NO LUMP REQUIRED

The Inflammatory Breast Cancer Research Foundation Registry

Part 3: Taking the Survey
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

Click to hear Ginny speak about the new IBC registry

Not currently signed in? Sign in please!
Sign in using this box and your previously created username.
You will see your previously selected image. Enter your password.
Click to start the survey.

Remember you can sign out to take a break, then sign back in to finish.
Welcome to No Lump Required!

Let's Get Started

This survey will take approximately 45 minutes to complete, depending on how much detail you provide. We'll ask some questions about you, followed by some questions about your inflammatory breast cancer and your health in general.

If you get tired you can take a break, and when you return, continue from where you left off. However, it is very important that you complete the entire survey so that everyone in the community has answered the same questions.

Thank you for your willingness to take part in this important work!

Select "Continue" to begin...
This survey asks the patient (or parent, or child of someone with IBC) to enter information about her (or his) IBC experience.

The survey includes sections of 'common data elements' such as gender, height, weight, etc. There are also questions about exercise, smoking, alcohol use, and other general health topics. These are included for epidemiological purposes.

This survey consists of questions in several formats. Examples will be illustrated here.
If you select the wrong button, click **Reset** to remove your check mark.

Some questions have a **Don’t know** option.

After making your selection(s) click **Save and Continue** to go to the next question.
Sometimes Other is the best answer for your circumstances. After you hit **Save and Continue**, you will see a fill in the blank box where you can explain what you mean by “other.”
For most questions, you will be able to see how others have responded.

If you selected the wrong button, click to change it.

Select the answer you wish, and click Save Changes.
Some questions ask for your input in a text box.
A few questions have a pop up box with a scroll bar on the right side.

Scroll down to see all possible choices.
A few questions are in a chart format. Select an answer for each line item.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Without any difficulty</th>
<th>With a little difficulty</th>
<th>With some difficulty</th>
<th>With much difficulty</th>
<th>Unable to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do chores such as vacuuming or yard work</td>
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<tr>
<td>Go up and down stairs at a normal pace</td>
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<tr>
<td>Go for a walk of at least 15 minutes</td>
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<tr>
<td>Run errands and shop</td>
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A couple of questions are open-ended, and you type into the box.
Congratulations!

You have now finished your survey.

Most published IBC patient data has focused on one institution and typically comes from the physician point of view. With NO LUMP REQUIRED we hope to capture the actual patient experience not what someone else thinks you experienced.

Thank you for taking time to assist the Inflammatory Breast Cancer Research Foundation with this critically important, patient focused, research project.