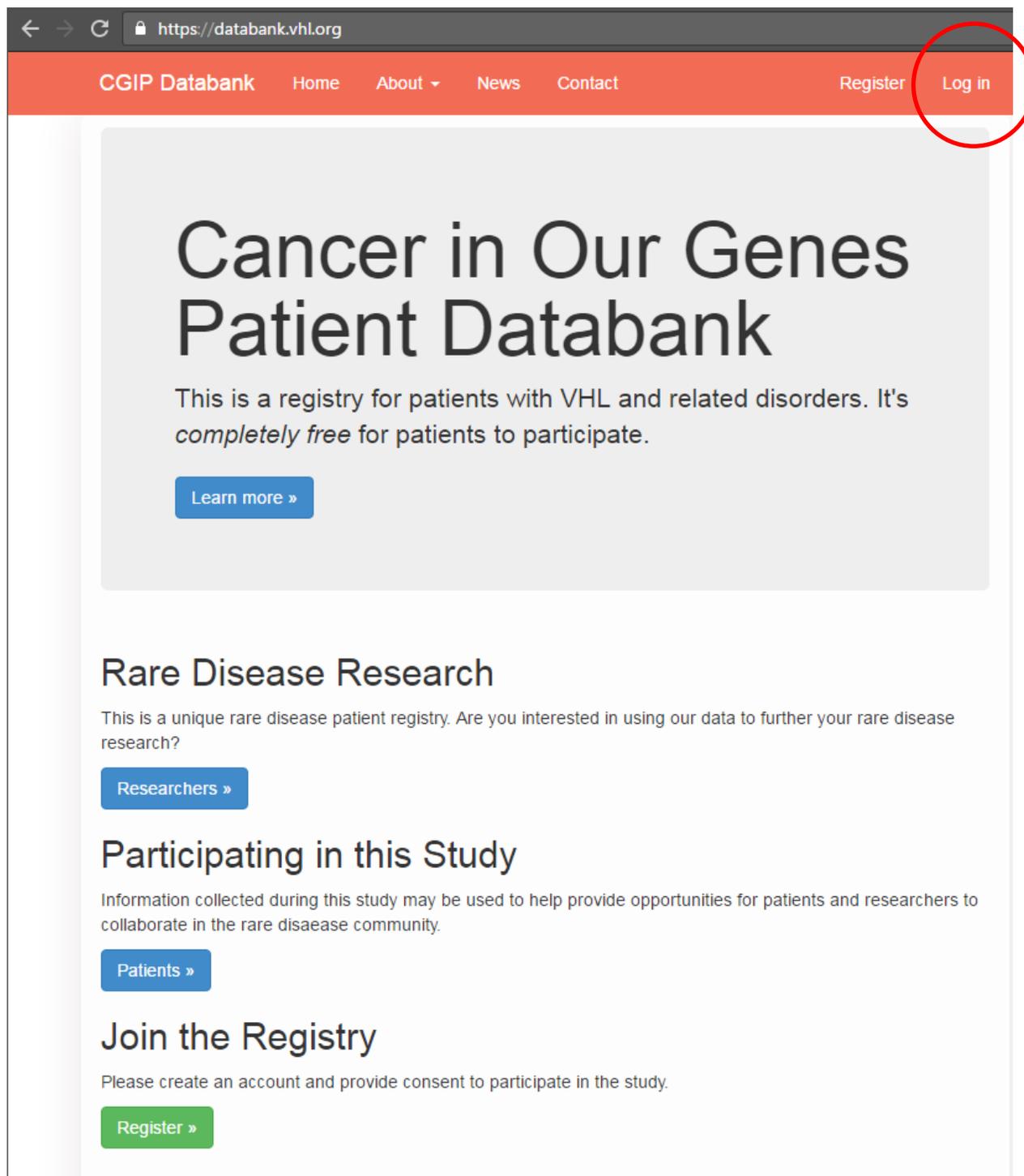
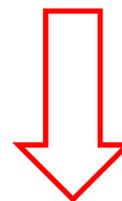


How to use the Patient Databank

Go to databank.vhl.org

Click the login button.



The screenshot shows a web browser window with the URL <https://databank.vhl.org>. The navigation bar is orange and contains the text "CGIP Databank", "Home", "About", "News", "Contact", "Register", and "Log in". The "Log in" button is circled in red. The main content area has a grey background with the heading "Cancer in Our Genes Patient Databank" and a subheading "This is a registry for patients with VHL and related disorders. It's *completely free* for patients to participate." Below this is a blue button labeled "Learn more ». Further down, there are three sections: "Rare Disease Research" with a blue button "Researchers »", "Participating in this Study" with a blue button "Patients »", and "Join the Registry" with a green button "Register »".

