



FGFR Syndromes Research Registry Participant User Guide

Register for an Account

- **Step 1:** Select the appropriate Account Type. If you need more information to help you choose, click “Not sure? Help me choose”.
 - If **you** have a diagnosis of an FGFR Syndrome, select **Participant Account**.
 - If you are entering information for **someone else** who has an FGFR Syndrome, select **Caregiver Account**.
 - If you are entering information for an FGFR Syndrome **patient who has passed away**, select **Caregiver Account**.

A screenshot of a web registration page for the Born A Hero Research Foundation. At the top, it says "Featuring" above the organization's logo. The main heading is "Select Account Type". There are two large white boxes with rounded corners. The left box contains the text "I have a rare disease, condition, and/or diagnosis." followed by "Participant Account". The right box contains the text "I am a family member or guardian of someone with a rare disease." followed by "Caregiver Account". At the bottom left, there is a link with a left-pointing arrow icon labeled "Return to login". At the bottom right, there is a link labeled "Not sure? Help me choose." The background of the page is a light blue and orange gradient with a faint pattern of footprints.

- **Step 2:** Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' page at Step 2, 'Terms & Conditions'. At the top is the logo for 'BOH A HERO RESEARCH FOUNDATION'. Below the logo is the title 'Caregiver Registration' and a progress bar with five steps: Terms & Conditions (active), Contact Info, Notifications, Review & Submit, and Confirmation. The main content area contains a paragraph explaining the purpose of the Terms of Use and Privacy Guidelines, followed by four checked checkboxes with their respective terms. At the bottom left is a 'Return to login' link, and at the bottom right is a 'Next' button.

BOH A HERO RESEARCH FOUNDATION

Caregiver Registration

Terms & Conditions Contact Info Notifications Review & Submit Confirmation

Below are links to the IAMRARE Terms of Use and Privacy Guidelines. The purpose of these documents is to outline your rights and responsibilities when using the platform. These documents include: 1) Standard policies for all studies on this platform, 2) A privacy statement that details how your data can be used, 3) Information outlining the unacceptable uses of the platform, and 4) Information about how to address questions and issues.

- You are at least 18 years of age, the age of majority in your state, province or country, and able to consent on behalf of yourself and/or an individual that you have legal responsibility for. *
- You agree to support the Platform's research activities by providing truthful, appropriate information and to not do anything that will put the Services or the information in the Platform at risk. *
- You understand that NORD will use reasonable efforts to keep the information you enter on the Services safe, but no data transmissions over the Internet can be guaranteed to be 100% secure. The information you provide will be available to authorized users at NORD for platform maintenance and research activities, as well as to the sponsor of the studies you consent to participate in. *
- You agree to the [Terms and Conditions & Privacy Policy](#). *

[Return to login](#) **Next**

- **Step 3:** Enter your personal information in the spaces provided. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' page at Step 3, 'Contact Info'. At the top is the logo for 'BOH A HERO RESEARCH FOUNDATION'. Below the logo is the title 'Caregiver Registration' and a progress bar with five steps: Terms & Conditions, Contact Info (active), Notifications, Review & Submit, and Confirmation. The main content area contains a 'Country of Residence' dropdown menu, two text input fields for 'First Name' and 'Last Name', and one text input field for 'E-mail'. At the bottom left is a 'Return to login' link, and at the bottom right are 'Previous' and 'Next' buttons.

