



## ACMP Patient Registry Participant User Guide

### Register for an Account

- Step 1: Read the Terms and Conditions and Privacy Policy and attest to the statements provided. When you are finished with this page, click "Next".

Featuring



### 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.

Acknowledgements:

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

Featuring



## Registration

Terms & Conditions    Contact Info    Notifications    Review & Submit    Confirmation

Country of Residence \*

First Name \*    Last Name \*

First Name    Last Name

E-mail \*

e-mail

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

- Step 3: Select whether you are interested in being contacted by NORD regarding available studies. When you are finished with this page, click “Next”.

Featuring



## Registration

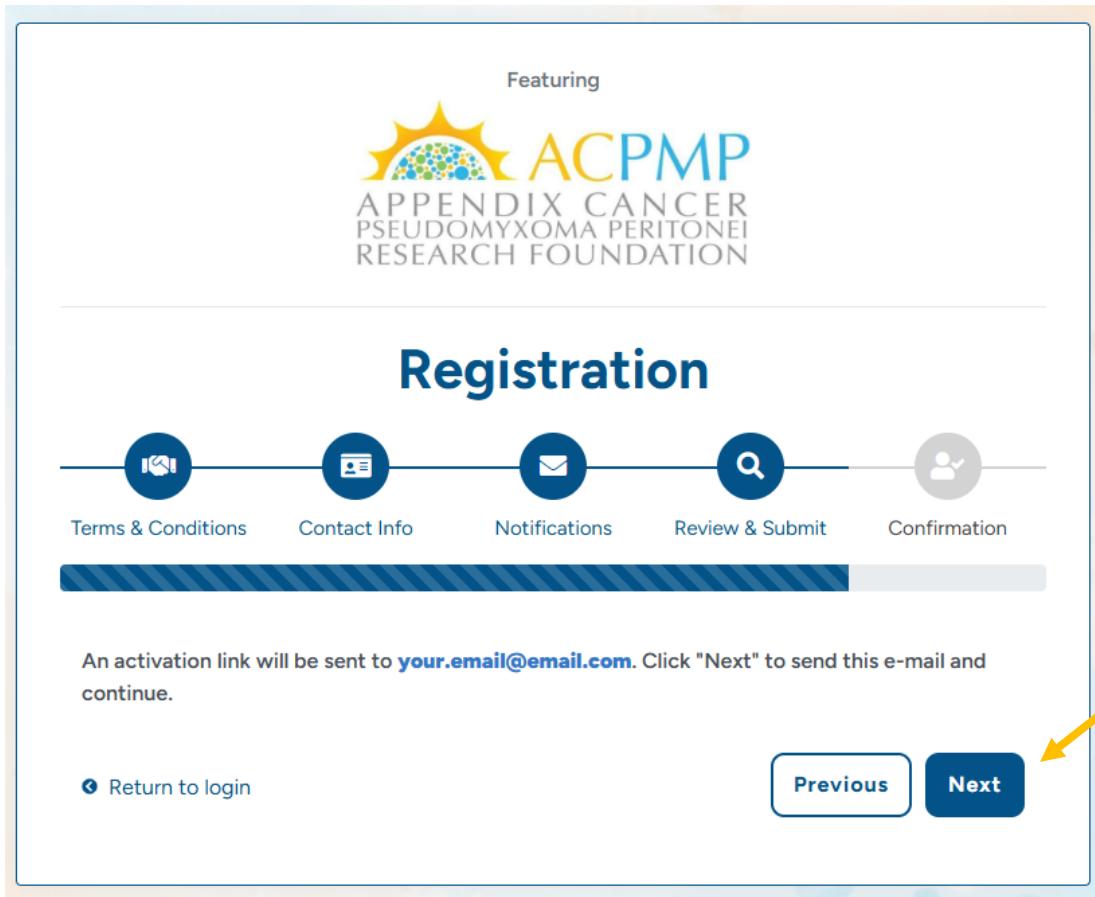
Terms & Conditions    Contact Info    Notifications    Review & Submit    Confirmation

