Better Patient Advocacy: Some Personal Assumptions, Observations, Suggestions and Conclusions Drawn From Ten Years of Advocacy in Parkinson's Disease

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Standing on the shoulders of giants

It is an article of faith in science that discoveries build upon previous knowledge. Sir Isaac Newton, discoverer of gravity inter alia, expressed this better than most when he said "if I have seen further it is only by standing on the shoulders of giants". In essence, whilst downplaying his own contribution, he acknowledged the nature of scientific research, discovery building upon discovery.

This is an important concept and equally valid today. Science does not reach conclusions without building upon solid foundations. Often those foundations are bound together by knowledge from different branches of learning. In some ways even that diversity may contribute to the strength.

In recent years, we have seen a substantial conceptual shift in the role of patients in medical research and discovery. Patients are evolving away from their traditional role as the guinea pigs of the scientists. Increasingly patients are involved in reviewing scientific applications, contributing to the process itself as often as not. There are even whisperings of patient driven and patient initiated research in the near future.

In many respects, these role shifts are the result of many years of patient campaigning and advocacy. We, as patients, take it as our right to be involved at the very core of the research endeavour. In essence we adopt the age-old motto "no decisions about us without us". Like a country's constitution, we hold it as quintessential that we have the right to represent ourselves, that nobody should speak on our behalf. To all intents and purposes, we demand parity with our scientific colleagues.

And herein lies the problem. We are not scientists. We are in essence asking for roles and responsibilities that in many cases we are not ready to implement. Put bluntly, we are often out of our depth.

Don't get me wrong – I believe entirely in the principle of patient involvement. It's not that it is the best way forward so much as the only way forward. Research about patients without patients is an absurdity. Of course patients have to be involved. We just need to find out how.

Let's return to Newton for a moment, his apples and his giants. Or more accurately, their modern counterparts in their laboratories around the world. When writing grant applications or research publications, it is taken as read that the modern research scientist is absolutely up-to-date on the latest research elsewhere, that they can recall their findings and place their own work in its appropriate context. In essence, they know the exact identity and detail of the giants upon whose shoulders they are standing. Research is iterative. It has to be. It builds on previous discovery and projects forward by inspired intuition and happy informed guesswork. Knowledge and understanding of "the literature" is imperative.

Theories created in isolation rarely find favour. Not because they are necessarily inherently flawed but because they fail to acknowledge the importance of previous discovery.

At worst, this amounts to rediscovering the wheel. Not surprisingly, grant awarding authorities take very little interest in work that shows such poor scholarship. Publishers likewise spurn manuscripts that fail to acknowledge the primacy of others' work.

But what, I hear you ask, does this have to do with patients and patient involvement in research? We're not scientists, you say. Certainly, but we aspire to equality in respect and understanding. And although we have those aspirations and seek those roles we are not, as I stated earlier, universally equipped to do so. And I believe the reasons for this are simple. We, as patients and advocates, stand at ground level. We do not stand on the shoulders of giants.

Parkinson's is a cruel mistress. As the years go by post diagnosis, we shift from timid ignorance to vocal experience before gradually disappearing again, raging against the dying of the light. It is one of the most brutal ironies that one reaches the greatest understanding of the condition only as one's ability to communicate that knowledge dwindles to the sound of silence.

This is the problem. These are our giants if we only but recognised them. And, if you will excuse the following excruciating mixing of metaphors, we rediscover the wheel because we do not stand on the shoulders of giants.

Let me personalise this. I have had Parkinson's for around 13 years. During that time I have witnessed – even been part of – many initiatives aimed at improving quality of life, better understanding the condition and even hastening a cure. Often these initiatives were led by advocates now gone. And as they faded away, so did their ideas.

And every few years, a new generation would appear, full of energy and inspiration, brimming over with "I'm different, I'm going to beat this thing". And as the new generation of leaders emerged, so did their followers. Chat rooms and discussion groups would emerge, with different names but strangely familiar content. Old issues have been recapitulated.

But the one thing signally absent in this process is communication between those dynamic young firebrands and the flickering embers of the old guard. The young were too busy to listen to the old and the old too self absorbed with simply surviving for there to be meaningful exchange between the two.