Featuring **BOH A HERO RESEARCH FOUNDATION**

Caregiver Registration

Terms & Conditions **Contact Info** Notifications Review & Submit Confirmation

Country of Residence *

First Name * Last Name *

E-mail *

[Return to login](#) **Previous** **Next**

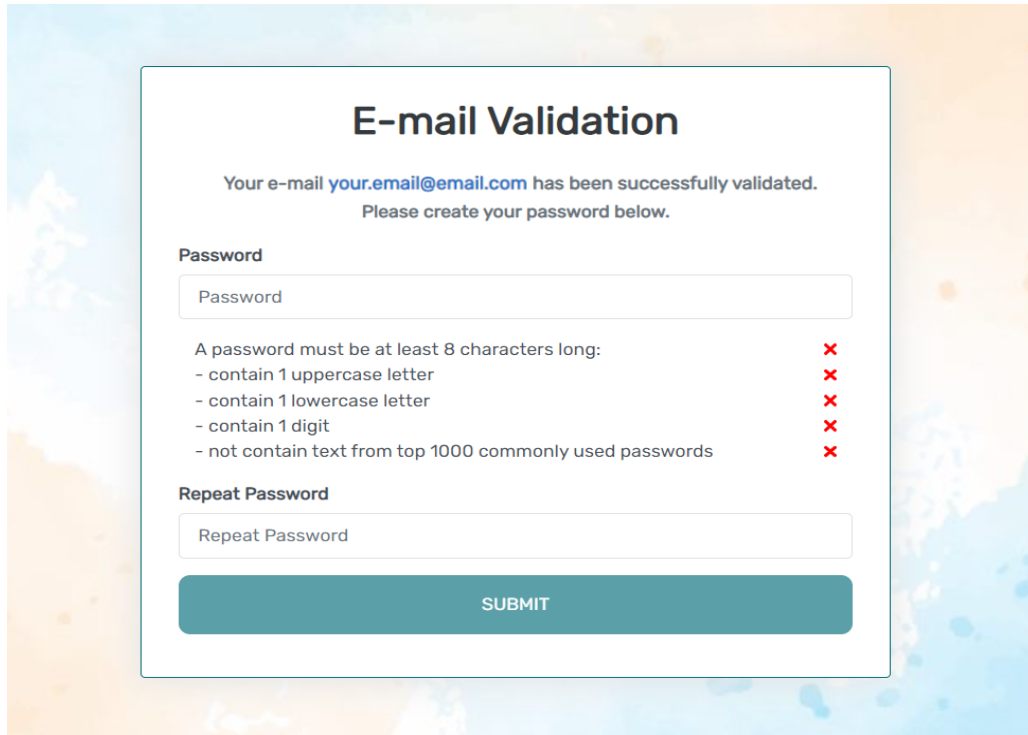
- Step 4: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

The screenshot shows the 'Caregiver Registration' form. At the top, it says 'Featuring' followed by the 'BORN A HERO RESEARCH FOUNDATION' logo. Below the logo is the title 'Caregiver Registration'. A progress bar shows five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The first three steps are completed, and the fourth step, 'Review & Submit', is currently active. Below the progress bar, there is a text input field with the text 'I am interested in NORD contacting me regarding available studies.*'. Underneath this field are two radio buttons: 'Yes' (which is selected) and 'No'. At the bottom left, there is a link 'Return to login'. At the bottom right, there are two buttons: 'Previous' and 'Next'.

- Step 5: Select “Next” so that an activation link is sent to your e-mail to complete registration.

This screenshot is identical to the one above, but the text in the input field has changed to 'An activation link will be sent to your.email@email.com. Click "Next" to send this e-mail and continue.' A purple arrow points to the 'Next' button at the bottom right of the form.

- Step 6: Click the link you are sent via e-mail. Please check your Spam folder if you do not see the e-mail. You will be taken to the following screen in a new tab within your browser. Set your password and click “Submit”.



E-mail Validation

Your e-mail your.email@email.com has been successfully validated.
Please create your password below.

