

## PD Frontline Registration Guidance

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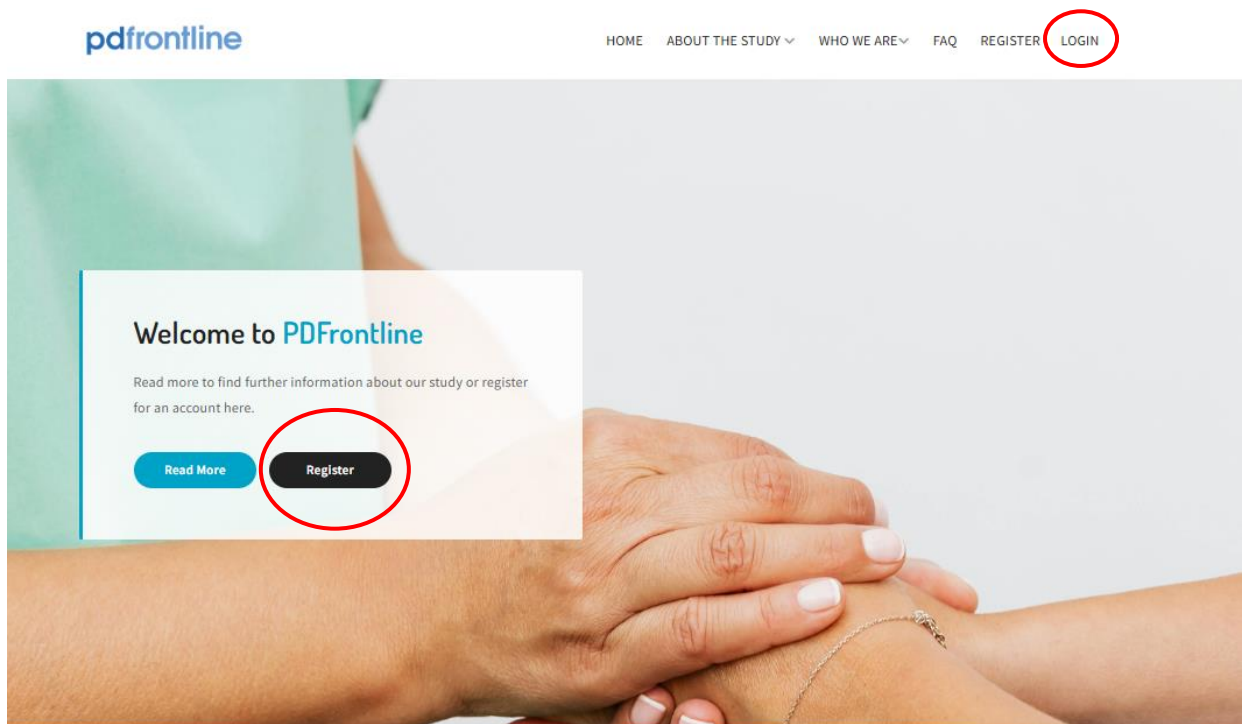
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### Signing up

To get started, you need to first sign up to PD Frontline. Please see guidance for this below:

1. Go to <https://pdf frontline.com/en> and select **register** complete the set of qualifying questions, or login to continue registration

To successfully register to PD Frontline, you will need to select **'YES'** to do you live in the UK, **'NO (I don't know)'** to do you carry a GBA mutation GBA gene status **'YES'** to Do you have a confirmed diagnosis of Parkinson's Disease from a Clinician.



DO YOU LIVE IN THE UNITED KINGDOM?

No Yes

DO YOU CARRY A GBA MUTATION?

No (I don't know) Yes

DO YOU HAVE A CONFIRMED DIAGNOSIS OF PARKINSON'S DISEASE FROM A CLINICIAN?

No Yes

2. You will be taken to the Consent form as in the photo below. Please read each statement carefully and provide an answer for each. Questions that are compulsory to take part in the study are marked (\*).

## Consent

Consent Form (Version 1.6) Consent form for Parkinson's disease subjects in PD Frontline, part of RAPSODI

Statements marked with a \* are compulsory

- I agree to participate/continue participating in the RAPSODI GD study
- I have read and understand the Participant Information Sheet for this study and have had the opportunity to ask questions (via email and telephone).
- I understand and give permission for the RAPSODI GD research team to gain access to my patient notes to document any previous testing results for the glucocerebrosidase gene (GBA).
- I agree to the results of my tests being stored on a secure website for the duration of the study and after its completion.
- I understand that any information collected will remain completely confidential.
- I understand that my involvement is voluntary, and I am free to withdraw at any time, without providing a reason.
- I understand I will be posted a sample collection kit for genetic studies
- I agree to complete a blood sample where requested for genetic testing (this will provide higher quality results through a simple, at home collection device that attaches to the upper arm – please see the PIS for more details)
- I agree to complete a saliva sample where requested for genetic testing

