

FAQ: CURE ID Treatment of Long COVID (TLC) Patient Survey

CURE ID for Long COVID Basics:

Q: What is the goal of this project?

A: Our goal at FDA / NIH (NCATS) / CDRC is to collect data on treatments you are trying for your Long COVID symptoms and whether you feel any of these treatments have improved your symptoms, have had no impact, or have made your symptoms worse. We hope that researchers will use this information to help choose treatments to study in large randomized controlled trials (RCTs), given that there are no FDA-approved treatments for Long COVID.

Q: What are we asking Long COVID patients (you) to do?

A: Share your treatment experiences by completing the CURE ID Treatment of Long COVID (TLC) research survey. We estimate it will take you 20-45 minutes to complete, but you can save and come back to it at any time. You can add as much or as little detail as you would like, and you only need to submit your case one time.

Q: How do I participate?

A: You will complete the CURE ID TLC survey by going to the CURE ID website ([CURE-ID \(ncats.io\)](https://cure-id.ncats.io)) or downloading the CURE ID mobile app from the Apple App store or the Google Play store. Once you register, you will be asked to share your treatment experience by completing a case report, after providing your informed consent.

CURE ID and CDRC Basics:

Q: What is CURE ID?

A: CURE ID is an internet-based repository (a treatment registry) that lets the clinical and patient communities report use of drugs for difficult-to-treat diseases through a website, a smartphone or other mobile device. The platform enables the crowdsourcing of medical information from health care providers, patients, and care partners to identify existing drugs that may be effective treatments for diseases that lack incentives for the development of new therapies. CURE ID was developed through the collaboration of the FDA and the National Center for Advancing Translational Sciences (NCATS), part of the National Institutes of Health (NIH). FDA and NIH are also collaborating with the World Health Organization and the Infectious Diseases Society of America to assess the global utility of CURE ID. CURE ID has received generous support from FDA, as well as the HHS Office of the Secretary's Patient-Centered Outcomes Research Trust Fund. With support from FDA's Oncology Center of Excellence (OCE), CURE ID is expanding beyond infectious diseases, to capture cases of drug repurposing for rare cancers, and other rare diseases.

Q: What is the CURE Drug Repurposing Collaboratory ([CDRC](#))?

A: CDRC is a public-private partnership led by the Critical Path Institute ([C-Path](#)), a non-profit 501(c)3 organization dedicated to catalyzing the development of new approaches to advance medical innovation and regulatory science. Initiated in June 2020 by C-Path and the U.S. Food and Drug Administration ([FDA](#)), in partnership with the National Center for Advancing Translational Sciences ([NCATS](#)), part of the National Institutes of Health (NIH), CDRC is designed to capture real-world clinical outcome data to advance drug repurposing and inform future clinical trials for diseases of high unmet medical need.

Q: What partners are engaged in CURE ID's Long COVID efforts?

A: FDA and NCATS/NIH host the CURE ID platform which will be used to gather cases of Long COVID treatment with repurposed drugs. CDRC is engaging with FDA, NIH, clinicians, patients, and other interested stakeholders to conduct outreach to patients with Long COVID, to analyze data contributed, and to help determine how best to ensure that promising treatments are studied in large randomized controlled trials.

Partners and Collaborators include:

- [Patient Led Research Collaborative](#)
 - [Dysautonomia International](#)
 - [#MEACTION](#)
 - [SOLVE M.E.](#)
 - [Discovery, The Critical Care Research Network, part of the Society for Critical Care Medicine](#)
 - [Stanford University School of Medicine's Long COVID Clinic](#)
 - [Emory University School of Medicine/Grady Long COVID Clinic](#)
 - [U.S. FDA](#)
 - [NCATS/NIH](#)
 - [CDRC](#)
 - [CDC Public Health Informatics Fellowship](#)
-

Data Sharing and Use:

Q: How will my data be used?

A: Anyone who goes to the CURE ID website will be able to view data from all patients' responses combined, as well as your individual case report including all of the details you entered (however, they will not be able to see that you were the person who entered the case, it is fully de-identified). Anyone can access this data via the Explore feature on CURE ID, by searching for Long COVID as a disease and selecting case reports. You will also be able to filter the data to see cases of particular interest.

Q: Will people know the case I published is mine (i.e., am I identified as the author of the case)?

A: No, all patient case reports are fully de-identified, in accordance with the [Privacy Act](#), so your name will not be shown as the author of your case. A limited number of CURE ID staff at NCATS/NIH will be able to see your name, but this information will not be shared publicly. If you prefer not to have even the CURE ID staff know, you could choose not to include your name in the registration process, only an email is required.

Q: What information about me will be shared publicly, even if my case is de-identified (i.e., my name is not shown as the author)?

A: All information that you share on CURE ID in the form of a case report or discussion post is made openly accessible. This means all other users will be able to view your case reports and discussion posts. This is because the goal of the community is to promote open data-sharing.

However, to protect patient privacy, we do not publicly show your name or other identifiable information (as defined by the [Privacy Act](#)) with any cases you submit.

Q: What will my case look like to others? Where do people see this information?

A: In the Explore Feature, this is what other users would see when looking at all cases.

☐ Other

Race

☐ American Indian or Alaskan Native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander

☐ White

☐ Unknown

Ethnicity

☐ Hispanic/Latino

☐ Not Hispanic/Latino

☐ Unknown

Patient-Submitted Report

Last updated on October 4, 2023

Patient 51-60 years | Female

Symptom(s) Muscle weakness, Fatigue, Loss of smell, Loss of taste, + 1 more

Drug(s) Hydroxyurea, Rivastigmine

[Leave your comments](#)

Patient-Submitted Report

Last updated on September 30, 2023

Patient 61-70 years | Male

Symptom(s) Post-Exertional Malaise (PEM), Fatigue, Nausea, Vertigo, Dizziness, + 5 more

Drug(s) Alpha-GPC, Amitriptyline, Boswellia, Budesonide, Low Dose Naltrexone (LDN), + 6 more

[Leave your comments](#)

Here is what it looks like for the actual full case report.


