Hilary Evans – Chief Executive, Alzheimer’s Research UK

In the UK, when people want to help those affected by diseases like Alzheimer’s, they often go to charities rather than the State

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Hilary Evans of Alzheimer’s Research UK (ARUK), the UK’s leading national research charity in the field of dementia, discusses her organization’s mission; the growing awareness of, and investment in, dementia research, care and diagnosis; and the enduring importance of international collaboration.

In recent years, we have seen awareness in dementia improve dramatically, to the point that dementia is frequently cited as the health issue of most concern to the over 50s. There is however a big dose of “stigmatization”, misconceptions and a lack of understanding. People tend to be fatalist: “there’s nothing we can do about getting older, so there’s nothing we can do about dementia”. Let’s start by introducing the overall mission of Alzheimer’s Research UK, the UK’s leading national research charity in this field.

Alzheimer’s Research UK has existed for over 25 years as a medical research funder. In the early years, we were a small, UK-centric medical research charity, successfully funding research looking at the diseases that caused dementia. I came into the organisation about 4.5 years ago, and one of the things that drove me was the frustration that, unless we accelerated the pace of understanding about the diseases that cause dementia and delivered new treatments, the health and care system would continue to buckle under the strain of looking after our ageing population. While the charity was growing at a rapid pace, the dementia research field was still not attracting the level of funding given to other serious health conditions, which was really holding back the ambition of the research community to really tackle this condition head on. In other disease areas, people get a diagnosis and then want to know what clinical trials are possible and how they can engage with the latest research. Whereas attitudes in dementia can be much more apathetic, “well you’re getting old, you’re just going to get dementia, it’s part of life, there is nothing we can do”. I wanted to change that, and some of the things we’ve done at Alzheimer’s Research UK is to change the conversation around dementia, with the ultimate aim of transforming the scale of funding for life-changing research to tackle it.

We launched our ‘Defeat Dementia’ Campaign in 2014 with the objective of raising GBP 100 million to ramp up ambitions around dementia research. We needed to be much more strategic in terms of how we funded medical research and to work much more closely with Government and industry to bring about new treatments. We wanted to encourage the pharmaceutical industry to continue to invest in this important area and incentivize them to do so. Ultimately, we want to be translating basic research into new diagnostics, preventions and treatments that are effective in the clinic. As a charity, we don’t receive government funding and rely on voluntary donations for all our research programmes. What we want and what our supporters are life-changing treatments for dementia that give them precious time back with their loved ones. Ideally, this would be a treatment that halts the progression of a disease like Alzheimer’s, and ultimately, can be given at a stage where it stops the disease ever developing.

We therefore launched a new research strategy to position us to do exactly that. A number of the initiatives we’ve set up as part of that have been to work at an international level, taking our funding outside the UK. We are pleased to say that today, we’re funding research across the globe, involving academic and industry and have helped forge collaborations across 28 different countries.

Alzheimer’s Research UK invested GBP 14.8 million in research in 2016. What are the current means and resources of the charity?

As an organization, we’ve been growing at a rapid rate in terms of what we’re able to raise and what we’re then spending on research. Thanks to a rise in donations, our research commitments have grown year by year, and as a charity we are growing roughly at a minimum of 20-25 percent each year. This is fantastic, it shows people’s willingness to support dementia research and above that, the fact people are fully behind our mission to bring about new treatments for dementia.

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Our flagship projects include our Drug Discovery Alliance, made up of three Drug Discovery Institutes at the University of Oxford, University of Cambridge and University College London. Such initiatives are based on the idea of juxtaposing high quality drug discovery expertise alongside a deep scientific and academic understanding of patients, disease mechanisms, and model systems. The intent is to translate cutting edge academic science into drug discovery, and to prosecute projects from target to lead status, and beyond.