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The following statements are optional

- I understand that, if I give permission, my GP will be contacted to inform them of my participation in the study.
- I understand that, if I give permission, my genetic results will be disclosed to my GP.
- I understand that, if I give permission, the clinician who looks after my Parkinson's Disease will be contacted to inform them of my participation in the study.
- I understand that, if I give permission, my genetic results will be disclosed to the clinician who looks after my Parkinson's Disease.
- I understand that, if I give permission, the research site (for instance an NHS Hospital) that introduced me to this study will be informed of my participation in the study.
- I understand that, if I give permission, my genetic results will be disclosed to the research site (for instance an NHS Hospital) that introduced me to this study.

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## Genetic testing

Statements marked with a \* are compulsory

- I understand and, if it has not already been carried out, give permission for genetic test for the GBA gene to be carried out.
- I understand and give permission for genetic testing for the LRRK2 gene to be carried out.
- I understand that by taking part in this study I agree to be informed of my genetic test results, i.e. the research team will inform me of whether or not I am a carrier of a mutation in the GBA and LRRK2 genes.

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## Clinical trial and other study permissions

Statements marked with a \* are compulsory

- I understand that a member of the study team may contact me, to offer me the opportunity to participate in clinical trials or other research studies. If I give permission, my details, including information related to my Parkinson's disease, will be passed onto them.
- I understand that I may be offered the opportunity to participate in other research studies, either by email, phone or post.
- I consent to my contact details, genetic status (GBA1 and LRRK2 genotype) and information regarding my diagnosis of Parkinson's disease to be shared with a local NHS trial site for discussion regarding enrolment into a clinical trial on Parkinson's disease.
- I understand that my sample may be transferred nationally or internationally to commercial and non-commercial collaborators for processing as part of genetic testing for the GBA and LRRK2 genes (eg: Psomagen who work with the Michael J Fox Foundation). I understand that confidentiality will be maintained at all times. Information that directly identifies you, such as your name, will be replaced with a 'code' or 'ID number.' Your name and other identifying information will not be shared with the relevant lab group.
- I understand that, if I give permission, any samples and associated data that I provide during my participation in the study may be transferred nationally or internationally to NON-COMMERCIAL collaborators. The purpose of this sample and data transfer will advance future research and the potential clinical significance of the study results through the use of more advanced analysis techniques such as artificial intelligence and whole genome sequencing. I understand that, if I give permission, confidentiality will be maintained at all times. Information that directly identifies you, such as your name, will be replaced with a 'code' or 'ID number.' Your name and other identifying information will not be shared with other researchers. [For a list of our collaborators and their work please visit [www.pdf frontline.com](http://www.pdf frontline.com)]
- I understand that, if I give permission, any samples and associated data that I provide during my participation in the study may be transferred nationally or internationally to COMMERCIAL collaborators. The purpose of this sample and data transfer will advance future research and the potential clinical significance of the study results through the use of more advanced analysis techniques such as artificial intelligence and whole genome sequencing. I understand that, if I give permission, confidentiality will be maintained at all times. Information that directly identifies you, such as your name, will be replaced with a 'code' or 'ID number.' Your name and other identifying information will not be shared with other researchers. [For a list of our collaborators and their work please visit [www.pdf frontline.com](http://www.pdf frontline.com)]

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## Wider study consent

The following statements are required.

- I understand that I may be required to complete a 'scratch and sniff' smell test, which will be posted to me 1-2 weeks after completing the surveys.
- I agree to be contacted in the future for neurological examination or further questions related to the study which may be video recorded.
- I understand that the research team may ask me to provide samples of blood, urine or cerebrospinal fluid, however not consenting to give these sample will not affect my ability to participate in the study.

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3. You will then be taken to the registration page where you will need to provide your name and an email address. This email address will be your username.
  
4. You will then receive an email with a link, which you need to click to verify your account. The link will prompt you to create a password and then log you back into PD Frontline.



Dear

Thank you for registering with the PD Frontline study.

Please [click here](#) to verify your email address and create a password.

Alternatively, please copy and paste the below in to an internet browser.

<https://mantal.pdf frontline.com/verify/d2d104169b0405833a76c60b7885c6e8>

Regards

The PD Frontline Team

5. You will then see the your profile page as in the picture below; you can update your password and email preferences in the **'Profile'** tab. Your genetic results are available to download once ready from the **'Genetic Results'** tab. To start the study you will need to click the blue **'Start'** button.

