ASKING QUESTIONS

Learn about the details of the study:

- What is the purpose of the study, and why is it important?
- Has it been shown that the treatment being studied might help my condition?
- Has this treatment been studied before? If so, what were the results, can I get them?
- If this is a placebo controlled trial, what are the chances of receiving the treatment that is being studied?
- When is the study expected to end?
- Does the study include post-study follow up care?
- Will I be able to receive the experimental treatment when the study ends?
- Who is sponsoring (funding) the study?
- How long has this study site been conducting clinical trials?
- How many are currently underway and how many have been completed?
- Does anyone on the clinical trial study staff have a financial association (e.g. ownership of stocks or other investments in the sponsor's company and consulting contracts) with the study, other than receiving compensation for the cost of the study itself?

Learn what will be required of you:

- What key information do I need to be aware of?
- How much of my time will be involved?
- Will I have to travel?
- What types of visits (outpatient, hospitalisation, home) will be required, and how long will they last?
- What tests will be given before I start the study? Will I get the results? If so, when?
- What tests will be given during the study? Will I get the results of these tests? If so, when?
- Will the treatment be uncomfortable? Will it have any side-effects? If so, for how long?
- If this is a medication study, can I take my Parkinson's medication and any other over-the-counter medicines along with the study medication?
- How could being in the study affect my daily life?

Learn about the benefits and the risks of participating in this study:

- What are the potential short-term and long-term risks/benefits of the study?
- What are the known side effects of the treatment being studied?
- What is likely to happen to my disease symptoms with or without this experimental treatment?
- Will participating in this study prevent me from volunteering for future studies, if so in what way?

Learn about whether there are other treatment options to consider:

- If I don't participate in this study, are there other study fields for which I might be eligible? If so, what are the risks and benefits of these?
- If this is a treatment trial, why do researchers believe that the new treatment might be better than my current treatment options?

- Will this treatment available outside of this study? If so, how do I get it/when will it become available?

Learn about how your expenses will be covered:
Some questions if you live in a country where your health is covered by insurance:
- Will I have to pay for any part of the clinical study, such as tests to determine eligibility, or the study drug itself?
- Which costs are likely to be covered by my health insurance? Are there any costs that are not covered by my health insurance?
- In the case of a drug trial or trial for a new treatment, will my insurance / the institution's insurance cover me if there I have a reaction or there is a problem (called an adverse event) and will long term care be offered? What alternative treatment will be offered?
- Who can help answer any questions from my insurance company or health plan? Who do I contact at the trial centre and at my insurance company if there is a problem?

Some questions about travel and reimbursement:
- Will there be reimbursement for my expenses (travel, overnight accommodations, caretaker accompaniment, childcare, etc.)?
- How and when will I be reimbursed for expenses that I incur while participating in the study?

Learn about how your health and safety will be monitored and your privacy protected:
- How will my health and safety be monitored during and following my participation in this study?
- What type of health records will I need to keep?
- Who is responsible for my care while I am participating in this study?
- Who will provide medical care in the event that I develop study-related complications during the trial?
- If I were to be harmed because of the research, what treatment would I be entitled to and how will this be managed?
- What type of follow up care will be provided?
- How will the study staff work with my Doctor to keep him or her informed about my care?
- Whom do I contact at the study centre if I have questions during the trial?
- Who will provide me with a comprehensive explanation of the information contained within the informed consent form that I am to sign?
- Who has access to the data collected and how will it be used?
- How will my privacy be protected?
- What procedures are in place in the event that, due to the progression of my disease, I am no longer able to make decisions for myself with regard to participation in this study?
- How will I be informed of changes in this study? Will I be given a new consent form to sign?
- If I leave the trial before it is over die to health problems resulting from being in the study, will treatment be available to me?
- How and to who are adverse events reported and how will I be informed?

Learn about what happens at the end of the study?

- Can I withdraw from the study at any time?
- What is the procedure for withdrawal from the study?
- If I stop participating, will I face any penalties or be denied future treatment?
- If I am in a study that uses a placebo, will I be told afterwards whether I received the placebo or experimental treatment?
- What happens to the information I provided once I stop being in the study?
- What procedures are in place for notification if my trial is halted or terminated?
- How and when will I be advised on what steps to take if the study is stopped?

Learn about how post-study information will be made available:

- How will I be notified about side effects, benefits and risks of participating, that become known following participation in the study?
- What will be done with the study results once the study is completed?
- Will I be notified of my own individual results?
- Will I receive a copy of the results? If so, when?
- How will both negative and positive study results be made available to study participants, researchers and the public?
- When will I receive the results of future trials using this treatment?