



FAGPR System User Guide

Patient/Proxy Portal

Version 2.1
February 16, 2020
Pulse Inframe Inc.

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1 OVERVIEW OF FAGPR SYSTEM

The intended overarching objectives of the Friedreich's Ataxia Global Patient Registry (FAGPR) website solution implementation and use are:

"Improve health outcomes and experiences of care through routine data collection to facilitate timely reporting to researchers and industry partners about outcomes and experiences that matter to patients."

The FA Global Patient Registry (FAGPR) is an open-ended patient registry for Friedreich's Ataxia (FA) that collects quality, real-world data to provide further understanding of FA and needs for its treatment. The FA Global Patient Registry has been launched by global FA advocacy parties to be the sole international registry for this disease.

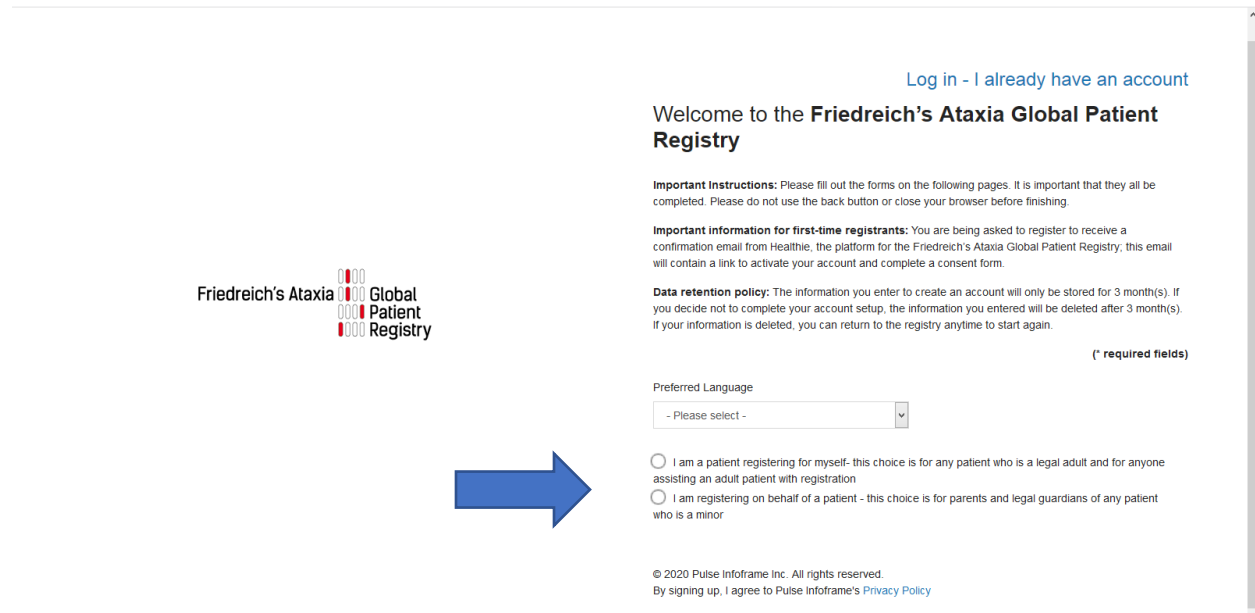
The goals of the registry include:

- understand FA from the point of view of patients and caregivers
- connect patients and families to opportunities for PRO research and clinical trials of potential new therapies

2 PATIENT/PROXY ACCESS TO E-CONSENT

2.1 REGISTERING IN THE FAGPR SYSTEM

Registration Screen is where the patient or their proxy will enter the information required. Select the preferred language from the drop down and indicate if you are patient or registering on behalf of a patient. **Please note choices (arrow)**. If you are using one email (username) to register several patients, either minor children or legal adults, choose the option "I am registering on behalf of a patient".



[Log in - I already have an account](#)

Welcome to the Friedreich's Ataxia Global Patient Registry

Important Instructions: Please fill out the forms on the following pages. It is important that they all be completed. Please do not use the back button or close your browser before finishing.

Important information for first-time registrants: You are being asked to register to receive a confirmation email from Healthie, the platform for the Friedreich's Ataxia Global Patient Registry; this email will contain a link to activate your account and complete a consent form.

Data retention policy: The information you enter to create an account will only be stored for 3 month(s). If you decide not to complete your account setup, the information you entered will be deleted after 3 month(s). If your information is deleted, you can return to the registry anytime to start again.

(* required fields)

Preferred Language

☐ I am a patient registering for myself- this choice is for any patient who is a legal adult and for anyone assisting an adult patient with registration
☐ I am registering on behalf of a patient - this choice is for parents and legal guardians of any patient who is a minor

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Example: Legal Guardian Registration screen

Friedreich's Ataxia Global Patient Registry

Legal Guardian Registration

Important Instructions:
Please fill out the forms on the following pages. It is important that they all be completed.
Please do not use the back button or close your browser before finishing.
(* required fields)

Relationship to Patient
Parent (biologic, adoptive, or step)

Legal Guardian's First Name
Deborah

Legal Guardian's Last Name
Dolittle

Legal Guardian's Phone Number
123-456-7890

Legal Guardian's Email
DDolittle@gmail.com

☒ I am the patient's legal guardian

If this is a new patient record, you will be associated as the "primary" data entry account holder for this patient. To ensure quality of the data collected in this registry, it is important to know who and how many people enter data about a single patient. Where possible, we encourage the same person to enter data about the patient, but we know this is not always possible. Please enter data under your corresponding account profile. You will have the option to add secondary data entry account holders at a later time (such as another parent or caregiver), and this secondary account will also provide a consent.

Your date of birth (You must be of legal age.)
1960 January 10

Your country of residence
United States of America

[Register as legal guardian](#)

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When you select the option to "Register as legal guardian" this screen will appear for you to complete:

Friedreich's Ataxia Global Patient Registry

Patient Registration

Important Instructions: Please fill out the forms on the following pages. It is important that they all be completed. Please do not use the back button or close your browser before finishing.
(* required fields)

Patient's First Name
Nikki

Patient's Last Name
Dolittle

Patient's date of birth
2000 March 4

Patient's country of residence
United States of America

☒ I understand that the above information is collected for the purpose of activating my account in the Friedreich's Ataxia Global Patient Registry.

☒ I agree to be contacted regarding my participation in the Friedreich's Ataxia Global Patient Registry.

☒ I understand that the registration details I provide will be retained for 3 month(s). An informed consent form will be required once I activate my account.

[Submit](#)

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Your registration for the Friedreich's Ataxia Global Patient Registry has been successfully completed.

Please check your email for instructions to activate your account.

Please complete your Informed Consent Form in order to continue participating in the registry. Your account will be deactivated after 3 month(s) if you decide not to complete the Informed Consent Form, and all information you have entered will be deleted at that time. If your information is deleted, you can return to the registry anytime to start again.



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If you are going to be PROXY for more than one participant you will need to follow the following to register:

your account setup, the information you entered will be deleted after 3 months. If your information is deleted, you can return to the registry anytime to start again.

