




## ACPMP 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

**ACPMP**  
APPENDIX CANCER  
PSEUDOMYXOMA PERITONEI  
RESEARCH FOUNDATION

## Registration

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

Country of Residence \*

First Name \* | Last Name \*

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

**ACPMP**  
APPENDIX CANCER  
PSEUDOMYXOMA PERITONEI  
RESEARCH FOUNDATION

## 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.

Featuring

**ACPMP**  
APPENDIX CANCER  
PSEUDOMYXOMA PERITONEI  
RESEARCH FOUNDATION

## Registration

Terms & Conditions   Contact Info   Notifications   Review & Submit   Confirmation

An activation link will be sent to **your.email@email.com**. Click "Next" to send this e-mail and continue.

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

- 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”.

## E-mail Validation

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

**Password**

Password

A password must be at least 8 characters long: ×

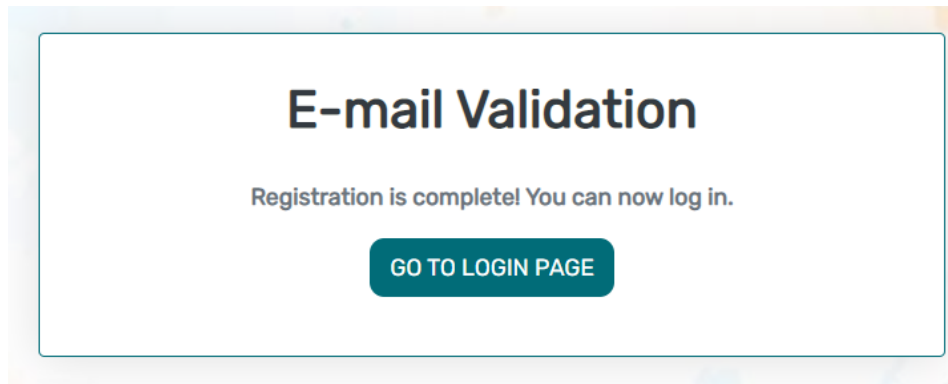
- contain 1 uppercase letter ×
- contain 1 lowercase letter ×
- contain 1 digit ×
- not contain text from top 1000 commonly used passwords ×

