

CURE ID Long COVID Treatment Survey



TLC: Treatments for Long COVID Survey

Are you a Long COVID patient interested in participating in a survey to help inform research, identify promising treatments, or treatments that are ineffective or harmful?

<https://cure.ncats.io>

Logos: NIH, National Center for Translational Sciences, CDRC, U.S. Food & Drug Administration, Discovery, The Critical Care Research Network, HMC Action, Patient-Led Research Collaborative, Solve M.E.

Join the NIH, FDA, and partners in advancing our understanding of the treatments of Long COVID. What treatments are you taking and how have they impacted you? Take the CURE ID Treatments for Long COVID Survey now by visiting [CURE ID](https://cure.ncats.io) or download the "CURE ID" mobile app now!

SCCM Congress



Thank you to [Society of Critical Care Medicine](#) for hosting another great SCCM Congress event! This event was a deep dive into the latest trends, innovations, and breakthroughs in critical care medicine. Here are some highlights from my experience:

- 1. Networking Extravaganza:**
Met incredible professionals in critical care from around the globe! Engaging discussions, sharing insights, and building connections with like-minded individuals dedicated to advancing patient care.
- 2. Cutting-Edge Research:**
Fascinated by the groundbreaking research presented at Congress! From novel treatment modalities to innovative technologies, it's clear that the critical care community is at the forefront of pushing the boundaries of medical science.
- 3. Collaboration Opportunities:**
Explored potential collaborations with industry leaders and fellow attendees. Exciting times lie ahead as we work together to shape the future of critical care medicine.

SFA Groundbreaking Patient Engagement Webinar

Take Part in a Patient Powered Research Webinar

Our goal is to better understand the current therapies being used for rare and ultra-rare sarcomas

January 18th, 2024
1:00 PM - 2:30 PM EST

Webinar Hosted By: SFA, CDRC, Partners & Collaborators: EMMES, U.S. Food & Drug Administration, HMC Action, Patient-Led Research Collaborative, Solve M.E.

Host: **David Fowler**, CEO, Sarcoma Foundation of America

Speakers: **William D. Tap, MD**, Chief of the Sarcoma Medical Oncology Service at Memorial Sloan Kettering Cancer Center; **Marco Schito, PhD**, Executive Director of C-Path's CURE Drug Repurposing Collaboratory (CDRC); **Tim Shumiller, PhD**, VP of Scientific and Medical Affairs; **Lennie Woods**, Executive Director and co-founder of the Clear Cell Sarcoma Foundation (formerly Sarca's Cure).

xCures, Sarcoma Foundation of America

In this webinar, we covered key aspects of the collaboration between xCures, The Cure Drug Repurposing Collaboratory, Sarcoma Foundation of America, and Memorial Sloan Kettering Cancer Center, providing valuable insights and practical knowledge that can benefit you both personally and professionally. Our patient advocate speaker, Lennie Woods, brings a wealth of knowledge and shared her valuable experiences from a patient and caregiver perspectives. Our goal is to generate clinical evidence from real-world data on the safety and effectiveness of off-label treatments.

[See FAQs here](#)

The Role of Drug Repurposing in Pregnancy

Obstetric conditions impact the lives of many pregnant individuals and medication use during pregnancy is common. While there are perceived barriers to traditional drug development for pregnancy-related conditions, drug repurposing is a promising strategy to improve the development of new obstetric drugs.

<https://www.mhf.org/2024/01/24/the-role-of-drug-repurposing-in-pregnancy/>

Events

Rare Disease Day at NIH 2024
Feb. 29, 2024 from 9 a.m. to 5 p.m. (Thursday) NIH Main Campus

Rare Disease Day® takes place worldwide, typically on or near the last day of February each year, to raise awareness among policymakers and the public about rare diseases and their impact on patients' lives. Since 2011, NCATS and the NIH Clinical Center have sponsored Rare Disease Day at NIH as part of this global observance. Rare Disease Day at NIH aims to raise awareness about rare diseases, the people they affect, and NIH collaborations that address scientific challenges and advance research for new treatments.

The goals of Rare Disease Day at NIH are to:

- Demonstrate the NIH commitment to helping people with rare diseases through research.
- Highlight NIH-supported rare diseases research and the development of diagnostics and treatments.
- Initiate a mutually beneficial dialogue among the rare diseases community.
- Exchange the latest rare diseases information with stakeholders to advance research and therapeutic efforts.
- Shine a spotlight on stories told by patients living with a rare disease, their families, and their communities.

Rare Disease Day at NIH seeks to bring together a broad audience including patients, patient advocates, caregivers, health care providers, researchers, trainees, students, industry representatives, and government staff. Attendees are expected to exercise professionalism, consideration, and respect when speaking, posting, and communicating with others.

Register here: [Rare Disease Day at NIH 2024 \(socio.events\)](#)

Public meeting: FDA Rare Disease Day 2024
March 1st, 2024, Virtual from 9:00 AM - 4:30 PM ET

FDA will host Rare Disease Day, a virtual public meeting, on March 1, 2024 in global observance of Rare Disease Week.

This year's Rare Disease Day is dedicated to patients and health care professionals. Panels will discuss:

- The legal framework for approving studies and medical products at FDA
- What FDA does during review processes to approve medical products
- Decentralized clinical trials and digital health technologies
- Where to find important information and documents related to clinical trials
- Information that can be obtained from medical product labels
- Legal and ethical requirements for consent forms in clinical trials
- FDA initiatives to advance medical product development for rare diseases
- Ways for patients to engage with FDA

Register Here: <https://www.surveymonkey.com/r/FDARD2024>

IR24: International Drug Repurposing Conference
March 6 & 7 2024, Barcelona, Spain

Bridging Boundaries: innovating, connecting, and reshaping drug repurposing, which is the REMEDI4ALL Annual Conference in Barcelona, Spain, March 6-7th, 2024 with pre-meeting of MERIT - the group of international regulators and publicly funded repurposing initiatives on March 5th. Heather Stone will be co-leading the opening plenary on medicines repurposing for all and Keyla Tumas will also be attending. We look forward to meeting you there!

