



FAQ - GP2 Recruitment of Large Families for the Monogenic Network

- **Would there be any compensation to the study participants?**

PIs could use the funds at their own discretion to compensate study participants.

Shipping costs to ship the samples to GP2 will be covered separately by GP2.

- **Is this a new research project?**

No, this initiative forms part of the work of the Monogenic Network and is not a new project.

- **Is a new agreement needed for this effort?**

No, existing agreements are sufficient, and no new agreements are necessary.

However, if the study participants are consented using *a different consent form* than the one GP2 has reviewed then the new consent form would need to be reviewed first.

- **How does this initiative fit into the existing GP2 projects/ structures?**

As stated above, this is not a new project. This is an initiative by the GP2 Monogenic Network to encourage the recruitment of large families or trios that will help in our efforts to identify new PD genes. Each case will be handled on a case-by-case basis to ensure that there is no conflict of interest and no duplication of efforts.

- **Is there a form or a process for us to indicate the probands and their relatives?**

Yes, please complete the form at <https://monogenic.gp2.org/LargeFamilyIncentive>

- **If I previously sent a sample for the proband to GP2, how can I now indicate that I have family members?**

Please complete the online form on the <https://monogenic.gp2.org/LargeFamilyIncentive> and indicate the GP2 ID number of the proband so that we can link this family to samples that you previously sent to GP2.

- **Will I get credited for large families that have already been submitted?**

No, the financial incentives scheme only applies to newly recruited families.

- **If I have a family with mutation-positive results (for example in LRRK2), would you still be interested in them?**

The Monogenic Network is interested in genetically solved probands and families, however, the financial incentives would not apply in this case since this is only for 'unsolved' families.

- **Could you explain what is meant by families with prior genetic testing?**

These are probands/ families who have previously been screened by GP2 or another laboratory for the PD causing genes and no pathogenic variants were identified.

- **If a pathogenic variant is identified, would we include them in the return of results (ROR) plan?**

Yes, that would be appropriate.

- **How much DNA/ blood is needed and where do we need to ship it to?**

Before you ship DNA/ blood, we first need to assess whether the family would be *appropriate* for this initiative by doing an assessment of the pedigree and the clinical data. Please **do not send** any biosamples yet.

- **If one or both parents of proband/ patient are dead, would the family still be considered?**

We are interested in three types of families:

- a. Trios – probands and BOTH parents (we need DNA/blood samples of both parents)
- b. Large recessive families with multiple affected individuals as well as unaffected individuals
- c. Large dominant families with multiple affected individuals as well as unaffected individuals

If your family fits into one of these three categories, they would be considered. However, all of this will be explained during the one-on-one Zoom/ Teams meeting that we arrange with you, after you have registered your interest on the website.

- **Can a clinician who is not a member of GP2 submit a family?**

The clinician would first need to register with GP2 by emailing cohort@gp2.org. This clinician could then collaborate with an existing member of GP2 (from the same country if possible) and use their consent form and ethics approval to recruit a family for this effort.

- **What is the process/ procedure that will be followed?**

1. First complete the online form on our website (<https://monogenic.gp2.org/LargeFamilyIncentive>) to register your interest.
2. We will then contact you to submit your pedigrees and clinical information.

3. A Zoom/ MS Teams/ Webex meeting will be arranged with you to discuss the family and if it meets the approval, half the funding will be provided up front.
4. Once the submitted samples have passed quality control, the second half of the funding will be paid.