I am interested in NORD contacting me regarding available studies. \*

Yes     No

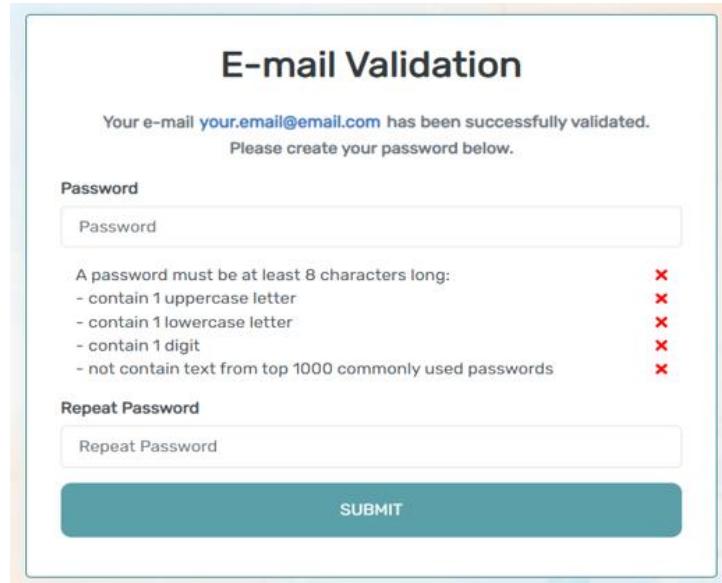
[Return to login](#)    [Previous](#)    [Next](#)

- Step 4: Select “Next” so that an activation link is sent to your e-mail to complete registration.



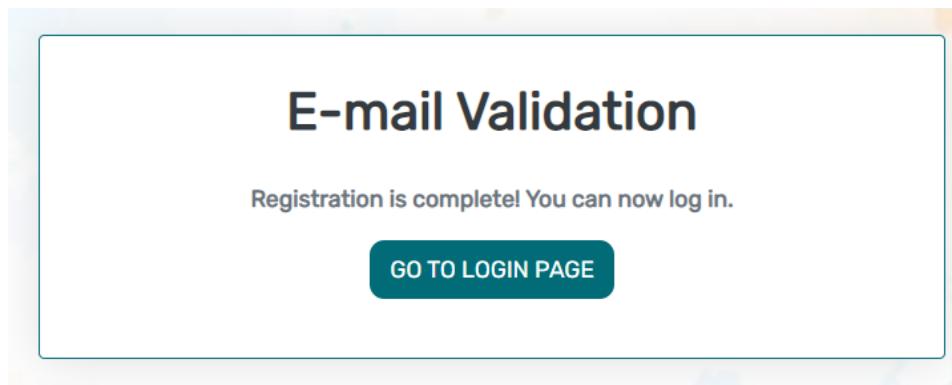
The screenshot shows the 'Registration' step of a registration process. At the top, it features the ACPMP logo and the text 'Featuring APPENDIX CANCER PSEUDOMYXOMA PERITONEI RESEARCH FOUNDATION'. Below this is a horizontal navigation bar with five steps: 'Terms & Conditions', 'Contact Info', 'Notifications', 'Review & Submit', and 'Confirmation'. The 'Review & Submit' step is highlighted with a blue bar. A message below the navigation bar states: 'An activation link will be sent to [your.email@email.com](mailto:your.email@email.com). Click "Next" to send this e-mail and continue.' At the bottom are three buttons: 'Return to login', 'Previous', and a large 'Next' button. A yellow arrow points to the 'Next' button.

- Step 5: 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”.

