

# Welcome to Eden!

Everything you need to know as you are getting started with our digital platform.



The **Epilepsy Digital Experience Navigator (EDEN)** is a platform designed specifically to help people with epilepsy and their caregivers track, manage and share their data with the epilepsy community.

In partnership with Embleema, the Epilepsy Foundation is bringing a solution for managing epilepsy in a user-friendly manner while sharing insights for research.

## Getting Started

### **What is a beta tester, and will I automatically become a beta tester when I sign up for EDEN?**

Beta testing is an opportunity for you to become an early adopter of EDEN and help us making sure it is easy to use and has features that are helpful for the epilepsy community before EDEN is publicly released later in 2022. Signing up for EDEN right now will make you an EDEN user and beta tester.

### **I created a login in Embleema to access EDEN and am not sure what I should do next?**

You need to verify your email address by clicking on a link that was sent to the email address you provided while registering on Embleema. Make sure to check your spam/junk folder for an email from Embleema with Subject: Confirm your email address.

### **Can I still use EDEN and view my information if I do not have an iPhone or Android device?**

Yes, you can use and view your information in EDEN in three different ways:

- On your desktop computer using a web browser at [app.embleema.com](http://app.embleema.com) and by
- Downloading the Embleema app through:
  - Apple Store
  - Android Google Play

## General

### **Who is Embleema?**

Embleema is a healthcare technology company based in New York. The Epilepsy Foundation has teamed with Embleema to provide a platform that organizes a patient's fragmented health information in a single place, enables them to securely share their de-identified data with caregivers and researchers, and receive personalized insights allowing them to better manage their condition. Embleema's platform is currently used by the Food and Drug Administration and the National Institutes of Health for their management of COVID-19 genomic data, 4 out of the top 10 health networks in the U.S. and many others in academia, life sciences and patient advocacy groups to build a healthier world for patients.

### **What if I have questions, concerns, or complaints about the Embleema app?**

You can contact Embleema at [eden@embleema.com](mailto:eden@embleema.com). Embleema is available between the hours of 8:00 AM and 7:00 PM EST, Monday to Friday.

### **What if I want to leave EDEN?**

You can leave EDEN at any time.

If you withdraw from EDEN, already collected data will be de-identified but not removed from the study database, unless you request us to erase your data in our systems by sending us an email at [eden@embleema.com](mailto:eden@embleema.com) or within the Embleema app.

**Learn more.**  
[epilepsy.com/eden](http://epilepsy.com/eden)



## Surveys

### What surveys should I take when I first start using EDEN?

You should take (4) surveys when you first sign up for EDEN. You will see the surveys at the top of your dashboard. The surveys include:

- Part 1: Let's Get To Know Each Other
- Part 2: My Epilepsy
- Mental Health
- Quality of Life in Epilepsy

### How will I know when I am ready to take another survey in EDEN?

Making sure you are active within EDEN will ensure you know when the next survey will be ready. On your dashboards, the surveys will pop up and alert you that it is now time to complete the survey.

### I am having trouble filling out the surveys and need help? What should I do?

Email Shel at [slessington@efa.org](mailto:slessington@efa.org) to set up a call and Shel will walk you through the questions and complete the survey with you.

### I want to check my mood again or my medication side effects, but I don't see the survey.

At this time, the mood and quality of life surveys will only appear every 3 months, and the side effect survey will appear monthly. In the future, the surveys will be available more frequently.

## Using S-check

### What if I have been seizure free for 3 months or more and do not want to track my seizures every day?

Tracking your seizures when you have them is great insight and information for you regardless of how often you have seizures. With EDEN, you will be able to select how often you would like to receive notifications to track your seizures. You can select to receive notifications: Daily, Weekly, Monthly or Quarterly (every 3 months).

### Can I track seizures even if I do not know the exact date they happened?

When you are asked the date, you can select a span of time for all your seizures from selecting a start and end date. You can also add a picture here.