Enter in your login information.

The image shows a web browser window displaying the login page for the CGIP Databank. The browser's address bar shows the URL <https://databank.vhl.org/Account/Login>. The page has a red navigation bar with links for Home, About, News, Contact, Register, and Log in. The main content area is titled "Log in" and includes a breadcrumb trail "Home / Log in".

The login form contains the following elements:

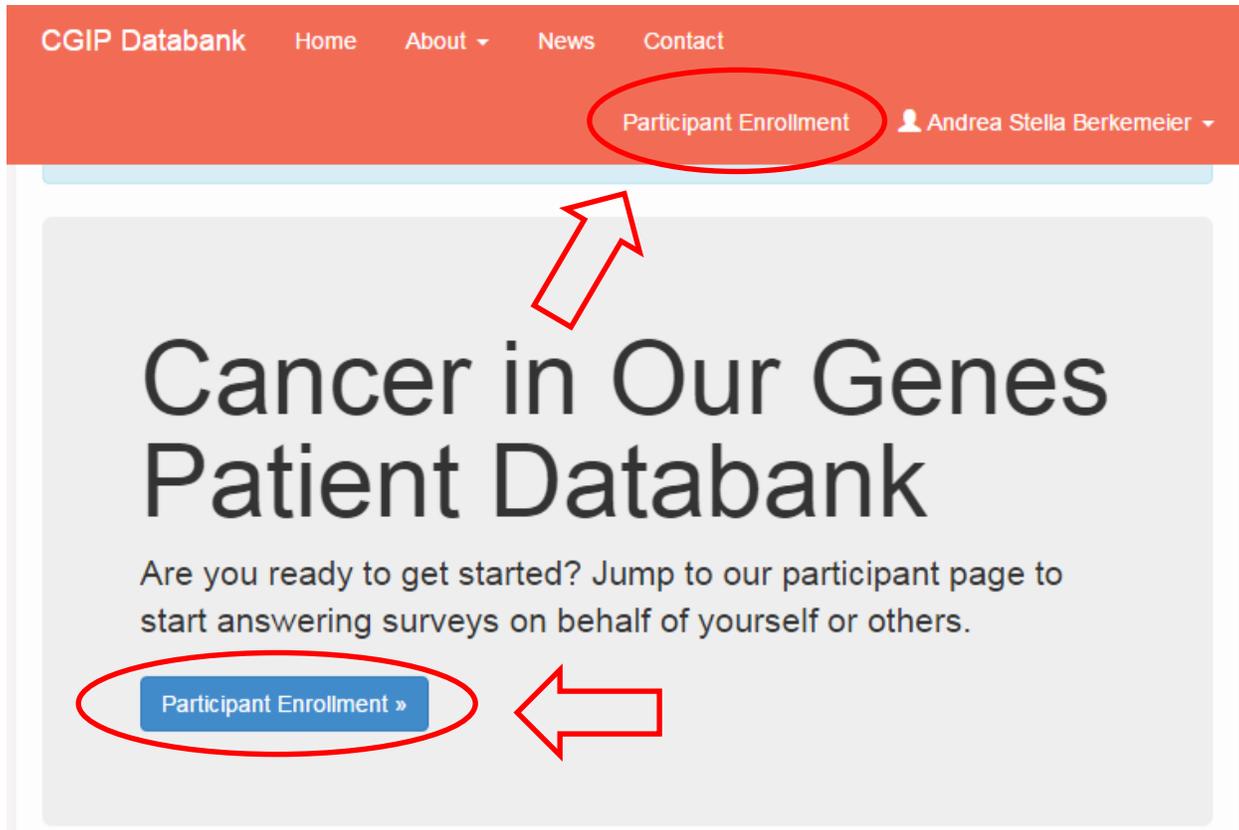
- User name ***: A text input field containing the email address `andrea.berkemeier@vhl.org`. A red annotation next to it reads: "1. Username = the email that used to register".
- Password ***: A password input field with masked characters. A red annotation next to it reads: "2. If you don't remember your password, Click here to reset it.".
- Remember me?**: A checkbox that is currently unchecked.
- Log in**: A button to submit the login information. A red annotation next to it reads: "3. Click Login.".