Case # a86971cf-94da-45cc-9095-d3736e91e9



Submitted by Heather Stone | Patient

Nov 28 2023

Disease	Long COVID
Drug(s)	Abacavir Abarelix Abatacept Abecma

 *This drug is approved by the FDA for this disease/indication.

^ Collapse All

Case Characteristics
<p>Age Group: 31-40 years</p> <p>Sex assigned at birth: Female</p> <p>Gender same as sex: No</p> <p>Gender: Unknown</p> <p>Country Treated: Afghanistan</p>
Other Conditions
<p>Underlying Conditions prior to COVID-19 infection: Autoimmune disorder (Sjogren's, Lupus, Celiac, Raynaud's, etc.), Migraine, Polycystic Ovarian Syndrome</p>

Q: Where will my data be stored?

A: Data submitted to CURE ID is stored on an Amazon Web Service (AWS) server, hosted by NCATS/NIH. The information that is contributed as part of the CURE ID TLC survey is then made publicly viewable (except names and email addresses, which are only visible to a limited number of NCATS/NIH staff).

Q: Who owns the data?

A: You remain the owner of your data and have the right to remove it from the CURE ID platform at any time. However, if you choose to submit your case to CURE ID, the platform has the right to make the data in that case report publicly accessible.

Q: Is my privacy/identity safe if I enter a case?

A: Yes! Your name and email address will not be shared publicly, and all other data entered as part of your case report will be de-identified to comply with the [Privacy Act](#). CURE ID staff at NCATS/NIH will be able to see that you are the author of the case, but your name will not be publicly visible to general users of CURE ID. You can be contacted through the site if other users comment on your case. In this situation, you will receive an email and/or push notification that a comment has been made on your case and if you respond, you will be shown as “Author of Report”, but your name will not be visible.

Q: How can I see the information you collect about me?

A: You can always visit CURE ID's website to view the cases you have submitted. If you go to the "Account" section on the top right of the platform and select "Activities" from the left menu bar, you can see any cases, discussions, etc. that you have saved or submitted. You can edit or delete your entries from this "Account" page, too.

The other information CURE ID collects are the details that you provide when registering. You are required to register with an email and password, and have the option to include your name, the type of participant you are (e.g., patient, medical doctor), and any institutional affiliation or particular specialty areas of interest. This information can also be edited at any time by visiting your profile, under your Account. You can also add favorite diseases or drugs to your profile to receive updates on those topics.

The screenshot displays the CURE ID website interface. At the top, the navigation bar includes links for Home, Explore, Create, Newsfeed, and About, along with a search icon, a notification bell, and an 'Account' link which is highlighted with a red box. Below the navigation bar, the left sidebar contains a list of options: Profile (highlighted with a red box), Interests, Activities (highlighted with a red box), Bookmarks, Notifications, Settings, Get Help, and About. The main content area, titled 'Activities', shows a list of case reports. The first entry is a submitted case report titled 'Long COVID is treated by Abacavir-Dolutegravir-Lamivudine, Abciximab, Abetimus, Clofazimine, Famotidine.' It includes details such as the Case ID, Disease (Long COVID), Patient (6-10 years | Female), and Drug(s) (Abacavir-Dolutegravir-Lamivudine, Abciximab, Abetimus, Clofazimine, Famotidine).

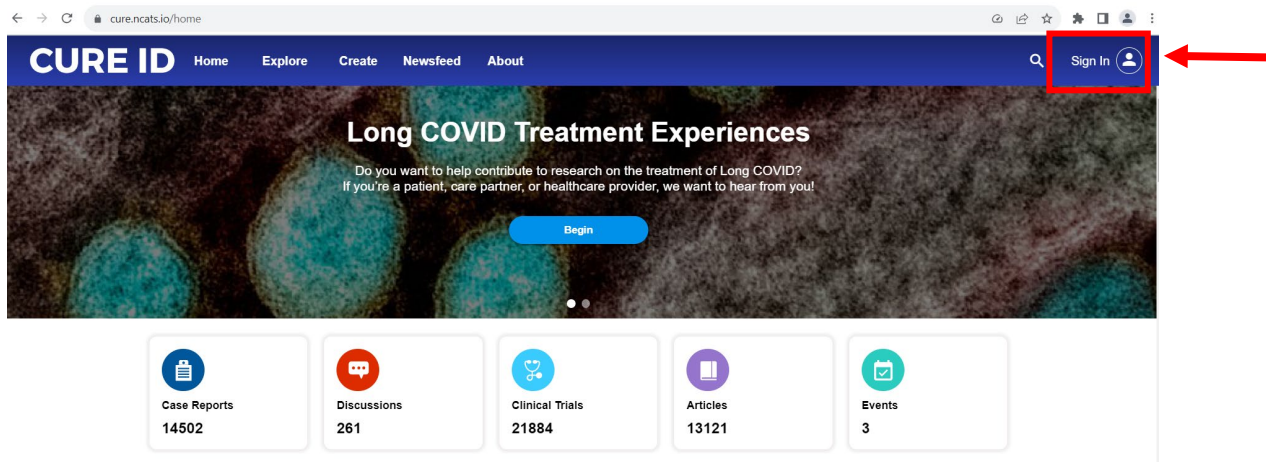
Q: Will my name be shown anywhere else on the website/app?

A: If you submit a discussion post and choose not to anonymize that post or if you comment on another user's case or discussion and choose not to anonymize your comment, then your name will be visible to other users.

