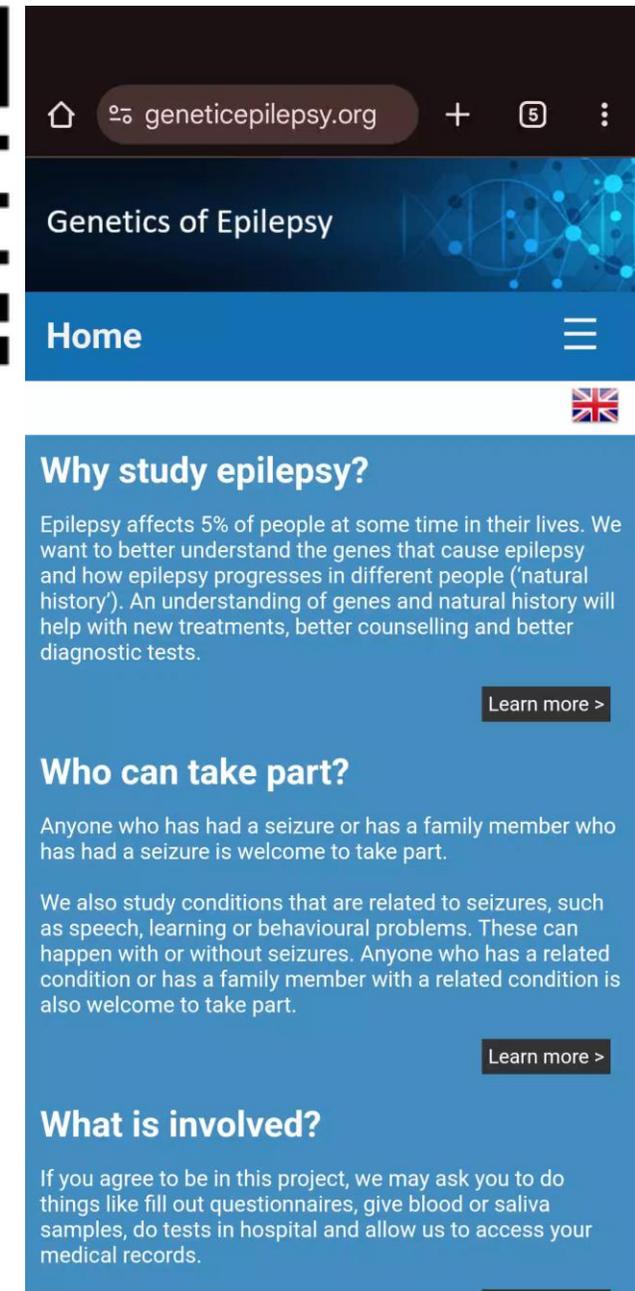




Our online portal is LIVE!



- QR code will take you to our website;
geneticepilepsy.org
- Scroll to the bottom and click 
- Enter your details and click 



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click

[Proceed to Study](#)

A screenshot of a mobile web browser displaying the 'Genetics of Epilepsy' website. The browser's address bar shows 'geneticpilepsy.org/in'. The website has a dark blue header with the title 'Genetics of Epilepsy' and a DNA double helix graphic. Below the header is a blue navigation bar with the word 'Home' and a hamburger menu icon. A small UK flag is visible in the bottom right corner of the page. The main content area has a blue background and contains three sections: 'Why study epilepsy?', 'Who can take part?', and 'What is involved?'. Each section has a short paragraph of text and a 'Learn more >' button.

Why study epilepsy?

Epilepsy affects 5% of people at some time in their lives. We want to better understand the genes that cause epilepsy and how epilepsy progresses in different people ('natural history'). An understanding of genes and natural history will help with new treatments, better counselling and better diagnostic tests.

[Learn more >](#)

Who can take part?

Anyone who has had a seizure or has a family member who has had a seizure is welcome to take part.

We also study conditions that are related to seizures, such as speech, learning or behavioural problems. These can happen with or without seizures. Anyone who has a related condition or has a family member with a related condition is also welcome to take part.

[Learn more >](#)

What is involved?

