Steve Ford – CEO, Parkinson’s UK

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Steve Ford, CEO of Parkinson’s UK, one of the UK’s leading research-based charities, discusses his organization’s recent Digital Leadership Award, presenting the needs of Parkinson’s patients to stakeholders, and why the UK will remain a leading research hub in the years to come.

Parkinson’s UK recently won the Digital Leadership Award and can be considered as some would say a ‘Charity 2.0.’ Could you please begin by introducing Parkinson’s UK and what you have been doing for the past 13 years to make sure it moves with the times?

We are the UK’s research and support charity for Parkinson’s. There are 145,000 people living with Parkinson’s in the UK, and we work hard to make sure we are a movement of people living with Parkinson’s. If you look at anything that we do, people with Parkinson’s are always involved with the charity, moving it, and giving their voice to it. And that gives us a real urgency to what we are trying to do.

There are three big themes that we have in the charity.

First, better treatment and a cure faster. We have always funded research. We have been here since 1969 and have invested over GBP 85 million in research. But I think a very fair question from people with Parkinson’s is, “what have we gotten from that? I’m still on a drug that has been around since the late 1960s and that only deals with some of my symptoms." One of our key challenges is therefore to show impact, and determine how we are using our research, influence, and money to accelerate treatment.

Second, people strive for good quality healthcare at every stage of the condition, particularly when for the NHS, neurology and Parkinson's have never been made a priority. The UK lacks a leadership position from the National Health Service around Parkinson's. We hence set up the UK-Parkinson's Excellence Network three years ago, which is a very innovative partnership between leading health professionals and the charity, to provide for this necessary leadership. We are going to identify the issues, set the standards and create a vibrant professional community to provide that leadership for Parkinson's.

The third area is about taking control. People with Parkinson's want to be empowered and live life to the full. As you would expect, the core business of charities is to provide information and support. We do that through helplines and websites. Our network of 125 local Parkinson's advisors across the UK is quite innovative. The challenge is not just about providing people with information, but helping them take control. It is a much greater sense of self-management and peer support. Exercise is a massive issue for us. We all know that it's good for us, but there are neuro-protective aspects to it. We really encourage the community to get involved in exercise on a regular basis.

It is in that sense that the agenda is being set by the Parkinson's community that allows us to work in very innovative ways to meet those challenges.

Tell us more about the innovative methods you are implementing to meet the challenges of the Parkinson's community.

Research is the first element to talk about. Our model, like a lot of typical charities, funds good quality research at universities that we hope will inevitably trickle through to new treatments. But we realize that's not always the case. Neuroscience is very challenging at the moment; industry has had its fingers burnt and is becoming more risk averse.

There is also a lack of biomarkers. Parkinson's isn't one homogenous condition which means that trials have failed, industry has gotten nervous, and we are seeing that gap. So our approach has been to think how we can provide leadership across this whole process. We brought in Dr. Arthur Roach who is a very experienced leader in neurosciences, and together we have developed a new strategy. As a charity we are doubling our spending in research to over GBP 10 million. We are making a very serious realignment in our focus and doubling of expenditures. We are not stopping the university spend, but we have created a Parkinson’s Virtual Biotech model that we launched last year. The aim is to take promising drug discovery projects and acting like a venture capital fund, take it to the next level, working in a virtual way, using contract research organizations. We are a year into this program and it is advancing very well. Our first project was to set up Keapstone Therapeutics in partnership with Sheffield University. If the project meets its milestones we will think about the next round of funding and how we bring in other people to add momentum. That’s new for us as a charity.

A second project we have is an investment in an American virtual biotech company. We are supporting them to take a drug for dyskinesia to bring to proof of concept phase. Finally, a third project, that went live just before Christmas. This collaboration, with Selcia (part of Eurofins), and computational chemistry software and services provider, Cresset Discovery Services, is centered on creating novel molecules that could stop or slow the progression of the condition. If this project is successful, we shall then determine what is the best model to take it forward with the urgency we need. We like the focus and clarity that comes with a single-asset company.

This new approach is generating interest and we have a lot of academics coming to explaore with us whether the virtual biotech model is a suitable vehicle to take forward their work.

How would you describe your relationship with Big Pharma in advancing this fight against Parkinson’s?

We’re also very conscious that the pharma industry is reluctant to invest in Parkinson’s because many trials have failed. But the question is, did they fail because the drugs don’t work or because the trials were not tested in the right way?

You are implying that the format is then not fit for purpose?

Yes, we are just including everybody who has a Parkinson’s diagnosis. We know that people respond differently to different drugs and have a different progression. Why are we surprised then when we do a trial on that same group that there is a mixed response to those treatments?

Three years ago, we launched an initiative called ‘Critical Path for Parkinson’s’, which is a global pre-competitive consortium working with regulators to change the way clinical trials are led, with a real focus on early diagnosed patients. We have nine pharma companies who partner with us on that to share data. We have had some early success in getting the EMA to indicate that DAT scanning should be a qualification criterion for early clinical trials, and we are developing disease progression models that we think will be a fantastic resource with regulatory approval and the standard for anyone wanting to do a clinical trial for Parkinson’s. We can be more confident that by pulling together all of our data, it will give a real boost to the whole community in terms of getting that better understanding for clinical trials. It’s a fantastic project in itself.