Navigating the Website and Mobile App/Where do I find....:

Q: How do I register on CURE ID?

A: To register on CURE ID (which you need to do to submit a case or discussion), click “Sign in” in the top right corner of the homepage or click “Account” on the bottom right corner of the app.

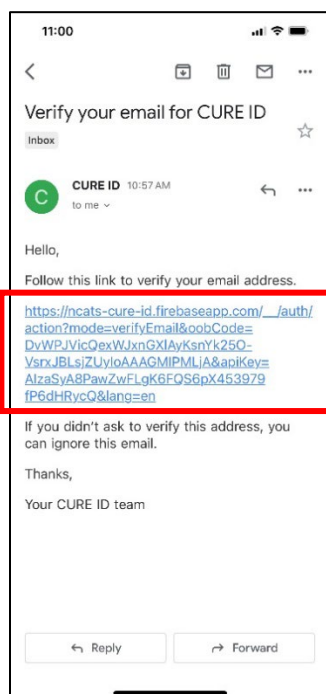


If you have an account already, you can sign in here, or if you have not yet registered, click “Create One” at the bottom of the page. You can also choose to sign up using a social sign-on, like Facebook or Google. If you choose to sign-in via a social sign-in, your name will still not be shown publicly if you enter a case. Only NIH staff will be able to see these details.

To create your account, enter an email and password and select the checkboxes agreeing to the terms and conditions, then click “Sign up”.

★ Note: Your password needs to be at least 8 characters long and should include an upper-case letter, lower-case letter, and a number.

You will then be directed to go to your email account and to click a link to verify your email.







Click on the link in the email to verify your account.

You will then reach a screen that notes that your email has been verified.

You can now return to the CURE ID website to log-in.

Sign In

Sign in with your social network

Email sign in

Forgot password? [Reset](#)

Don't have an account?
[CREATE ONE](#)

By continuing, you are indicating that you accept our [Terms & Conditions](#) and [Privacy Policy](#).



Once you login with the email and password you just created, you will be given the option to add additional information to your profile. This information is entirely optional, and you can skip this page if you don't want to share these details. You can always add them later by editing your profile. Even if you share your name in the registration process, this information will not be shared with your case report. CURE ID staff at NCATS/NIH will be able to see your name and email, but no one else will with your case. If you choose to submit a discussion post, you are given the option of whether you want your name to be shown as the author of the post or not.

11:12 Signal icons

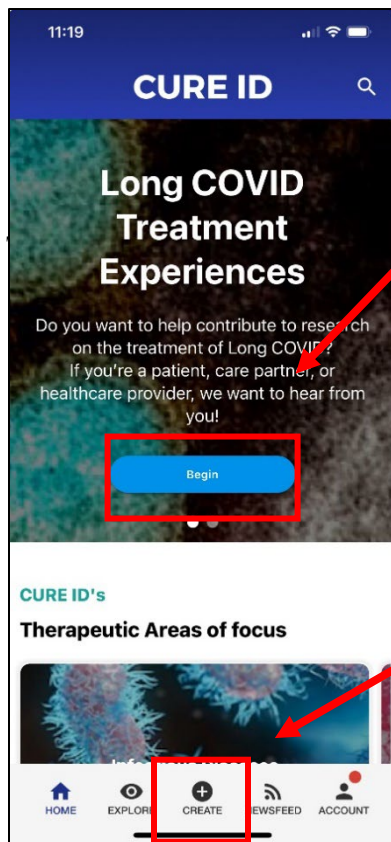
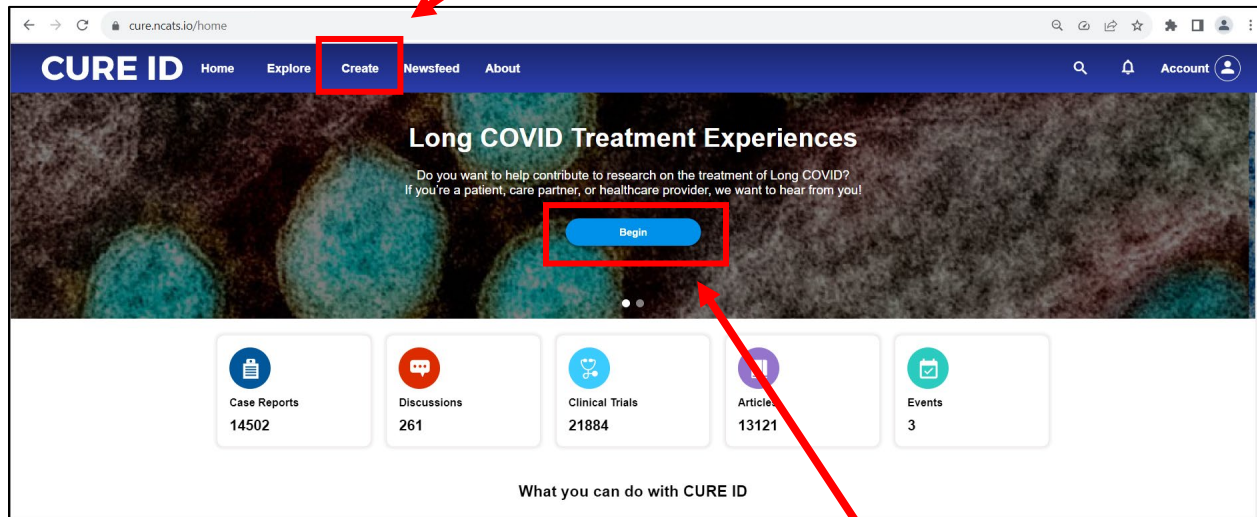
[Skip](#)

Tell us about yourself or skip to continue without sharing

*You can always complete your profile on the "Account" section.