This is a terrible state of affairs. The older, or perhaps I should simply say more experienced, patients have walked the same roads that the youngsters now tread. If the youngsters looked hard enough, they would see their footprints. They would see where discoveries had been made or ideas refuted.

But this isn't about the inability of the newer generation to listen to their forebears. It is as much an admonishment of the older generation for failing to pass their ideas on to those best equipped to implement them.

This is where we differ substantially from scientists. Whereas their very success depends on their knowledge of what has been done previously in their fields, this is not the case in patient advocacy. The younger generation are not absorbing or even aware of the treasure chest of knowledge to be tapped by conversation with the previous Parkinson’s advocacy generation so to speak. And the older generation are failing to show the youngsters where the treasure chests are. This I sincerely believe is essential if we are ever to claim our rightful positions at the tables of research charities, policymakers and discoverers. We have to find ways to build on the experience of previous generations. Only then will we truly be standing on the shoulders of giants.

Passing the baton

Until the 1960s and the advent of L-dopa, the lot of a person diagnosed with Parkinson’s disease was a pretty miserable one. Typically six years from diagnosis to death, and six rather unattractive years at that. Progression was largely untouched by the drugs available which, in any case, carried a significant cognitive payload. Six years in which to put your affairs in order, squeeze the last pleasures from one’s former life and come to terms with one’s imminent extinction. No wonder my mother, who had nursed end-stage Parkinson’s patients in the 1940s and 1950s sobbed when I told her of my diagnosis.

But the introduction of L-dopa in the early 1970s changed that picture significantly. And although it did not cure the illness it delayed the deterioration to some extent. A life expectancy of six miserable years became 12 years, 18 years and beyond. Parkinson’s patients who anticipated a brief agonised exit suddenly found themselves with time on their hands. And although that single observation alone is not enough to explain the rise in advocacy over that timeframe, it is most certainly a contributor. It is my firm belief that medical conditions with relatively long post diagnosis lifespans are the breeding grounds for advocacy.

Let me explain. I believe that the best patient advocacy is the product of a relatively long post diagnosis lifespan and a poor and deteriorating quality of life. In essence two interacting facets. A rapidly terminal illness, such as one of the many cancers, affords the sufferer little time to do anything much beyond write their will, say goodbye to relatives and set their house in order. It certainly doesn’t allow sufferers to build a useful programme of patient advocacy. Conversely, conditions with a long lifespan but little deterioration, although providing the timeframe necessary for advocacy, to not have the necessary burden of illness.

Both a lengthy period of illness and a significant and increasing burden are necessary. In these conditions (Parkinson’s, Multiple Sclerosis, cystic fibrosis for instance), it is not surprising that patient advocacy flourishes. We should be grateful for that. And in many respects we are. Advocacy is our way of drawing people without the condition into our world, of helping people understand what we go through. Because otherwise “if you haven’t got it, you don’t get it” as a fellow patient once said to me.

Advocacy serves its purpose, if its purpose is considered to be that of raising awareness among the general public, attracting funding and thus increasing the amount of research. Laudable aims but somehow still not a very high bar. For many Parkinson’s advocates this is not enough. We expect to be involved in all aspects of the condition from diagnosis, through research and the lived experience, to quality-of-life and end-of-life issues. Nothing falls outside our perceived remit.

And, as outlined in the previous section, therein lies the problem. We have fought and achieved roles in most aspects of research and care. We have learned much along the way and have been inspired by many brave and imaginative people. But where we have failed, and perhaps it is simply a victim of our success to date, is in transferring that knowledge and understanding from one parky generation to another. Knowledge accrued by one generation seems somehow to be taken to the grave by that same generation. Either they have failed to communicate their learning to the youngsters with the energy to run with it or, equally likely, the newer generations simply never knew what had already been established. So much is lost, as Rutger Hauer memorably said “like tears in rain”.

We have to find a way to value the knowledge of the older generations. We have to find a way of recognising their value as, in essence, the giants upon whose shoulders we stood. I don’t believe we are currently doing so. I believe so much of that knowledge is lost. As the condition progresses, it inevitably diminishes our capacity to communicate. Whether we recognise it or not, eventually our diminished powers of communication somehow ossify the knowledge gained over a lifetime with the condition. The older generation watches as the youngsters make the same mistakes, hit the same brick walls.