Below the form, there are two links: "Register if you don't have an account." and "Forgot your password? Click here to reset your password." A red arrow points from the "Forgot your password?" link to the "2. If you don't remember your password, Click here to reset it." annotation.

At the bottom of the page, there is a link to "Sign up for VHLA newsletters" and logos for the VHL Alliance and NORD (National Organization for Rare Disorders).

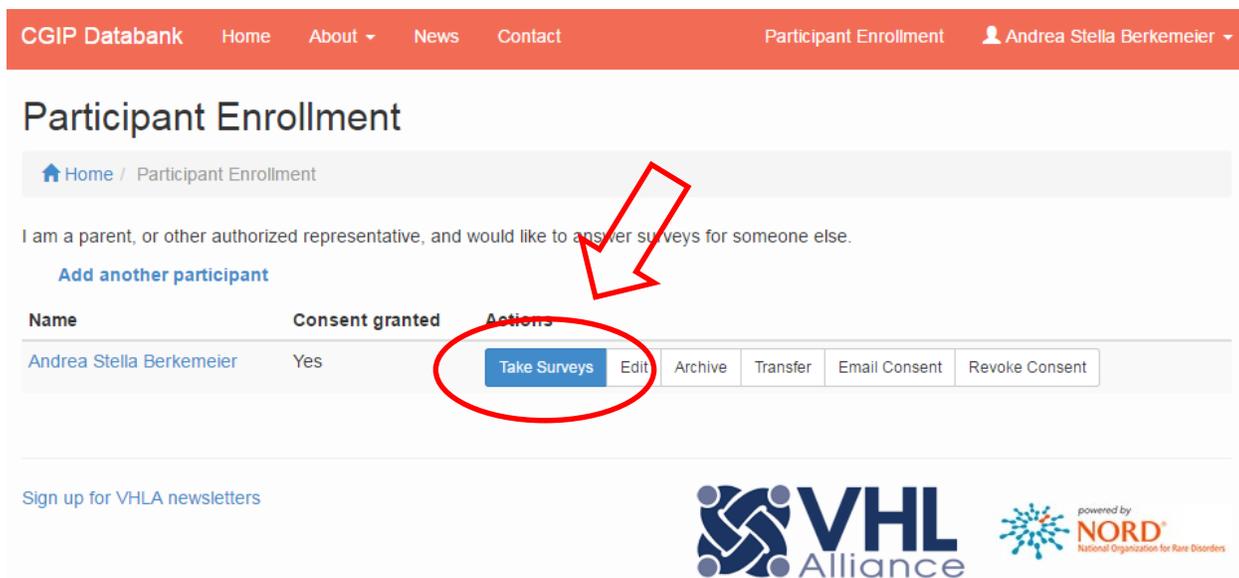
Click **Participant Enrollment**.

There are two buttons that you can click.



The screenshot shows the top navigation bar of the CGIP Databank website. The navigation items are "CGIP Databank", "Home", "About", "News", and "Contact". The "Participant Enrollment" link is circled in red. Below the navigation bar, the main heading reads "Cancer in Our Genes Patient Databank". Below the heading, there is a call to action: "Are you ready to get started? Jump to our participant page to start answering surveys on behalf of yourself or others." A blue button labeled "Participant Enrollment »" is circled in red. Two red arrows point to the "Participant Enrollment" link in the navigation bar and the "Participant Enrollment »" button.

Click **Take Surveys**.



The screenshot shows the "Participant Enrollment" page. The navigation bar includes "CGIP Databank", "Home", "About", "News", "Contact", "Participant Enrollment", and a user profile for "Andrea Stella Berkemeier". The main heading is "Participant Enrollment". Below the heading, there is a breadcrumb trail: "Home / Participant Enrollment". A message states: "I am a parent, or other authorized representative, and would like to answer surveys for someone else." Below this message, there is a link "Add another participant". A table lists participants with columns for "Name", "Consent granted", and "Actions". The "Take Surveys" button in the "Actions" column for "Andrea Stella Berkemeier" is circled in red. A red arrow points to this button. At the bottom of the page, there is a link "Sign up for VHLA newsletters" and logos for "VHL Alliance" and "powered by NORD National Organization for Rare Disorders".

If this is your first time taking surveys in this Databank, click the Initial Surveys tab.

Surveys for Andrea Stella Berkemeier

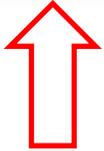
[Home](#) / [Participant Enrollment](#) / Surveys for Andrea Stella Berkemeier

Initial Surveys

Started

Surveys to Retake

Completed



To take a survey, click on the Survey Title.