If you agree to be in this project, we may ask you to do things like fill out questionnaires, give blood or saliva samples, do tests in hospital and allow us to access your medical records.



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click
- Takes you to the Patient Portal

Proceed to Study

6:19 87%

geneticepilepsy.org/sit

Genetics of Epilepsy

UK

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

* Are you registering for yourself or for someone else?

Myself Someone else

* Contact Telephone

Comments

You may leave this section blank. Or you may include the best times to call you, how you heard about our research or other information you would like us to know.



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click [Proceed to Study](#)
- Takes you to the Patient Portal
- Select the hospital where your child usually goes for care

6:19 87%

geneticpilepsy.org/sit

Genetics of Epilepsy

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

* Are you registering for yourself or for someone else?

Myself Someone else

* Contact Telephone

Comments

You may leave this section blank. Or you may include the best times to call you, how you heard about our research or other information you would like us to know.



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click [Proceed to Study](#)
- Takes you to the Patient Portal
- Select the hospital where your child usually goes for care
- Register for yourself or for someone else (i.e. your child)

6:19 87%

geneticepilepsy.org/sit

Genetics of Epilepsy

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

* Are you registering for yourself or for someone else?

Myself Someone else

* Contact Telephone

Comments

You may leave this section blank. Or you may include the best times to call you, how you heard about our research or other information you would like us to know.



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click [Proceed to Study](#)
- Takes you to the Patient Portal
- Select the hospital where your child usually goes for care
- Register for yourself or for someone else (i.e. your child)
 - If for your child – select if they are over or under 18 years

6:32 86%

geneticpilepsy.org/sit

Genetics of Epilepsy

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

* Are you registering for yourself or for someone else?

Myself Someone else

* Is the person you are registering for over or under 18 years?

18 years or over Under 18 years

* Your child's(participant's) full name

* Contact Telephone



Our online portal is LIVE!



6:32 86%

geneticpilepsy.org/sit

Genetics of Epilepsy

UK

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

* Are you registering for yourself or for someone else?

Myself Someone else

* Is the person you are registering for over or under 18 years?

18 years or over Under 18 years

* Your child's(participant's) full name

* Contact Telephone

- Takes you back to Home page
- Scroll to the bottom and click **Proceed to Study**
- Takes you to the Patient Portal
- Select the hospital where your child usually goes for care
- Register for yourself or for someone else (i.e. your child)
 - If for your child – select if they are over or under 18 years
- Type in your/their name and phone number



Our online portal is LIVE!



- Takes you back to Home page
- Scroll to the bottom and click **Proceed to Study**
- Takes you to the Patient Portal
- Select the hospital where your child usually goes for care
- Register for yourself or for someone else (i.e. your child)
 - If for your child – select if they are over or under 18 years
- Type in your/their name and phone number
- Click **Save**

6:35 📶 🔋 86%

Myself Someone else

* Is the person you are registering for over or under 18 years?

18 years or over Under 18 years

* Your child's(participant's) full name

* Contact Telephone

Comments

You may leave this section blank. Or you may include the best times to call you, how you heard about our research or other information you would like us to know.

SAVE **Cancel**

Please note; age category, full name, telephone number and comments will not be stored in our study database until we receive your consent to participate in our study. These values will be sent in an email to our research team so they may contact you to discuss the study in more detail.