Each new generation rediscovers past learning, often without realising. They fail to notice the giants watching their every move with interest. And the giants, paralysed with the burden of the years, let each firebrand pass without speaking up. This is a problem. If we do not, collectively and individually, pass on our knowledge as we approach the autumn time, that knowledge and learning will be lost. We need to find a mechanism of ensuring that the baton is passed in a systematic and helpful way. But how?

It would be warming to believe that it can be left to individuals to buddy up with advocates from different generations, mentoring the younger whilst still listening to our forebears. It’s an appealing notion but not one that is readily scalable. Relationships like that build organically – they cannot be imposed. Success is predicated on the basis of personal relationships. Ultimately this is insufficient to carry the baton forward in a meaningful way. What is needed are stories – the basis of a collective knowledge.

Let me explain. Many of the more ancient cultures still surviving today owe their culture to the oral tradition. In many cases, written language appeared later. But it was the oral tradition – spoken stories – that was passed from generation to generation.

Before the influx of voluntary (and some less voluntary) immigrants to Australia in the last 300 years, the country was populated, albeit sparsely, by aborigines for over 50,000 years. And during that time, the aborigines maintained a lot of their cultural identity through repeated stories of a mythical prehistory. This prehistory, The Dreamtime, was handed down orally from father to son over more than 1000 generations.

In North America, Native Americans lived under the eye of Wakan Tanka and practised animistic rituals to appease their multiple deities. Again these traditions were oral, passed among tribes and down lineages. Nothing was written down in anything we would consider written language.

Even in Europe, with its widespread intermingling of populations through trade and war, there are traditions. We owe our understanding of the great Nordic sagas to books. But it should be remembered that these stories predated their littoral transcription.

The point I’m making is that the oral tradition is a powerful means of communication and information transfer down the generations. The ancient peoples were unencumbered by the need to write down stories. Consequently their oral traditions are all the stronger.

This is telling us something. Something both informational and sociological. We have to be able to transfer knowledge of the elders to the youngsters. I take that as read. We have to find a way of passing the baton that negates the generational mistrust prevalent in modern society. We have to find a way in which the youngsters will wish to hear the wise words of the elders. Not only will this prevent us reinventing the wheel but it will also surely strengthen the sense of community amongst people with Parkinson's.

In essence we need to find a way, a more modern means, of storytelling within our community. We need to create great blocks of knowledge and wisdom that can be recapitulated and built upon. This is how we pass the baton.

The dying of the light

Communication, in any form, is a two-way process. Even a monologue requires a degree of reciprocation. Without this it is meaningless, just words drifting out into space. The monologue requires reciprocity, an acknowledgement that it has been heard even if it has not found favour from a receptive audience. It is still communication and it is still two-way.

Parkinson's is a multifactorial neuro-psychopharmacopathological condition. No, it's not simply a movement disorder – let's put that one to bed once and for all. Parkinson's is an extraordinarily complex condition or series of interlinked conditions depending on whether one takes a holistic or reductionist position. But the reality of the condition, whichever philosophical stance one adopts, is an arduous day-to-day grind. We can philosophise all we like but the truth is simple. Parkinson's is a nightmare condition, sapping our strength and gnawing at the very sinews of our resilience.

We all know how the story ends. And for many of us, the end of the story is so distant that we may put it aside or prefer not to think of it. We all, to some extent perhaps, mortgage our futures for better todays. The future is unpredictable, the present is at least partly under our control.

But in the same way that the condition has a beginning and an end so too does advocacy. There are few advocates before diagnosis (obviously) and, at the end, equally few. In between, the nature of an individual's advocacy shifts and changes like the sands. In part this is a dynamic woven out of the individual's internal disposition, personal circumstances and the wider community.

There have been several attempts to map advocacy roles as a function of time with some models claiming distinct stages in advocacy. Personally I would stop short of that myself but I do acknowledge that they can, to some degree, be helpful in an academic sense. But let me tackle the issue of advocacy at a slightly more visceral level, viewing how it projects onto the post diagnostic lifespan of a person with Parkinson's. These are generalities and generalisations so please bear that in mind before putting pen to paper on whether I really meant three years and not 33 months. Chances are I didn't.