(* required fields)

Preferred Language



☐ I am a patient registering for myself- this choice is for any patient who is a legal adult and for anyone assisting an adult patient with registration

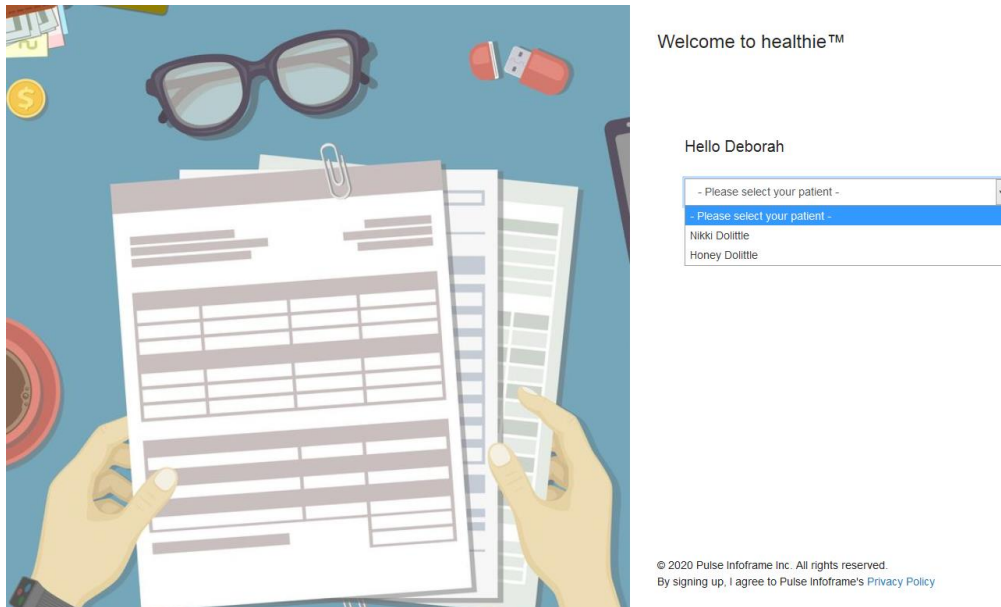
☒ I am registering on behalf of a patient - this choice is for parents and legal guardians of any patient who is a minor

Register new patient with current account

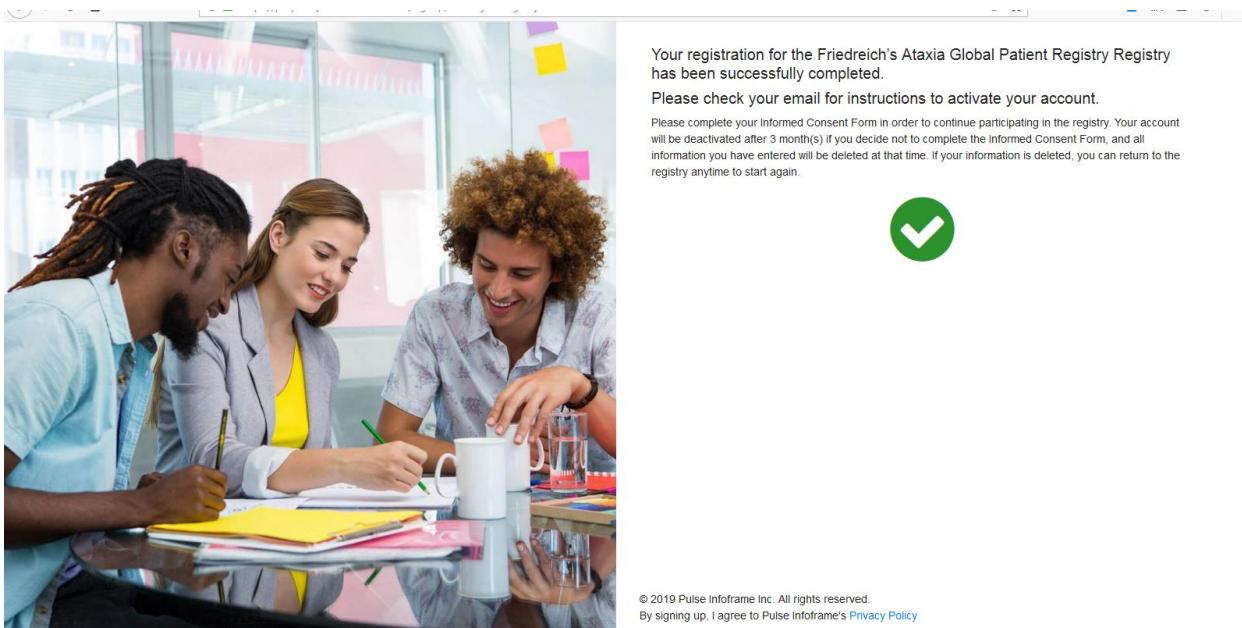
Continue new registration

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If you are a PROXY for more than one participant this is the log-in screen that will prompt you to select the patient for whom you are completing information:

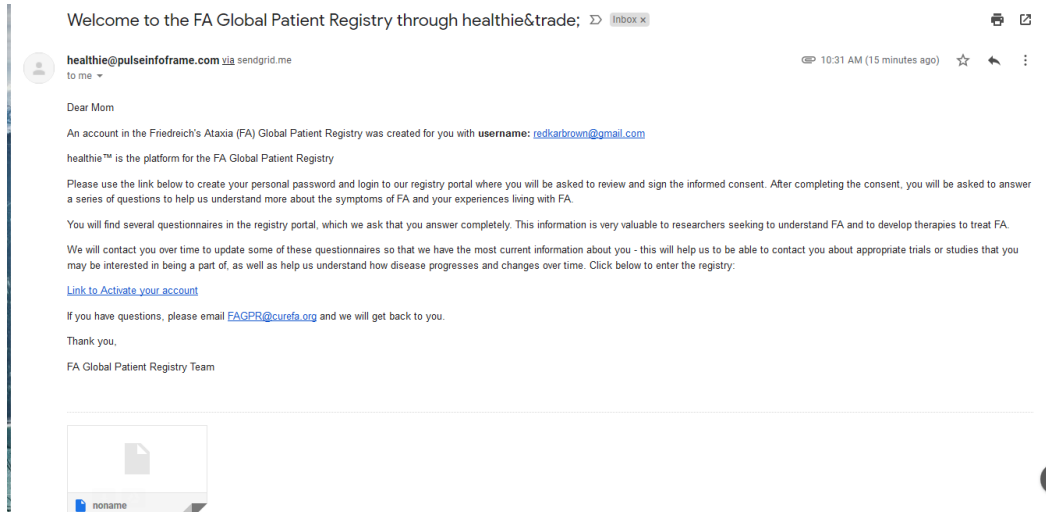


Once you have completed registration you will see this:



2.2 EMAIL TO ACTIVATE ACCOUNT

Once you have registered your information into the FAGPR system you will receive an Email similar to the one below which will give directions to activate your account and create the password you will use in accessing the FAGPR system. **The email you used for registration will be your username.**



2.3 LOG IN

You will then be re-directed to the FAGPR system login page. For the first time you access you will be required to create a password. If you already are registered click the sign in link



Welcome to healthie™

Create password*

Confirm Password*


[Activate User](#)

[Already have an active account? Sign in](#)

 Friedreich's Ataxia  Global Patient Registry

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Once you create your password for the first time, you will be re-directed back to the login page.



Welcome to healthie™

Log into your account


[Login](#)

[Forgot password?](#)

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2.4 PASSWORD RECOVERY


If you cannot remember your password note the “**Forgot Password**” link on the Log in page. Click on this link and then follow the email instructions to reset your password.