Globally, the WHO states that the number of people living with dementia will increase from 50m in 2017 to 152m in 2050 (a 204 percent increase). In the UK alone, there are currently 850,000 people living with dementia and one in 14 people over 65 will do so. One of Alzheimer's Research UK's key roles is to raise awareness towards the authorities. In March this year, it will be 2 years since the British Government launched the 2020 plan for dementia research, care and diagnosis. What has been the contribution of Alzheimer's Research UK in designing this blueprint, and what concrete actions have been implemented?

The 2020 Implementation Plan came off the back of what was the Prime Minister's Dementia Challenge in 2012 in the UK. David Cameron was one of the first global leaders to make a personal pledge on dementia. He saw this as one of the biggest healthcare challenges that government faced. He came to the conclusion that not one country could do this on its own, and he used the G8 meeting in December 2013 to make dementia a focus and call other world leaders to make similar pledges in their own countries. The 2020 Implementation Plan is a blueprint for how to carry on that commitment. I think some of the real concrete wins from that program for us would be to substantially increase government spend on dementia research; it has more than doubled since the 2012 Challenge and we have a commitment to secure further growth in government spending on dementia research. We are one of the founding partners of the UK Dementia Research Institute, established in 2016, which will be a UK-wide flagship institute pulling together some of the best scientific research happening across six universities across the UK. It is a jointly funded initiative, with GBP 150m of government funding through the Medical Research Council, GBP 50m from Alzheimer's Research UK and another GBP 50m from Alzheimer's Society. As a founding partner, we're working closely to ensure the Institute works as effectively as possible to become a worldleader in pioneering discovery science in dementia.

Another area where the government plan has been successful is on the diagnosis front. Diagnosis rates used to be incredibly low, at 42 percent in 2012 and this has risen up to 69 percent. It is very important that people get a timely diagnosis; not only for people to understand what is happening to them and get appropriate care, but for the research community to understand more how we might treat the diseases behind dementia. Research is showing that the earlier we can intervene in diseases like Alzheimer’s, the more successful future treatments are likely to be. For that reason, early and accurate diagnosis is also a key element in designing successful clinical trials for new treatments. That’s why improving diagnosis is a key strand of Alzheimer’s Research UK’s Research Strategy.

Another success story from the Dementia Challenge and 2020 Implementation Plan has been Join Dementia Research – a matchmaking system to help the public volunteer for research studies into dementia. This is really helping to boost the number of volunteers available to help important studies get off the ground, and in recruiting to large multinational clinical trials.

A few words on having the former Prime Minister David Cameron as president of Alzheimer’s Research UK?

Mr Cameron joined us as president almost exactly 12 months ago. When leaving government, he spent some time thinking about what he wanted to do, as an ex-PM with time on his hands he was very keen to continue what he had started. He helped us launch our Defeat Dementia campaign at the G8 Dementia Summit meeting in 2014. He said at the time he would help Alzheimer’s Research UK achieve its mission and he’s stood by that. He is now President of our organization, holds the highest voluntary position and acts as an ambassador for us internationally and strategically, supporting the work we do as a charity.

Pfizer just recently announced it was pulling out of neuroscience research, implying two major consequences. First of all, the research to find the first medicine to slow or halt Alzheimer’s will now proceed without one of the biggest forces in drug development, and secondly, that’s less private funding for the fight against dementia. What are your thoughts on this?

We don’t want to see any companies pulling out of this area, so it is sad news for the field. It’s not good for people with dementia or for all of us working in dementia research. That said, what we are seeing is other companies reinvesting in neuroscience and Alzheimer’s disease, so I don’t think it’s all doom and gloom. That’s a company’s decision based on their priorities going forward. What we’re focused on is working with pharma companies who do want to invest in this area, working with academia to de-risk targets and encouraging new investment in dementia drug discovery. We have to acknowledge that there have been high failure rates, we have to acknowledge there have been no new drugs licensed in over 10 years and there are still no drugs out there to slow or stop diseases like Alzheimer’s. But that’s not a reason to give up – there are too many people who need these efforts to succeed. What we need to look at is how we can work together across sectors to bring about new treatments. We acknowledge as a medical research charity that we can’t bring drugs through phase III without the weight and expertise of pharmacuetical companies. What we do know is there is going to be huge demand for any successful treatment for the diseases that cause dementia. We also know that we are very quickly building up a good base of knowledge about diseases that cause dementia. Our understanding has never been better and this is a positive base to build on

