Telling the story: raising public awareness of the importance of research foundations

Mark Henderson
Head of Communications
Wellcome Trust
Building Capacity conference, 27 January 2015
WORLD’S TOP 20 DONORS 2014

(Please click on the below organisations to find out more about each one)

<table>
<thead>
<tr>
<th>Rank</th>
<th>Organisation</th>
<th>This year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bill &amp; Melinda Gates Foundation</td>
<td>£2.16bn</td>
</tr>
<tr>
<td>2</td>
<td>Wellcome Trust</td>
<td>£581.5m</td>
</tr>
</tbody>
</table>

2. 

Wellcome Trust

The Wellcome Trust has come a long way in a short time. In less than 80 years it's gone from a charity with £15,000 and no offices or staff to one of the highest spending charitable foundations in the world.

The trust funds 4,000 scientists and a wide array of medical and biomedical research including areas such as how genes affect health, how the brain functions as well as working on solutions to combat a variety of infectious diseases.

Its funding was key to ensuring data from The Human Genome Project – the complete set of genetic information for humans – was placed in the public domain. And it was the trust’s researchers which developed the Artemisinin anti-malarial drug, which is having a major impact on the treatment of the disease.

Founded 1936

Researchers don’t exist in a bubble outside society. Ultimately society owns that research in some way.

Jeremy Farrar, director

Read more on our Wellcome Trust page
America and Alibaba help Wellcome to roll in riches

Wellcome Trust, Britain’s biggest charity, has chalked up a £137 million profit on Alibaba shares, helping to sustain its record of double-digit returns for the third successive year.

The trust, which funds medical research, reported a total investment return of £2.5 billion in the 12 months to September, boosting its massive portfolio of shares and property to £19.5 billion.
Understanding the genome
Artemisinin combination therapies for malaria
Emergency ebola research
Francis Crick Institute
Wellcome Collection and public engagement
How well do you feel you know...?

- Know very well
- Know a fair amount
- Know just a little
- Heard of but know nothing
- Never heard of

All MPs

2% 12% 50% 34% 3%
WHY ARE WE, AND OTHER FOUNDATIONS, NOT WELL KNOWN?
WHY SHOULD FOUNDATIONS INVEST IN COMMUNICATING?
Mitochondrial donation

The woman who lost all seven children

By Robin Bamber

BBC World Service
Gene isolated as girl becomes first in Britain to have entire DNA code read
“We strive to embed science in the cultural landscape, so that it is valued and there is mutual trust between researchers and the wider public…

“Alongside support for dialogue and informed debate, we will seek to spread the delight and interest many derive from science and its intrinsic spirit of curiosity.”
Partnerships

Europe and Global Challenges Initiative

The Wellcome Trust has entered into a partnership with the Volkswagen Foundation in Germany and the Riksbankens Jubileumsfond in Sweden to support the Europe and Global Challenges funding initiative.

The funding initiative is open to teams of researchers, working in European and non-European countries, who have research proposals that address global challenges, problems such as food security, global pandemics and economic instability. All need solutions that can only be achieved by building collaboration across borders.

Depending on the goals and scope of the projects, successful groups will receive between 500,000 and 800,000 euros in total (gross) for up to three years’ research. Funds can be provided for both non-personnel expenditure (including travel costs) as well as staff costs. We aim to fund six to eight projects from this funding call.
Building influence
HOW ARE WE APPROACHING THE CHALLENGE?
‘It is imperative we stop this cruel disease being passed on’

As the mother of a baby with a life-limiting genetic disease, Victoria Holliday urges MPs meeting today to support a procedure that could allow her and others to have healthy children

Through her big brown eyes and dark lashes, our baby daughter looks so normal life continues around her. From a crying, you may not realize that anything is wrong, but, if you get close you notice her feeding tube taped across her cheek and disappearing into her nose. When you spend time with Jessica, you notice that for a baby, she’s unremarkingly quiet. She doesn’t cry, make expressively movements or smile. Jessica absorbs the time away. Unable to sit, crawl or support her own head, she is slipping behind in all her basic developmental milestones.