Welcome to healthie™

Log into your account

[Login](#)

[Forgot password?](#) 

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<https://preprod.pulseinframe.com/forgotPassword>

2.5 ELECTRONIC CONSENT

All patients will be presented an electronic consent form on the patient portal providing appropriate information about the system, and the privacy and use of your submitted data so participants can make

an informed decision about their participation in the FAGPR system. By signing the electronic consent, you are agreeing to the collection of your personal health information and use of your data by appropriate research entities in a de-identified form.

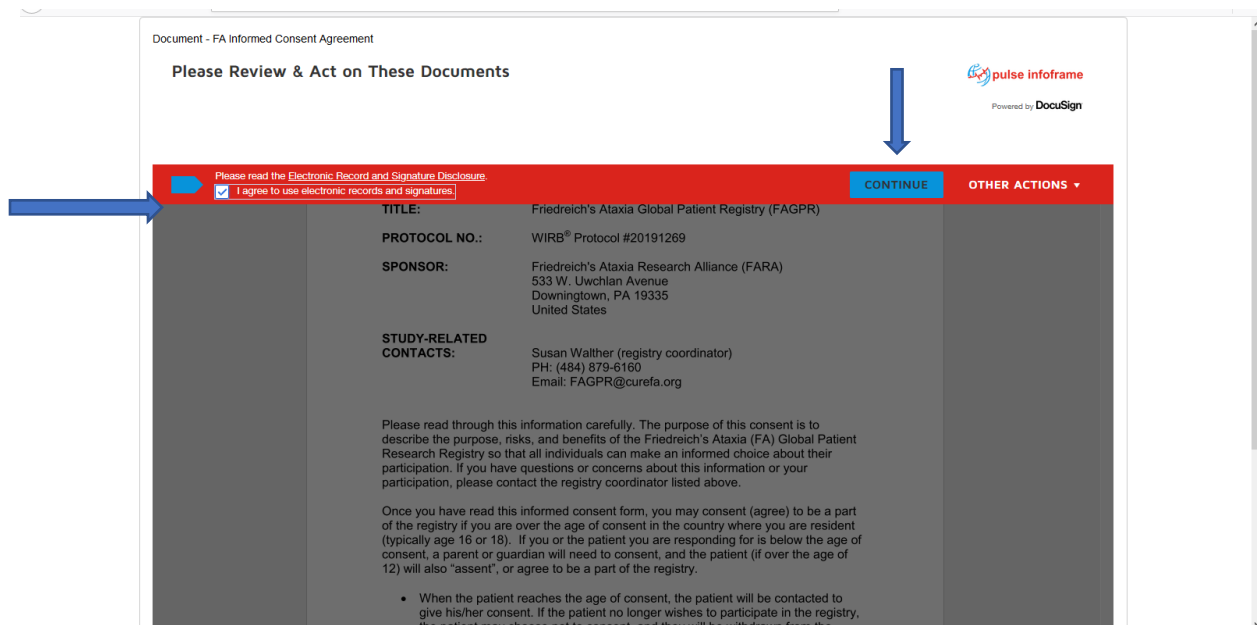
If you choose to consent/opt in, you will be agreeing to participate in survey collection outlined in the FAGPR system. If you decide to withdraw your consent/opt out, you will no longer be asked to complete surveys and no further information will be collected.

Please read through the consent thoroughly and ensure you fully understand the purpose of the FAGPR system and what you are being asked to do. If you have any questions, please contact the FAGPR coordinators at FAGPR@curefa.org.

In addition to consent, if a minor patient is between the age of 12 and the legal age of their country (for example 18), there will be an assent form listed under the consents section.


The minor patient is expected to read and complete that assent form. The minor patient won't have a login, so it will be done under their proxy's login.

If you are comfortable and ready to proceed, use the DocuSign function, which is a secure way to electronically sign and provide your consent to participate in the FAGPR system. Check the box with the statement, "I agree to use electronic records and signatures". Once that box is checked the CONTINUE button will activate:



Document - FA Informed Consent Agreement

Please Review & Act on These Documents

 **pulse inframe**
Powered by DocuSign

Please read the Electronic Record and Signature Disclosure.
☒ I agree to use electronic records and signatures

CONTINUE **OTHER ACTIONS**

TITLE: Friedrich's Ataxia Global Patient Registry (FAGPR)

PROTOCOL NO.: WIRB® Protocol #20191269

SPONSOR: Friedrich's Ataxia Research Alliance (FARA)
533 W. Uwchlan Avenue
Downingtown, PA 19335
United States

STUDY-RELATED CONTACTS: Susan Walther (registry coordinator)
PH: (484) 879-6160
Email: FAGPR@curefa.org

Please read through this information carefully. The purpose of this consent is to describe the purpose, risks, and benefits of the Friedrich's Ataxia (FA) Global Patient Research Registry so that all individuals can make an informed choice about their participation. If you have questions or concerns about this information or your participation, please contact the registry coordinator listed above.

Once you have read this informed consent form, you may consent (agree) to be a part of the registry if you are over the age of consent in the country where you are resident (typically age 16 or 18). If you or the patient you are responding for is below the age of consent, a parent or guardian will need to consent, and the patient (if over the age of 12) will also "assent", or agree to be a part of the registry.

- When the patient reaches the age of consent, the patient will be contacted to give his/her consent. If the patient no longer wishes to participate in the registry, the patient may choose not to consent, and they will be withdrawn from the

You will find the signature box at the bottom of the form. Please click **"Accept electronic signature below"** to enter your signature.

Document - FA Informed Consent Agreement

Please review the documents below.

FINISH **OTHER ACTIONS**


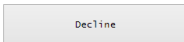
NEXT PAGE

- ☐ I accept that allowing my data to be stored on this database does not mean that I will automatically be entered into future clinical trials.
- ☐ I understand that the data that I enter will be stored in the FA Global Patient Registry with servers in the US and Canada.
- ☐ I understand that my data and/or information may be shared with third parties (such as advocacy groups, academics, clinicians and drug development companies) who would use such data and/or information for secondary research purposes, but that these parties will not get access to information that will allow them to know who I am.
- ☐ I understand that my data and/or information may be transferred to countries other than my own country, including the United States, and such other countries may not have the same, or as strict privacy laws as my own country.
- ☐ I understand that the data I provide may be used to inform and plan future research.
- ☐ I understand that the results from future research may not have any direct implications for me or my family.

By clicking "Accept" below, I understand that I give consent for the storage of data on myself in the FA Global Patient Registry.

☐ Accept

Append electronic signature below

Page 6 of 6

Docusign will create a signature template for you; you do not need to print the form to sign. Please click "ADOPT AND SIGN" to use the signature template.

Document - FA Informed Consent Agreement

Select the sign field to create and add your signature.

ADOPT AND SIGN **OTHER ACTIONS**

NEXT PAGE

Adopt Your Signature



Confirm your name, initials, and signature.

* Required

Full Name* Initials*

SELECT STYLE **DRAW**


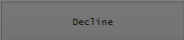
PREVIEW [Change Style](#)

DocuSigned by:  

53CBD94DFDB5431...

By selecting Adopt and Sign, I agree that the signature and initials will be the electronic representation of my signature and initials for all purposes when I (or my agent) use them on documents, including legally binding contracts - just the same as a pen-and-paper signature or initial.

ADOPT AND SIGN **CANCEL**

Page 6 of 6

You must then select "FINISH" in order for your signed consent to be saved and then you may close the form.

Document - FA Informed Consent Agreement

Select the sign field to create and add your signature.

