NO LUMP REQUIRED

The Inflammatory Breast Cancer Research Foundation Registry

Part 2: Setting Up Your Primary Health Profile
The Inflammatory Breast Cancer Research Foundation Registry

The new IBC community's 'privacy assured' registry is the best chance we have to collect information that will facilitate the diagnosis of inflammatory breast cancer and help to improve treatment. We need you to participate by sharing your information! Simply click on Start Now! to begin, or Sign In if you are a returning user.

It's Easy as 1, 2, 3

1. Register (or sign in)
2. Enter Health Information
3. Let Researchers Find YOU!

"We want to give patients the power to determine how much they share and what they share, and this project allows that on a whole new level... We need to have patients focused on the research."

Ginny Mason, RN, BSN
Inflammatory Breast Cancer Survivor
Executive Director & President, IBCRF

Not currently signed in? Sign in please!
Sign up using this box and your previously created username.
You will see your previously selected image. Enter your password.
The process is slightly different if the profile is for yourself or for someone else. You may set up a profile for a spouse, parent, or child (living or deceased).
Create a nickname.

Use the < and > symbols to move back 10 years at a time. Click on the birth year. A box will ask for birth month, select the desired month. A box will ask for birth day, select the day.
Select the country, state from the drop down box by clicking the down arrows.

Enter the zip or postal code by filling in the blank.
If you need to stop, click this. When you return, you be asked to sign in.
Next step is to set up who may view your data, or the data for the spouse, parent or child whose profile you set up.
Privacy Settings

Privacy settings have not been set for Nicky's profile!

Who can see my data and for what purposes

Inflammatory Breast Cancer Research Foundation respects each person's right to control access to his or her own information. In accordance with our Privacy Policy, we enable you to specify who can access your information and for what purposes, as well as the ability to change these settings in the future. In order to assist you in this regard, Inflammatory Breast Cancer Research Foundation has asked several trusted members of the community to reflect on the range of settings they feel may provide a good starting point for persons with generally high, moderate or low concerns about privacy. You can consider their suggestions as a starting point, or manually create your own settings starting from Inflammatory Breast Cancer Research Foundation's default selections that will apply any time you have not set such levels. Click on "Select My Privacy Settings" to continue...

Select My Own Privacy Settings
We have 3 guides with different privacy settings. Choose a guide.

You will be able to modify privacy settings or choose to set all of them manually.
Review the settings and if you like those, click accept and continue.

To change some or all of the settings, click customize.
<table>
<thead>
<tr>
<th>Who can access your data and for what purpose...</th>
<th>Find/Analyze</th>
<th>Export/Link</th>
<th>Get Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>(click any column or row name for more information)</td>
<td>except for name and contact details</td>
<td>except for name and contact details</td>
<td>find, view, use and export contact details</td>
</tr>
<tr>
<td></td>
<td>(click for details)</td>
<td>(click for details)</td>
<td>(click for details)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Inflammatory Breast Cancer Research Foundation (IBCRF)</th>
<th></th>
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<tbody>
<tr>
<td>Allow: You have granted this entity permission to view your anonymous information in search results.</td>
<td>Allow: You are authorizing the export of your anonymous health data to this entity.</td>
<td>Allow: You have granted this entity permission to view your contact information.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researchers recommended by IBCRF</th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Allow: You have granted this entity permission to view your anonymous information in search results.</td>
<td>Allow: You are authorizing the export of your anonymous health data to this entity.</td>
<td>Ask Me: You will be notified when this entity wants to make contact, and you can then decide whether to permit it.</td>
</tr>
</tbody>
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<table>
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<tr>
<th>Other Researchers</th>
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<td>Researchers addressing your condition</td>
<td></td>
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</table>

**This screen allows you to review your data privacy selections.**

[This image is shortened due to space limitations.]
Enter your name, address and phone number. You previously entered your email, zip and state. Click **Continue** and you will see this confirmation message.

You can update your contact information at any time in the future.
Privacy settings can be modified at any time. Log in to your account, then click on privacy settings.
Congratulations!

You have now finished setting up your Primary Health Profile, data sharing, privacy, and access settings. Remember you can change or modify data sharing, privacy, and access settings at any time in the future.

You may log out at this point or continue on to taking the survey.

Please see the next tutorial--Part 3: Taking the No Lump Required survey.