A red outline arrow pointing from the left towards the first survey title, 'About the participant'.

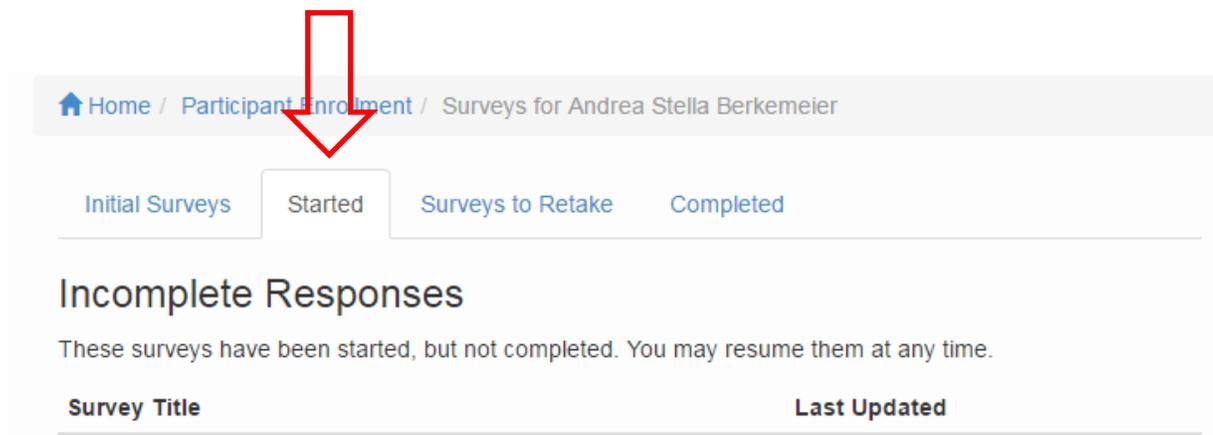
Survey Title	First Taken	Next Follow-Up
About the participant	October 8, 2014	As needed
Diagnosis and medical history	December 1, 2014	As needed
Genetics questions	December 1, 2014	As needed

Complete the Survey.

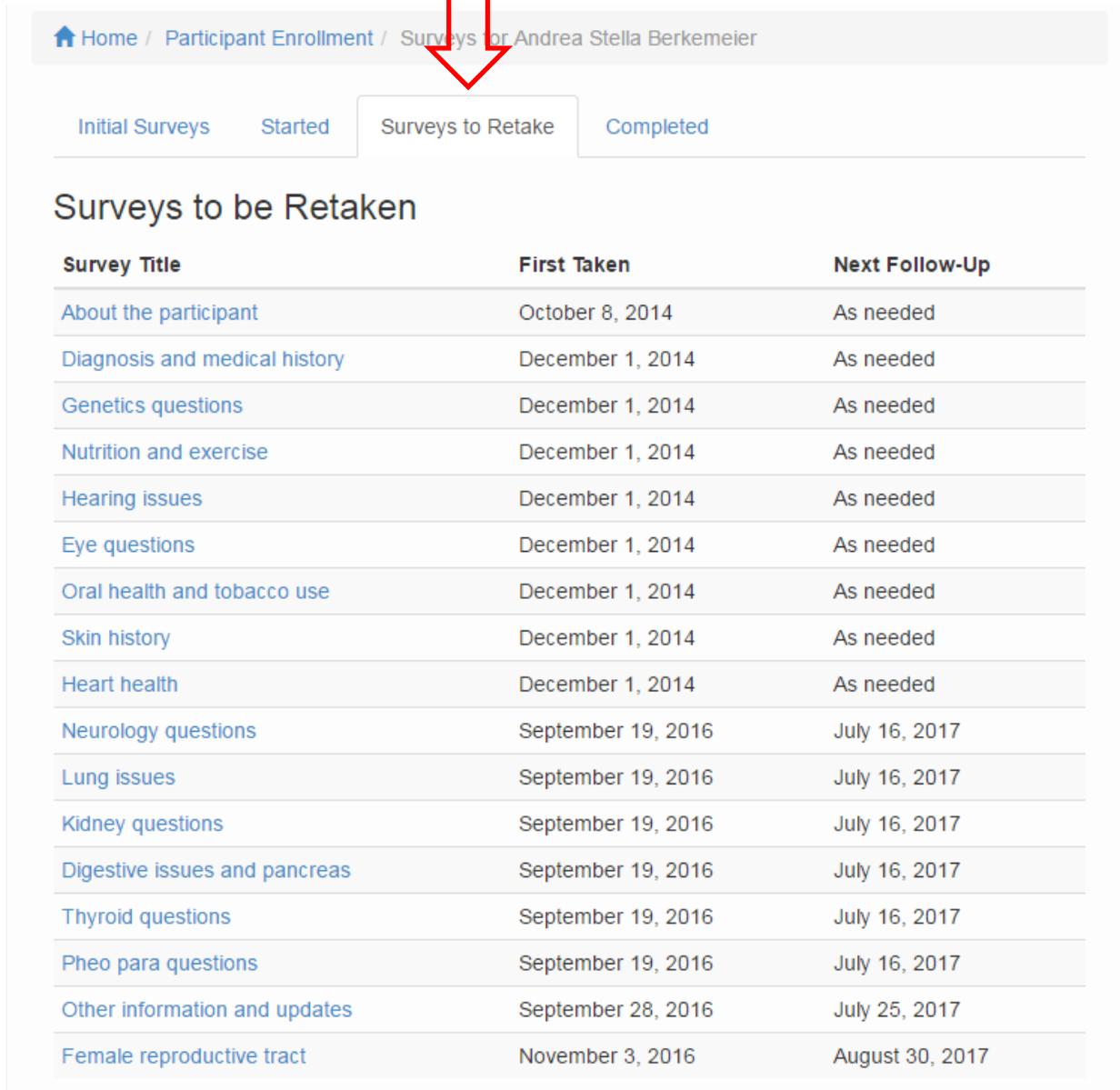
When you are finished with the survey, submit it by scrolling to the bottom of the page and selecting **Submit as final response**.