**Repeat Password**

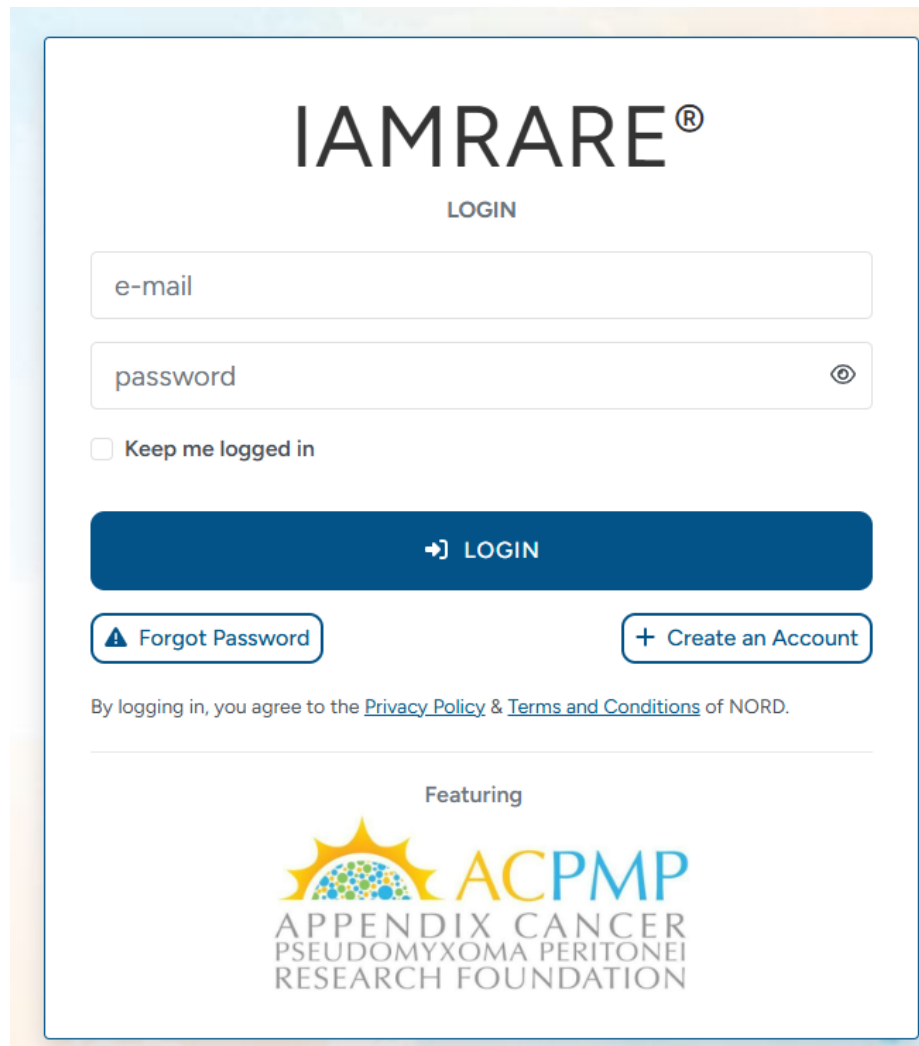
Repeat Password

**SUBMIT**

- 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.

English ▾

**ACPM**  
APPENDIX CANCER  
PSEUDOMYXOMA PERITONEI  
RESEARCH FOUNDATION

**Welcome, Jane!**

Welcome to the IAMRARE® program, home of **ACPM Patient Registry**.

If you are a new user, click on the **Create New Profile** button below.

If you are transferring a record from another IAMRARE account, click on the **Transfer a Record** button below.


Transfer a Record

Create New Profile

[Don't show this again](#)