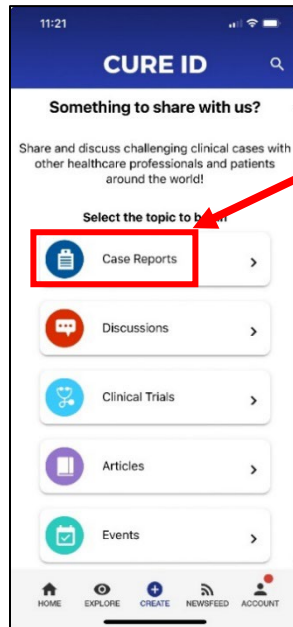
Q: How do I add a case report?

A: To add a case report, first click on “Create” from the top header of the website or the bottom menu of the app.



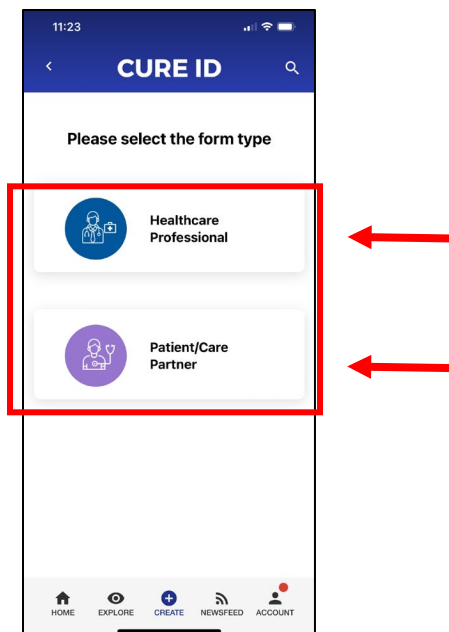
You can also add a case of Long COVID or MPOX through the banner on the homepage.

To enter a case for any disease, click on create from the menu.

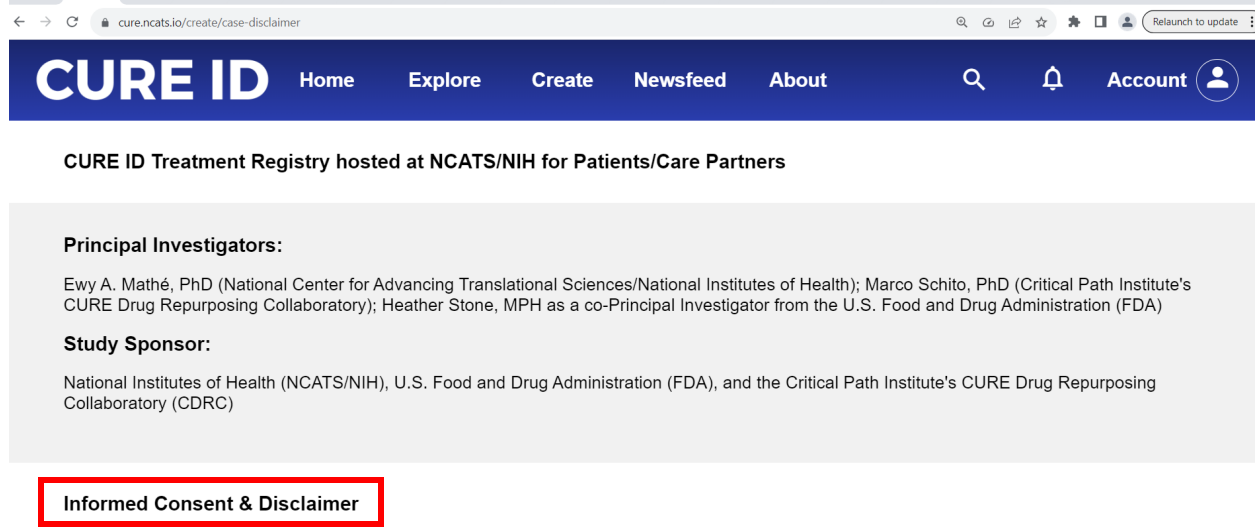


Select Case Reports from the menu to begin sharing your case.

You will then be asked which version of the case report you want to complete, the healthcare professional version (e.g., if you are a doctor submitting a case about a patient you treated), or the patient/care partner version (if you are submitting a case about yourself or a loved one).



You will then be presented with some screening questions and an informed consent document which you must agree to in order to continue.



The screenshot shows the CURE ID website interface. The header includes the CURE ID logo and navigation links: Home, Explore, Create, Newsfeed, About, a search icon, a bell icon, and an Account link with a user profile icon. Below the header, a banner states "CURE ID Treatment Registry hosted at NCATS/NIH for Patients/Care Partners". The main content area is titled "Principal Investigators:" and lists Ewy A. Mathé, PhD (National Center for Advancing Translational Sciences/National Institutes of Health), Marco Schito, PhD (Critical Path Institute's CURE Drug Repurposing Collaboratory), and Heather Stone, MPH (U.S. Food and Drug Administration). Below this, the "Study Sponsor:" section lists the National Institutes of Health (NCATS/NIH), U.S. Food and Drug Administration (FDA), and the Critical Path Institute's CURE Drug Repurposing Collaboratory (CDRC). A red rectangular box highlights the "Informed Consent & Disclaimer" section.

You are invited to take part in a research study. The purpose of the study is to learn whether healthcare providers, patients, or their care partners feel that drugs patients are taking have made their disease (or symptoms of their condition) better or worse. If you choose to participate, you will be asked to complete a survey asking about the disease/symptoms experienced, the medications that were taken, and the outcome of treatment (or whether you noticed any improvement or deterioration in symptoms that you think is due to one of the medications).