Diagnosis, the starting point of the journey (and know that I really don't like the word "journey" with its connotations of destination) sets the clock running. And often it sends the patient running. To the Internet. To Google and Wikipedia. Fear is swiftly replaced by terror, anxiety by panic, the doldrums by despair. In an afternoon searching on the Internet, one's future is mapped out. And for the most part it's an entirely inaccurate picture, conjured of our darkest imaginings.

Some never get beyond this point, abdicating any future pleasure in an orgy of self pity. And it is easy to do. Indeed most of us have probably been there at some point. And if the Internet were the only source of information, that would be the end of it. Fortunately there are other sources of knowledge, much more positive and creative to help guide the newbies. I am talking of course about patient advocates, role models for the community.

And so it begins. Gradually panic, despair and blind terror are replaced by the purifying sunlight of experience, both personal and collective. Patients terrified by the diagnosis at time zero, learn that they can control some aspects of the illness by accrued knowledge. As time goes on, their own knowledge becomes something bigger, something to be shared. This is the transition from passive recipient of information to informer, from freshman to sophomore.

And before long, the informers become critical informers, no longer simply imparting received knowledge but questioning its authority and forming their own wider view of the condition and its manageability. These critical informers often become opinion leaders, taking their views onto a wider national or even global platform. Often they look back on their former bewildered lives in the year or two post diagnosis with a sense of distance.

Opinion leaders set the tone for communities. Their perspectives on the condition and its context can have huge influence for good or bad.

As time progresses, apathy, the most pernicious of all parkinsonian symptoms, takes its toll. Gradually the informers and opinion leaders fall away. You have to remember of course that the position and status of the opinion leaders is often a reflection of the timespan of their own illness. By its very nature, the condition will have progressed much further in these individuals than in the newbies. The giants may still be there but their voices are quieter. Where once they roared like lions, now they whisper.

As I said before, herein lies the conundrum. The point at which advocates have most to impart is the point at which their capacity to do so is most compromised by the simple day-to-day struggle for survival. And that’s not an exaggeration. No matter how brilliant, persuasive and important, it’s hard to do anything much use when it takes an hour to get dressed, to eat breakfast and to answer emails. Then it’s lunchtime followed by physiotherapy, exercise or whatever. There simply aren’t enough hours in the day.

I should declare my perspective at this point. I have had the condition 13 years. I don’t regard myself as a newbie any more. Nor do I regard myself as one of the giants with broad shoulders. I’m somewhere in the middle. I look up to the giants with the same admiration as ever. But now I have to cup my hands to my ears to hear what they’re saying. And I watch the brightest and best of the young sophomores building their own communities.

It was ever thus.

The most enthusiastic, the most energised and driven are the ones building the future for Parkinson’s advocacy. And they are building it in their own image, a young image. This is all well and good but neglects the vision and knowledge of the giants. And although the numbers are changing, the needs of the older Parkinson’s patients are just as important as those of the young onset Parkinson’s patients (YOPD). As someone with YOPD (I was diagnosed at 49) but now older (nearly 62 since you ask), I am acutely aware of the separation of the two schools. I’m not sure whether I have 1 foot in each camp or no feet in any camp.

As I said earlier, it’s all about passing the baton. And I believe that oral testimonies may well be the route by which the baton is passed. But if it was that simple, I wouldn’t be writing. But there are more than one baton. And it’s not always clear who is holding But of course the real question is which baton and who is holding it.

Many readers the first two pieces in this series have felt that I am disparaging of their efforts and blame them for the number of wheels being reinvented. Actually, I don't. I don't believe that they are singly to blame. I feel that the giants are every bit as culpable. Although their voices may be fading, they still have a wealth of knowledge to impart. And like Rumsfeld's unknown unknowns, only they can know the full depth of knowledge.

It is time for them to rage against the dying of the light.

A new model army

Whenever you mention the word advocacy in the context of an illness such as Parkinson's, most people nod in recognition of same. We all know what advocacy is, don't we. It's about raising public awareness, right? Well, yes and no. Yes, in the broadest sense it probably is a question of raising awareness but also no, because it goes much further.