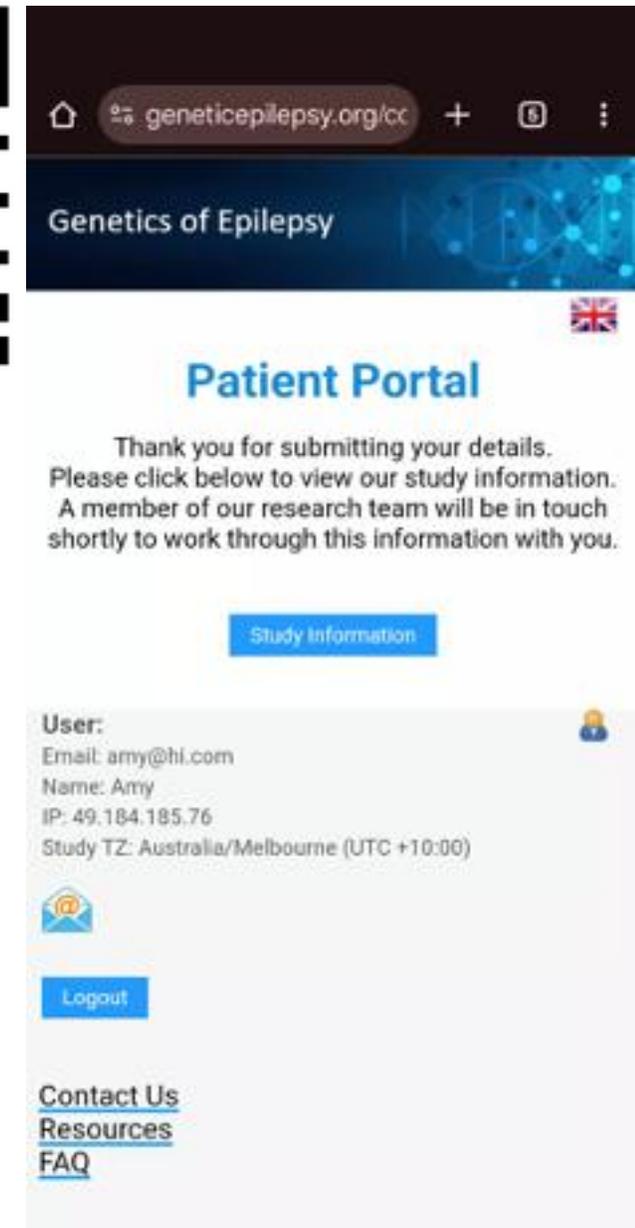
◀ ● ◻



Our online portal is LIVE!



- Click [Study Information](#) to view our study information sheet





Our online portal is LIVE!

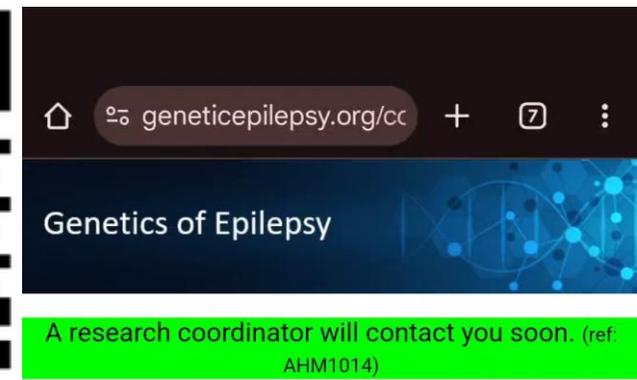


- Click [Study Information](#) to view our study information sheet
- Each section can be expanded

A screenshot of a web browser displaying the "Genetics of Epilepsy" Patient Portal. The browser's address bar shows "geneticpilepsy.org/cc". The page has a dark blue header with the text "Genetics of Epilepsy" and a DNA double helix graphic. Below the header, a blue button labeled "Study Information" is visible. A user profile section shows the name "Amy", email "amy@hi.com", IP address "49.184.185.76", and time zone "Australia/Melbourne (UTC +10:00)". A "Logout" button is located below the user information. At the bottom of the page, there are links for "Contact Us", "Resources", and "FAQ". A small UK flag is visible in the top right corner of the page content.



Our online portal is LIVE!



- Click [Study Information](#) to view our study information sheet
- Each section can be expanded
- Or click  to view/download a pdf of the study information

[Back](#)

Study Information



Participant Information and Consent Form

Consenting adult and mature minor

Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online portal is LIVE!



