

## Progressive Familial Intrahepatic Cholestasis Patient Registry

### Registry FAQ

#### 1 What is the Patient Registry?

The Registry is a combined questionnaire which will take approximately 30 minutes to fill out. You can fill it out online, via email or mail.

#### 2 Who can participate?

All diagnosed with, or caring for a child with pfic of all subtypes, BRIC patients, and all ages are encouraged to register.

#### 3 Why was it created?

The PFIC Network Patient Registry was created because of the difficulty locating PFIC patients and PFIC data to use for research on the disease. Our aim with the Registry has been to add the patient's voice to the PFIC research process.

#### 4 What does the Registry do?

Track PFIC disease status and symptoms, assist in clinical trial recruitment, facilitate drug safety monitoring, and allow patient participation in research. Makes larger clinical studies possible in a search to find a cure.

#### 5 How does the Registry help us?

Assist with our goal of improving the lives of patients and families.

Helps identify knowledge and resource gaps so we can better serve the community.

#### 6 What if I have a question?

Please reach out to [emily@pfic.org](mailto:emily@pfic.org) for any questions regarding the registry.

For technical issues, please email [cords@sandfordhealth.org](mailto:cords@sandfordhealth.org)

#### 7 Is my data secure?

The registry is housed on a platform that abides by National Institutes of Health standards for privacy and confidentiality.

No personal information is shared with the platform or PFIC Network.

#### 8 Are translation options available?

Yes. Please email [cords@sandfordhealth.org](mailto:cords@sandfordhealth.org) to request a questionnaire in your language. You will receive a translated questionnaire in the mail.

A call with a PFIC ambassador and interpreter is also an option.

#### 9 Where can I find more information about the Registry?

[pfic.org/pfic-patient-registry](http://pfic.org/pfic-patient-registry)

Here you can find more info and join the registry.