Let freedom ring for science: an American perspective

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Dr Martin Luther King's immortal phrase 'let freedom ring' is as thrilling today as it was when he first uttered it in 1963. Now, nearly half a century since the 1968 assassination of one of the most revered civil rights and moral leaders of our time, we celebrate Dr King's words as a touchstone and inspiration. With the famous march on Washington in 1963, Dr King attempted something extraordinary and the impact was enormous, driving social change and making an enduring difference in our society. Indeed, his successful strategy for achieving civil rights inspired millions of people worldwide, including patient advocates for research who also dreamed of changing the world. Since the time of Dr King, in the US and in many parts of the world, there have been many high-profile patient marches – and walks, runs and bicycle rides – organised to call attention and say 'enough'. People march in protest about ignoring or stigmatising HIV/AIDS; they march and rally to end breast cancer, Alzheimer's, diabetes, mental illness and many other diseases we don't have answers for yet, diseases for which research would give us answers, were it well supported.

The US political system responds to public protest, including protests expressed through marches, although it often takes a long time for a response to crystallise. I believe that if scientists, who are well respected by the public, joined patients in marching for research – both literally and through other means of stepping into the public arena – they would have great impact on political leaders. Unfortunately, scientists are rarely interested in doing so. It is not part of the culture of science to be active in engaging the non-science trained public. Not yet. But we are not going to have more science and more freedom of science, or more freedom of scientific enquiry, until the science community itself becomes more visible and engaged with the public and elected officials.

Based just outside Washington DC, Research!America is an alliance working to make the case for science. One example of our work is an advertising campaign intended to get the attention of the public, media and policymakers. The advertisement, which shows a warning label on a

prescription medication container, says quite boldly: ‘Washington politics just might kill you’. The advert generated a great deal of attention, allowing us to drive home the message that the inaction that characterises Congress then and now is not working to allow scientists to find the solutions to what ails us. Research!America works through social media as well. Social media is a very active, influential environment in which people learn and exchange information – good and bad information; accurate and inaccurate. Research!America is engaged in trying to make sure that people know where to get accurate information. In fact, we are working in every kind of media to make the case for research – truly the best promise of better health and well-being in the future for all of us. Unfortunately, that promise is too much at risk right now.

Science of all kinds is at risk in the US today. There have been cuts to federal government science funding for well over a decade. A breath of fresh air was provided in 2018 with increased funding for medical research, but the damage done by years of cuts has not been overcome. And there are problems beyond money. A number of elected officials threaten to shut down various kinds of science, including embryonic stem cell research and the social, behavioural and economic sciences. The tendency to either ignore or demonise science is made easier when the science community remains essentially invisible to political actors and the public. Largely because of this invisibility, US politicians rarely talk about science. Unlike in many other countries, and unlike in the US in the past, few elected officials in the US today have training in science. This can make them reluctant to talk about science. They are concerned that they might be asked a question they cannot answer. It is also a fact that they don’t hear from many voters – their constituents – that research is important, and in general they are not being pressed for action. Complicating the situation is that, like many Americans, politicians often take scientific progress for granted. Because we have all seen a lot of scientific progress in our lifetimes, it is all too easy to overlook what it takes to assure that progress continues. But the problem is broader still.

In the US today, vocal groups are opposed to the government’s role in science. In addition, there are many people, including elected members of Congress, who believe that we cannot afford to spend any more money on science. They say that the nation just does not have the money. Well, that is simply not true! There is a lot of money in the US; it is a matter of setting priorities as to how we choose to spend that money. For example, in 2017 pet owners in the US spent \$70 billion on their pets (APPA 2017). Pets are wonderful, but the problem is that people don’t see that with just a little more money devoted to science, not only they, but also their pets might have healthier lives. The \$70 billion sum is about twice the budget of the entire National Institutes of Health (NIH). Of course, we don’t advocate taking money spent on pets to put towards medical research. But using examples like this illustrates the point that money, *per se*, is not the problem

we sometimes tell ourselves it is. We engage in false economies when we as a nation choose not to invest robustly in research. We are spending money on treating diseases such as Alzheimer's and many more, and at the same time we are starving research into those very diseases. One of the founders of Research!America, the philanthropist Mary Lasker said, 'If you think research is expensive, try disease.' She is right. What are we thinking? Why don't we spend more to prevent, eliminate or at least ameliorate disease and disability, rather than continuing to suffer physical, emotional and economic pain?