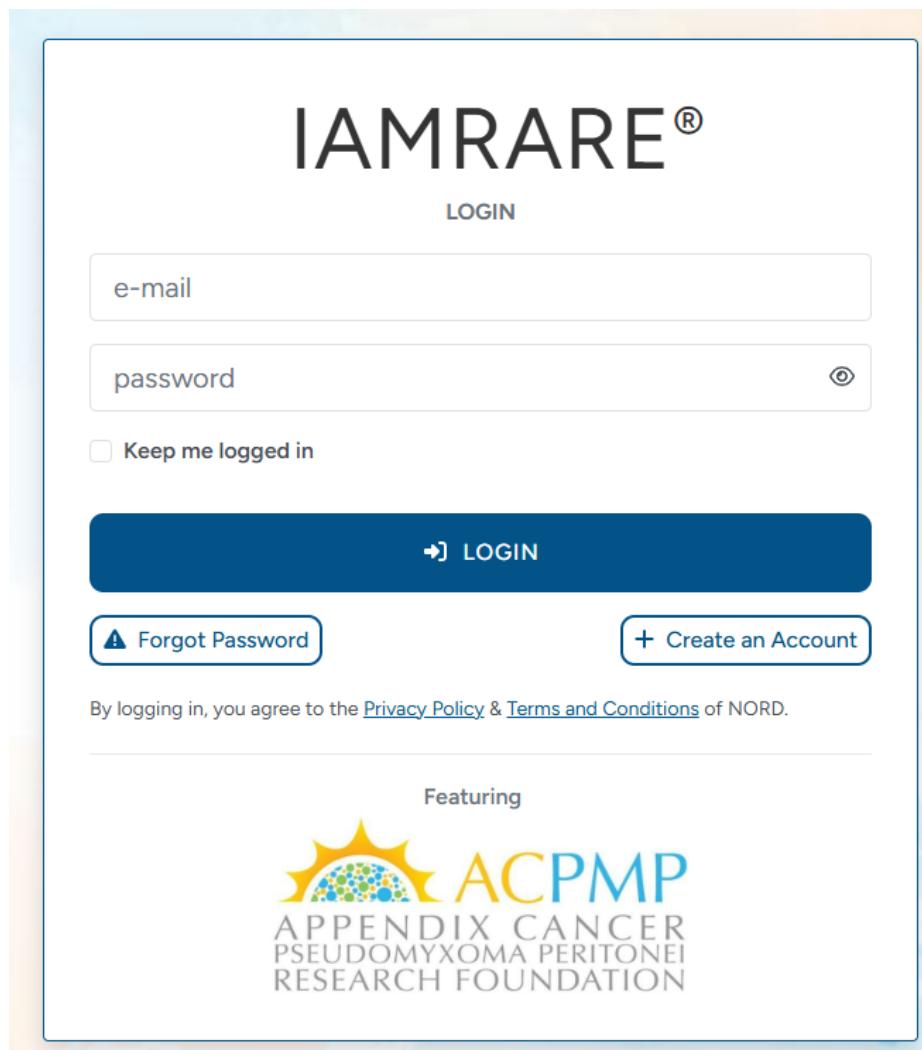


The screenshot shows the 'E-mail Validation' step. It displays a message: 'Your e-mail [your.email@email.com](mailto:your.email@email.com) has been successfully validated. Please create your password below.' Below this is a 'Password' input field with a note: 'A password must be at least 8 characters long:'. To the right of the note are five red 'X' marks. The requirements listed are: '- contain 1 uppercase letter', '- contain 1 lowercase letter', '- contain 1 digit', and '- not contain text from top 1000 commonly used passwords'. Below the password field is a 'Repeat Password' input field. At the bottom is a large teal 'SUBMIT' button.

- Step 6: Your validation is now complete. Select “Go to Login Page”.

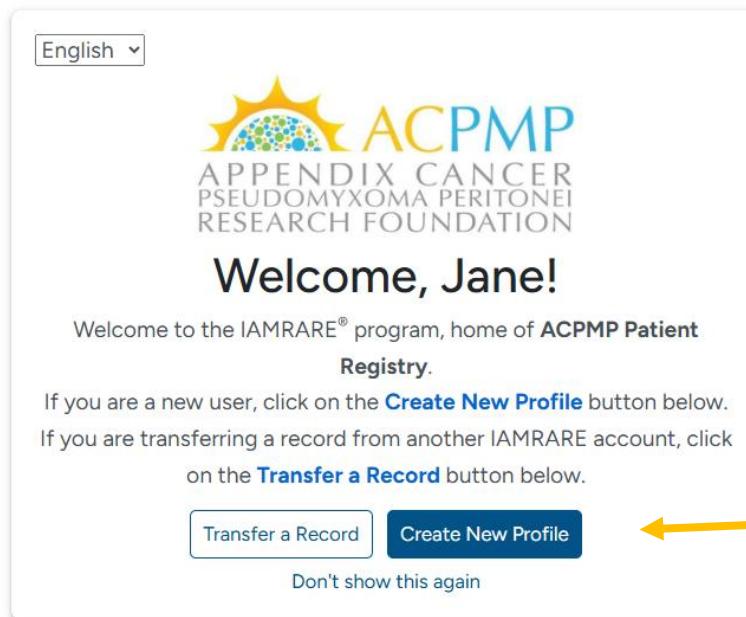


- Step 7: Log in using your new e-mail and password.