If you are only part-way finished with the survey, you can click **Save as Draft** and return later to finish the survey. The surveys that you save as a draft will be listed under the Started tab.



Use the **Surveys to Retake** tab to retake surveys.



Home / Participant Enrollment / Surveys for Andrea Stella Berkemeier

Initial Surveys Started **Surveys to Retake** Completed

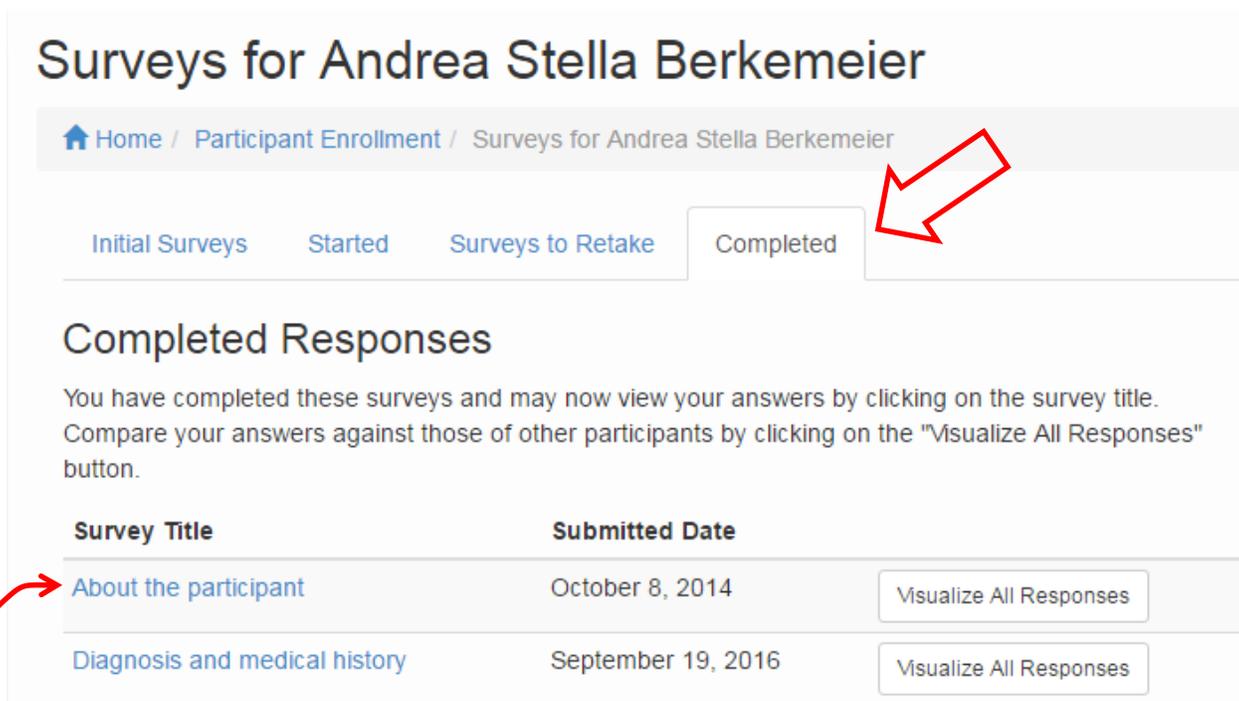
Surveys to be Retaken

Survey Title	First Taken	Next Follow-Up
About the participant	October 8, 2014	As needed
Diagnosis and medical history	December 1, 2014	As needed
Genetics questions	December 1, 2014	As needed
Nutrition and exercise	December 1, 2014	As needed
Hearing issues	December 1, 2014	As needed
Eye questions	December 1, 2014	As needed
Oral health and tobacco use	December 1, 2014	As needed
Skin history	December 1, 2014	As needed
Heart health	December 1, 2014	As needed
Neurology questions	September 19, 2016	July 16, 2017
Lung issues	September 19, 2016	July 16, 2017
Kidney questions	September 19, 2016	July 16, 2017
Digestive issues and pancreas	September 19, 2016	July 16, 2017
Thyroid questions	September 19, 2016	July 16, 2017
Pheo para questions	September 19, 2016	July 16, 2017
Other information and updates	September 28, 2016	July 25, 2017
Female reproductive tract	November 3, 2016	August 30, 2017

The third column tells you when you should retake the survey. If a survey says “as needed” you only need to retake the survey if your responses have changed. For example, in you recently had an eye surgery, retake the **Eye questions** survey.

Don't remember how you answered the last survey? (ie: Did I already report that I had an eye surgery?) Fear not.

Use the **Completed** tab to see the surveys you have submitted.



The screenshot shows a web interface for a participant named Andrea Stella Berkemeier. At the top, there is a breadcrumb trail: Home / Participant Enrollment / Surveys for Andrea Stella Berkemeier. Below this, there are four tabs: 'Initial Surveys', 'Started', 'Surveys to Retake', and 'Completed'. A red arrow points to the 'Completed' tab. Underneath the tabs, the section is titled 'Completed Responses'. A text block explains that users can view their answers by