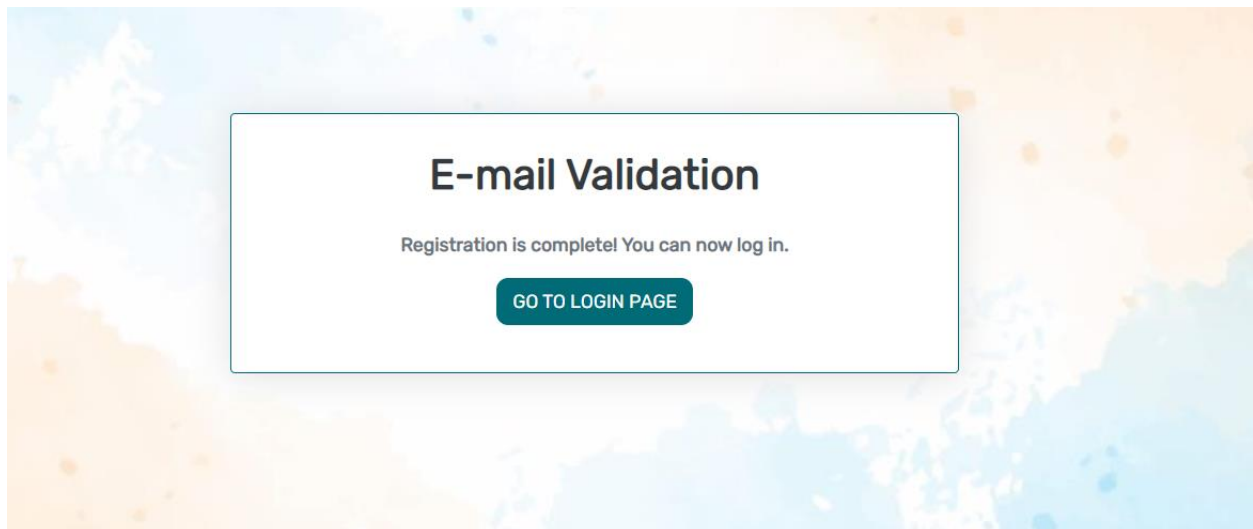
Password

A password must be at least 8 characters long: ✘
- contain 1 uppercase letter ✘
- contain 1 lowercase letter ✘
- contain 1 digit ✘
- not contain text from top 1000 commonly used passwords ✘

Repeat Password

SUBMIT

- Step 7: Your validation is now complete. Select “Go to Login Page”.

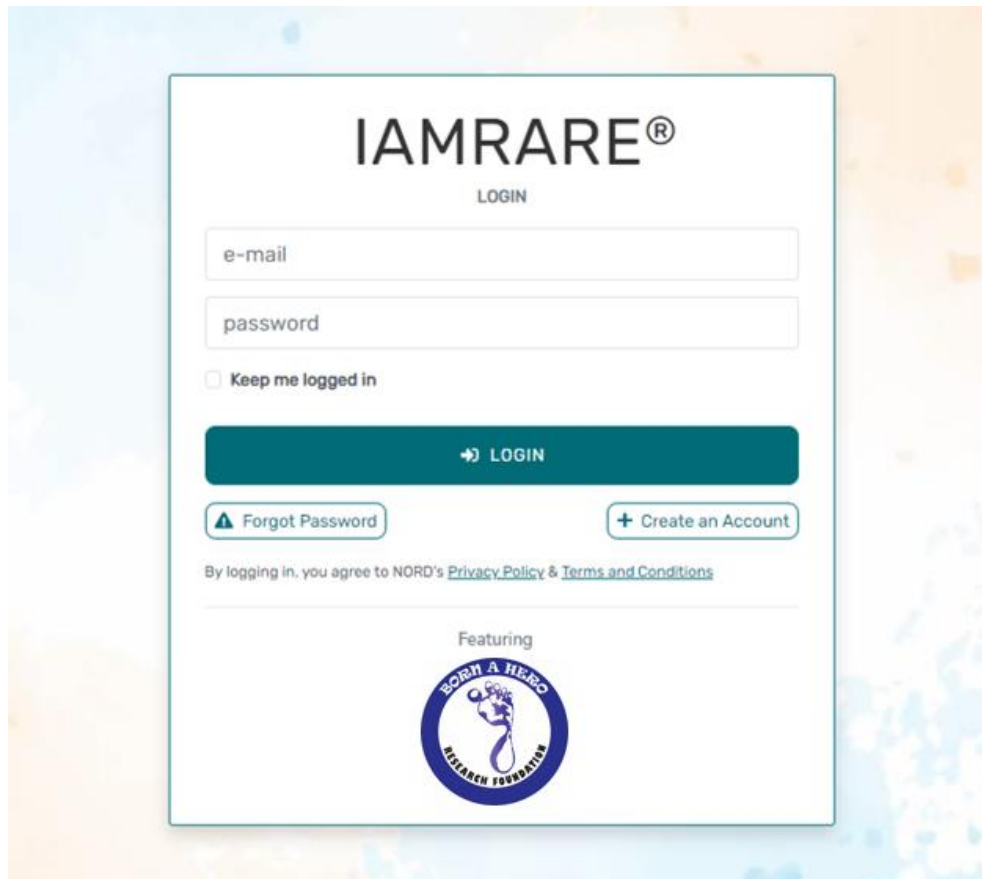


E-mail Validation

Registration is complete! You can now log in.