For many diseases (e.g., MPOX, Balamuthia), the case information in the survey can be completed in 5-20 minutes. However, for patients with diseases with more complex treatment histories (e.g., XDR-TB, Sarcoma) and for conditions like Long COVID with many potential symptoms and treatments to add, the form may be expected to take 20-45 minutes to complete. The form may be completed by either a healthcare provider, the person with the condition, or by a loved one or care partner on the patient's behalf. We believe there are minimal risks associated with this research study; however, a risk of breach of confidentiality always exists and we have taken steps to minimize this risk. While your name (optional) and email are collected, in addition to information about your demographics, symptoms, and treatments, this information will be secured and protected to comply with the Privacy Act of 1974, as amended (5 U.S.C. 552a).

While the research is of minimal risk, there are also no direct benefits to you for your participation in the survey. Your contributions may, however, help to inform future research on potential treatments for conditions with unmet medical need. Taking part in this research project is voluntary and there is no compensation for your participation. You do not have to participate, and you can stop at any time. If you have questions about this project or if you have a research-related problem, you may contact the researcher(s) at curesupport@mail.nih.gov.

By clicking ""I agree"" below you are indicating that you are at least 18 years old and have read this consent form and agree to participate in this research study. You are free to skip any question that you choose, except for the questions about the disease, treatment, and outcome. Please print a copy of this page for your records.

Case study posting criteria

CURE ID is an independently populated database for use by healthcare providers and public health officials to report information on disease case studies. Patients and care partners may now also share case reports describing their treatment experiences on the platform. However, case study submissions are expected to meet certain criteria and FDA and NIH maintain the right to remove submissions that do not meet the inclusion criteria listed below. FDA and NIH also reserve the right to remove cases which are flagged as highly suspect by users (e.g., such treatment was not used, case was made up, dangerous suggestion, etc.) or otherwise inappropriate or offensive.

Case Study Criteria:

- CURE ID is presently limited to cases regarding the treatment of patients with certain diseases (e.g., infectious diseases, cancer, Long COVID); cases of patients with other diseases will be excluded.
- CURE ID is limited to treatment of human disease; cases of drug administration to animals will be excluded.
- Cases must contain treatment with a drug.
- In order to be accepted, a case report must include information on at least the following categories:

- o Disease Name
- o Drug Name
- o Treatment Outcome (including outcome unknown/not yet determined)

Healthcare providers, patients, and others entering information in the case report form should be careful not to include any personally identifiable information about the patient, or PII. CURE ID moderators will review the case reports once submitted and may make minor modifications to the content to ensure patient privacy.

A treatment outcome that is Unknown or Not Yet Determined is acceptable and users are given such an option. Users will also be asked if they would like to receive a reminder in the future to update their case or add an outcome later. While the questions are worded in the past tense, this should not dissuade users from entering cases of ongoing treatment, or where an outcome has yet to be ascertained.

Please also note that clarifying questions may be asked of the author by administrators or other users. Cases where the disease listed is determined to be a synonym of a disease already supplied in the drop-down list will be mapped to the appropriate disease name.

☒ I agree to the terms and conditions and agree to participate in this research study.

CANCEL

AGREE

Now you are ready to submit your case! Enter the disease and the form will adjust to the correct form for that disease (e.g., a cancer form if you enter sarcoma, or a Long COVID form if you enter Long COVID).

CURE ID
Home
Explore
Create
Newsfeed
About

Disease
Challenge
Case Characteristics
Country
Other Conditions
Immunosuppressant Drug

Step 1 of 21

Disease

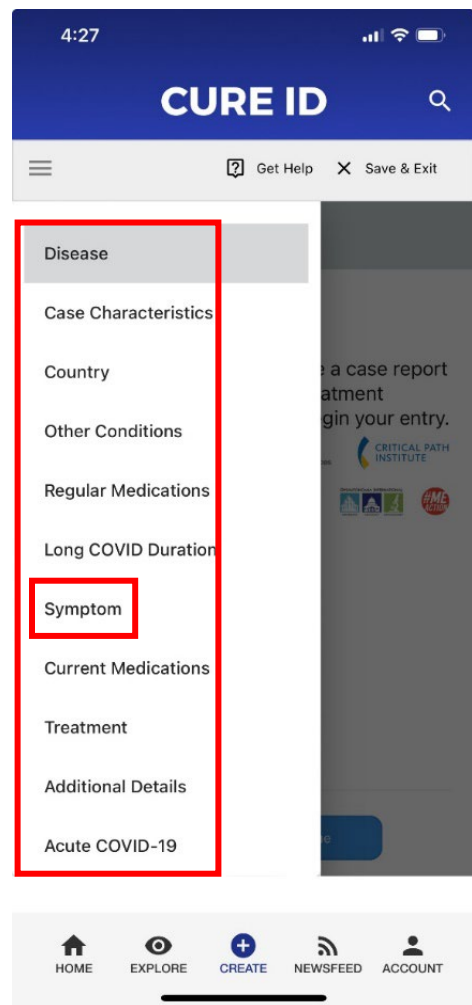
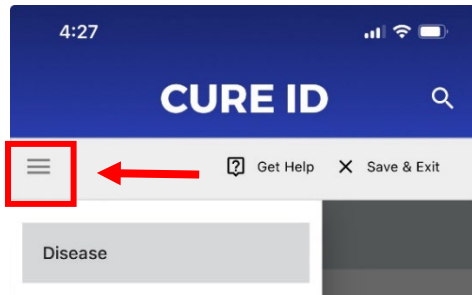
Thank you for choosing to create a case report of your treatment experience.

What is the disease that you are reporting that you received treatment for? *

Note: Users may add a term that is not currently in the list by typing the term and pressing enter.

Q: How do I navigate throughout the Case Report Form on the mobile app, without repeatedly clicking Continue?