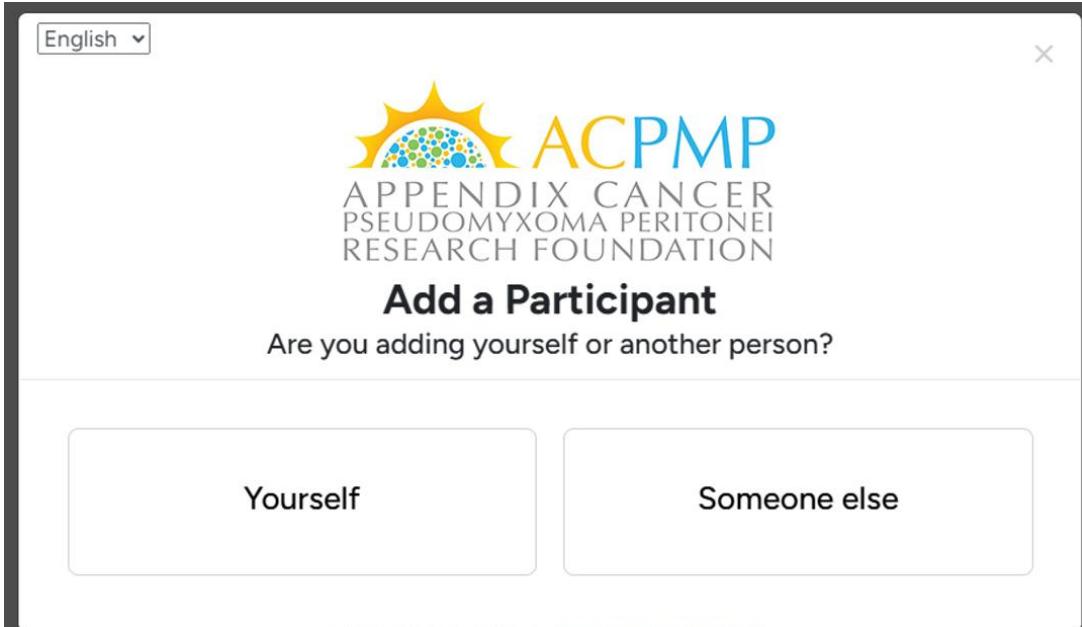


## Add a Participant

- Step 1: To start, click Create New Profile.



- Step 2: Select who you will be providing information about.



- Step 3: Fill out the Participant's information.

**Add Participant**

Who Is Being Added as a Participant?  Self  Other

Preferred First Name *	Current Last name *
Preferred First Name	Current Last Name

First Name on Birth Certificate *	Middle Name on Birth Certificate *
First Name on Birth Certificate	Type 'NA' if none

Last Name on Birth Certificate *	Date of Birth * <small>(mm/dd/yyyy)</small>
Last Name on Birth Certificate	mm/dd/yyyy

Sex Recorded on Birth Certificate * <small>(mm/dd/yyyy)</small>	
Sex Recorded on Birth Certificate	▼

Country of Residence * <small>(mm/dd/yyyy)</small>	State/Province/Region of Residence * <small>(mm/dd/yyyy)</small>
Choose country	Type 'NA' if none

Country of Birth *	City/Municipality of Birth *
Choose country of birth	City/Municipality of Birth

### 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.”

Jane Smith

## Consent to ACPMP Patient Registry

### Consent Overview

Those eligible to participate in our study include:

Participant: An individual diagnosed with AC/PMP 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 with AC/PMP 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 AC/PMP. This role is defined as a spouse, parent, sibling, offspring, close relative, close friend, guardian and/or significant other of the individual who had AC/PMP who had knowledge of 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.

Caregiver: An individual (such as a family member or guardian) who serves as a caregiver for someone with AC/PMP who is a legal adult and can 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 and will only provide information about their role as a Caregiver.

**Please tell us about yourself and your enrollment in this study. \***

I am an adult who has AC/PMP. I would like to contribute information about my experience with the disease.

I am an adult who is a Caregiver of someone with AC/PMP. I would like to contribute information about my experience as a caregiver.