GO TO LOGIN PAGE

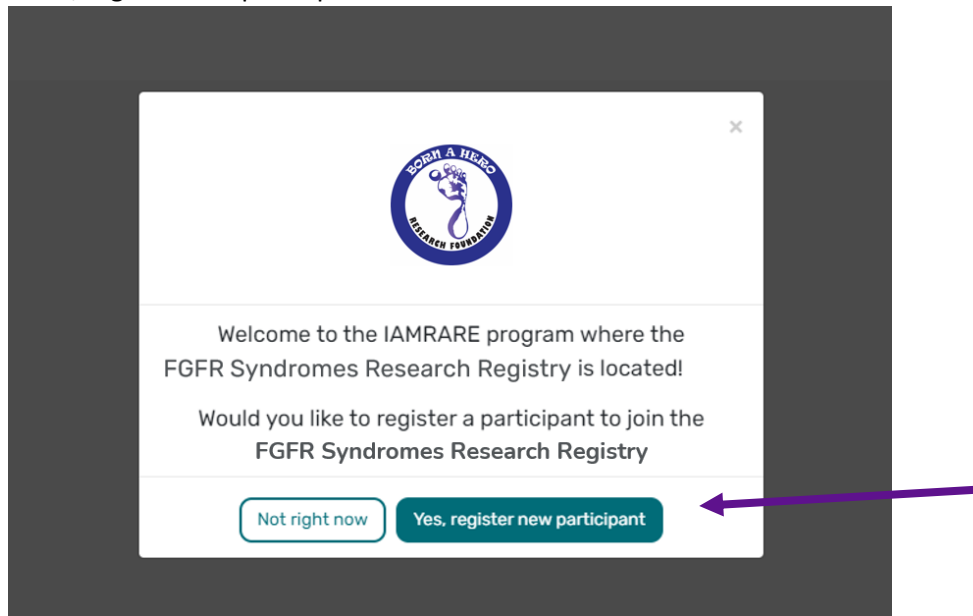
- Step 8: Log in using your new e-mail and password.



The image shows a login form for IAMRARE. At the top, it says "IAMRARE®" and "LOGIN". Below that are two input fields: "e-mail" and "password". There is a checkbox labeled "Keep me logged in". A large teal button with a right arrow and the text "LOGIN" is positioned below the inputs. Underneath the button are two smaller buttons: "Forgot Password" (with a warning triangle icon) and "Create an Account" (with a plus icon). A line of text below these buttons reads: "By logging in, you agree to NORD's [Privacy Policy](#) & [Terms and Conditions](#)". At the bottom of the form, it says "Featuring" above a circular logo for "BORN A HERO RESEARCH FOUNDATION". The logo depicts a muscular arm holding a fist.

Add a Participant

- Step 1: To start, click Yes, register new participant.



The image shows a dialog box with a dark grey background. At the top center is the "BORN A HERO RESEARCH FOUNDATION" logo. Below the logo, the text reads: "Welcome to the IAMRARE program where the FGFR Syndromes Research Registry is located!". The next line of text asks: "Would you like to register a participant to join the FGFR Syndromes Research Registry". At the bottom, there are two buttons: "Not right now" and "Yes, register new participant". A purple arrow points to the "Yes, register new participant" button. A close button (X) is in the top right corner of the dialog box.

- Step 2: Fill out the Participant’s information.

X

Add Participant

Acknowledgement*

By checking this box, you acknowledge that information collected on this platform will only be used for research purposes by NORD and in ways that will not reveal who you are. Federal or state laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of any studies running on this platform. You will not be identified in any publications.

