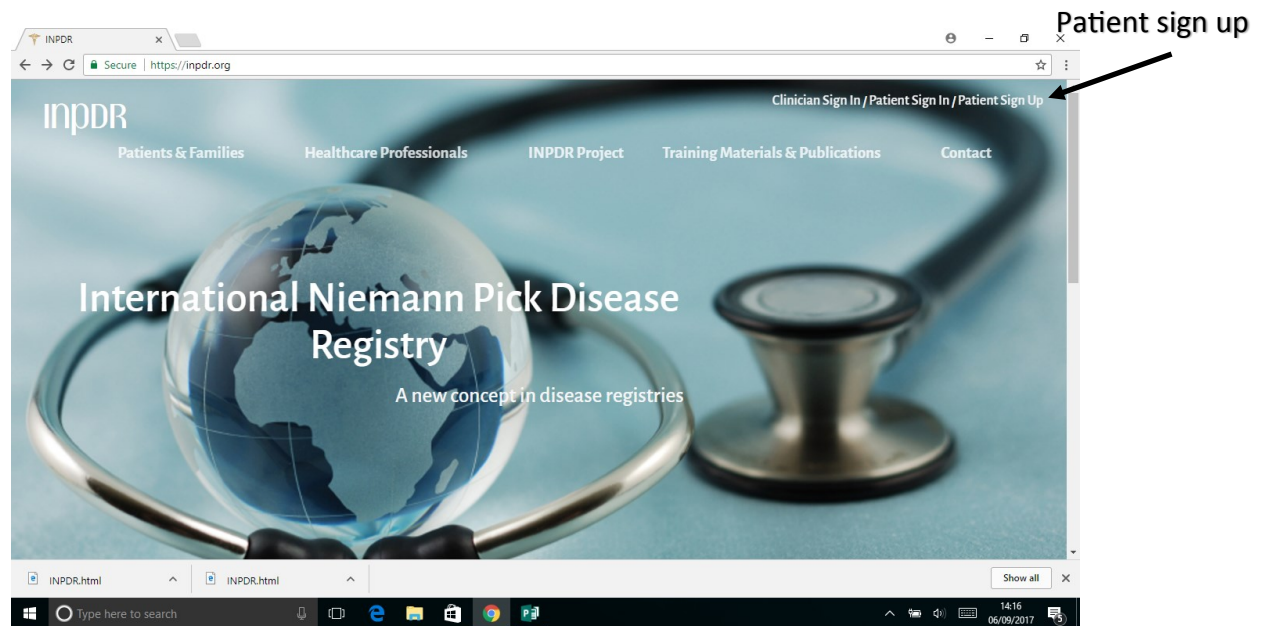


Self registration for patient reported data

1



2

WELCOME TO THE INPDR!

Introduction to the project.....[SIGN UP](#)

3

INPDR

Contact Us Log in

Sign up

* Email

* Password

8 characters minimum

* Password confirmation

Back Submit

Log in

Didn't receive confirmation instructions?

Didn't receive unlock instructions?

The registry is owned by the International Niemann-Pick Disease Alliance (INPDA), an alliance of non-profit NPD patient support organisations. It is managed by an international consortium of professionals and is hosted at the University Hospital's Birmingham NHS Foundation Trust (UHB) in the UK. The project to develop the INPDR received funding from the European Union, in the framework of the Health Programme.

Terms and Conditions.
Privacy Statement.

INPDA
International Niemann-Pick Disease Alliance

4

Thank you for registering in the INPDR

Your registration is now being processed. We will be in touch via e mail as soon as possible with your user name and password. You will then be able to log into the registry and complete the patient reported questionnaires.

In the meantime, if you have any questions at all you can contact us at inpd@uhb.nhs.uk. And again, THANK YOU for your involvement

5 Welcome to the International Niemann-Pick Disease Registry

You have successfully signed up to the INPDR, your username is :
niemann-pick@.....

Please now confirm your account email by clicking on the link below:

6 What you will need before you start entering your data

Clinician name and e mail address ,hospital name and phone number, date of diagnosis and genetic mutations if known.

7 Read the CONSENT FORM carefully.

If you have any questions or concerns do contact the INPDR

8

Signed in successfully.

Welcome niemann-pick@zetnet.co.uk

Registered Patients

Registrant First Name	Registrant Last Name	Relationship to Patient	Patient First Name	Patient Last Name		
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Enrolled patients

Note: You can only create/complete a questionnaire after your enrolment information has been verified. You will be contacted via the email you provided when this has been completed. We also note that once a questionnaire has been completed, it is not possible to enter a new questionnaire until a period of 3 months have lapsed.

Patient ID	Verified	Enrolment Form	# of Completed Questionnaires		
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[Add new patient](#)

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9 You now have 4 short pages around the type of NPD and diagnosis

10 Thank you for enrolling in the INPDR.

Your enrolment details are now being processed. We will be in touch via e mail as soon as possible to confirm your registration. You will then be asked to log into the registry and complete the patient reported questionnaires.

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And again, THANK YOU for your involvement