A: On the mobile app, if you click the three horizontal lines in the top left corner of the screen, a menu will open up and you can select the section you wish to navigate to.



Select any of the sub-headings from the menu to navigate to that section of the case report form.

Q: Can I save my case part way through if I need a break?

A: Yes, absolutely! Just be sure to select the “Save and Exit” button on the top right of the screen in the case report form.

The screenshot shows the CURE ID case report form. The top navigation bar includes 'Home', 'Explore', 'Create', 'Newsfeed', and 'About'. On the right, there are links for 'Get Help' and 'Save & Exit', with the latter highlighted by a red box and a red arrow. The main content area is titled 'Disease' and includes a progress bar for 'Step 1 of 15'. Below the progress bar, there is a message: 'Thank you for choosing to create a case report of your patient's Long COVID treatment experience, press continue to begin your entry.' The form also features logos for the FDA, NIH, and Critical Path Institute, as well as other initiatives like Solve ME/CFS, Discovery, Patient-Led Research Collaborative, and #ME Action. At the bottom, there are 'Back' and 'Continue' buttons.

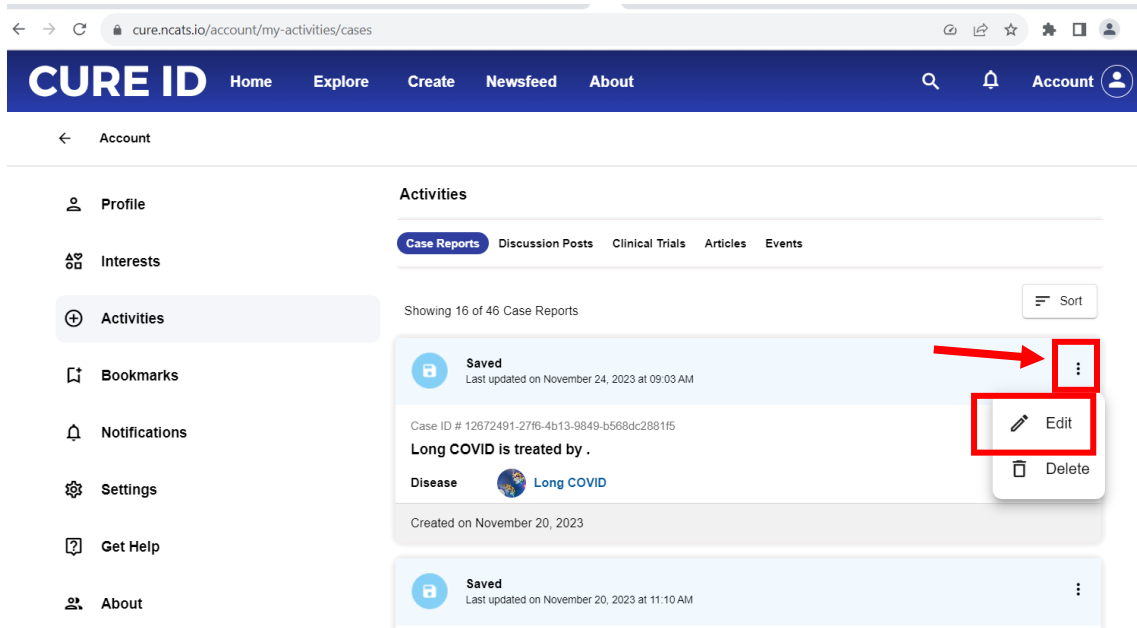
Q: Where can I find my saved case reports?

A: You can find your saved and submitted content (case reports, discussions, etc.) under your Account, and the “Activities” section

The screenshot shows the CURE ID account page. The top navigation bar includes 'Home', 'Explore', 'Create', 'Newsfeed', and 'About'. On the right, there is a link for 'Account', which is highlighted by a red box and a red arrow. The main content area is titled 'Account' and includes a sidebar with links for 'Profile', 'Interests', 'Activities', 'Bookmarks', 'Notifications', 'Settings', 'Get Help', and 'About'. The 'Activities' link is highlighted by a red box and a red arrow. The 'Activities' section is titled 'Activities' and includes a sub-section for 'Case Reports', which is also highlighted by a red box and a red arrow. Below the 'Case Reports' section, there is a list of case reports. The first case report is titled 'Submitted' and includes the following information: Case ID # 2c0fd6c0-adb7-4d90-a01d-b8a070da2c49, Long COVID is treated by Abacavir-Dolutegravir-Lamivudine, Abciximab, Abetimus, Clofazimine, Famotidine. The case report is for a patient with Long COVID, 6-10 years old, Female. The drugs listed are Abacavir-Dolutegravir-Lamivudine, Abciximab, Abetimus, Clofazimine, and Famotidine. The case report was created on November 24, 2023.

