Ciitizen Onboarding Patient Guide

Welcome to Ciitizen!

Our mission is to empower seven billion citizens across the planet with all of their health data. When you control your data, you have more options. For your care and to advance research to find cures.

This guide will walk you step-by-step through the short onboarding process.
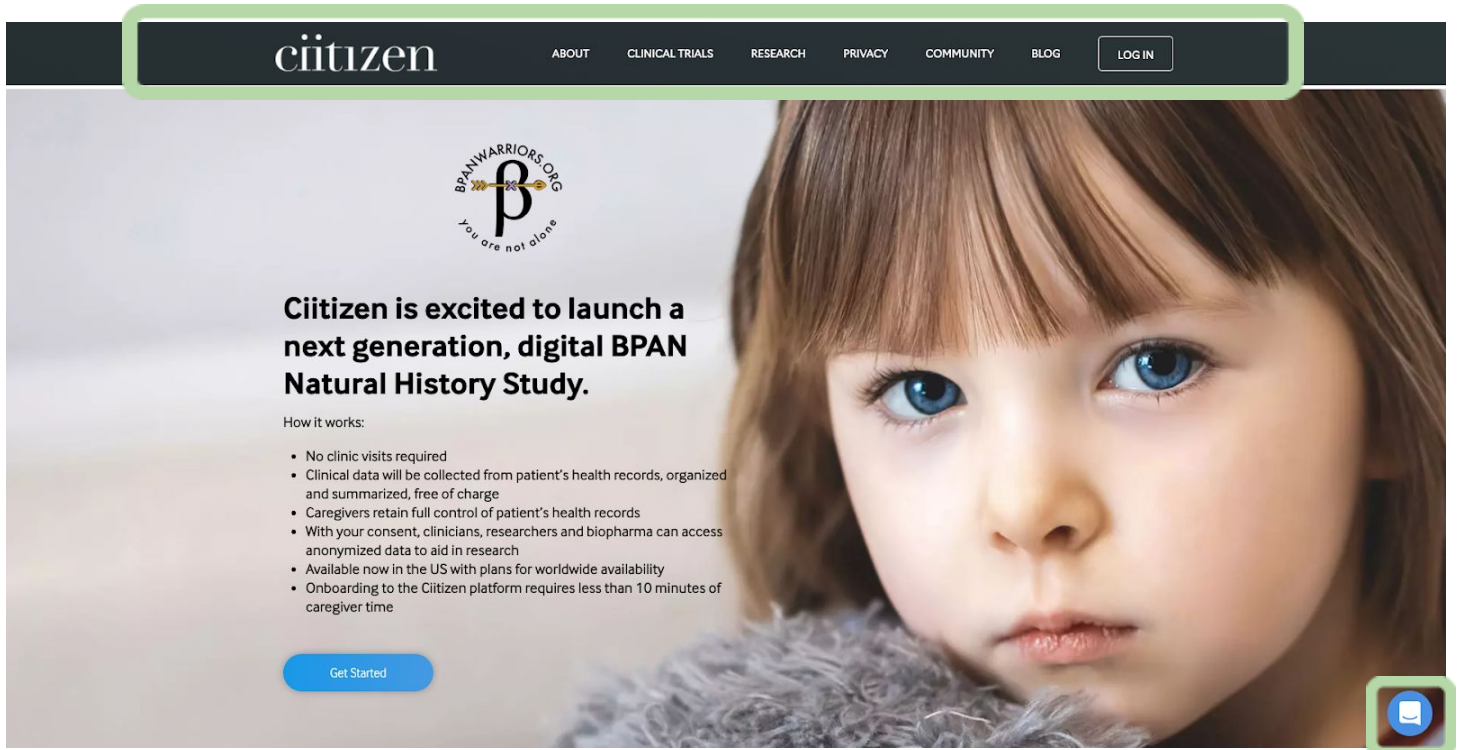

TIPS

Before getting started, please have the following ready:

- Your Driver's License
- if on behalf of a minor, their Birth Certificate
- if your loved one is over 18, their healthcare proxy

We recommend taking a picture of the documents with your phone and emailing them to yourself so that you can quickly upload them from your computer.

