

Your experience – Our inspiration.



The research group of PD Avengers needs your help to develop ***Sparks of Experience***. Parkinson's research needs a breakthrough idea and it may just be your idea that we are looking for.

No-one knows the condition better than those living with it day in day out. It is complex and very variable, both between patients and within patients. Even the experts are puzzled. Living with Parkinson's means making significant changes to life as we learn strategies and tactics to make life as easy as possible. We are constantly alert to any factors that seem to make a difference. Living with this pesky and perplexing condition demands a great deal of self awareness and self education and many give a lot of thought to their experiences. You may think to yourself "I wonder why my symptoms are worse in the winter.", or "How would it be different if I were left-handed?" or "Why is it I am always at my best when I go to see the consultant?" When you try to find the answers you think "Why isn't anyone researching this?!" We want to collect these sort of thoughts from around the globe and highlight them to researchers and funders.

We all know stories of important scientific moments, like Fleming's discovery of penicillin. It may appear to have been accidental and leaving the petri dish on the window sill may not have been planned, but it was no accident that Fleming's curious mind made a breakthrough. We believe that there are curious minds that will set new directions to work towards a cure or novel treatments for Parkinson's and yours might be one of them. Your experiences could provide the inspiration for a new direction for research and that so far elusive key to unlocking the mystery of Parkinson's.

There are already good, well known examples of inspiration in the Parkinson's world too, including an observation by a patient back in 1969 who noticed that her Parkinson's symptoms improved while she was taking the prophylactic Influenza

drug Amantadine. The drug was redeveloped as a Parkinson's treatment. More recently we heard about PD Avenger Joy, with a sensitive nose, and how she noticed a change in the way her husband smelled long before his PD diagnosis. She brought it to the attention of a researcher and the resulting projects have provided exciting developments working towards a simple diagnostic test.

What do you ponder about? No matter how quirky, off the radar or even boring and obvious it may seem to you, please send us a couple of paragraphs describing your thoughts and ideas **in your own words**. We will collate the list, see if there are common threads, highlight the most frequently occurring and make sure that researchers and funders around the world get a copy. We'll try to find researchers who work in appropriate fields and send them collected thoughts. Who knows where your curious ponderings may lead.

We've already had many different experiences and observations sent to us but we are still getting new ones. We'll keep on collecting until no new ideas come up and we can be sure we've got most of them. Please e-mail, we'll be pleased to hear from you.

e-mail to :- sparksofexperience@gmail.com