For more information: <https://remedi4all.org/international-drug-repurposing-conference/>

CDRC 2023 Annual Meeting

CDRC CURE ID CHALLENGING CASES... NEW APPROACHES

CURE DRUG REPURPOSING COLLABORATORY ANNUAL MEETING
APRIL 18- 20, 2023

Hyatt Regency Crystal City, 2799 Richmond Highway
c-path.org/cdrc

On behalf of the CURE Drug Repurposing Collaboratory (CDRC), you are invited to view the recorded sessions from Day 3 of the CDRC 2023 Annual Meeting. Meeting participants discussed recent accomplishment, including the multiple efforts that CDRC and our collaborators worked on for drug repurposing. This included our COVID-19 pilot project, the development and implementation of tools to automate the extraction of data from electronic medical records, novel clinical trial designs, rare cancers and a global regulatory workshop, all centering to advance drug repurposing.

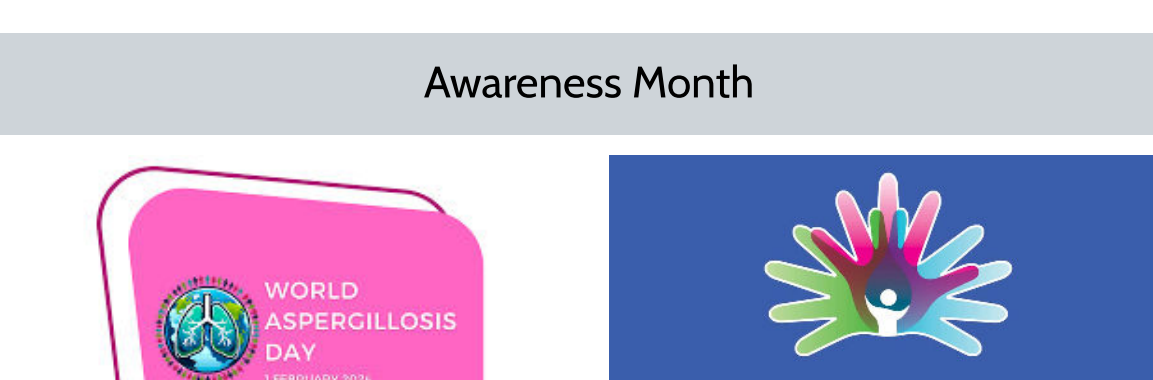
Learn more at <https://c-path.org/journals/cdrc/>

Trending Articles

[The Impact of Hydroxychloroquine on Primary Feto-Placental Endothelial Cells from Healthy and Early-Onset Preeclamptic Placentas.](#)

[Long-Term Effects of COVID-19](#)

Awareness Month



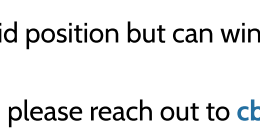
CURE ID/CDRC Clinical Scholar's Program

[Looking to become a social media ambassador?](#)

CURE ID is looking to recruit individuals interested in help promoting our web-based app. The platform enables healthcare providers, patients, and care partners to share their real-world experiences of treatment using repurposed drugs. We currently have are recruiting for the next group of scholars.

This is an unpaid position but can win CURE ID/CDRC swag.

If interested please reach out to cbassett@c-path.org



Be Heard

[Tell Your Drug Repurposing Story in 2023](#)

Our Impact stories share the value and impact C-Path's and CDRC's work brings to patients, patient organizations, drug developers, the academic community, regulators and more. Enjoy and share!

[Impact Stories | Critical Path Institute \(c-path.org\)](#)

Reach out to the Communication and Patient Engagement Manager, Claire Bassett at cbassett@c-path.org if interested in sharing your story through an Impact Story.

Joining the CDRC

CDRC CURE DRUG REPURPOSING COLLABORATORY

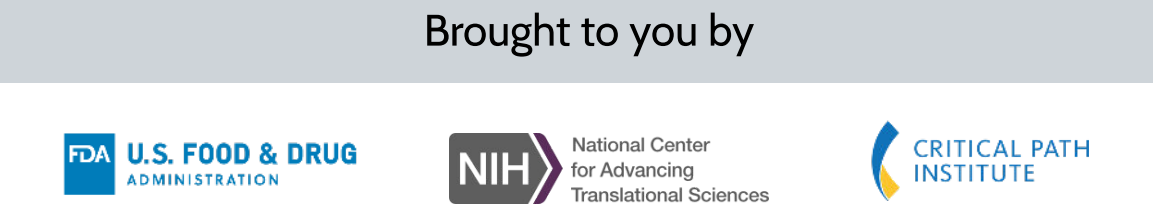
The CURE Drug Repurposing Collaboratory (CDRC) is a public-private partnership initiated in June 2020 by C-Path and the U.S. Food and Drug Administration (FDA) in partnership with the National Center for Advancing Translational Sciences (NCATS), part of the National Institutes of Health (NIH).

If interested, please feel free to get involved with the CURE Drug Repurposing Collaboratory (CDRC), here: <https://c-path.org/cdrc>

Collaborators



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Visit CURE ID

Visit the CURE ID website for more information.
<https://cure.ncats.io>



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