Simon Gillespie – Chief Executive, British Heart Foundation (BHF)

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Simon Gillespie of the British Heart Foundation (BHF), the UK's leading national heart charity, outlines the organization's mission, the issues surrounding translational research, and the potential impact of Brexit on the UK life sciences landscape.

For over 50 years, the British Heart Foundation (BHF) has pioneered lifesaving research and has already halved the number of people dying from heart and circulatory disease in the UK. Please introduce the overall mission of BHF, the UK's leading national heart charity.

We were founded in 1961 by a group of clinicians who saw that heart circulatory disease, heart attacks, strokes, and other conditions, were responsible for 1 in 2 of all deaths in the UK in the '50s. At that point – although difficult to believe now – we didn't know what caused these conditions and what could be done to treat them. Consider if you had a heart attack, even into the '60s and '70s, you were pretty much left to your own devices and there was little treatment other than pain relief. It was a matter of chance whether you lived or died. A group of medical professionals saw the answers to these problems as being through research. They therefore started a charity called the Heart Fund which eventually became the British Heart Foundation, and the idea

was to try and tackle these problems through research. Over the years we've reached a position where we're funding more than half of the academic research in UK universities. At any one time we've have more than 1000 research projects underway, and each year we commit GBP100m worth of new research. Our overall strategic commitment is GBP500m over 5 years and we're slightly ahead of that target. We fund from basic science to clinical and translational medicine. Our model is based on raising money from the public, and we don't receive any funding from the British government. We therefore need to reassure these people that we are looking at the best possible use of their money. Since 1961, we've seen death rates from heart disease come down from 1 in 2 to 1 in 4, but globally they are still at 1 in 3. So it is not a finished task.

Shortly after your arrival at the helm of the British Heart Foundation, a comprehensive Strategy 2020 was launched (in 2014) with some very clear ambitions: funding GBP100m of life saving research each year, and launching a translational research program that bridges the gap between lab-based science and new treatments for patients. Three years down the line, what have been some of the key achievements, and what challenges are still to be addressed?

We've increased our research investment by 25-30%. That provides a challenge because we don't have revenue streams. We have to justify to our supporters that we're worth supporting on this basis. We put a lot of effort into trying to inform people about the science we fund, and the impact this has on their daily lives.

Looking at the translational medicine space, we now have 12 products which are either well down the line or we've agreed to fund them and they're about to start. This is part of a big drive for us on how we can make sure that the lab discoveries can be translated into patient benefit ASAP. Quite often there aren't huge investments to fund an experiment to demonstrate it might work or demonstrate there isn't a particular risk in a given area. It's designed not to fund it right through the pipeline, but to make it attractive enough for an investor or a pharma or a biotech company.

Where does your responsibility start and stop?

The partnership branch is interesting. Typically, we don't receive money from industry, although we're looking at how we might broaden our partnership base. We believe that what we are doing should be purely driven by public and patient interest. As a charity, in order to be regulated, you

have to demonstrate public benefit. Of course, that doesn't mean we are antagonistic to pharma, but it means we have to be careful to make sure we have arrangements that are clear and transparent. When someone asks for advice, we run a helpline, we have a website with about 45,000 unique visitors a day. Most of those people are looking for advice about a particular treatment and they rely on us to provide absolutely independent advice.

Is this research then transferred to industry?

It can be. We also do research into services, what mechanisms work and while research is the bulk of what we do, just under GBP30m a year is invested in what we call our 'prevention survival support activities', giving advice to people on how they can reduce their risk. There is a stream of activity on how for example, we can improve survival rates in hospital cardiac arrests situations. At the moment, it's fewer than one in ten, but elsewhere in the world it's 1 in 4. Then we look at how we can support both patients and healthcare professionals, and also, how we can work with the NHS to improve services for people.

You are also President of the European Heart Network, and of course, our interview today would not be complete without speaking about Brexit. One of Brexit's key consequence on the research front is that the UK needs to replace investment revenue coming from European sources. What are your thoughts on this key concern, and how is BHF working to protect the UK life sciences landscape from the impact of Brexit?

Funding for research is one of three areas we are concerned about. We need to look at the overall picture, where there is funding, people and regulation. On the funding issue, the UK has been a net beneficiary of research funding from European sources. The British Heart Foundation is a funder per se and we don't receive any money directly from European sources. However, we know the institutions in which we fund our research do / can receive EU funding. There is therefore an issue if there is a reduction in the funding from those European sources, on what impact that might have on the infrastructure of the institution and does it make it less viable for us to be funding particular types of research in particular institutions. The UK government has made a couple of assurances about the mechanisms in place. A lot of this is actually what we'd want to be doing whether in the EU or not… As a funder we are not tied into just funding in the UK. As a matter of internal decision making, we have built a lot of research capability here in the UK, whether brick and mortar investment or investment in people. We think the UK has a lot to offer, as much of the research we

do in this country has been world class. We fund and support a few projects outside the UK, particularly increasing looking at responses. Even before Brexit, we were looking at our international profile, and we have always been looking for world-class quality.