**Next**



Jane Smith

## Consent to ACPMP Patient Registry

### Adult Consent

Consent to Participate in the ACPMP Research Foundation Appendix Cancer / Pseudomyxoma Peritonei Patient Registry (ACPMP Patient Registry) and to Allow Your Data to be Shared for Future Research

**Title:** ACPMP Research Foundation Appendix Cancer / Pseudomyxoma Peritonei Patient Registry (ACPMP Patient Registry)

**Principal Investigator:** Deborah M. Shelton, Executive Director

**Phone:** (833) 227-6773

**E-mail:** [registry@acppm.org](mailto:registry@acppm.org)

**Sponsor:** ACPMP Research Foundation

**Key Information**

You are invited to take part in a research study for individuals with Appendix Cancer and/or Pseudomyxoma Peritonei (AC/PMP). 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.

**Previous** **Next**



**Consent to ACPMP Patient Registry**

Jane Smith

**Authorization**

The following statements are intended to:

- Make sure that you have had the time and opportunity to consider whether you 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 your participation;
- That you wish to provide personal data to the registry for the purposes of the Study;
- That you allow for your data to be used for future research; 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 ACPMP Patient Registry. 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.

[Previous](#) [Next](#)

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

**Consent to ACPMP Patient Registry**

Jane Smith

Please continue to select your opt-ins. Once you have made your selections, please click Save and Review. You will then be ready to take surveys and participate in this study.

[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 ACPMP Patient Registry**

Select Opt-Ins for this study

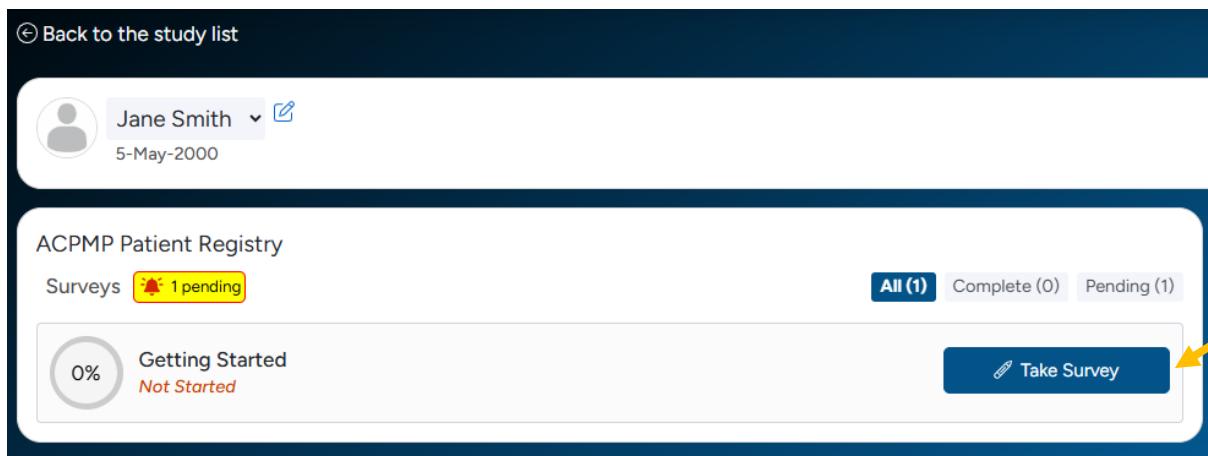
Interest in hearing about other studies from [Appendix Cancer PMP \(ACPMP\) Research Foundation](#)  
 Interest in hearing about relevant clinical trials  
 Interest in donating specimens or DNA (biobanking) for future research  
 Interest in genetic testing  
 Interest in learning more about [Appendix Cancer PMP \(ACPMP\) Research Foundation](#)  
 Interest in signing up for a [Appendix Cancer PMP \(ACPMP\) Research Foundation](#) newsletter  
 Support from other Patient Advocacy Groups  
 Interest in learning about upcoming events such as webinars and conferences

[Save and Review](#)

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

## Taking Surveys

- Step 1: Click “Take Survey” for an available survey.