### If I missed one of my seizure checks, can I go back and still report from the last time I checked in?

When you enter S-Check, it will remind you when you last checked in, even if you missed your check-in. You can add any seizures that happened since that date.

### I made a mistake tracking one of my seizures. Can I take it out of my data?

Not at this time but will be able to in the future.

### What if I want to track a seizure on the day it happens, instead of waiting for my check-in so I don't forget it?

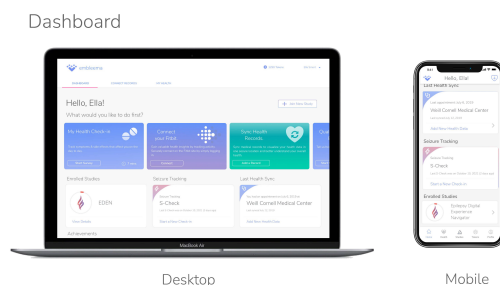
You can always go into EDEN and check-in at any time. When you check-in, you will see when you last checked-in as well, and can add any other seizures you have not yet tracked.

## Sync Health Records

### What if I don't see my doctor or provider in the 'Finder My Search'?

Please email [eden@emblem.com](mailto:eden@emblem.com) to let us know the name of your health center.

You can either download the Continuity of Care Documents from your healthcare provider online's patient portal or request it from your doctor's office. You can then upload it to EDEN.



Learn more.  
[epilepsy.com/eden](http://epilepsy.com/eden)



## **What is Continuity of Care Documents and is this what I should ask for from my doctor's office?**

Yes, the documents you need are called Continuity of Care Documents. These are files that store your clinical information in electronic form and are comprehensive ways that doctors and care facilities capture a patient's medical history, current condition, office, emergency room and hospital visits. It is the most common way to share patient medical information from one health center to another and you are entitled to receive your Continuity of Care Documents from your medical provider.

## **Viewing Health Data**

### **Will my labs upload automatically when I open the app?**

No, you will only be able to see your recent health information when you re-connect your health records. To do this, click "Add new health data" on the block on the main page that has the name of your hospital or clinic, and go through the sign-in for your electronic health record.

### **Can I add health records for more than one health care provider?**

Yes, you can add data from all the health providers you have visited. Just click "Add new health data" and search for the provider where you received care.

### **Where is my health data on the app?**

You can view health data under the tab "My Health".

### **How do I track my lab results?**

You can choose labs that get frequently (for example a liver test, a medication level) to track. When you do this, you will see the level and whether it has increased or decreased since it was last checked.

## **Connecting Fitbit**

### **What information does EDEN get from connecting my Fitbit?**

You will be able to view your activity and sleep in EDEN every day that you wear your Fitbit.

### **Can I still participate in EDEN if I do not have a Fitbit?**

Yes! Not having a Fitbit does not mean you cannot participate in EDEN. There are many other things you can track. If you are interested in purchasing a Fitbit, there are many discounts and sales on select products.

## **Data Privacy**

### **Can I get a copy of the consent I signed for my own records?**

Yes, you can click 'Send me the signed consent by email' to the bottom right of the screen before you finish signing the consent. An email will be sent to you with the Subject: 'Study Consent'.

### **Who controls my data?**

You are in control of your data. Embleema has a system that better protects your data privacy and lets you decide with whom you share your data with. You will always be able to see who has accessed your data and can update your permissions at any time.

### **Who can access my data, and will it be visible to anyone?**

Your name, email address or other personal details are removed before any of your data is shared for research purposes.

## **Dashboard**

### **What are the tokens for?**

You collect tokens when you complete an activity on the platform. The more tokens you have the more "active" an user, you are. In the future, we intend to allow users to exchange their tokens for prizes or merchandise. Stay tuned!

### **I see a tab that says "Join a new study" - Is there another study I can join?**

No, there is no other study you can join at this moment, but there will be in the future.