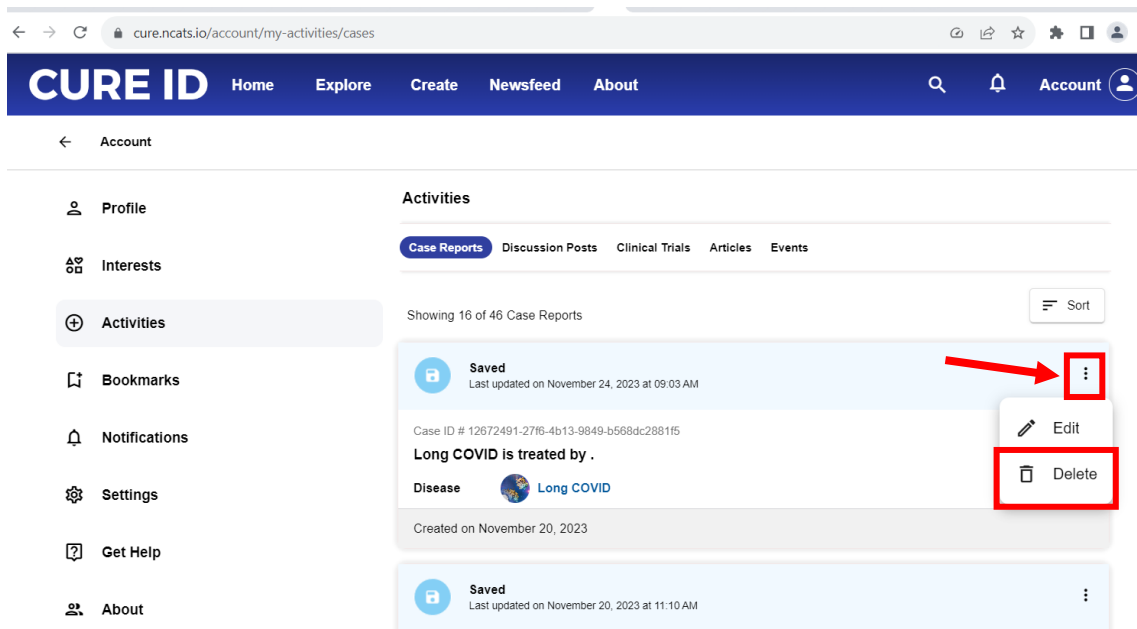
Q: How do I edit a previously saved or submitted case report?

A: To edit a case report or other entry, select the three vertical dots and click “Edit”



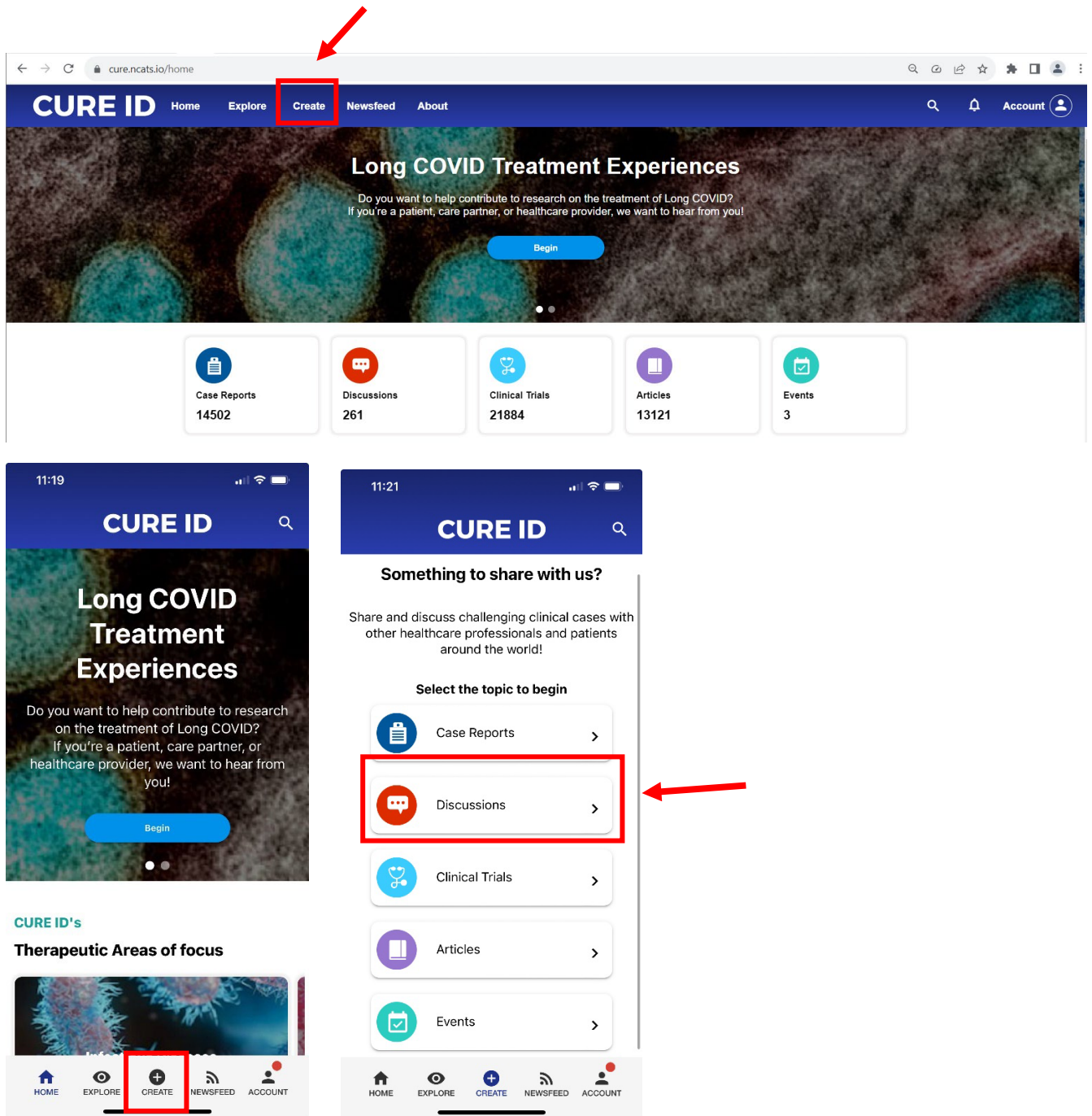
Q: How do I delete a case report I previously saved or submitted?

A: Select the three vertical dots next to the case and then select “Delete”.