Back to the study list

Jane Smith 5-May-2000

ACMP Patient Registry

Surveys 1 pending

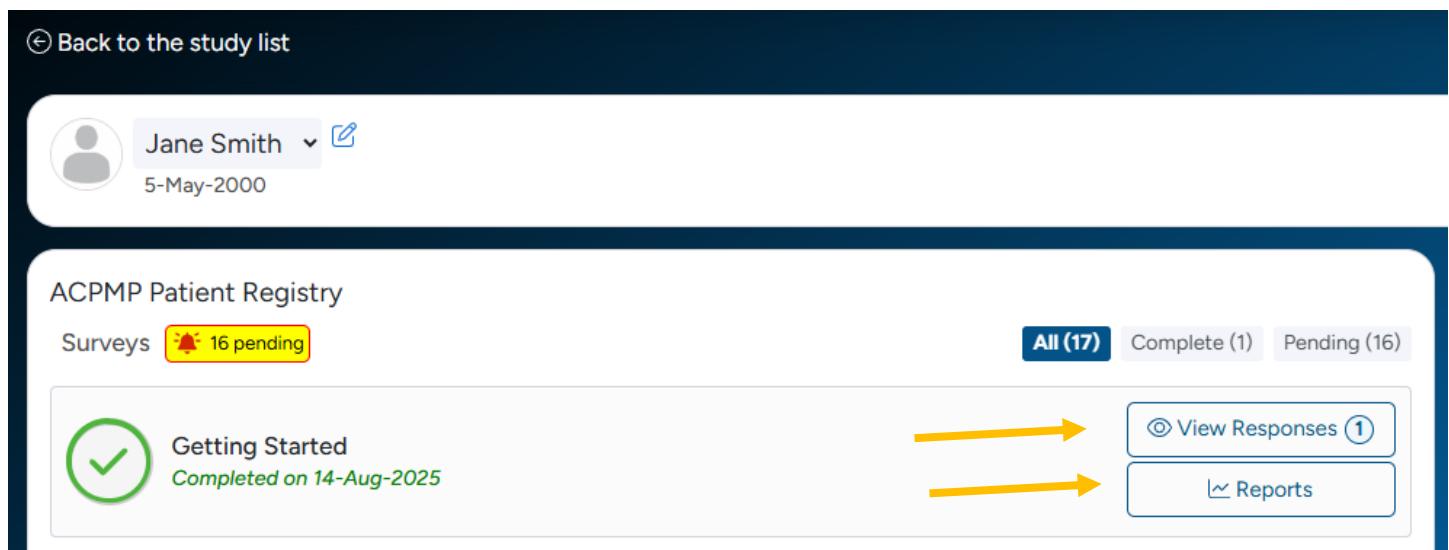
All (1) Complete (0) Pending (1)

0% 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.



Back to the study list

Jane Smith 5-May-2000

ACMP Patient Registry

Surveys 16 pending

All (17) Complete (1) Pending (16)

Getting Started Completed on 14-Aug-2025

View Responses 1 Reports

## View Consent and Opt-Ins

- Step 1: Once you have consented to the study, you are able to view your consent at any time. Navigate to the Enrolled Studies page. Then, click “Consents/Opt-Ins” to see your consent and opt-ins.

The screenshot shows the participant's profile at the top: Jane Smith, 5-May-2000. Below is the 'Enrolled Studies' section with a yellow arrow pointing to the 'Enrolled Studies' heading. The 'Consents/Opt-Ins' section is highlighted with a yellow box and a yellow arrow pointing to the 'Consent/Opt-Ins' button in the 'Shortcuts' box.

- Step 2: You may revoke your consent at any time by clicking “Revoke”. You may also edit your Opt-Ins by clicking “Opt-Ins”.

The screenshot shows the 'Consents/Opt-Ins' section with a yellow arrow pointing to the 'View Consent' button. Another yellow arrow points to the 'Revoke' button. The 'Opt-Ins' button is also highlighted with a yellow box and a yellow arrow pointing to it.

## Dark Mode Settings

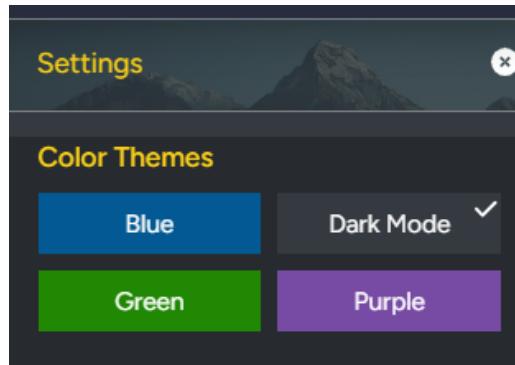
- Step 1: You can view the platform in Dark Mode. First, click Settings.