Who Is Being Added as a Participant? *

Self Other

Preferred First Name *

Current Last Name *

First Name on Birth Certificate *

Middle Name on Birth Certificate *

Last Name on Birth Certificate *

Date of Birth *

Sex Recorded on Birth Certificate * ⓘ

Country of Residence *

State/Province of Residence *

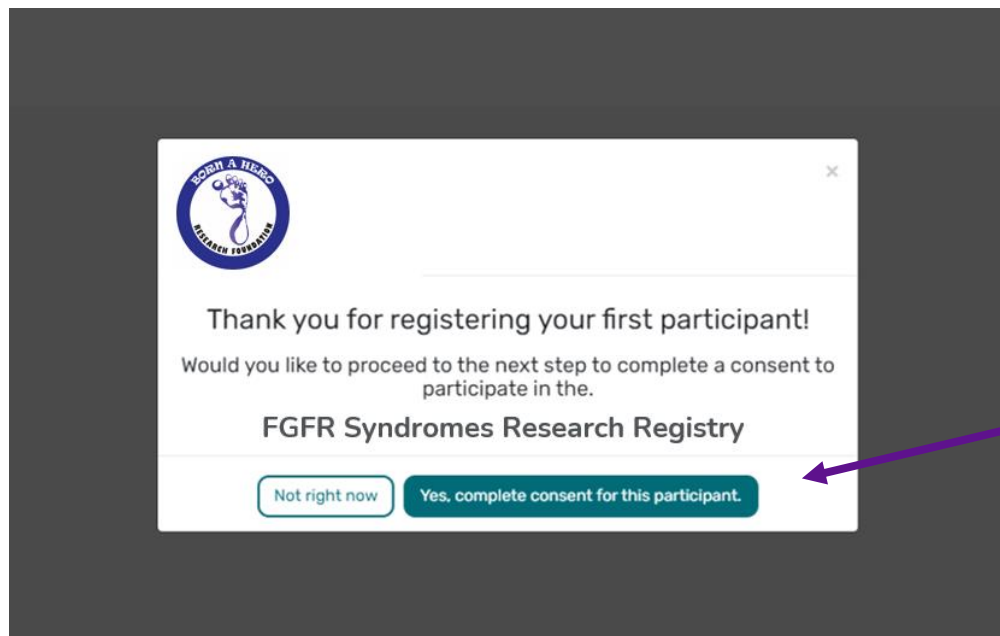
Country of Birth *

City/Municipality of Birth *

What Is Your Relationship to? *

Consent to the Study

- Step 1: Click on “Yes, complete consent for this participant.”



- Step 2: Scroll down and read through the consent form thoroughly. Once you finish each page, click the “Next” button. Once you reach the Authorization form, read through the statements thoroughly. If you are comfortable consenting to participate in the study, please read each statement and authorize your consent. After checking the boxes, click “Next.”

Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with an FGFR Syndrome who is at least 18 years of age, the age of majority in their state, province or country, and able to provide consent for themselves.

Legally Authorized Representative: an individual (such as a family member or guardian) who is legally responsible for the healthcare of the Study Participant who is a minor (child under the age of 18) or an adult who is unable to contribute their own data. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

Designated Representative: A legal adult who was the caretaker of an individual who passed away from an FGFR Syndrome, defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had an FGFR Syndrome and who had knowledge and participated in their medical care. This individual must also be at least 18 years of age and the age of majority in their state, province or country.

1. Please tell us about the Participant you would like to enroll in this study. [Clear](#)

- They are a minor or an adult who is unable to contribute their own data. I am currently their caregiver.
- They were a patient with an FGFR Syndrome. I participated in their medical care.

Next



Title: FGFR Syndromes Research Registry

Principal Investigator: Carolina Sommer, Founder/CEO

Phone: 425-894-8448

Email: registry@bornahero.org

Sponsor: Born a Hero Research Foundation

Key Information

You are invited to take part in a research study for individuals with a syndrome caused by a mutation in an FGFR gene on behalf of the person in your care. We hope that this form will help you decide whether or not to participate, but you can also call or e-mail the study staff at the contacts above if you have any other questions.