Step 1: Go to Ciitizen's BPAN page

Here is the direct link to the page: BPAN - Ciitizen

TIPS

Need help through the process? Click on the chat button.

Want to read more about Ciitizen? Check out the navigation bar up top!

Step 2: Click 'Get Started'

Step 3: Review the questionnaire

To join the Ciitizen platform, you MUST meet the following criteria:

- Patient has received care in at least one US institution. Note, we are only supporting patients within the US currently.

- Patient has a genetically confirmed BPAN alteration.

- Caregiver speaks English.

Do you and the patient meet these criteria?

○ Yes
○ No

Next >

Step 4: Complete the Consent form.

Consent #1: BPAN Warriors & Ciitizen Collaborative Research Databank

BPAN Warriors is an advocacy group dedicated to promoting research and education for the diagnosis, treatment and cure of Beta-propeller protein-associated neurodegeneration (BPAN) and to provide support to affected individuals and families.

BPAN Warriors has engaged with Ciitizen to collaborate in creating a databank of clinical and survey data on a cohort of children and adults living with BPAN, to be utilized for future research needs in collaboration with academic and pharmaceutical researchers (the "Databank").

Ciitizen is a novel, patient-mediated online platform which allows patients to collect and store their medical records. Ciitizen turns these medical records into structured, longitudinal data that can be shared by patients (or their parents or legal

- ○ (for adult) I consent to participating in the Ciitizen-BPAN Databank
- ○ (for parent/guardian) I am the parent or guardian of a child and give consent to the child participating in the Ciitizen-BPAN Databank
- ○ I do not consent

‹ **Previous**   **Next** ›

When consenting as a parent or guardian, you will be prompted to answer a few questions.

○ (for adult) I consent to participating in the Ciitizen-BPAN Databank

◉ (for parent/guardian) I am the parent or guardian of a child and give consent to the child participating in the Ciitizen-BPAN Databank

○ I do not consent

Child's First Name *

Child's Last Name *

First Name of Consenting Parent/Guardian *

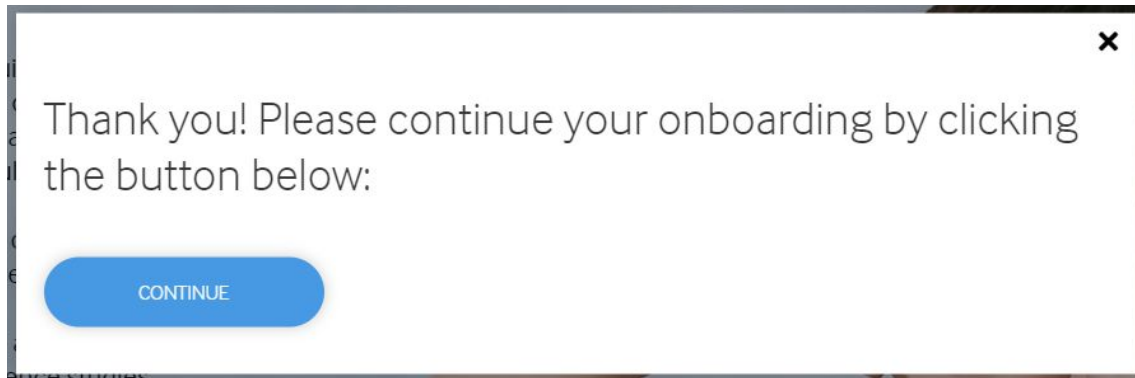**Last Name of Consenting Parent/Guardian** *