The screenshot shows the participant's profile at the top: Jane Smith, Member since Nov 16, 2024. Below is the 'Participants' section. A yellow arrow points to the 'Settings' button in the top right corner.

- Step 2: Select Dark Mode.

The screenshot shows the 'Settings' page with a yellow arrow pointing to the 'Dark Mode' button in the 'Color Themes' section. The 'Dark Mode' button is highlighted with a yellow box and a yellow arrow pointing to it.

- Step 3: Exit the Settings menu, and your selection will be saved.

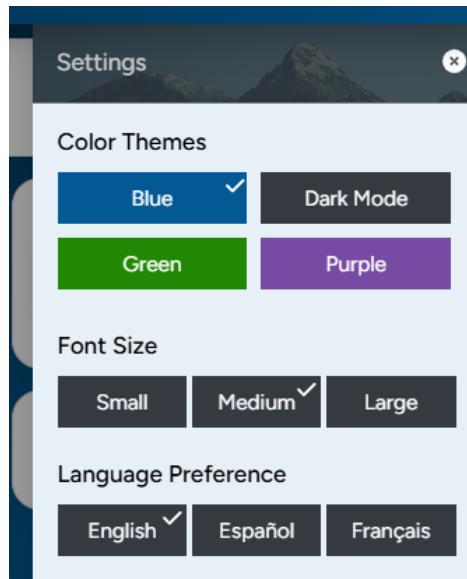


## Display Settings

- Step 1: You can change the platform display settings. First, click Settings.

The screenshot shows the IAMRARE® platform dashboard. At the top, there is a header with the IAMRARE logo, navigation links (Home, Help, Settings, Hi, Jane!), and a 'Add Participant' button. Below the header, a message 'Good Afternoon, Jane!' is displayed, along with 'Member since Nov 16, 2024'. In the center, there is a 'Participants' section with a count of 22 and a 'Shortcuts' button. The main content area is currently empty.

- Step 2: Select a color theme, a font size, or language preference.



- Step 3: Exit the Settings menu, and your selection will be saved.

## Microsite Visibility

- Step 1: You can change how you view the microsite [insert URL] using an Accessibility menu. Click the icon of a person at the bottom of the screen. You are able to change the settings such as the contrast, text sizing, and text spacing.



For Researchers

### Drive Research

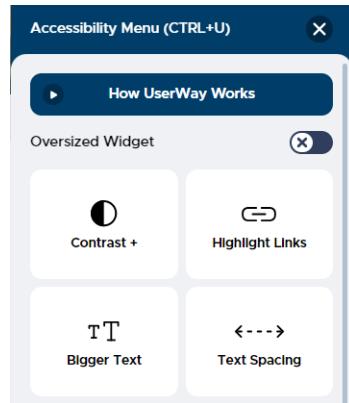
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



For Patients

### Get Involved

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.



## Need Assistance?

- Step 1: If you need help while using the platform, click Help.
- Step 2: Select an Inquiry Type and type a message.

Home
Help

Have a question?

Please enter your message below and click submit. We will be in touch shortly. We cannot provide medical advice or answer specific medical questions – to find out about resources to support people with your rare disease, please visit the NORD website at [rarediseases.org](http://rarediseases.org).

**Inquiry Type \***

-- Select Inquiry Type --

**Message \***

Your message

Cancel
Submit

- Step 3: Click Submit.
- You may also contact the study sponsor directly by using the contact information shown on your dashboard or the study website.

**Appendix Cancer PMP  
(ACPMP) Research Foundation**  
[acppm.org](http://acppm.org)

<p><b>Contact</b> Deborah Shelton</p> <p><b>E-mail</b> <a href="mailto:patientregistry@acppm.org">patientregistry@acppm.org</a></p> <p><b>IRB E-mail</b> <a href="mailto:info@northstarreviewboard.org">info@northstarreviewboard.org</a></p> <p><b>Social Media</b></p>	<p><b>Phone</b> (833) 227-6773</p>
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