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

English ▾

**ACPM**  
APPENDIX CANCER  
PSEUDOMYXOMA PERITONEI  
RESEARCH FOUNDATION

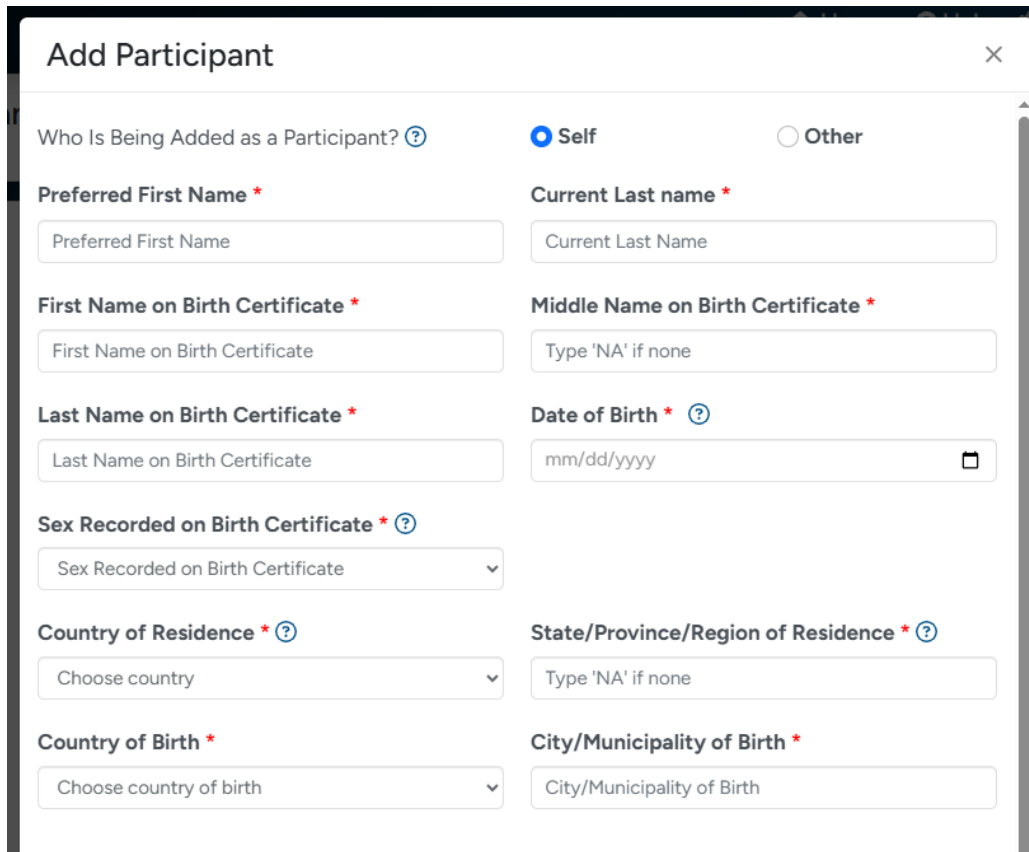
**Add a Participant**

Are you adding yourself or another person?

Yourself

Someone else

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



The 'Add Participant' form is a web-based interface for adding a new participant. It features a title bar with a close button (X) in the top right corner. Below the title bar, there is a question 'Who Is Being Added as a Participant?' with a help icon (?). Two radio buttons are present: 'Self' (selected) and 'Other'. The form is organized into two columns. The left column contains fields for 'Preferred First Name \*', 'First Name on Birth Certificate \*', 'Last Name on Birth Certificate \*', 'Sex Recorded on Birth Certificate \* (?)', 'Country of Residence \* (?)', and 'Country of Birth \*'. The right column contains fields for 'Current Last name \*', 'Middle Name on Birth Certificate \*', 'Date of Birth \* (?)', 'State/Province/Region of Residence \* (?)', and 'City/Municipality of Birth \*'. Each field is a text input box, except for the 'Sex Recorded on Birth Certificate' and 'Country of Residence' fields, which are dropdown menus. The 'Date of Birth' field has a date picker icon. The form is styled with a clean, modern look, using a light gray background and blue accents for the selected radio button and the 'Yes, complete consent' button in the subsequent screen.

### Consent to the Study

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



The consent screen is a web-based interface for obtaining consent from a participant. It features a logo at the top center, which consists of a stylized sun with a colorful, dotted interior, followed by the text 'ACPM P' in large, bold, blue letters, and 'APPENDIX CANCER PSEUDOMYXOMA PERITONEI RESEARCH FOUNDATION' in smaller, gray letters below it. Below the logo, there is a message: 'Thank you for registering your first participant! Would you like to consent to participate in ACPMP Patient Registry?'. At the bottom of the screen, there are two buttons: 'Not right now' (a light gray button with a thin blue border) and 'Yes, complete consent for this participant.' (a solid blue button). A yellow arrow points to the 'Yes, complete consent for this participant.' button. The screen has a title bar with a close button (X) in the top right corner.

- 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 to ACPMP Patient Registry

Jane Smith

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

Consent to ACPMP Patient Registry

Jane Smith

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@acpmp.org](mailto:registry@acpmp.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.

The screenshot shows the top navigation bar with a "Back to the study list" link. Below it is a user profile for Jane Smith, dated 5-May-2000. The main section is titled "ACPMP Patient Registry" and shows "Surveys" with a "1 pending" status. A progress bar indicates "0% Getting Started" and "Not Started". A "Take Survey" button is visible on the right, highlighted by a yellow arrow.

## 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.

The screenshot shows the same user profile for Jane Smith. The "ACPMP Patient Registry" section now shows "Surveys" with a "16 pending" status. The progress bar indicates "Getting Started" and "Completed on 14-Aug-2025". Two yellow arrows point from the progress bar to the "View Responses" and "Reports" buttons on the right.

