauma, have a genetic component and an environmental component. One of the projected outcomes of the Human Genome Project is the development of personalised medicine. All patients who share the same diagnosis for a certain disease do not respond the same way to treatment. In some cases, we are already able to determine, based on genetic profiles, which patients will be responsive to specific drugs, and then to specifically deliver the most appropriate to eradicate the disease.<sup>4</sup>

We have entered a new era of multigeneration, population-based research. This will facilitate innovative genetic studies to identify the paediatric precursors of specific adult diseases, based on the comparative analyses of genetic profiles of children, their parents, and grandparents. Imagine the possibility of identifying genes in newborns responsible for cardiac disease, or diabetes, or arthritis, or specific cancers — and then managing and/or preventing the onset of these diseases. The overall improvement in quality of life would be extraordinary, and we are closer than you might think to achieving this goal.

Many scientists have suggested the concept of newborn genetic “passports” in which the complete genetic profiles of newborns will be documented in medical files at birth. On the one hand, this sounds quite exciting, but the social implications are profound. As doctors and scientists, we must act now and we must act together

to establish rigorous guidelines and boundaries for the use of genetic informatics with respect to:

- health insurance;
- genetic information and the workplace;
- genetic privacy and confidentiality; and,
- the forensic use of genetic information.

Accordingly, the US National Human Genome Research Institute in Bethesda, Maryland, has developed the Ethical, Legal and Social Implications Research Program to ensure that genetic research is conducted in an ethically sound manner; that genetic technologies are integrated appropriately into clinical and non-clinical settings; that genetic information is correctly interpreted and appropriately used; and that health professionals and the public become more genetically literate.<sup>3</sup>

**How important is advocacy in supporting the mission of research and addressing critical social issues?** John Porter, former Illinois Congressman and Chairman of the US Subcommittee on Labor, Health and Human Services, and Education, stated:

Since most members of Congress are not scientists, citizen scientists must individually inform, educate, inspire, and direct their representatives regarding public policy decisions affecting science.<sup>4</sup>

When Americans were polled by Research!America about who they believe should have the most influence on how government medical research funds are spent, they indicated that patients (first) and scientists (second) should have the most influence.<sup>4</sup> (Research!America is a not-for-profit, membership-supported public education and advocacy alliance for medical and health research.)

Scientists must continue to remember that it is a privilege to be engaged in research, and that the relationship between science and society is growing ever more intimate. The spirit of enquiry behind science is not self-sustaining — it is increasingly dependent on societal support. Thus, we have a moral responsibility to be good stewards of this support and to communicate our findings to the public in order to build on that trust and seek broad input.

It is critical for greater success that advocacy groups work together for better healthcare and biomedical research. Typically, in the US, joint advocacy on many issues will involve the Association of American Medical Colleges (AAMC), research institutes, academic institutions, hospitals, state and local organisations, voluntary health associations, philanthropic foundations, individuals, and business and industry, as well as biomedical professional societies. As a representative of American scientists, I have valued opportunities to work closely with the US Congress. From 2000–2002, I was privileged to serve as President and Immediate Past-President of the Federation of American Societies for Experimental Biology (FASEB) — over 70 000 scientists speaking with one voice. Through directed advocacy effects of “acting now and acting together” we were successful in:

- doubling the NIH budget (1999–2003), from \$13.6 billion to \$27.2 billion;
- securing federal funding for human embryonic stem cell research;
- supporting genetic non-discrimination legislation to protect the use of private, genetic information (a work in progress); and

- developing debt-relief programs for physician–scientists to encourage this endangered species into the pipeline.

**What are the economic benefits of investing in research?** Simply put by the Lasker/Funding First Foundation, “Investment in research saves lives and money”. Increases in life expectancy have contributed to national budgets. For example, in Australia between 1960 and 1999, longevity improved from 73.9 years to 81.8 years for females and from 67.9 to 76.2 years for males, at an estimated worth of \$5.4 trillion.<sup>5</sup>

With respect to government support of biomedical research, the statistics when comparing the US with Australia were astonishing to me. I have recently learnt that in the 2000–2001 budget year, whereas the budget for the NIH was \$17.8 billion, the Australian Commonwealth budget for health and medical research was a more modest \$665 million.<sup>5</sup> This represents a fourfold difference per citizen, with the US government spending about \$130 per person and the Australian government about \$33. I felt humbled, acquiring a more profound respect for my world-class Australian medical research colleagues, who, with truly limited resources, have made significant contributions to the field. Among these contributions are the discovery of lithium in treating bipolar disorder, as well as major advances in childhood diseases of spina bifida and sudden infant death syndrome.

Australian researchers have also discovered a powerful secret to success — working collaboratively in interdisciplinary teams towards a common goal. Researchers around the world could all learn a lesson from Australian scientists; as the US budget for research begins to shrink, American scientists will have to adopt the Aussie philosophy in order to survive in the “business”.

**With competing demands on government resources, who will pay for tomorrow's discoveries?** I believe that projects leading to future discoveries will be paid for by creative partnerships between academic, philanthropic, corporate and government agencies. I also believe such projects should be guided by advocacy, led by scientists, to advance treatments and cures. We should always remember the wise words of Paul Rogers, Chair of Research!America: “Without research, there is no hope.”

**Mary J C Hendrix**

President and Scientific Director  
Children's Memorial Research Center, Chicago  
and Professor of Pediatrics  
Northwestern University, Feinberg School of Medicine  
Chicago, Illinois, USA  
MJAHendrix@childrensmemorial.org

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4 Research!America. Official website of Research!America. Available at: www.researchamerica.org (accessed Nov 2004).

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