Things you should know:

We are doing this research to gain a more comprehensive understanding of the approximately 15 FGFR Syndromes involving mutations in FGFR1, FGFR2, or FGFR3 genes, including the relationship between disease symptoms and genes. The hope is to gather information that will help researchers and clinicians develop better ways to treat affected patients. The syndromes included are:

1. Antley-Bixler syndrome without genital anomalies or disordered steroidogenesis
2. Apert syndrome
3. Beare-Stevenson cutis gyrata syndrome
4. Bent bone dysplasia syndrome
5. CATSHL syndrome (Camptodactyly, tall stature, and hearing loss syndrome)
6. Crouzon syndrome
7. Crouzon syndrome with acanthosis nigricans
8. Hartsfield syndrome (holoprosencephaly, ectrodactyly, and bilateral cleft lip/palate)
9. Hypogonadotropic hypogonadism 2 with or without anosmia (Kallmann syndrome with anosmia)
10. Jackson-Weiss syndrome
11. LADD syndrome (Lacrimalauriculodentodigital syndrome)
12. Nuenke syndrome
13. Osteoglyphonic dysplasia
14. Pfeiffer syndrome, type 1, 2 and 3
15. Thanatophoric dysplasia, type I and 2

If you choose to participate on behalf of the participant, you will be asked to complete the survey initially, and to update approximately once a year, or when there are new events to report. The initial report may take an average of 2 hours to complete, depending on treatment history, and updates should take less than one hour each. The survey does not need to be completed in one sitting. You can save your responses and return at your convenience.

Previous

Next



Authorization

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you and the Study Participant want to participate in this registry;
- Have had your questions answered; and
- Agree to participate in the study as described.

You will be asked to acknowledge:

- That you have read the consent form and have no further questions about the registry and the Study Participant's participation;
- That you wish to provide the Study Participant's personal data to the registry for the purposes of the Study;
- That you allow for this data to be used for future research;
- That you have explained the study to the Study Participant to the extent they are able to understand; and
- That you are of legal age.

This is a web-based form. Your digital signature is the same as if you had signed your name to a paper document. By answering "Yes" to all of the following statements, you are giving your consent to participate in the FGFR Syndromes Registry on behalf of the Study Participant. After signing, a copy of the consent form will be e-mailed to you. If you cannot comfortably answer "Yes" to these statements, please do not check the consent boxes in the following section.

I have read this Consent and Authorization Form to provide the Study Participant's personal and medical data to be shared for the purpose of research. All my questions about the FGFR Syndromes Registry have been answered to my satisfaction, and I understand the purpose of the registry and the risks of participation.

I wish to provide the Study Participant's research data to the FGFR Syndromes Registry for the purposes described above under Study Aims.

I wish to provide the Study Participant's research data to the FGFR Syndromes Registry for future research within recognized ethical standards for scientific research, as described under How We Use The Data.

Previous

Next



- Step 3: Once you click “Next” and reach the Thank You page, click “Continue to Opt-Ins”.

Consent to FGFR Syndromes Research Registry ×

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Thank You

You have completed the consent. You are now ready to take surveys and participate within the study. Thank you.

[Previous](#) [Continue to Opt-Ins](#)

- Step 4: Once you click “Continue to Opt-Ins” read through the opt-ins thoroughly. If you would like to receive information about the topic, check the box, and click “Save and Review”.


Opt-Ins for FGFR Syndromes Research Registry ×

Select Opt-Ins for this study

- Interest in hearing about other studies from [BORN A HERO Research Foundation](#)
- Interest in hearing about clinical trials you may be eligible for
- Interest in donating specimens or DNA (biobanking) for future research
- Interest in genetic testing
- Interest in learning more about [BORN A HERO Research Foundation](#)
- Interest in signing up for [BORN A HERO Research Foundation's](#) newsletter
- Support from [BORN A HERO Research Foundation](#) Ambassador / Care Coordinator
- If eligible, I have interest in receiving [BORN A HERO Research Foundation's](#) merchandise that would be sent via electronic or postal mail

[Save and Review](#)

- Step 5: Once you’ve reviewed your consent, click “Close”. You will then have access to start taking surveys.


FGFR Syndromes Research Registry
✔ Consented

● You have 1 pending surveys.

Surveys 🔔 1 pending All (1) Complete (0) Pending (1)

● **Getting Started**
Not Started [Take Survey](#)

View Responses and Reports

- Step 1: Once you have submitted a survey, you are able to view your responses to that survey as well as the graphs for any questions that are programmed to show graphs. Click “View Responses” to see your completed survey. Click “Reports” to see any available graphs.



View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Click “Consents/Opt-Ins” to see your consent and opt-ins. You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

