

## **PRoBaND (Tracking Parkinson's)- Guide notes for involving relatives in the study**

- You will be sent a list of patient ID codes for PRoBaND patients that have been selected for this
  - One patient is shown on each page
  - This is called the Relatives Contact Sheet
- The information collected from the patient on the Family History form has been used, and shows:
  - First name and City where a brother or sister lives
  - The nearest PRoBaND (Tracking Parkinson's) study centre for each sibling
- Please see the patient, and ask them further about involving their siblings
  - This can be at the patient's next scheduled visit, or as an extra visit (e.g. if a young onset patient has completed the study)
  - You may wish to use the "Site record of patient contact regarding relatives" to record the contact with the patient (optional)
- Please inform the patient that they have been randomly selected to invite their sibling(s) into the study
  - Ask the patient to speak to their sibling(s) about the study, to find out if they may be willing to participate in the study (and that – if they agree to be contacted - you will need their names, ages, and phone numbers)
  - The patient may wish to post the Relative Information Sheets to their relative(s) – if so, give the patient one copy for each sibling, with stamped envelopes (provided from Glasgow).
  - Call the patient about two weeks later to check whether their siblings can be contacted
    - note the outcome (agrees to be contacted – yes or no) on the Relatives Contact Sheet for each sibling
    - for siblings that have agreed to be contacted, obtain their names and phone numbers, and record this on the Relatives Contact Sheet
    - copy this information to ClinBase *including the outcome for cases that have not agreed to take part*
      - go to Data Centre, then option 2. View or edit data for a case, then use the ID code for the patient, and select Relatives Contact Sheet – enter the data then click Update, or....
      - if you do not enter data online at your site, scan and email the page to [data@proband.org.uk](mailto:data@proband.org.uk), or fax to 0141 447 0618
- If the patient's sibling has agreed to be contacted and is local to your centre, proceed with inviting them to attend, and go through the study information sheet, and obtain written consent and follow the study protocol
- If the patient's sibling is living elsewhere in the United Kingdom and has agreed to take part, and is close enough to a PRoBaND study centre, the invitation to the study will be made from their local centre. Note that you may therefore receive notifications of this – via Glasgow – for siblings of patients taking part in other centres
- *The following have been screened out using the Family History information collected, but may need checked or updated*
  - *If the patient does not live in the United Kingdom, they cannot be included.*
  - *If the relative has a diagnosis of Parkinson's disease, they cannot be included.*