There is still a way to go, but we’re working alongside industry across that entire bench to bedside trajectory. We have to be smart in how we invest our money, and need to work with pharma companies to help share some of that early risk.

Tell us more about the Dementia Consortium: how did it all happen and what has been the industry’s reaction?

There has been a huge amount of interest in the Dementia Consortium. It was actually one of the first large-scale initiatives we launched. We went to industry with translation experts LifeArc and invited them to join us in forming a Consortium.

The idea goes as follows: each of those pharma companies joins Alzheimer’s Research UK in putting money into a pot that academic scientists and SMEs can apply for. The Consortium provides drug discovery resources, project management, industry expertise and tools as well as full funding support for projects. We support small molecule or antibody-based strategies and aim to generate tools to achieve preclinical target validation. These are typically the sort of early-phase projects pharma companies themselves wouldn’t initially be investing in because they are too high risk. But the Consortium allows interesting targets to be de-risked and encourages the pharmaceutical industry to invest long-term in the most promising new approaches.

In your view, what will be the role of the UK in the post-Brexit fight against dementia?

I think the UK has a huge role to play that goes above and beyond matters around Brexit and have set a benchmark for excellence in research that is looked to across the world. But the UK alone cannot cannot defeat dementia, it must be a global effort, which is why our Research Strategy is seeing us work increasingly with international partnersThe EU has had some fantastic initiatives and I think it would be incredibly sad if we saw any of that research damaged by Brexit negotiations. Securing international research talent and access to innovative funding streams has to be a priority for the UK.

Some fantastic clinical cohort data and projects that involve industry, universities, research institutes, and charities like ours are done on a pan-European basis. We need to make sure the UK still has a strong position in these collaborations and to avoid having to renegotiate all these different working groups and contracts because of Brexit. Alzheimer’s Research UK is working hard to ensure these important issues are on the government agenda around Brexit and championing the views of our research community.

The British charity model is very admirable for outsiders. What do you think has made British charities so successful?

In the UK, when people want to help those affected by diseases like Alzheimer’s, they often go to charities rather than the State. They want to be involved in something and surround themselves with other people with the same mindset. I think it comes to that! In several other countries, one would just expect government to fund medical research. Here in Britain, people don’t believe so. There are very few other charities doing the dementia research we are doing, and who are purely focused on medical research and finding life-changing new treatments. We are accountable to the people who support us, and I think it is a fantastic model; the way people go out of their way to fundraise for us. We have children who donate their pocket money, high-level donors who donate millions of pounds to help our initiatives get off the ground. They’re all doing it for the same reason. They’ve been affected by dementia in some way and they believe in what we’re doing.

Isn’t there a risk in leaving public health issues to the will of the people and donors?

I don’t think there is a risk. It allows you to raise a huge amount of money to do things a little differently. I don’t think any government would do some of the things we’ve done, which have been very successful. We aren’t politically driven as any government funding would be, which allows us more freedom to be innovative and many of the risks we have taken in supporting innovative research have paid off and allowed researchers to gain larger government grants to take their investigations to the next level.

A few words to conclude?

The UK needs to continue to lead the way in dementia research, but can’t do this on our own. We need to drive ideas and innovative thinking across the globe and have a united ambition. We need to work together to continue to invest in dementia science because we still aren’t at the point where we have the knowledge we need, but we are starting to see that evidence build and we owe it to people around the world to deliver on the hope for treatment.

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