



Dear Patients,

We are a group of people with Parkinson's and carers, currently under the care of the International Parkinson's Centre of Excellence at King's College Hospital NHS Foundation Trust, part of King's Health Partners in London.

We form members of a nationally recognised and accredited "expert patient group", **CRISP** (Community for Research Involvement and Support for people with Parkinson's), which was formed in 2011 and functions under the Parkinson's research group at King's led by the team of Professor K Ray Chaudhuri.



As a group we are key members of the research strategy group for Parkinson's research at King's College Hospital. We have supported many new projects such as the development of a new "pain questionnaire" and a "pain scale", which will allow, for the first time, doctors and nurses to measure pain that may affect people with Parkinson's.

The purpose of this letter is to highlight the importance of participation of people with Parkinson's in clinical research. There is a perception that taking part in research means being a "guinea pig" and it has no important part in your treatment. As patients and carers ourselves, and being proactive in research, we would like to enlighten our fellow people with Parkinson's that this is not at all the case and hope that we can encourage some of you to join us and take part.

Taking part in research that promotes improved treatment and quality of life for all of us in the future is very important. Research studies can take many forms and some are simple observation exercises and others may mean trying a new form of medication, which in some cases may involve a placebo ("dummy" preparation). It is the involvement of patients in clinical studies that will ensure better treatment in future.

From our own experiences in taking part in clinical research, all have been a positive and worthwhile activity to take part in. If you feel unsure that research may not be for you, you can be confident that the study team at King's will discuss every aspect of the research with you and you can opt out at any stage with no obligations.

We would like to ask that you consider joining us and taking part in clinical research by letting your medical team know during your appointment that you would like to be considered for any appropriate opportunities to take part.

We really hope you will consider participation in research studies and of course we are very happy to be contacted should you need any further information or advice.

Yours sincerely,

On behalf of CRISP:

U. Rizos S. Pitto D. M. Chaudhuri [Signature] [Signature]
[Signature] . Steve Roberts. [Signature]

If you have any questions, please contact a.rizos@nhs.net.