The British charity model seems to be working really well in advancing the fights against particular diseases. Why are the British people so good at this charity business? What is it in your culture and mindset that have enabled charities to blossom so well in the UK?

It's a very good question. First, we have a very long history and tradition in supporting charities. Famously, the first bit of charity legislation was the *Statute of Elizabeth* in 1601, so it's quite old as a legal concept. That concept has grown very significantly. There is that undercurrent of philanthropy and a growing middle class with disposable income that didn't just want to be the preserve of rich aristocrats. A lot of that ties into liberal political thought in the UK and a more general altruistic feeling. It also comes into people's view of the role of the state as well. In some countries medical research funding seems to be fundamentally a state responsibility. Here we do not believe so.

Our charity sector has built up over so many years, and British people understand the concept of charity. The charity sector is well trusted by the public, actually better trusted than the government itself or its major institutions.

Another of your objectives is to increase BHF's sustainable income by GBP30m per year by 2020, and donors by 50% to GBP150 million. Why and how I that going to happen?

Because there is more work to be done! If you look at mortality figures, yes we've had huge success, and many of the reasons for the reduction in mortality of heart disease is due to BHF funded research. However, over the last couple years, there has been a plateauing of those mortality figures and potentially the indication of slight growth. Still 1 in 4 deaths a year in the UK is caused by heart disease, so that's still a big problem. In addition, we still have 7m people that have survived of a heart condition but are often struggling on a daily basis.

Are donors international or just in the UK?

They are largely here in the UK. But what you'll see over the course of this year again is a much more international look for the BHF. We are if not the biggest, the second biggest non-for-profit funder of research in the world. The quality of what we do is really outstanding. But we have to recognize that we are facing a series of global issues here. If you consider the amount of research put into cancer which also kills 1 in 3 people, the amount of research put into all other causes, HIV AIDS, other infectious diseases, accidents, which all account for a third, the underinvested part is heart disease. There are real unsolved issues in human terms, as well as in a community and a nation. We are increasingly looking at how we can galvanize local thinking about this and bring the best minds together.

How do you see potential collaboration with industry evolve when looking towards the future?

We've always traditionally had a sort of arm's length relationship with industry. We don't take money from industry and therefore we preserve our independence. In fact, preserving our independence of thinking and that trust from the public is essential to us. Increasingly, as we are moving more into translational medicine and the clinical medicine space, we are bumping more often into industry. The last thing we want to do is get to a situation where we end up detracting from patient benefit. Industry is part of the solution and in the coming years, BHF will much more be recognizing publically that we have to work together.

You have extensive experience of charity and non-profit governance, having notably led for several years the Multiple Sclerosis Society. What do you feel are the keys to success to manage a charity like the BHF?

It's more than managing an organization. I actually had in both cases a family connection that drove my personal interest. My father died of a heart attack the day before his 58th birthday when I was in my first year at university. It doesn't give you all the answers, but it gives you a reason to come to work in the morning which is more than just a salary. One of the key matters for us is that we don't have direct customers. We ask people to give us money and essentially, we give that money to benefit other people. You don't have that an in-built supplier-customer relationship in a way that you would have in commercial organisations. We have to be very careful that what we are doing is always in the interests of the patients. Clearly some of them are about judgment, but unless you're thinking, what on earth is this doing for patients all the time, then that is a problem.

There’s also something about motivations that many of the staff have. We have about 3,500 staff; most of them work in retail. Of the paid staff, many have a personal connection. In terms of our volunteers, we have around 23-24,000 volunteers at one time. Most of them are working in retail.

Looking to the future, what role would you like to see the UK play in the fight against heart disease in the European and more global context?

I think the UK is very strongly positioned, and not just for its own benefit. Whether we are in or out of the EU, we still have to form partnerships and work in a global environment. We are well placed to use a lot of critical factors. Firstly, the research base here is very good. Secondly, we have a very well-established national health service through the NHS, which means we can access patient records and test novelties out. We can go beyond pure basic research science and look into possible outcomes for a particular treatment and therapy. We are leading what I hope will become a new coalition about patient information and data and how we can better use that. This will enable the UK to reemphasize its position as ‘the place to be’ for clinical trials because the mechanisms of that are much more effective.

I think the UK is an attractive option overall, but as I said, we won’t be able to this all on our owns. We cannot claim excellence in all areas, so we need to look for those broader networks. The scientific world exists on that strange combination of collaboration and competition. People work together, they collaborate, and we want to encourage that.

*This interview was conducted in January 2018. In July 2019, the BHF announced that Simon Gillespie would retire in December 2019.

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