But let's at least make this easy and start with the concept of raising public awareness. But we want to do this scientifically, right? So first we need to be able to define public awareness. What is "public awareness" then? And what are its units? We need to know the units. After all we don't measure the speed of cars in kilograms or the size of the Earth's gravitational field in calories. We need to know the units.

Still think it's easy? Well obviously not and at this point you probably feel that I am dabbling in needless pedantry. It may look like that but I'm making a simple point – if you can't measure something then you can't measure a change in that something. And if you can't measure a change in something then you cannot demonstrate that your outcome has been achieved if you can't measure public awareness of Parkinson's then how are you going to show that it has been increased? And, believe me, if you think this is pedantic, I've barely broken a sweat.

I'm constantly impressed by the number of people who have "raised public awareness of Parkinson's" or who intend to do so without the slightest idea of what that might look like. If my objective was to raise public awareness of Parkinson's, I would want to be sure not only that the objective been attained but also that this could be described numerically. Numbers are the currency of science. If something cannot be described in numbers, then I would have a hard time calling it science.

This is the very simplest situation and, in advocacy terms, perhaps the low hanging fruit. If advocacy can achieve nothing else, one would at least hope that it could raise public awareness.

Even allowing for liberties in terms of what it is, how it may be measured and defined, there is still the great unanswered question of why. Raised public awareness is surely not an end point in its own right but a staging point or a surrogate measure. It is tacitly assumed that raised public awareness will somehow achieve some greater good – raise money for research, influence governmental policy, improve living conditions, maybe even hastening a cure for Parkinson's. This is almost taken for granted. No double-blind studies have been conducted to demonstrate the link between raised public awareness and modified governmental policy. So, if there is no benefit in terms of the things one really wants to change, is raised public awareness a legitimate advocacy objective? Shouldn't advocates be doing something more useful with their time?

I would argue "yes" and, moreover, the best advocates are eschewing nebulous objectives in favour of more direct action. This is to be applauded.

I would argue that if you want more research, then raise money not awareness. If you want to modify government policy, tackle government directly. Raised public awareness counts for little here. If you want a cure sooner, promote better research.

These are more direct means of influencing change and, to my mind, this is what advocacy is or should be about – high-level interactions with high value outcomes. We should be seated on every drug advisory board, every research steering group, every expert panel, every governmental committee. In essence, we should be represented (by ourselves) in every circumstance where decisions are taken that are of direct concern to us.

But I would go further.

Throughout the first half of the 17th century, armies in Britain were geographically constrained, often acting as garrisons or local militia. There was sparse interaction between such forces and their roles were little more than guarding towns. In 1645, Oliver Cromwell formed the New Model Army, a mobile military force of highly trained soldiers constructed around veteran professionals and young conscripts, the old helping to train the young.

This is directly analogous to the current and, I would like to believe, future role of advocates. Currently, advocates are siloed. Individual charities, research bodies and drug companies have their own advocates with their own policies, remits and strategies. In essence militia. Some things are done well, some less well but there is no sharing of best practice. To my mind, we need a New Model Army of advocates and advocacy.

I believe that advocates have much to learn from each other and from their forebears. I believe that, by sharing best policies and actions, it will be possible for advocacy to evolve into a kind of super advocacy. I see this as a natural progression, organic in many ways, and one which best serves the community. We need to share old knowledge from our wiser heads. We need to share new initiatives from our younger brighter minds. And we need to focus on direct, achievable high-level objectives. This means improving the knowledge base and aspirations of the advocate corps. Raising public awareness simply isn’t enough anymore. Our new advocates need to be aiming higher.

Return of the Jedi

In part one (standing on the shoulders of giants), I suggested that, although we had unalienable rights to represent ourselves and our interests, we often fell short of our scientific colleagues by failure to build upon existing knowledge in the way that scientists do routinely. I suggested that we needed to take a leaf from their book. In part two (passing the baton), I speculated that we, as a community undervalued and underutilised learnings of past generations and I made the case for storytelling and the oral tradition. Part three (the dying of the light) presented a major conundrum in the sense that wisdom and knowledge gained through experience was at its strongest in the community least able to express that knowledge. In part four (a new model army), I tried to clarify what I understood by advocacy and some kind of expanded future role for advocates.