- Click [Study Information](#) to view our study information sheet

- Each section can be expanded

- Or click  to view/download a pdf of the study information

- Progress paused



[Back](#)

Study Information



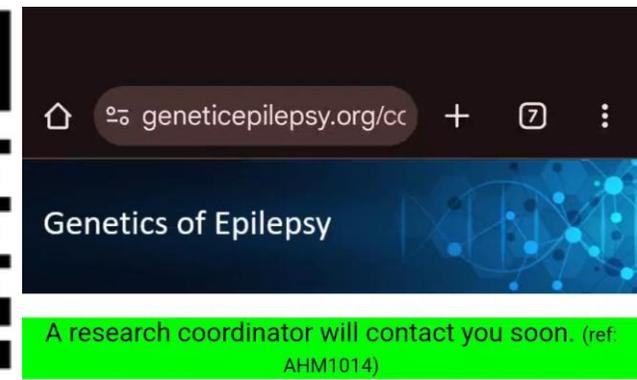
Participant Information and Consent Form

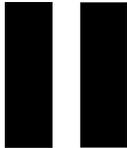
Consenting adult and mature minor

Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online portal is LIVE!



- Click [Study Information](#) to view our study information sheet
- Each section can be expanded
- Or click  to view/download a pdf of the study information
- Progress paused 
- Our team will speak to you to work through the study information and consent form together

[Back](#)

Study Information

Participant Information and Consent Form
Consenting adult and mature minor

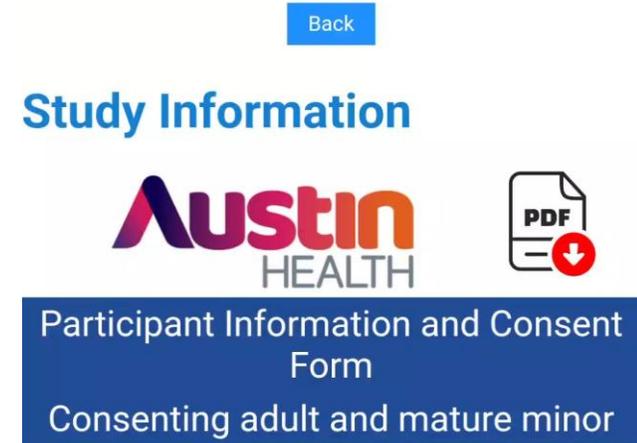
Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online portal is LIVE!



- Click [Study Information](#) to view our study information sheet
- Each section can be expanded
- Or click  to view/download a pdf of the study



Talia

Amy



Bek

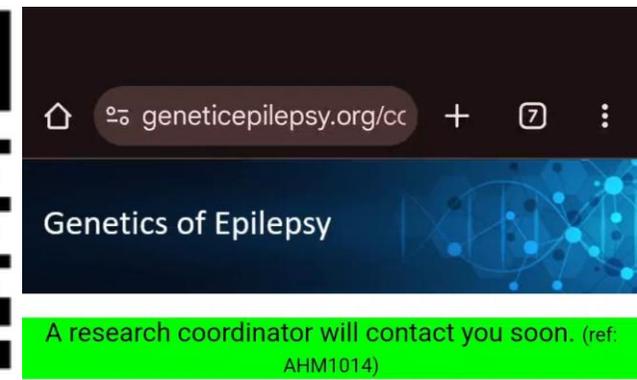


Caitlin

Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online Portal is LIVE!



- Once you have spoken to our team...
- They will update your account to allow consent to be signed

[Back](#)

Study Information



Participant Information and Consent Form

Consenting adult and mature minor

Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online Portal is LIVE!



- Once you have spoken to our team...
- They will update your account to allow consent to be signed
- Please click [Back](#)

[Back](#)

Study Information



Participant Information and Consent Form

Consenting adult and mature minor

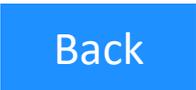
Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal Investigator	Professor Ingrid Scheffer
Principal Investigator	Professor Piero Perucca



Our online Portal is LIVE!



The screenshot shows a mobile browser interface for the 'Genetics of Epilepsy' portal. At the top, the URL 'geneticpilepsy.org/st' is visible. Below the header, there is a navigation bar with a 'Home Page' button. The main content area displays a user profile for 'ID: 1015' with 'YoB: Unknown' and a red warning 'No consent yet'. There is an 'Add Person' button and a 'Logout' button. At the bottom, there are links for 'Contact Us', 'Resources', and 'FAQ'.

