

NO LUMP REQUIRED

The Inflammatory Breast Cancer Research Foundation Registry

Part 2: Setting Up Your Primary Health Profile

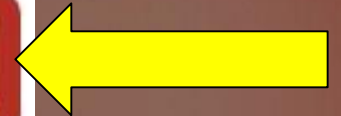
The Inflammatory Breast Cancer Research Foundation Registry

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) [Start Now!](#)
- 2 Enter Health Information
- 3 Let Researchers Find YOU!



Not currently signed in? Sign in please!

Sign Up

This service uses Private Access to allow you to specify exactly who can see your information and for what purpose. If you do not already have a free account, enter valid email address to sign up now.

Returning user?

 remember me[forgot username](#)

First time user?

 I am at least 18 years or older (In Colorado, 21 years or older)

Sign in using this box and your previously created username.

Sign in

This service uses Private Access to allow you to specify exactly who can see your information and for what purpose.

Image : red poppies [What's this?](#)



Password

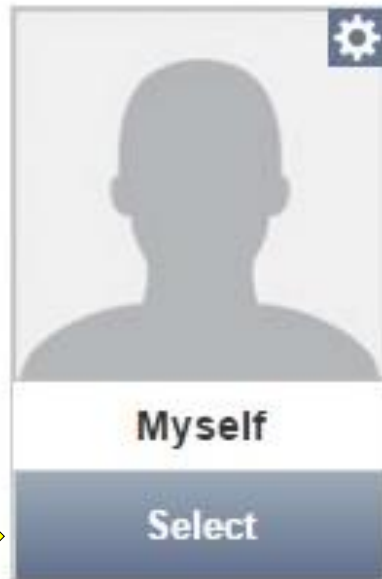
Sign in

[Forgot Password? Click Here](#)

You will see your previously selected image. Enter your password.

Select a profile

Select whether you plan to enter information about yourself or someone else...



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 Profile

Please assure the following information is accurate and complete.

Refer me as...

Nickname: Nicky

Date of Birth:



Continue >>

< 2010-2019 >

2009	2010	2011
2012	2013	2014
2015	2016	2017
2018	2019	2020

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.

Please assure the following information is accurate and complete.

▼ My location...

Country: United States of America ▼

State: Select State ▼

Postal code:

Continue >>

▶ Refer me as...

- Select State
- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District Of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana

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Select the country, state from the drop down box by clicking the down arrows.

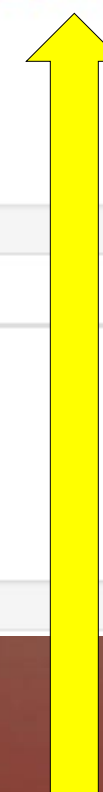
Enter the zip or postal code by filling in the blank.

Profile Complete!

▼ Nicky's profile is complete!

Click Continue to go to Nicky's list of activities.

Continue >>



If you need to stop, click this. When you return, you be asked to sign in.

List of Activities

Select from any of the following activities...

 View Answers

Who can see my data and for what purposes

Not Started

Start

No Lump Required: About You & Your IBC

Not Started

Start



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.

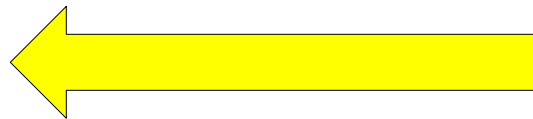
Privacy Settings

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](#)





Phyllis Johnson
Retired Teacher and IBCRF Board Member

Choose as guide

Phyllis grew up in Silver Spring, Maryland. Diagnosed with inflammatory breast cancer in 1998, she quickly realized that she needed help to cope with this rare disease and became active in on-line support groups for people affected by IBC. She writes about breast ca..[More >>](#)



What's this?



Ginny Mason
Inflammatory Breast Cancer Survivor and
Executive Director & President of IBCRF

Choose as guide

Since her diagnosis of inflammatory breast cancer in 1994, Ginny Mason has been educating patients to take an active role in their own health. Her nursing background has helped her bridge the gap between the patient and research communities, and bring a much-needed pa..[More >>](#)



What's this?