## 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 'Enrolled Studies' page for Jane Smith (5-May-2000). At the top, there is a 'Back to participant list' link and a 'Search Studies' button. Below the participant information, the 'Enrolled Studies' section is highlighted with a yellow arrow. It contains instructions: 'Click a study to see the list of surveys. Click the i icon to see more information about the study. Click "Search Studies" above to find additional studies.' To the right, a 'Shortcuts' section contains two buttons: 'Request Transfer' and 'Consent/Opt-Ins', with a yellow arrow pointing to the latter.

- 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' page for Jane Smith (5-May-2000). At the top, there is a 'Back to the study list' link. Below the participant information, the 'Consents/Opt-Ins' section is highlighted. It contains a table with the following data:

Study Name	Consent Status	Consented On	Actions
ACPMP Patient Registry	✓ Consented	14-Aug-2025	<a href="#">View Consent</a> <a href="#">Revoke</a> <a href="#">Opt-Ins</a>

Yellow arrows point to the 'Revoke' and 'Opt-Ins' buttons in the Actions column.

## Dark Mode Settings

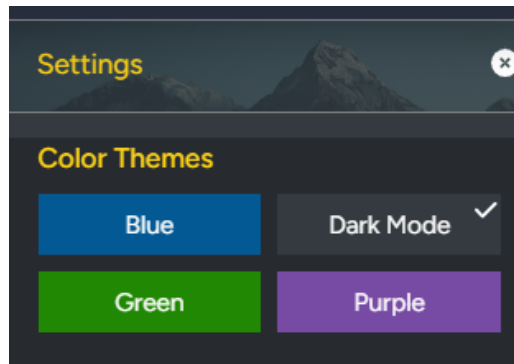
- Step 1: You can view the platform in Dark Mode. First, click Settings.

The screenshot shows the IAMRARE® user interface. At the top, there is a navigation bar with 'Home', 'Help', 'Settings', and a user profile 'Hi, Jane!'. Below the navigation bar, there is a greeting 'Good Afternoon, Jane!' and a '+ Add Participant' button. The 'Participants' section is highlighted with a yellow arrow.

- Step 2: Select Dark Mode.

The screenshot shows the 'Settings' dialog box. Under the 'Color Themes' section, there are four buttons: 'Blue' (selected with a checkmark), 'Dark Mode', 'Green', and 'Purple'.

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

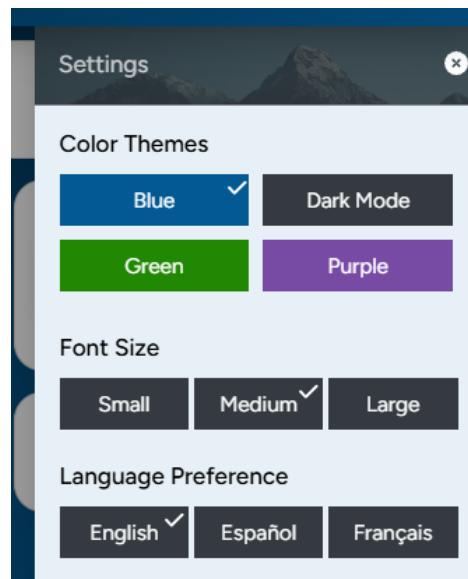


## Display Settings

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




- 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

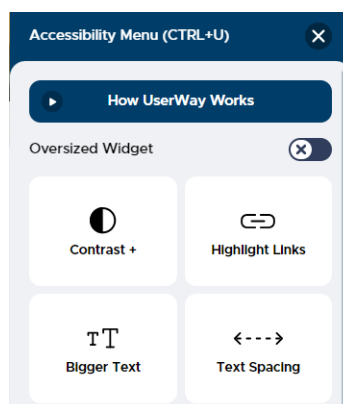
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?



**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  
(ACMP) Research  
Foundation**

[acmpmp.org](http://acmpmp.org)

**Contact**

Deborah Shelton

**Phone**

(833) 227-6773

**E-mail**

[patientregistry@acmpmp.org](mailto:patientregistry@acmpmp.org)

**IRB E-mail**

[info@northstarreviewboard.org](mailto:info@northstarreviewboard.org)

**Social Media**