- Once you have spoken to our team...
- They will update your account to allow consent to be signed
- Please click 
- Click the person icon 



Our online Portal is LIVE!



Patient Portal - Consent



Back

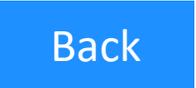
Informed Consent (Parent/Guardian) -

electronic



Participant Information and Consent Parent/Guardian Form

Short Name of Project	Genes4Epilepsy
Full Name of Project	Genetics of Epilepsy
Coordinating Principal	Professor Ingrid

- Once you have spoken to our team...
- They will update your account to allow consent to be signed
- Please click 
- Click the person icon 
- Takes you to the information sheet + *consent form at the bottom of the page (it's a long way down!)*



Our online Portal is LIVE!



- Enter your child's and your name
- Agree/Disagree to a number of optional consent questions

7:17

85%

Consent to optional parts of the

* Your child's name

* Name of Parent/Guardian of Participant

* a. First optional consent – Cell line and iPS cells: I agree to my child's blood or skin sample being used to grow a cell culture and make induced pluripotent stem (iPS) cells.

Agree Disagree

* b. Second optional consent – Tissue collected for clinical care: I agree to the release of DNA and tissues collected for my child's clinical care for use in this research project.

Agree Disagree

* c. Third optional consent – Photographs and videos: I agree to photographs or videos being taken of my child for use in this research project.

Agree Disagree





Our online Portal is LIVE!



- Enter your child's and your name
- Agree/Disagree to a number of optional consent questions
- Click the blue button to sign the form

7:20 84%

geneticpilepsy.org/cc

release of DNA and tissues collected for my child's clinical care for use in this research project.

Agree Disagree

* c. Third optional consent – Photographs and videos: I agree to photographs or videos being taken of my child for use in this research project.

Agree Disagree

* Future Research: I agree to my child's de-identified information, samples and genetic data being shared with researchers who are working independently from this project for any future research.

Agree Disagree

Click to SIGN this form

I DECLINE to participate

I would prefer to sign this consent using a paper form



Our online Portal is LIVE!



- Your child is now enrolled in our Natural History Study!





Our online Portal is LIVE!



- Your child is now enrolled in our Natural History Study!
- Study forms appear in Patient Dashboard

The screenshot shows a mobile web browser interface for the 'Genetics of Epilepsy' portal. The address bar shows 'geneticpilepsy.org/d:'. The page title is 'Genetics of Epilepsy'. Below the title is a 'Patient Dashboard' section for a user named 'Amy' with ID 'AHM1020 (BL)'. There is a 'Back' button. Underneath is a 'Data Collection Forms' section with an 'Upload Document' button. Three form options are visible: 'Contact Information (Minor)' (highlighted in blue), 'Developmental history (initial)' (with a rocket icon), and 'Seizure history (initial)' (with a head and lightning bolt icon). Each form option has a red diamond icon next to it.



Our online Portal is LIVE!



- Your child is now enrolled in our Natural History Study!
- Study forms appear in Patient Dashboard
- To enrol yourself as parents:
 - Click [Back](#)

The screenshot shows a mobile web browser interface for the 'Genetics of Epilepsy' portal. The address bar displays 'geneticsepilepsy.org/di'. The page title is 'Genetics of Epilepsy'. Below the title, there is a 'Patient Dashboard' section for a user named 'Amy' with ID 'AHM1020 (BL)'. A 'Back' button is visible in the top right corner. Underneath, there is a 'Data Collection Forms' section with an 'Upload Document' button. Three form categories are listed: 'Contact Information (Minor)', 'Developmental history (initial)', and 'Seizure history (initial)'. Each category has a corresponding icon and a red plus sign indicating that a form is available for completion.



Our online Portal is LIVE!