As will been abundantly apparent by now, I don’t have all the answers. But, like the old scientist that I am, I am nonetheless aware that wisdom lies not in knowing the answers but in knowing the questions. In the words of Charles Caleb Colton, a 19th-century English cleric and writer, “examinations are formidable even to the best prepared for the greatest fool may always ask more than the wisest man can ever answer”.

In some respects I am no closer to the answers or the questions. Writing these pieces has been an exercise and an exorcism. I have felt for a long time that patient advocates have important roles to play but that we frequently fail to match qualifications and skills with desired outcomes and objectives.

We stand at a crossroads. Our scientific and clinical colleagues increasingly recognise the value of our input. Whether that is indicative of a seachange in philosophy or simply enlightened pragmatism in the face of such demands by research boards is moot. Ultimately it doesn't matter. For whatever reason, we have been offered these opportunities and we would do well to grasp them.

But to be of greatest service to our community, we need to bring our "A" game. We need also to expand our definition of advocacy. That's always assuming we can define it in the first place. Advocates are powerful instruments of influence. All of the research charities in Parkinson's have advocates in one form or another. Often their roles are focused by the charities themselves but there is a degree to which their roles have a wider, more philosophical dimension. As advocates grow into their roles, they recognise their place in the universe so to speak and evolve into it.

The fresh-faced newbies struggling to come to terms with a crippling lifelong diagnosis are, over the span of time, the veterans and broad shouldered giants upon which our knowledge base and understanding are built. We should treasure them. They come in many forms – fighters to philosophers, thinkers and doers, movers and shakers. Each, in their own way, fitted into the larger jigsaw. Some saw the value of evolution, others of revolution. There were those who wanted to build while others saw demolition is necessary. Some sought to persuade, others to sweep aside. Some become bright beacons to others, rallying points in the darkness. Others flickered and burnt like wildfire, their brilliance sparkling for a brief few moments. Some focused on their own strengths, building edifices of knowledge and experience. Others flitted from flower to flower like butterflies. Some lights are dimmed, while other stars are in the ascendant. I won't name names. For the most part you know who you are. But I will make one exception.

Of all the advocates who have influenced the Parkinson's world, none has had greater influence than Tom Isaacs. No, I don't propose to deify him. He was, and he would admit this himself, an ordinary man driven to extraordinary actions by his illness. In many respects it gave him a purpose in life that he probably felt was missing. I had the pleasure and privilege of working with him for several years. He was inspiring and exasperating. He drove himself hard, aware that he was running out of time (like all of us). He made light of his lack of qualifications when surrounded by highflying academics. But his greatest strength was his ability to get people talking to each other. Oh I nearly forgot to mention – he founded a charity to cure Parkinson's. He always believed in direct action.

Above all, people listened to Tom. They wanted to hear what he had to say. And I think that therein lies the challenge to all of our senior Parkinson's advocates. We need to somehow capture what made Tom so compelling. The senior advocates whose voices are quietly fading away are a resource too easily lost for good. They are like the old Jedi, knights of an older order. They knew about non-motor symptoms years ago. But still, each generation rediscovers them for themselves, reinvents that wheel. We talk about young onset Parkinson's disease as though it was something new. But there were YOPD groups 20 years ago. They came, they went. In the UK, there was Tina Walker, an inspirational leader. She passed on a couple of years ago. And if it were not for voices still alive passing that information on, we would be starting from scratch with yet another wheel.

It's time for these voices to be heard again. They should never have been forgotten. It's time if you will for the return of the Jedi.

I want to end with a list. It's a list of those people with Parkinson's who have influenced me over the years. Sometimes it can be in small ways, maybe a single thing I remembered. Sometimes these are huge influences in my life. I make no distinction in the list below. There is an inherent danger with lists. A danger that one will upset or antagonise those not on the list. It's a bit like a wedding. There will always be some relative who fails to make the cut and trumpets their displeasure widely. Nevertheless, I'm going to take that chance and list those patient advocates who I feel have influenced me over the years. I place here the usual caveat that this list is not complete. Nor is it in any order. Some have shown me their inspiration on a single issue. Others have run like a leitmotif through my life. All have contributed something to shape my philosophy of what an advocate is, could be and should be. If you're not on the list, it's probably my fault not yours. Or you may not have Parkinson's.