FINISH **OTHER ACTIONS**

NEXT PAGE

- ☐ I accept that allowing my data to be stored on this database does not mean that I will automatically be entered into future clinical trials.
- ☐ I understand that the data that I enter will be stored in the FA Global Patient Registry with servers in the US and Canada.
- ☐ I understand that my data and/or information may be shared with third parties (such as advocacy groups, academics, clinicians and drug development companies) who would use such data and/or information for secondary research purposes, but that these parties will not get access to information that will allow them to know who I am.
- ☐ I understand that my data and/or information may be transferred to countries other than my own country, including the United States, and such other countries may not have the same, or as strict privacy laws as my own country.
- ☐ I understand that the data I provide may be used to inform and plan future research.
- ☐ I understand that the results from future research may not have any direct implications for me or my family.

By clicking "Accept" below, I understand that I give consent for the storage of data on myself in the FA Global Patient Registry.

☒ Accept

Required - Signature Applied

Signature of Deborah Deltelle

Decline

Page 6 of 6

Note: Please select the Finish button to complete the consent, and then select the close button. You have the option to print the signed form for your records, if you wish (see below for instructions). There are multiple options where you can choose to print the signed consent by choosing the "OTHER ACTIONS"

You can confirm your consent has been signed on the patient dashboard. The button next to the consent form will turn from red to green when the form is signed.

The consent form (and assent form for children age 12 to 18) must be signed before you will be able to complete the Patient Profile or the survey forms.

Friedreich's Ataxia Global Patient Registry

Welcome redkarbrown@gmail.com
Logged in as PROXY

Dashboard

Consents

Sign

Patients

Forms

CONSENTS > SIGN

CONSENTS

Document name

Patient	Document Name	Request To Sign	Signed Date	Status	
Nikki, RescueLab	FA Informed Consent Agreement	August 02, 2019 10:31:14	August 05, 2019 10:29:23	Signed	View

« Previous 1 Next »

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To review the consent document and print or save for your records go to **CONSENTS** on the dashboard. In the upper right select the **VIEW MORE** button.

The screenshot shows the dashboard with the following data:

Patient	Document Name	Request To Sign	Status
Nikki, RescueLab	FA Informed Consent Agreement	August 02, 2019 10:31:14	Signed

Patient(s)	Profile	Submission date	Status
Nikki, RescueLab	FA Global Patient		Not Submitted

Form	Date	Total
FA Diagnosis		0

This is the screen after **VIEW MORE** was selected. Notice the icons which allow you to download or print the Consent Form for your records.

Document - FA Informed Consent Agreement

This document is now complete. [CLOSE](#) [OTHER ACTIONS](#)

DocuSign Envelope ID: CEDA0D7E-B26E-45A1-8BA5-2027988DA888

IRB Approved
May 16, 2019

**Participant Information Sheet
and Informed Consent Agreement**

TITLE: Friedreich's Ataxia Global Patient Registry (FAGPR)

PROTOCOL NO.: WIRB® Protocol #20191269

SPONSOR: Friedreich's Ataxia Research Alliance (FARA)
533 W. Uwchlan Avenue
Downingtown, PA 19335

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[Close](#)

2.6 LOG OUT

You may log out of the system by navigating to the upper right hand corner of the panel and click on the “Logged in” area. There will be a drop down – Settings and Log out. Select Log out to complete your session.

The screenshot shows the dashboard of the Friedrich's Ataxia Global Patient Registry. The user is logged in as PROXY for Nikki Dolittle. The dashboard includes a sidebar with navigation options: Dashboard, Consents, Patients, Forms, and My Library. The main content area displays a welcome message and a table of consents. A dropdown menu is open in the top right corner, showing 'Settings' and 'Log out' options. A blue arrow points to the 'Log out' option.

Patient	Document Name	Request To Sign	Status
Nikki, Dolittle	FA Informed Consent Agreement	January 22, 2020 12:10:30	Signed

2.7 SETTINGS

This screen populates when the SETTINGS option is selected. There are areas that are available to edit if necessary as well as having the option to “Withdraw from Registry” (see Section 5 for further instructions). Save changes or cancel the activity.

The screenshot shows the USER SETTINGS page. The user is logged in as PROXY for Nikki Dolittle. The page displays fields for User Name, First Name, Last Name, Email, and Password. A blue arrow points to the 'Withdraw from Registry' link. The page also includes a 'Save' button and a 'Cancel' button.

USER > USER SETTINGS

USER SETTINGS

User Name* redkarbrown@gmail.com

First Name* Deborah

Last Name* Dolittle

Email* redkarbrown@gmail.com

Password*

☐ Remember me

⚠ You have the right to withdraw from the registry at any time. To formally withdraw from the registry, please click here to place your account on hold and complete a brief survey regarding your withdrawal preferences. [Withdraw from Registry](#)

[Save](#) [Cancel](#)

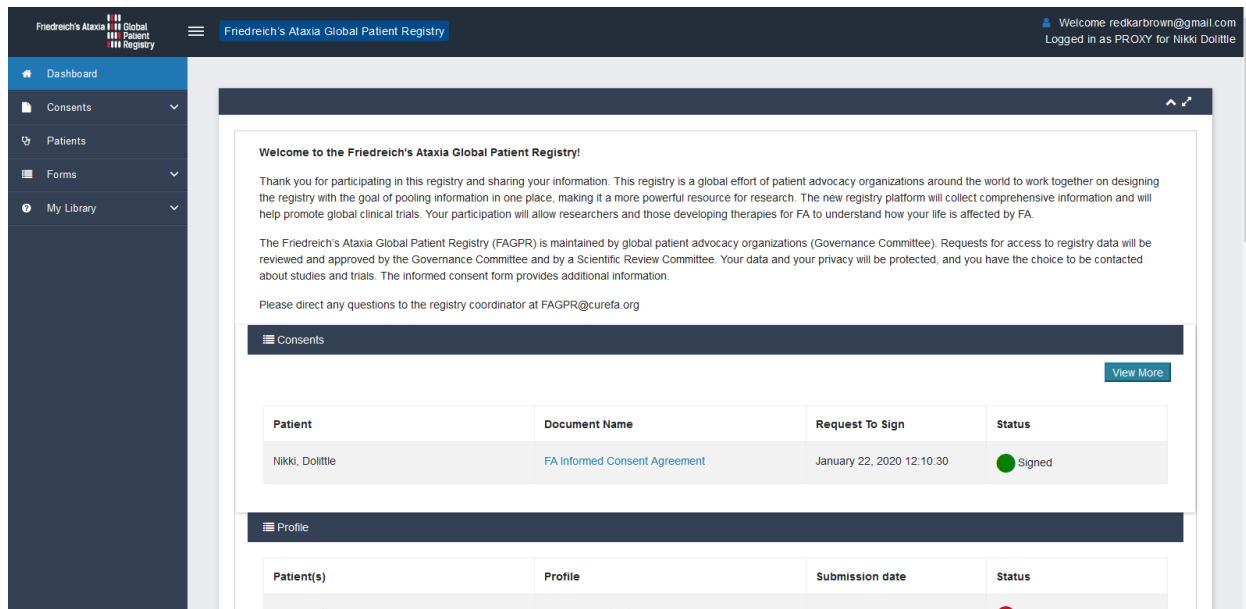
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3.0 YOUR DASHBOARD AND ENTERING YOUR INFORMATION

3.1 YOUR DASHBOARD

Once you complete the consent process, and any time you log in to the FAGPR system, you will be directed to your dashboard which will give you information about your account and survey completion status.