If available, name of other parent/guardian

Email *

‹ **Previous**   **Next** ›

TIP

Please be sure to note the email address you used! This will be the same email used across the platform.
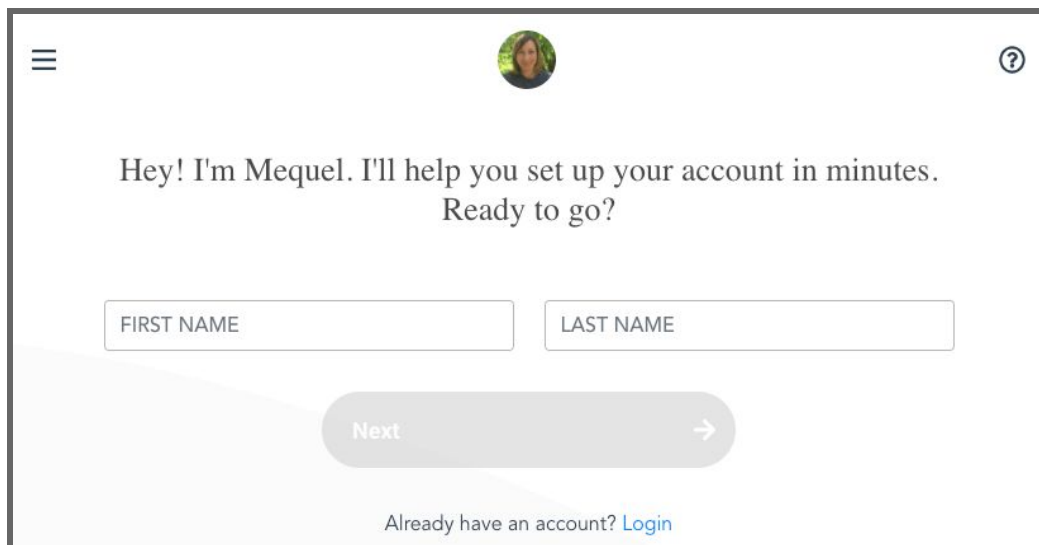
From here, you will be redirected to the Ciitizen Onboarding platform.

Let's Keep Going!

Step 5: Create your Ciitizen account

TIPS

- For more information or to log-out, click on the bars in the upper left.
- Have questions, click on the ? in the upper right to connect to the Chat feature.

Great to meet you test! Let's create your account

danielle+5@ciitizen.com

••••••••••

✅ At least 8 characters
✅ One uppercase character
✅ One lowercase character
✅ One number

By creating an account, you agree to Ciitizen's
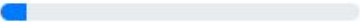Terms of Service and Privacy Policy.

Create Account →

Already have an account? Login

TIP

Remember to use the same email address from the consent!
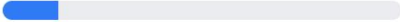
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Step 6: Let us know if this is for yourself or your loved one.

We will now ask you a series of questions related to your or your loved one's diagnosis

Find your (or your loved one's) Diagnosis in the drop-down.

Select the facility where you (or your loved one) were diagnosed

Where were you diagnosed with BPAN?

SEARCH FOR LOCATION

Search by physician instead

Next →

Where were you diagnosed with BPAN?

Red Hospital ✕

Red Hospital
349 Blue Oak Lane, Los Altos, CA
94022

Next →

If you received specialty care for your diagnosis at other facilities and would like for us to search for records from them, let us know!

Is there another location where test is receiving specialty care?

○ Yes

● No

Next →

Would you like us to search for records from other healthcare institutions where you have received care?

● Yes (Recommended)

○ No

Next →

Would you like to join our community of patients committed to fighting disease together?

A de-identified summary of your health data will be shared with Ciitizen's research partners.

1. Only your summary data is shared with research partners (like academic researchers, advocacy groups, and pharmaceutical companies); includes only select data with common identifiers like your name, address, and phone number removed.
2. You could help others by advancing scientific discovery even if you may not personally benefit from this research.
3. You will not get advance notice of specific research projects that include your data.
4. Your information will be made available to researchers until you tell us to stop. We may not be able to recover summary data that has already been shared with research partners.

You may withdraw your consent at anytime. For more information see the Ciitizen Research Initiative Consent .

◉ Yes

◯ No

◯ Ask me later

Next →

Now is the time to ensure that your documents are ready to be uploaded (Driver's License & Birth Certificate for minors).

TIP

Tip: By using a driver's license with a current address, this information will automatically populate. All you will have to do later is verify accuracy!

I need to get a clear picture of your photo ID.

Next →

Please make sure the photo of your ID is clear!

How's it look? The ID should be clear and legible.

Looks good →

Re-take photo

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Are there any prior names your records may be found under?

○ Yes

○ No

Next →

If a minor, a picture of the Birth Certificate will be required.