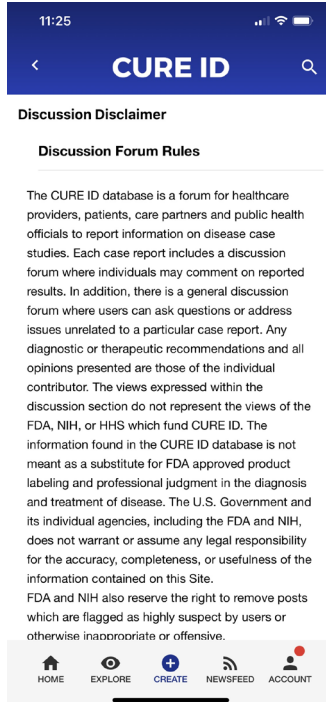


Q: How do I add a discussion post?

A: To add a discussion post, go to “Create”, and then select “Discussions”.



You'll then see a Discussion Disclaimer which you will need to agree to.



11:25

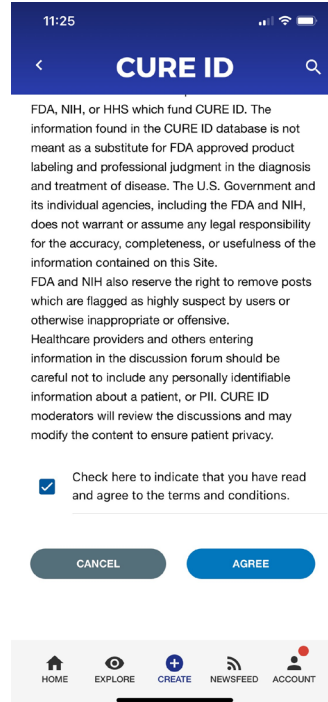
< CURE ID >

Discussion Disclaimer

Discussion Forum Rules

The CURE ID database is a forum for healthcare providers, patients, care partners and public health officials to report information on disease case studies. Each case report includes a discussion forum where individuals may comment on reported results. In addition, there is a general discussion forum where users can ask questions or address issues unrelated to a particular case report. Any diagnostic or therapeutic recommendations and all opinions presented are those of the individual contributor. The views expressed within the discussion section do not represent the views of the FDA, NIH, or HHS which fund CURE ID. The information found in the CURE ID database is not meant as a substitute for FDA approved product labeling and professional judgment in the diagnosis and treatment of disease. The U.S. Government and its individual agencies, including the FDA and NIH, does not warrant or assume any legal responsibility for the accuracy, completeness, or usefulness of the information contained on this Site. FDA and NIH also reserve the right to remove posts which are flagged as highly suspect by users or otherwise inappropriate or offensive.

HOME EXPLORE CREATE NEWSFEED ACCOUNT



11:25

< CURE ID >

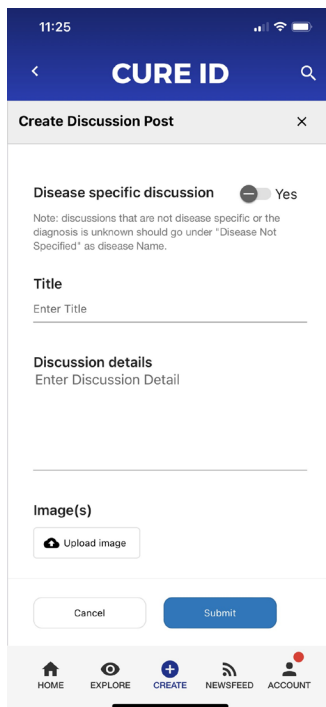
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☒ Check here to indicate that you have read and agree to the terms and conditions.

CANCEL AGREE

HOME EXPLORE CREATE NEWSFEED ACCOUNT

Now you're ready to enter your discussion!



11:25

< CURE ID >

Create Discussion Post X

Disease specific discussion Yes

Note: discussions that are not disease specific or the diagnosis is unknown should go under "Disease Not Specified" as disease Name.

Title
Enter Title

Discussion details
Enter Discussion Detail

Image(s)
Upload image

Cancel Submit

HOME EXPLORE CREATE NEWSFEED ACCOUNT

Drug Repurposing:

Q: What is Drug Repurposing (also known as off-label use)?

A: Drug repurposing involves identifying existing drugs that may be effective for diseases that they were not initially developed for. Drug repurposing includes drugs that are being used in a new way, such as to treat a different disease from the one it was originally studied and approved to treat; in a very novel dose, route, or duration; in a new combination with other drugs, or in a new population (e.g., pregnant patients, pediatrics, neonates, etc.).

Q: How do I know if the drug I am taking is repurposed?

A: All existing, FDA-approved drugs that are being used to treat Long COVID are repurposed drugs, as there is currently no approved treatment that has been demonstrated to be safe and effective for Long COVID. An example is: Low-dose naltrexone for Long COVID.

You can determine if a drug is repurposed by looking at the FDA approved drug labeling (drugs@FDA). If the condition you are taking it for is listed in the section entitled “Indications and Usage”, then the drug has been determined by FDA to be safe and effective for your condition and has been approved for use and marketing for that indication and population. If, however, the reason you are taking the drug is not listed in the labeled indications then it means the drug is being used “off-label” and is an example of a repurposed drug. Repurposed drugs may also describe drugs that are being used for the same disease, but in a very different way such as a novel dose, duration, population, or combination.

Miscellaneous:

Q: Will I be compensated for participating?

A: No, participation is voluntarily and there is no compensation available for participation.

Q: Will my doctor(s) be contacted?

A: No.

Q: What if I live outside the United States?

A: CURE ID is accessible worldwide. If you live outside of the U.S., we encourage you to submit your cases as well.

Q: Where can I learn more, ask additional questions, or ask for help if I'm having trouble entering my case?

A: Please email curesupport@nih.gov or CDRC@c-path.org.

CURE ID Disclaimer

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