This is the first section of the “Dashboard” which displays the welcome message and Consent status.



The screenshot shows the dashboard interface. On the left is a sidebar with navigation links: Dashboard, Consents, Patients, Forms, and My Library. The main content area displays a welcome message and a table of consents.

Welcome to the Friedrich's Ataxia Global Patient Registry!

Thank you for participating in this registry and sharing your information. This registry is a global effort of patient advocacy organizations around the world to work together on designing the registry with the goal of pooling information in one place, making it a more powerful resource for research. The new registry platform will collect comprehensive information and will help promote global clinical trials. Your participation will allow researchers and those developing therapies for FA to understand how your life is affected by FA.

The Friedrich's Ataxia Global Patient Registry (FAGPR) is maintained by global patient advocacy organizations (Governance Committee). Requests for access to registry data will be reviewed and approved by the Governance Committee and by a Scientific Review Committee. Your data and your privacy will be protected, and you have the choice to be contacted about studies and trials. The informed consent form provides additional information.

Please direct any questions to the registry coordinator at FAGPR@curefa.org

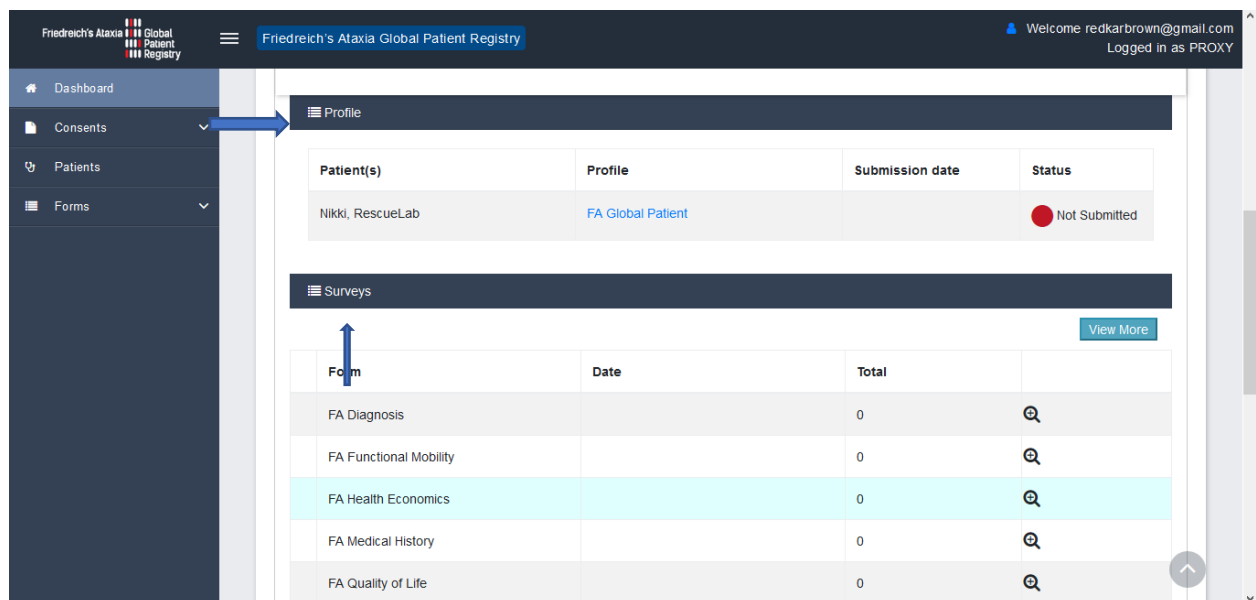
Consents

Patient	Document Name	Request To Sign	Status
Nikki, Doltle	FA Informed Consent Agreement	January 22, 2020 12:10:30	Signed

Profile

Patient(s)	Profile	Submission date	Status
Nikki, Doltle	FA Global Patient		Not Submitted

This the next section of the “Dashboard” showing Profile and surveys:



The screenshot shows the dashboard interface with the Profile and Surveys sections. The sidebar on the left has a blue arrow pointing to the 'Consents' link. The main content area displays the Profile table and a Surveys table.

Profile

Patient(s)	Profile	Submission date	Status
Nikki, RescueLab	FA Global Patient		Not Submitted

Surveys

Form	Date	Total	
FA Diagnosis		0	🔍
FA Functional Mobility		0	🔍
FA Health Economics		0	🔍
FA Medical History		0	🔍
FA Quality of Life		0	🔍

3.2 ENTERING YOUR INFORMATION AND VIEWING ASSIGNED SURVEY SETS

To enter your patient profile information: At the dashboard select **"Patients"** and **"Profile"**. This is the first page section that you will see.

3.2a Entering Identification

Please note that you must use the scroll bar to navigate the lower portions of the profile page. Once you select the **"Next"** button the data you have entered in the form will be saved.

Once you have saved the identification information by selecting **NEXT** you will see the **RESEARCH** section that requires completion.

Identification

Research

Back Cancel Next

Has the patient previously participated in any clinical trials related to their rare disease which involved an investigational/experimental medication, device, or other treatment?*

- Please select -

Has the patient previously participated in any other types of research related to their rare disease which did not involve an investigational/experimental medication, device, or other treatment (such as a registry or a research questionnaire)?*

- Please select -

Does the patient currently participate in any clinical trials related to their rare disease?*

- Please select -

Is the patient willing to be contacted about future research studies?*

- Please select -

Is the patient willing to be contacted about donating a sample of blood, tissue, or other biospecimen for research in the future?*

- Please select -

Enter your information under each of the following headings:

3.2 b Research

This is where you will enter the required information about preferences for contact about research participation and willingness to donate biospecimens. Remember to scroll down to complete the entire form. When you have completed the information click the “Next” button to save.

PATIENT > RESEARCH

RESEARCH

Identification

Research

Back Cancel Next

Has the patient previously participated in any clinical trials related to their rare disease which involved an investigational/experimental medication, device, or other treatment?*

No

Has the patient previously participated in any other types of research related to their rare disease which did not involve an investigational/experimental medication, device, or other treatment (such as a registry or a research questionnaire)?*

Yes

Does the patient currently participate in any clinical trials related to their rare disease?*

Yes

Is the patient willing to be contacted about future research studies?*

Prefer not to answer

Is the patient willing to be contacted about donating a sample of blood, tissue, or other biospecimen for research in the future?*

Yes

Which biospecimen types would the patient be willing to consider donating?*

Blood

4 COMPLETING SURVEYS

You may be assigned multiple survey with different due dates. Assigned surveys will be open for you to submit two weeks prior to the due/expiry date. You will receive an email when a new survey is due for updates. You can then login to the FAGPR system and navigate to the survey page. The following is an example of the survey schedule:

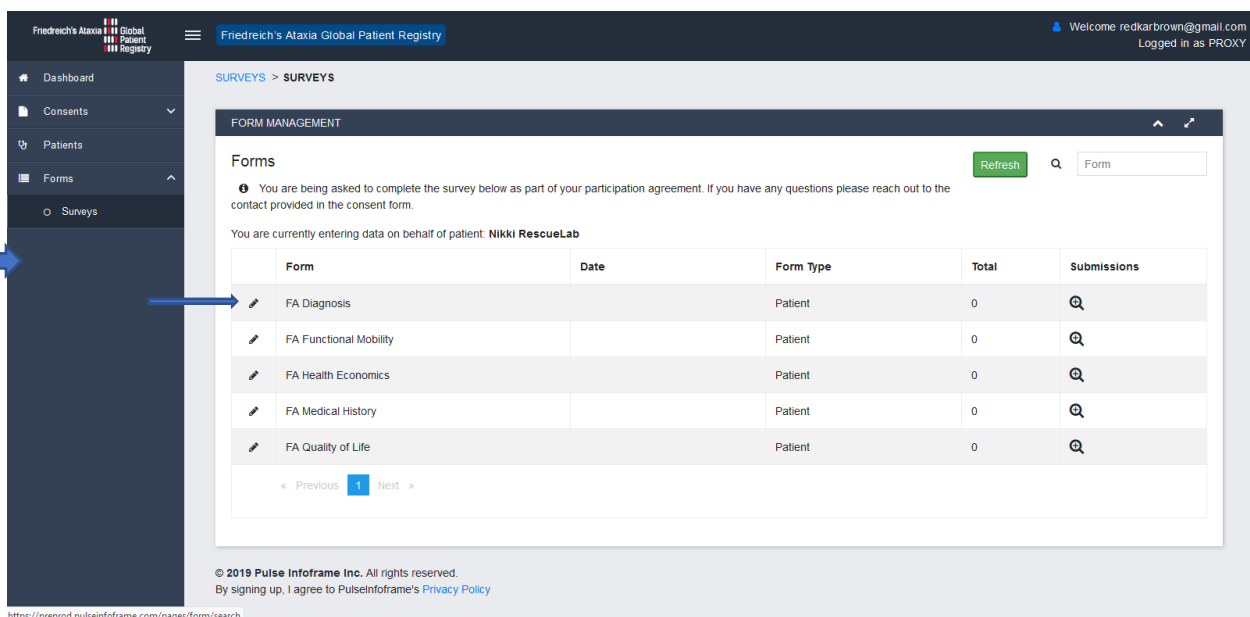
- Survey/Questionnaire (order and timeline)
- [FA Diagnosis](#) - Fill only once
- [FA Medical History](#) – Annually
- [FA Functional Mobility](#) – Annually
- [FA Quality of Life](#) – Annually
- [FA Health Economics](#) – Annually
- The four (4) Annual Form opens 1 month before anniversary; You will receive a reminder email to update your survey forms one month before the anniversary date, on anniversary date, and one month after the survey form opens for updates.

Select > Forms>Surveys from the dashboard. In this screen you will see the FA surveys with a pencil



icon. Click on this icon to gain access to the questionnaire. Research surveys that you can complete will be available and indicated with the pencil icon.

Any new research survey that is posted in the FAGPR will have ethics review board approval and be approved by the FAGPR scientific review committee.



Friedrich's Ataxia Global Patient Registry

WELCOME: redkarbrown@gmail.com
Logged in as PROXY

SURVEYS > SURVEYS











FORM MANAGEMENT

Forms Refresh

Forms

Forms You are being asked to complete the survey below as part of your participation agreement. If you have any questions please reach out to the contact provided in the consent form.

You are currently entering data on behalf of patient: **Nikki RescueLab**

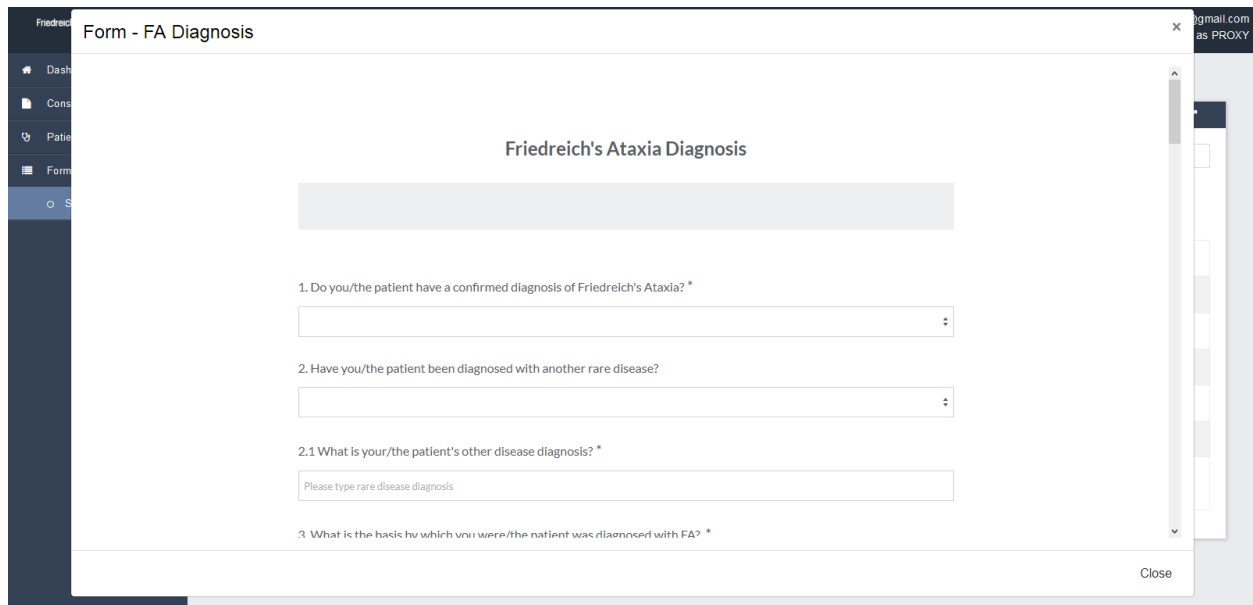
Form	Date	Form Type	Total	Submissions
 FA Diagnosis		Patient	0	
 FA Functional Mobility		Patient	0	
 FA Health Economics		Patient	0	
 FA Medical History		Patient	0	
 FA Quality of Life		Patient	0	

« Previous **1** Next »

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<https://preprod.pulseinfoframe.com/pages/form/search>

This is the view when the FA Diagnosis form is selected:



Form - FA Diagnosis

Friedreich's Ataxia Diagnosis

1. Do you/the patient have a confirmed diagnosis of Friedreich's Ataxia? *

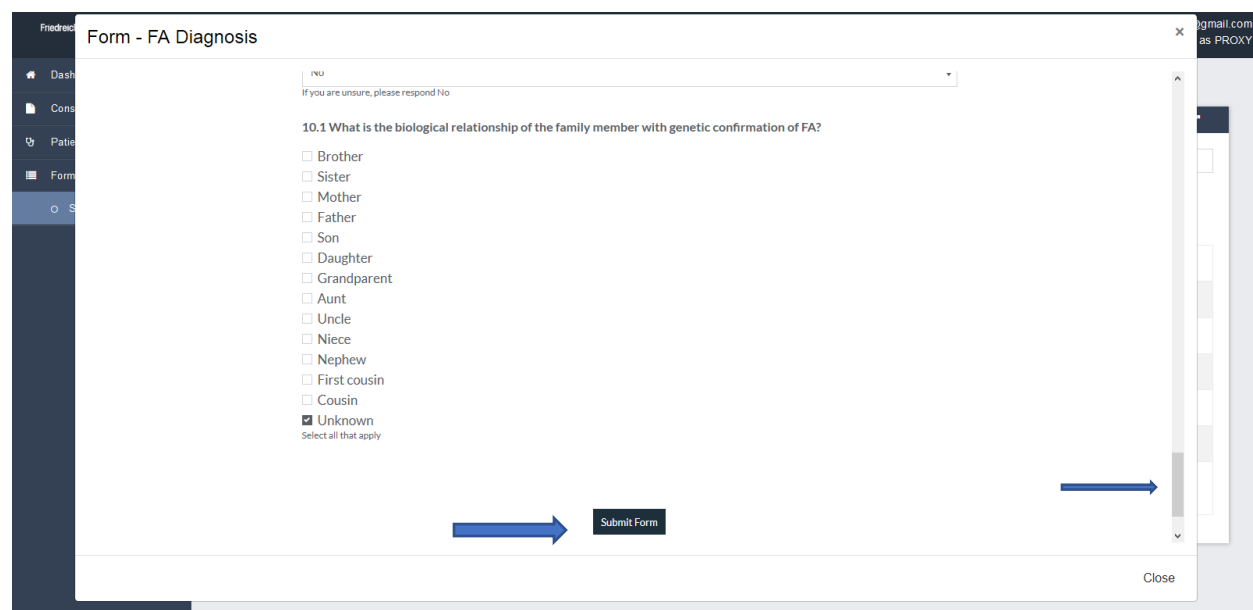
2. Have you/the patient been diagnosed with another rare disease?