COUNTY OF LOS ANGELES

sample

Which number should we use to contact you with questions about this records request?

📞 456-123-4568

Next →

Almost Done!

Verify I have your information correct here:

PATIENT NAME
test test

PATIENT DATE OF BIRTH

PATIENT ADDRESS

PATIENT PHONE NUMBER
456-123-4568

DIAGNOSING PROVIDER
Red Hospital

Make Changes ✏️

Looks good →

Now just sign below to authorize Ciitizen to collect health records on your behalf.

Your signature should match your ID signature as much as possible

Clear Signature

Authorize →

One last check to make sure we have everything we need...

Patient info verified ✓

Facility Verified ✓

Records collection authorized ✓

Next →

Enter your mobile number if you'd like to receive live updates about your health records.

(optional)

📞 MOBILE NUMBER

☐ I agree to receive SMS, text, and voice messages sent by Ciitizen via automated technology. Message and data rates may apply. Message frequency varies. For more information, visit our Privacy Policy.

Next →

Well done! Your records have been requested.

Providers have up to 30 days to get records to us but we'll notify you as soon as the records have been received and are available for viewing.

Next →

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If you have your genomics report handy, please upload them here!

Do you have any medical records that you'd like to upload?

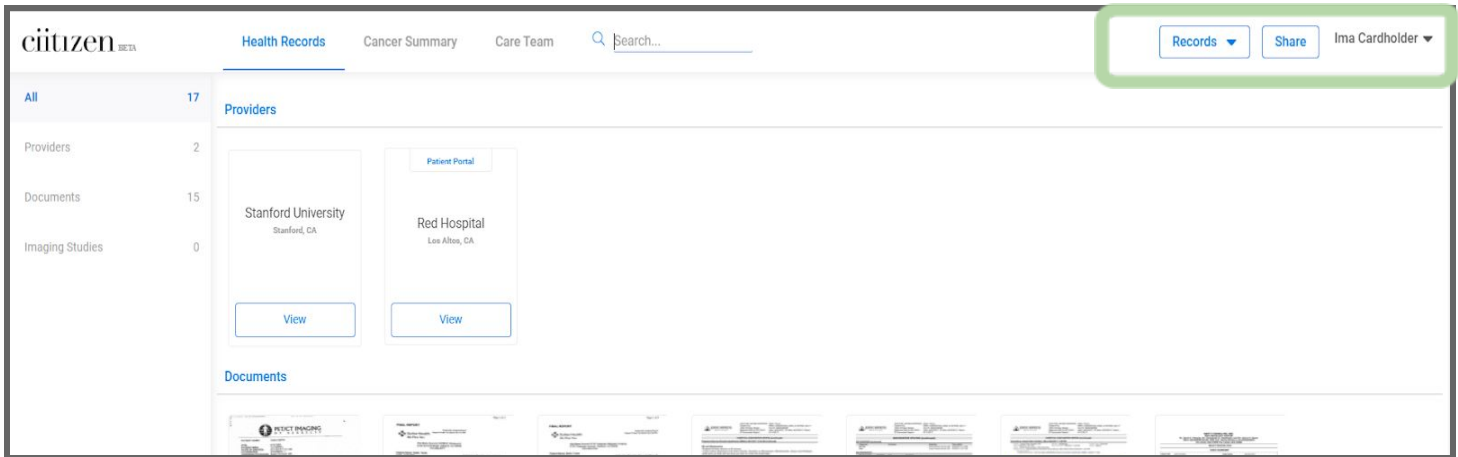This can include imaging, visit summaries, pathology and genomics reports.

( ) Yes

( ) No

Next →

Congrats, you have completed your Ciitizen set-up !

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Welcome to your Patient Portal!

Bookmark this website for future use: https://app.ciitizen.com/

Navigating through your Ciitizen portal

Records

1. This is where you can request records from providers.
2. This is also where you can upload your records.

Share

1. Share your records with who you would like!

Drop Down Menu by your name

1. My info
   a. Verification documents, Patient Info, and Consents
2. Invite a Friend
3. Sign Out

The Chat button is back!

As your records come in and are processed, the patient portal will populate with your documents!

Welcome, and we are glad you are here!