Research!America has one mission: to make research to improve health a high priority in the US. (We have four similar sister organisations in Sweden, Australia, Canada and New Zealand, and work with other like-minded organisations worldwide.) Founded in 1989, we are a not-for-profit alliance representing over 125 million Americans through their various organisations, universities, industry, patient groups and scientific societies. We are led by a magnificent volunteer board of well-respected individuals, many of whom have served in public office, as members of Congress and as leaders of federal agencies such as the NIH, the Centers for Disease Control and Prevention and the Food and Drug Administration. Our goals are to achieve more funding – we talk about money all the time! – and to ensure a positive, empowering policy environment that does not impede research in either the academic or the private sector. We make the case for public–private partnerships. We work to make sure that the public hears about research directly and via the media, and we also work to empower members of the science community to become effective spokespersons for research. Research!America's Chair Emeritus, a former member of Congress, the Honourable John Edward Porter, speaks often to members of the science community saying: 'You can change the image of things to come but you cannot do it sitting on your hands, you have to reach out to the Congress and build bridges.'

Scientists are often surprised to learn that most Americans cannot name a living scientist. In fact, 84 per cent say that they cannot name a scientist (Research!America, 2018). This shocking percentage is why I say that scientists are invisible in the US. Also troubling is that most Americans don't know where research is conducted: 66 per cent cannot give the name of a place where science is conducted (Research!America, 2018). President Abraham Lincoln, who established the US National Academy of Science in 1863, pointed out that 'public sentiment is everything. With public sentiment, nothing can fail; without it nothing can succeed'. We must take it to heart that earning and maintaining public sentiment – if you will, public trust – is essential. We can understand and track public sentiment via public opinion surveys. We know, for example, that the public supports basic research funded by the government; we know that the public supports STEM education – that is, science, technology, engineering and mathematics – and we know that the public believes that the government should make

both science and STEM education a priority. However, some of the news we learn from commissioned surveys is not so good. People are split on their point of view as to whether the government should play a role in behavioural research; questions are raised as to whether the government should be involved in funding research to find answers to problems that involve personal choices, even when public safety and population health are at stake. If scientists were more visible and outspoken about the value of behavioural research, the public would be more inclined to listen. Public views do change, as they have about embryonic stem cell research. The public is now more likely to be positive than negative about this science, but it took a lot of work by many organisations and inspired individuals, including Bernard Siegel, to reverse what was once negative public opinion. It takes many people of conviction working together to speak out to influence public opinion, and with it policy and resource decisions. We should feel optimistic since history shows that advocacy works.

Importantly, we also know from surveys that the public say they are not well informed regarding what their elected representatives are doing and saying about medical and health research. In the 2016 U.S. elections, only 14 per cent of the public in fact said that they were very well informed of the positions of the candidates for president of the US regarding public policies and public funding for science and innovation, which is why we developed a programme that is used every election year to persuade those running for office to declare their views on research for health and science overall (Research!America 2016). We reach out to potential voters via social media and advertising to urge them to become informed (we don't take sides or back particular candidates). And we reach out to candidates to ask them to specify what their positions are regarding research. Our goal is to reach the point where anyone considering running for political office knows that she or he must articulate a position on medical research and science broadly, if they expect to be a successful candidate.

As our Chair Emeritus John Edward-Porter says, 'Wouldn't it be wonderful if all candidates had science advisers and advisory committees?' They would, if individual scientists step up and volunteer to be advisers to a candidate or an elective official. Physicist Dr John Holdren, who served as President Obama's scientific adviser, frequently remarks: 'Everybody in the science and technology community who cares about the future of the world should be tithing 10 per cent of his or her time to interacting with the public in the policy process . . . if all us just got out to the public more and talked to policymakers more, we would get more of this done.' What a difference that would make!

To again quote Dr Martin Luther King: 'Our lives begin to end the day we become silent about things that matter.' Science matters. It's time for scientists to overcome their reluctance to engage the non-science-trained public, addressing questions and talking about how they are serving the public's interest; describing how and why science matters to our society.

References

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