Neil Spector, MD
Inflammatory Breast Cancer Researcher and
Sandra P. Coates Professor at Duke
University

Choose as guide

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.



Phyllis suggested settings for persons with: Moderate concerns about privacy

1. Choose a level of concern about privacy that more closely reflects your views.
2. To accept Phyllis's suggested privacy settings shown below, click 'Accept and continue'.
3. If not, either click 'Customize' to refine these settings, or 'Go Back' to choose a different guide.

<< Go Back

Customize

Accept and continue >>



What's this?

Who can access your data and for what purpose...

Click any column or row name for more information

Who can access your data and for what purpose...	
▼ Inflammatory Breast Cancer Research Foundation	
📘 Inflammatory Breast Cancer Research Foundation (IBCRF)	
📘 Researchers recommended by IBCRF	
▼ Other Researchers	
📘 Researchers addressing your condition	
📘 All researchers	
▼ Data Analysis Platforms	

Find/Analyze except for name and contact details (click for details)	Export/Link except for name and contact details> (click for details)	Get Contact find, view, use and export contact details (click for details)
✔ Allow	✔ Allow	✔ Allow
✔ Allow	✔ Allow	⚠ Ask Me
✔ Allow	✔ Allow	⚠ Ask Me
✔ Allow	✔ Allow	⚠ Ask Me

Review the settings and if you like those, click **accept and continue.**

To change some or all of the settings, click **customize.**

Who can access your data and for what purpose...

Click any column or row name for more information

Find/Analyze

except for name and contact details
[\(click for details\)](#)

Export/Link

except for name and contact details>
[\(click for details\)](#)

Get Contact

find, view, use and export contact details
[\(click for details\)](#)

▼ Inflammatory Breast Cancer Research Foundation

i Inflammatory Breast Cancer Research Foundation (IBCRF)

✔ Allow : You have granted this entity permission to view your anonymous information in search results.

✔ Allow : You are authorizing the export of your anonymous health data to this entity.

✔ Allow : You have granted this entity permission to view your contact information.

i Researchers recommended by IBCRF

✔ Allow : You have granted this entity permission to view your anonymous information in search results.

✔ Allow : You are authorizing the export of your anonymous health data to this entity.

⚠ Ask Me : You will be notified when this entity wants to make contact, and you can then decide whether to permit it.

▼ Other Researchers

i Researchers addressing your condition

✔ Allow : You have granted this entity permission to view your anonymous information in search results.

✔ Allow : You are authorizing the export of your anonymous health data to this entity.

⚠ Ask Me : You will be notified when this entity wants to make contact, and you can then decide whether to permit it.

This screen allows you to review your data privacy selections.
[This image is shortened due to space limitations.]

Contact Information

Because **ALLOW** or **ASK ME** was set for one or more CONTACT settings, the following information is necessary.

First Name:	<input type="text" value="First Name"/>	Email:	<input type="text" value="REDACTED"/>
Last Name:	<input type="text" value="Last Name"/>	Mobile:	<input type="text" value="Mobile Number (Optional)"/>
Address:	<input type="text" value="Address"/>	Country:	<input type="text" value="United States of America"/>
Apt#:	<input type="text" value="Apt#"/>	Zip:	<input type="text" value="REDACTED"/>
City:	<input type="text" value="City"/>	State:	<input type="text" value="REDACTED"/>

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.

Your contact details have been saved successfully and will only be released in those cases when you have expressly permitted this.

OK

Privacy settings can be modified at any time. Log in to your account, then click on privacy settings.



 Nicky's Health Profile (change/add)

[List of Activities](#)

[Privacy Settings](#)

 0 Notifications

(sign out)



List of Activities

Select from any of the following activities...

 [View Answers](#)

No Lump Required: About You & Your IBC

Not Started

[Start](#)



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.