clicking on the survey title and compare them with other participants by clicking on the 'Visualize All Responses' button. Below this is a table with two columns: 'Survey Title' and 'Submitted Date'. The table lists two surveys: 'About the participant' (submitted October 8, 2014) and 'Diagnosis and medical history' (submitted September 19, 2016). Each row has a 'Visualize All Responses' button. A red arrow points to the 'About the participant' survey title.

Surveys for Andrea Stella Berkemeier

Home / Participant Enrollment / Surveys for Andrea Stella Berkemeier

Initial Surveys Started Surveys to Retake **Completed**

Completed Responses

You have completed these surveys and may now view your answers by clicking on the survey title. Compare your answers against those of other participants by clicking on the "Visualize All Responses" button.

Survey Title	Submitted Date	
About the participant	October 8, 2014	Visualize All Responses
Diagnosis and medical history	September 19, 2016	Visualize All Responses

If you click the title of the survey, you can see how you responded when you submitted your survey.

(For example, this is what it looks like when I click **About the participant.**)

About the participant

[Home](#) / [Surveys for Andrea Stella Berkemeier](#) / [About the participant](#)

Taken by Andrea Stella Berkemeier

Last update: Oct 8, 2014

Participant's Last Name or Family Name as it appears on the birth certificate (maiden name for women)

Berkemeier

Has the Participant died?

No

What is the Participant's sex?

Female

If nothing has changed on a particular survey since the last time you completed it, you don't need to retake it. 😊

If things *have* changed, use the **Surveys to Retake** tab to retake the survey.

When you are finished, click **Log Off**.

CGIP Databank Home About News Contact Participant Enrollment Andrea Stella Berkemeier

Surveys for Andrea Stella Berkemeier

[Home](#) / [Participant Enrollment](#) / [Surveys for Andrea Stella Berkemeier](#)

Initial Surveys Started Surveys to Retake Completed

- Edit Profile
- Change Password
- Change Username/E-mail
- Log Off

If you experience any difficulties with the databank, please contact:

databank@vhl.org or 617.277.5667