Tom Isaacs, Jean Burns, Anders Leines, Jill Carson, Shel Bell, Gaynor Edwards, Colleen Henderson Haywood, Eros Bresolin, Simon Laverick, Peggy Willocks, Pete Langman, Linda Ashford, Bob Kuhn, Matt Eagles, Vicky Dillon, Claire Lindley, Martin Taylor, Dilys Parker, Brian Toronyi, Omotola Thomas, Jordan Webb, Andy McDowell, Steve DeWitte, Claire Jones, Emma Lawton, Georg Sternberg, Samuel Ng, Soania Mathur, Larry Gifford, Leslie Davidson, Richard Windle, David Jones, John Humphreys, Reidar Saunes, John Rooney, Les Roberts, Stefan Strahle, Ben Stecher, Karen Raphael, Philip Beckett, David Lohr, Jo Collinge, Ryan Tripp, David Sangster, Heather Kennedy, Tom Gisby, Tim Brandt, Sara Riggare, Elizabeth Ildal, Sara Lew, Mariette Robijn, Rune Vethe, Brian Lowe, Dale Sherriff, Madonna Brady, Jenny Nelson, Phil Bungay, Maria de Leon, Nan Abraham, Niki Oldroyd, Michael Peachey, Alison Anderson, Ian Meadon, Tim Hague, Catherine Oas, Rachel Gibson, Mark Whitworth, Alison Smith, Karen Rose, Kelly Sweeney, Hedley Cox, Bryn Williams, Tina Walker, Nan Little, Sheila Roy, Mags Mullarney , Israel Robledo, Alan Lewin, Margaret Owen, John Silk, Karen Green, Ron Rutkowski, Connie Elliott, Perry Cohen, Kirk Hall, Fulvio Capitanio, Bruce Jockelson, Rachel Clarke, Ray Wegrzyn, Tim Bracher, Kevin Krejci, Briony Cooke and Steve Shea.

Jon Stamford is a man with a dual interest in Parkinson's. A neuroscientist by training with a PhD (1985) from the University of London and a BSc (1980) and DSc (2000) from the University of Bath, he spent more than 20 years heading a small research team looking (inter alia) at dopamine function in the basal ganglia and its relationship to Parkinson's disease and treatment. Apart from brief spells working in the United States, most of this research was conducted at the same institution – The Royal London Hospital and London Hospital Medical College – where James Parkinson had trained. In 2006, he acquired a different perspective when he was himself diagnosed with Parkinson's in his 40s. However this quickly became a source of motivation and, since 2008, he has been an active patient advocate, helping to improve public and scientific understanding of this enigmatic condition. He served on the editorial board of Parkinson's UK's magazine THE PARKINSON for two years and was one of the original 16 ambassadors for the WORLD PARKINSON CONGRESS in Montréal in 2013. In 2010 he was a co-founder of PARKINSON'S MOVEMENT, a global

patient advocacy group focused on ensuring high level patient representation and involvement in research and development. He remained director of Parkinson's Movement and worked for the CURE PARKINSON'S TRUST as a scientific and advocate communications coordinator until his (partial) retirement in April 2017. In 2014 he founded PARKINSON'S INSIDE OUT, a small think tank of clinicians and neuroscientists who also had Parkinson's. Jon is also a keen supporter, and research consultant for SPOTLIGHT YOPD. Always keen to find an educational dimension to the experience of living with Parkinson's, Jon is a popular invited speaker and an active contributor to many advisory and research boards . He enjoys writing and, from 2012 to 2016, was editor in chief of ON THE MOVE, an online English and foreign language magazine for the global Parkinson's community. He has also written several scientific books as well as others describing the patient experience of Parkinson's and for many years wrote a popular weekly blog entitled SLICE OF LIFE. Jon also serves on the editorial boards of NEURODEGENERATIVE DISEASE MANAGEMENT and the JOURNAL OF PARKINSON'S DISEASE.