But through it, we have found that it has enabled us to form the relationship with pharma companies to understand their pipelines and establish partnering opportunities so they know what we are doing in virtual biotech. This is a novel approach to research, but this is underpinned by the fact there are so many people with Parkinson’s who are interested in research. Within our overall community, we have a research support network of over 4,000 people who really want to shape the research agenda. It is a community that we can recruit into clinical trials and provide a patient voice for pharma companies so that when they talk about how to design a study, all of the people with Parkinson’s can challenge some assumptions.

Vast sums have been invested in Parkinson’s research but there is little to show for it. Why do you think that is? What other reasons are there besides failures of clinical trials?

The amounts of money poured in our area haven’t been insignificant? – certainly, this is related to the complexity of Parkinson’s. Much like Alzheimer’s, it is very hard to change the path of these degenerative conditions. It has to do with the heterogeneity of the condition, and the question is: are we measuring things in the right way? We have had this view that Parkinson’s is a movement disorder, which it is, but if you talk to people with Parkinson’s, they will elaborate on other aspects too, such as cognitive declines or sleep problems and communication issues that are equally debilitating. There’s a whole range of issues which are not necessarily captured in the traditional ways we approach Parkinson’s as of now.

Currently, when we are doing clinical trials on people, they have probably already lost 70 to 80% of their dopamine-producing neurons. Hence early detection is a top priority.

You have mentioned that within the UK, Parkinson’s has not enough been a priority. What are you doing to move it up on the agenda of authorities?

Our approach over the years has been to get the government to make neurology and Parkinson’s a priority at the national level. We have asked to work more with individual commissioning bodies, but unfortunately, none of these actions have worked.

That being said, a major realignment we made was when we created the Excellence Network. The ideas were to form a partnership with that community and create some clinical leadership roles. The way the clinical community has welcomed this with open arms has been fantastic. Now we have a clinical director, lead nurses, and lead therapists. Every two years we do a big clinical audit. We are currently analyzing the 2017 audit data where we have 477 teams across the UK entering their data as part of it. Ten-thousand patient records have been analyzed. The outcome will be a handful of priorities that will enable us to make sure people have access to multidisciplinary teams or are getting the drugs on time when admitted to hospital.

A fantastic measure of success would be the following. When we started the Excellence Network, only 50% of people receiving a diagnosis of Parkinson’s were referred to Parkinson’s UK. Although we have the world’s best resources to support people with Parkinson’s, only half of them were signposted to the charity to the point of diagnosis. We have made this a priority, and today, there are 84% of people being signposted to us. The increase has been through us working with the clinical community and identifying what those pathways look like.

It is interesting and unique to see that among the constellation of different actors in the UK, it is the non-profit sector playing such a large role in the UK…

It seems to be a British and North American issue. I believe that across Europe, other organizations or even professional associations where neurologists come together to focus on Parkinson’s, are not playing the same role at the scale we are. This is one of the UK’s major strengths. Still, it is quite a crunch time for charities to assess whether we should play a traditional role or do something really different in providing the leadership that no one else has. That’s what has been fantastic: our community today is not just people living with Parkinson’s, it is anyone who is interested in how they can make a difference.

Where does the UK stand in terms of its approach to Parkinson's? Where in the world is there more emphasis being played?

The US, Canada, Germany, Sweden and the UK provide that leadership, and I believe Parkinson's UK has played a key role. Maybe those GBP 85 million of research haven't led to new treatments yet, but they have certainly supported career developments and created a very strong research base in the UK. If you look at the top-cited publications around Parkinson's, Britain is listed highly. We are funding the biggest cohort studies looking at how Parkinson's is progressing.

To what extent does Brexit threaten to derail some of that?

It seems to me that research is always incredibly international in its nature. And people, through their career paths, want to work together. A lot of our collaborations are with North America and, yes, some of them are with Europe. But I don't know for sure whether they are because of the EU.

Do you expect your operations to be business as usual?

I think so. Clearly there are issues around the workforce, and people recognize how important that is. Some real risks we have identified are around the EMA and regulations, but with the recent statements from our Prime Minister on a continued affiliation between the EMA and MHRA, we are confident. We however don't want to be complacent. We don't receive any government funding, and every single penny comes from people going out and inspiring others to raise money for our charity. The impact on the economy is something we want to assess. We are constantly monitoring the trends to see if there are any downward trends, and we haven't yet identified any.

You have headed Parkinson's UK for 13 years. What have been the keys for success for managing such well-established and large charities like this?

It is about making sure that the voice of people living with the condition is right at the heart of everything we do. We had our induction day for staff yesterday, and the day was led by people with Parkinson's. We talked about the three goals of our strategy but it was a staff member and someone with Parkinson's who spoke about our goals.

This is something we need to make sure is built into the way we work. When a charity works in that way, it provides the necessary confidence when speaking with the authorities. The tone of voice can be more assertive, direct, and honest. Having that voice at the heart means that we recruit people who are passionate and driven by what we want to achieve. It’s that combination of fantastic staff and volunteers working together with focus that make a charity successful.

I would like to conclude by saying these are exciting times for Parkinson’s, and the UK can play a major role in this field. Through our Virtual Biotech model, we want to encourage the pharma industry to look at the opportunities there are to work together, perhaps in a different way than they envisaged. We would like to welcome some innovative partnerships between us.

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