2.1 What is your/the patient's other disease diagnosis? *

3. What is the basis by which you were/the patient was diagnosed with FA? *

Close

When you have completed the information on the form (ensure to scroll down to visualize the entire form) select the **Submit Form** button.



Form - FA Diagnosis

10.1 What is the biological relationship of the family member with genetic confirmation of FA?

☐ Brother

☐ Sister

☐ Mother

☐ Father

☐ Son

☐ Daughter

☐ Grandparent

☐ Aunt

☐ Uncle

☐ Niece

☐ Nephew

☐ First cousin

☐ Cousin

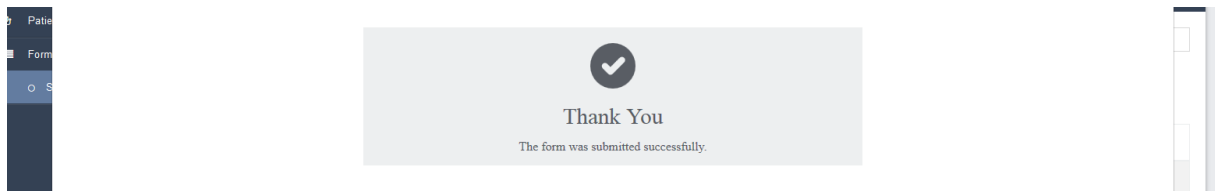
☒ Unknown

Select all that apply

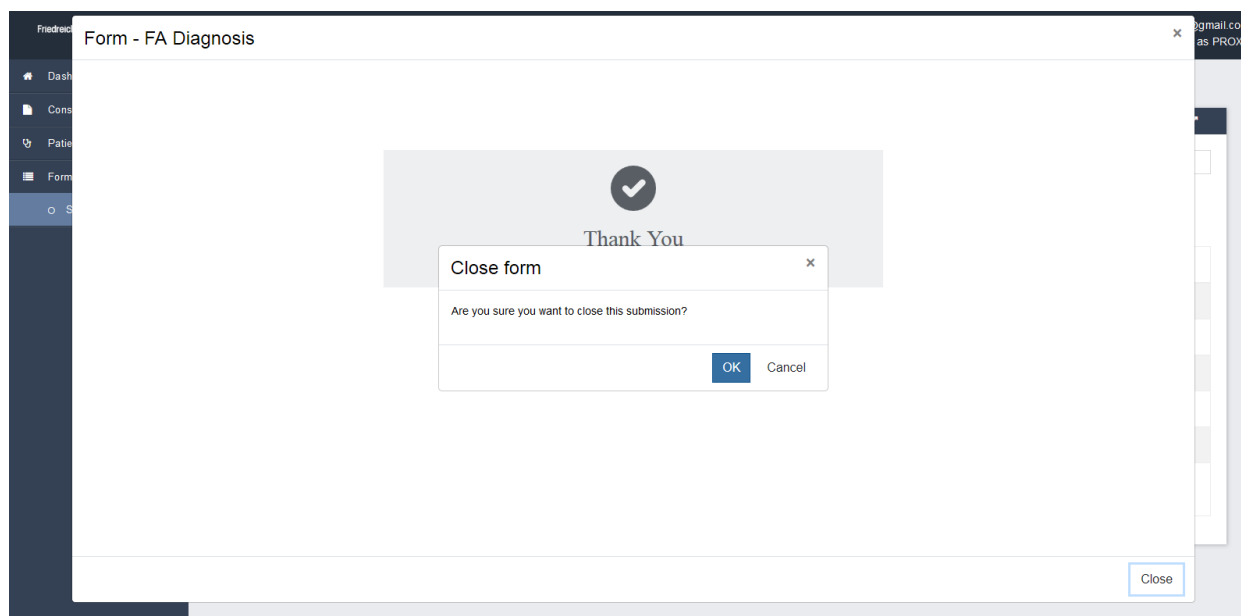
Submit Form

Close

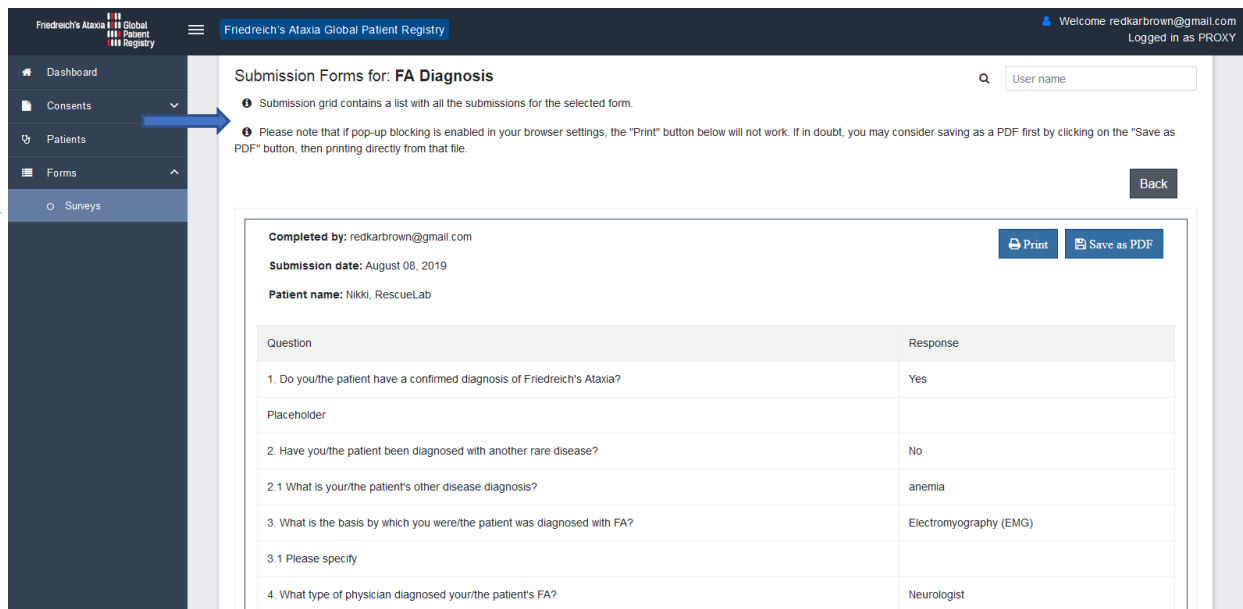
You will receive confirmation that the submission was successful:



Finally, **Close** the form: If you have clicked to the submit the form, you must choose “OK” on the pop-up menu. Currently, each of the annual survey forms is only accessible for updates annually.