Jessica is 10 months old and has Leigh syndrome, a devastating life-limiting mitochondrial disease that has left her severely brain damaged. In her case, the faulty gene that causes her condition was inherited from me, my mother. The gene was in the mitochondria – the batteries of the cell – that are not passed down in the eggs only from the mother.

Jessica’s DNA was isolated from her liver and transferred to a laboratory. It was then introduced into a special line of cells. As there are over 100 steps in this process, this meant that the donated cells were then grown in a petri dish in the laboratory.

We don’t know how long you have left with your little girl’. To their find out, is my partner Keith and I have, that there is an enormous risk that any future child we conceived with her eggs will suffer from the same, mitochrondrial disease is a remote, our child. The cruel hand of fate is going to take our beautiful baby girl from us and could leave our dreams of having a family in tatters.

Mitochondrial donation is a technique that could give an hope for the future. It’s a new IVF technique that will allow us to have our own genetic child who will also benefit from new genetic material donated with a single, healthy.

The technique has been encouraged and independently scientists agree that there is no evidence that it is unsafe. It is never possible to be certain that a new medical procedure will not have risks until it is tried for the first time on patients – but experts think it’s “safe enough” to reach that next stage.

When Jessica was born, she was pale with thin limbs, her skin was not covered. In her first days, she was running out for us to be able to take advantage of this new technique. Some MPs who oppose this technique have called for further delay until more safety checks are be done, but, while this might sound reasonable, it is not.

Jessica is precious. Seeing her graduate love the skills she once had is hard to bear. Science, screening and medically unexplainable acceptances. Only families who have been subject to such daily anguish truly know the impact that mitochondrial disease can have on affected children. It is imperative that something is done to stop this cruel disease being passed on.

Endnotes like ours deserve a chance. For us to have that chance, the Government must pass these regulations in this Parliamentary session. There is a general election next year if progress is not made, it could be a year or more before the regulations come to a vote. The House of Commons science committee considers this issue today. I hope its members will remember that further delay, for couples like us, could be fatal in the term of having a healthy family.
Ebola

Health Agency’s New Assessment of Epidemic Is More Dire Still

New figures published Monday by the World Health Organization reveal a far worse outlook than it had previously anticipated for the Ebola epidemic in West Africa.

In addition to projecting a much larger death toll, the new report for the first time assesses the possibility that the epidemic could be brought under control and that the virus could become endemic in West Africa, meaning that it could reach steady-state and become a constant problem there.

“The epidemiologic outlook is bleak,” the report said.

If control does not improve now, there will be more than 20,000 cases by Nov. 2, and the number of cases and deaths will continue increasing from hundreds to thousands per week for months to come, according to the report. The death rate is about 70 percent in each of the heavily affected countries, Guinea, Liberia and Sierra Leone.

The new estimates were published online in The New England Journal of Medicine by a team of more than 50 scientists. An earlier prediction by the health organization was for low data, saying there might be 20,000 cases in nine months.

Ebola Facts: When Did Ebola Arrive and Spread at a Dallas Hospital?

Questions and answers on the scale of the outbreak and the science of the Ebola virus.
Drug-resistant infections
Mitochondrial donation

UK government backs three-person IVF

By James Gallagher
Health and science reporter for News

The UK looks set to become the first country to allow the creation of babies using DNA from three people, after the government backed the IVF technique.

It will produce strict regulations later this year and the procedure could be offered within two years.

Experts say three-person IVF could eliminate debilitating and potentially fatal mitochondrial diseases that are passed on from mother to child.

Opponents fear that other forms of genetic modifications could follow.

Opponents say it is unethical and could set the UK on a "slippery slope".

They also argue that affected couples could adopt or use egg donors instead.

Mitochondria are tiny, biological "power stations" that give the body energy. They are passed from a mother, through the egg, to her child.