The screenshot shows a mobile browser interface for the 'Genetics of Epilepsy' portal. At the top, the address bar shows 'geneticpilepsy.org/st'. Below the address bar, the page title is 'Genetics of Epilepsy' with a UK flag icon. The main heading is 'Genetic of Epilepsy' in blue. Below this, there is a prompt: 'Click the person icon below to proceed with the study.' There are two person icons: one large one and one smaller one with a plus sign and the text 'Add Person'. A blue button labeled 'Home Page' is to the right. Below the icons, the user's information is displayed: 'Amy ID: AHM1014', 'YoB: Unknown', and '28/04/2025' with a calendar icon. A 'User:' section follows, showing 'Email: amy.schneider02@gmail.com', 'Name: Amy', 'IP: 116.91.223.226', and 'Study TZ: Australia/Melbourne (UTC +10:00)'. There is a blue button labeled 'Logout' and a blue envelope icon. At the bottom, there are links for 'Contact Us', 'Resources', and 'FAQ'.

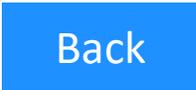
- Your child is now enrolled in our Natural History Study!
- Study forms appear in Patient Dashboard
- To enrol yourself as parents:
 - Click [Back](#)
 - Click Add Person icon

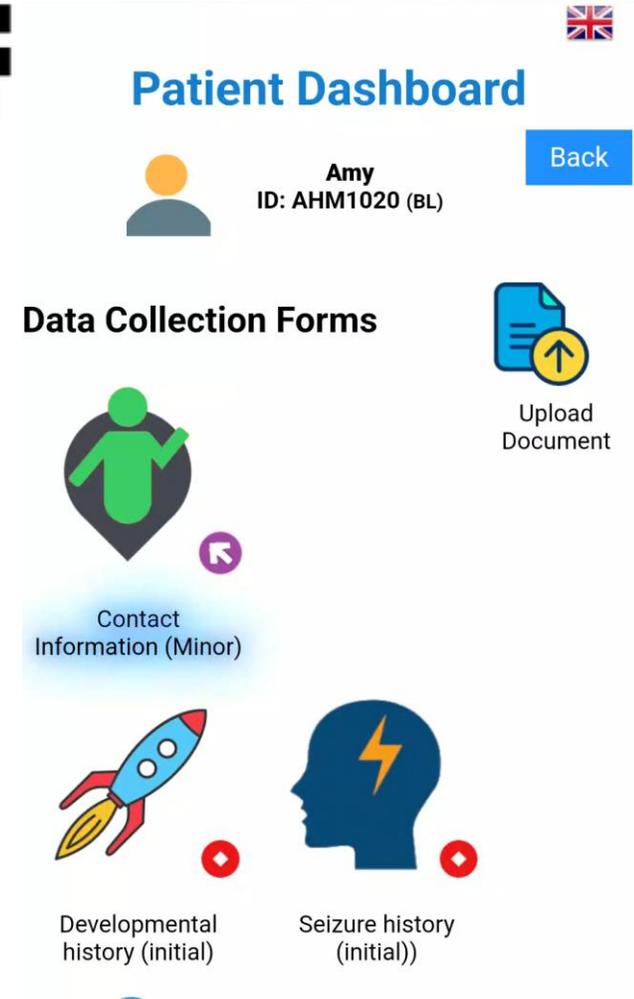




Our online Portal is LIVE!



- Your child is now enrolled in our Natural History Study!
- Study forms appear in Patient Dashboard
- To enrol yourself as parents:
 - Click 
 - Click Add Person icon 
 - Select the same hospital as your child





Our online Portal is LIVE!



6:19 87%

geneticepilepsy.org/sit

Genetics of Epilepsy

UK

Patient Portal

* Select the hospital where you/the participant usually go for care

Please select a value

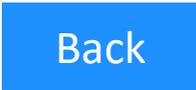
* Are you registering for yourself or for someone else?

Myself Someone else

* Contact Telephone

Comments

You may leave this section blank. Or you may include the best times to call you, how you heard about our research or other information you would like us to know.

- Your child is now enrolled in our Natural History Study!
- Study forms appear in Patient Dashboard
- To enrol yourself as parents:
 - Click 
 - Click Add Person icon 
 - Select the same hospital as your child
 - Complete the form for yourself