From the Surveys tab you can view previous submissions, see the due date of upcoming surveys, and open and submit surveys that are currently available to be completed. Double click on the survey to open it. This screen represents the selected survey and its content. Note the directives at the top left of the panel which describe how to print or save the information.



Submission Forms for: FA Diagnosis

Submission grid contains a list with all the submissions for the selected form.

Please note that if pop-up blocking is enabled in your browser settings, the "Print" button below will not work. If in doubt, you may consider saving as a PDF first by clicking on the "Save as PDF" button, then printing directly from that file.

Completed by: redkarbrown@gmail.com


Submission date: August 08, 2019

Patient name: Nikki, RescueLab

Question	Response
1. Do you/the patient have a confirmed diagnosis of Friedreich's Ataxia?	Yes
Placeholder	
2. Have you/the patient been diagnosed with another rare disease?	No
2.1 What is your/the patient's other disease diagnosis?	anemia
3. What is the basis by which you were/the patient was diagnosed with FA?	Electromyography (EMG)
3.1 Please specify	
4. What type of physician diagnosed your/the patient's FA?	Neurologist

You can view your previous submissions for a specific survey set by clicking the spyglass + icon.

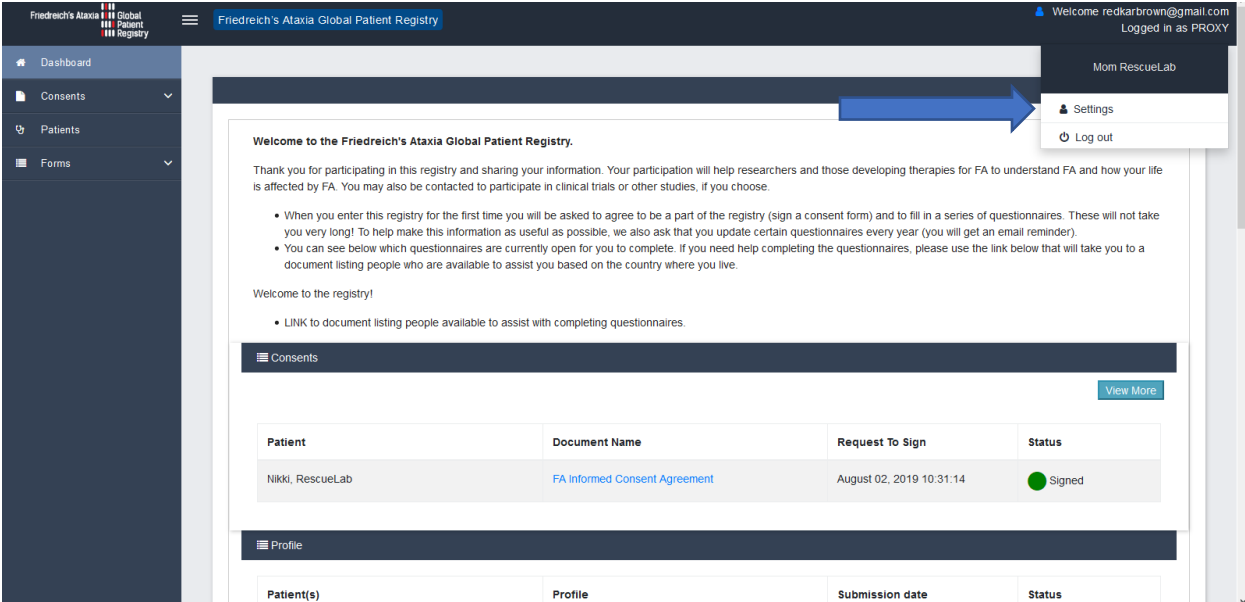


The pencil icon  indicates open surveys that you can fill out or update.

5 WITHDRAWING CONSENT OR OPTING OUT OF FAGPR

If you decide that you no longer wish to participate in the FAGPR, you are able to withdraw your consent to participate in surveys. You are also able to change the option to be contacted about research study participation without withdrawing from FAGPR entirely if you wish that the survey data be available to FA researchers.

To delete your access to the FAGPR system, go to **SETTINGS** in your patient profile screen accessible from the upper-right corner of the screen.



Welcome redkarbrown@gmail.com
Logged in as PROXY

Mom RescueLab

Settings
Log out

Welcome to the Friedrich's Ataxia Global Patient Registry.

Thank you for participating in this registry and sharing your information. Your participation will help researchers and those developing therapies for FA to understand FA and how your life is affected by FA. You may also be contacted to participate in clinical trials or other studies, if you choose.

- When you enter this registry for the first time you will be asked to agree to be a part of the registry (sign a consent form) and to fill in a series of questionnaires. These will not take you very long! To help make this information as useful as possible, we also ask that you update certain questionnaires every year (you will get an email reminder).
- You can see below which questionnaires are currently open for you to complete. If you need help completing the questionnaires, please use the link below that will take you to a document listing people who are available to assist you based on the country where you live.

Welcome to the registry!

- LINK to document listing people available to assist with completing questionnaires.

Consents

View More

Patient	Document Name	Request To Sign	Status
Nikki, RescueLab	FA Informed Consent Agreement	August 02, 2019 10:31:14	Signed

Profile

Patient(s)	Profile	Submission date	Status
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This screen represents the area to select to begin the withdrawal from the registry.

USER > USER SETTINGS

USER SETTINGS

User Name* redkarbrown@gmail.com

First Name* Mom

Last Name* RescueLab

Email* redkarbrown@gmail.com

Reset Password ☐

⚠ You have the right to withdraw from the registry at any time. To formally withdraw from the registry, please click here to place your account on hold and complete a brief survey regarding your withdrawal preferences. [Withdraw from Registry](#)

[Save](#) [Cancel](#)

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Here you can select “Withdraw consent”.

- By withdrawing your consent, you are opting out of participating in the FAGPR System.
- By confirming your withdrawal, you will be logged out and will no longer be able to login.
- You can rejoin and re-consent at any time by contacting the registry coordinator via email: FAGPR@curefa.org

Once you click the “Withdraw” button this screen will appear to remind you about the implications of withdrawing.

USER > USER SETTINGS

USER SETTINGS

User Name* redkarbrown@gmail.com

First Name* Mom

Last Name* RescueLab

Email* redkarbrown@gmail.com

Reset Password ☐

⚠ You have the right to withdraw from the registry at any time. To formally withdraw from the registry, please click here to place your account on hold and complete a brief survey regarding your withdrawal preferences. [Withdraw from Registry](#)

[Save](#) [Cancel](#)

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Withdraw from registry

By withdrawing from the registry you will no longer have access to the system. Are you sure you want to continue?

[OK](#) [Cancel](#)

Once your consent to participate is withdrawn, previously entered data and completed survey responses will remain in the FAGPR system and may be used in aggregated reports. No further data can be entered from the point of consent withdrawal and you will no longer have access to the FAGPR system. You will no longer receive reminder notifications from the FAGPR system.

After withdrawal, the patient will receive an email containing a link to download their data. The link is available for 2 months.

6 ACCESSING ADDITIONAL INFORMATION / HELP

NOTE: If you are having issues with your account, contact FAGPR@curefa.org