Related Stories

Analytical: A bold step for science and society
The woman who lost all seven children
Three-person IVF: Your stories
Medical research regulation
Establishing spokespeople

At Home

Wellcome Trust director Jeremy Farrar
By Annie Macaboy Bergof

The flu expert discusses the global war on infectious diseases

It is a brilliant Saturday afternoon in north Oxford, with lilac spilling over the pavement beside the terraced house owned by Jeremy Farrar, director of the Wellcome Trust, the £16.4bn medical foundation based in London. The front door swings open and two large dogs bound over. “Don’t mind the horses,” says a cheerful Farrar, leading the way into a modern white and stainless-steel kitchen. Sitting around the kitchen table are Farrar’s mother, brother and sister-in-law, in town for a set of celebrations.
Media training a broad range of staff

Antibiotic resistance: 6 diseases that may come back to haunt us

Still think of TB, typhoid and gonorrhoea as infections from the past? WHO’s terrifying report will make you think again.
“Thanks to technological advances in the last few years it has become possible to identify correlations between genetic arrangements and clinical conditions,” said Michael Dunn, head of genetics and molecular sciences at the Wellcome Trust, which is building the project centre at the Genome Campus in Cambridge.

“But in order to find any meaningful correlation, it is necessary to do the research at scale. The UK has an advantage in medical genomics because the integrated health service will allow it to compare a lot of genomic information for statistical analyses.”
Experimental Medicine in a Time of Ebola

By Robert Farkas, David Heffernan and Peter Piot

A virologist once did nerve experiments in a lab in the 1950s. Five years ago, he punctured his finger. This time, it was the Sars-CoV-2 virus, the strain currently raging today in Ontario, Miami, and New York City. There is no approved treatment or vaccine for Ebola, or even one that has passed the first phase of clinical trials in human volunteers. Yet unlike those exposed to Ebola in West Africa recently, the Hamburg virologist was quickly offered an experimental vaccine.

The only way to discover whether new interventions are effective is to test them during an epidemic.

This vaccine hadn’t yet been tested on humans, but it had been shown in other primates to protect against Ebola infections. For the virologist, it wasn’t a good option, but it was the only one available in the face of a virus with an extremely high mortality rate.

We chose to take the vaccine.

We expect it is a risk we would take if one of us were exposed to Ebola. The Hamburg virologist didn’t fall ill. It is unclear exactly how the vaccine worked, or indeed whether she was ever infected.

What is important is that immediately access to an experimental vaccine allowed him to try something with the potential to protect him. It is highly likely that if Ebola were to erupt in a Western country, the government or private sector would not be able to ensure that patients affected by the virus could get treated.

Instead of the usual medical interventions, those exposed to Ebola in Liberia have been entered into experimental therapies, which they have accepted.

There are antiviral drugs, monoclonal antibodies, and vaccines under study that have shown varying degrees of effectiveness in animals that have been infected with or exposed to the Ebola virus. Medical agencies in rich countries affected by Ebola would begin discussions with companies and labs developing these products and then make rapid decisions about which of them might be appropriate for compassionate use.

The African countries where the current outbreaks of Ebola are occurring should have the same opportunity. African governments would be allowed to make informed decisions about whether or not to use these products, for example to protect and treat health-care workers who run extremely high risk of infection.

The World Health Organisation could assist African countries with scaling up rigorous protocols for the use and study of experimental approaches to treatment and prevention, while coordinating more traditional containment measures. As the only body with the necessary international authority, it must take on this greater leadership role.

A number of communities would need to be made fully aware regarding treatment options through open and responsible communication. The international community must work hard to break down the barriers of fear and misinformation. In a region ravaged by civil war and poverty, international agencies need to be aware of infrastructure limitations, as well as those imposed by cultural and religious sensitivities. Experimental treatments shouldn’t be relied on generally without prior safety testing. But in the face of the critical challenges in West Africa, the WHO and Western medical agencies should be helping countries weigh the risks and benefits of a limited deployment of the best candidates to those in the greatest need, while continuously monitoring safety and efficacy.

This epidemic is new to so many that we can expect it to last for some months yet. That means the West must first track safety testing of drugs and vaccines in unaffected countries, so that those which perform well could go into larger trials in the affected region before the outbreak ends. Even if results come too late to allow trials this time around, this approach would allow studies to begin quickly when Ebola next strikes.

Ultimately, the only way of discovering whether these new interventions are effective will be to test them in an Ebola epidemic. Experimental treatments aren’t a substitute for standard infection-control measures. Past Ebola outbreaks have demonstrated which containment approaches are effective and which aren’t, and which will work on health workers, and how best to coordinate, and placing those exposed under fever surveillance and isolation for a full 21 days.

These measures, however, have failed to stop the West African outbreak, because of profound distrust in authorities and health services, strong traditional beliefs concerning disease causation and funeral practices, and, until recently, a lack of leadership. Populations have grown, people travel more and there are more people living in major cities—all of which complicates the containment of Ebola and other highly infective diseases and multiplies the risks of catastrophic outcomes. These circumstances call for a more robust international response.

Dr. Farkas is director of the Wellcome Trust. Dr. Heffernan heads the Chatham House Centre on Global Health Security, where he is also a senior fellow. Dr. Piot is director of the London School of Hygiene and Tropical Medicine.
Comment: Telegraph, drug resistance

Drug resistance will be a bitter pill to swallow

JEREMY FARRAR

We need to change public and medical attitudes – as well as find new antibiotics

And now we should be bracing ourselves for another public health crisis. Drug resistance is already causing alarm among health authorities. The World Health Organization has warned that we are facing a "triple threat": a superbug known as NDM-1 is spreading globally, antibiotic resistance is on the rise, and we no longer have new antibiotics to treat infections. If we fail to act now, we may soon see diseases that were previously treatable become deadly again.

In the world of antibiotics, we have to think like a detective. We need to find new ways to combat drug resistance. One potential solution is to improve the way we use antibiotics. For example, instead of using them as a last resort, we should use them more sparingly to prevent resistance from developing.

Another solution is to develop new antibiotics. This is a challenging task, but recent advances in the field of synthetic biology offer hope for the development of new antibiotics.

In conclusion, we must act now to combat drug resistance. We need to change public and medical attitudes, and find new antibiotics. If we do not act soon, we may see diseases that were once treatable become once again deadly.
Comment: Guardian, “luxury journals”
Wellcome Trust raises ‘concerns’ over Pfizer bid for AstraZeneca

By Elizabeth Rigby, Andrew Ward and Miles Johnson

Britain’s biggest medical research foundation has told the government it has “major concerns” over Pfizer’s £65bn offer for AstraZeneca, as the Wellcome Trust became the latest powerful voice to weigh in over the mooted deal.

Sir William Castell, the chair of the world’s third largest charitable foundation, and Jeremy Farrar, director of Wellcome Trust, outlined their concerns in a private letter to George Osborne last Friday as the US drugmaker made its opening offer for the UK firm.
Wellcome Collection
Experiment boxes for schools
Mosaic: open source science journalism

The future of sex?

When first launched, the female condom was derided for resembling a jellyfish or Edvard Munch's The Scream: Two decades on, it could help kickstart a new sexual revolution.

Life questions

Recently we asked 100 leading figures from the worlds of science and beyond what single question about life they most want scientists to answer. Now it's your turn to tell us your key questions.
Social media
Dear Mr Castledine,

President-elect Mr Jean-Claude Juncker has asked me to thank you very much for your message of congratulations which you sent to him on the occasion of his election as future President of the European Commission on behalf of Cancer Research UK and other UK-based research organisations.

Mr Juncker and his team look forward to working to give the European Union a new start, as set out in the President-elect’s political guidelines presented at the European Parliament on 15 July and at the European Council on 16 July.

The President-elect has also taken note of your views about the post of Chief Scientific Adviser.

During his meetings with different political groups in the European Parliament, Mr Juncker expressed a preference for independent scientific advice, without specifying in which form and institutional set-up it should be given. This is a decision which will be taken later in the process and many interesting options could be considered.

Yours sincerely,

[Signature]

Ms Catherine CASTLEDINE
Events: World Economic Forum
Events: Top 1,000 Londoners

The 1000 most influential people in London

The 1000 power list: London’s most influential people celebrate Evening Standard’s magazine launch

Influential: George Osborne and Stephen Hawking at the King’s Cross party (Picture: Dave Bennett)

London’s most influential people from scientists and cabinet ministers to tech entrepreneurs and theatre directors were tonight celebrating the launch of the Evening Standard’s The 1000 magazine at the Francis Crick Institute.

The acclaimed physicist Stephen Hawking was among the leading figures to attend the party, which recognised the one thousand most influential people in the capital.
Events: Celebrity MasterChef
IT’S BECAUSE WE DON’T NEED TO BRAND THAT OUR BRANDS CAN BE SO VALUABLE