

SARCOMA PROJECT SOCIAL MEDIA TOOLKIT

Twitter Graphics



Sample Tweets:

- Join xCures and CDRC to crowdsource patient data on sarcoma treatments.
- Exciting times in cancer research! 🤖 Drug repurposing is an option for #sarcoma treatment. We need your help to identify new therapies to help patients fight this aggressive disease.
- Repurposing existing drugs for #sarcoma treatment could be a game-changer! @xcures and CDRC are exploring new avenues to combat this rare cancer, looking to improve outcomes and better quality of life for patients
- Drug repurposing is an option in the fight against #sarcoma, bringing renewed hope to patients, care partners and physicians. Let's support these groundbreaking efforts!
- Did you know that some existing drugs are being investigated for #sarcoma treatment? Check out xCures and CDRC's patient partnered sarcoma project for more information!
- Empowering the fight against sarcoma with innovation! Drug repurposing is breaking barriers, uncovering potential treatments that may transform the landscape of sarcoma care. Help support xCures and CDRC in this initiative.
- Together, we can rewrite the story of sarcoma! Drug repurposing brings new hope and renewed determination to conquer this rare cancer. Let's spread awareness and support research for better treatments.
- Your patient information is essential for progress in sarcoma research! By contributing anonymized data, patients play a crucial role in accelerating medical breakthroughs and improving treatment options.
- Your information could be key to unlocking the treatment mysteries of sarcoma! Your privacy and security are our top priorities. Join xCures and CDRC to contribute your data and be part of a movement that strives for better outcomes and a brighter future.
- Patients are the heart of sarcoma research! Your data is valuable to better understanding this rare cancer. Join xCures and CDRC by sharing your anonymized data to drive discoveries that can impact countless lives.

Hashtags:

#cancerresearch, #medicalinnovation, #hopefulfuture, #cancerawareness #medicaladvancements,
#Sarcomaawareness, #cancerfight, #DrugRepurposing, #sarcomacare, #sarcomacommunity,
#PatientData, #PatientPartners

People to tag:

@id_cure, @xcures_platform, @EHEfoundation, @anticancerfund, @everycure, @MSKCancerCenter,
@CureSarcoma

Facebook/Instagram Graphics



Sample Language:

- Let's Crowdsource Patient Data on Sarcoma Treatments:
 - Are you ready to make a difference in cancer research? xCures and CDRC are teaming up to gather patient data and insights on sarcoma treatments. Your contribution can help improve the future of care for this aggressive disease. Join us in this collective effort to drive meaningful change. 📌 #SarcomaResearch #PatientData
- Exciting Times in Cancer Research! 📌 Drug Repurposing for Sarcoma Treatment:
 - The landscape of cancer research is evolving, and we're excited to be part of the change! Drug repurposing is offering promising avenues for sarcoma treatment. We invite you to be a part of this journey and help us identify new therapies to empower patients against this challenging disease. #HopeInResearch #SarcomaTreatment
- Empowering Sarcoma Care Through Drug Repurposing:
 - Together, xCures and CDRC, along with other stakeholders (the EHE Foundation, Sarcoma Foundation of America, and many more), are breaking new ground in the fight against sarcoma. By exploring innovative paths like drug repurposing, we're aiming to enhance outcomes and quality of life for patients. Join us in supporting this important initiative! #SarcomaWarriors #InnovationInCare
- Discover New Possibilities in Sarcoma Treatment:
 - Have you heard about the exciting potential of repurposed drugs in sarcoma treatment? Dive into xCures and CDRC's patient-partnered sarcoma project to learn more. Together, we can pave the way for improved therapies and a brighter future for patients. #SarcomaResearch #Empowerment
- Patients at the Heart of Sarcoma Research: Contribute Your Data:
 - The heart of sarcoma research beats within patients like you. Your anonymized data can be invaluable in understanding and treating this rare cancer. Join forces with xCures and CDRC to make a lasting impact. 💖 #PatientContributions #SarcomaResearch

Language for a Press Release

You can expedite the search for safe and effective Treatments by sharing your journey with [rare sarcomas or insert subtype].

Drug Repurposing is a global effort that every person living with [a rare sarcoma or insert subtype] can contribute to. With the goal to identify drugs that are proven to be safe and effective in other diseases, drug repurposing can accelerate the availability of effective treatments for [rare sarcomas or insert subtype].

Your lived experience can:

- Help identify existing FDA-approved drugs used for other diseases that may be repurposed as a new treatment for [rare sarcomas or insert subtype] simply by donating your medical history (your data)
- Generate real-world evidence from your lived experiences, to support the expansion of a repurposed drug's label to include [rare sarcomas or insert subtype]
- Inform the design of clinical trials that can test a potential drug for repurposing in [rare sarcomas or insert subtype]
- Educate doctors and researchers about the natural history of your disease – if you have had treatment or have never had treatment.

Please Contact: EMAIL for more information about our Sarcoma Project

Follow-Up Messaging

Dear [insert name]

I hope you're doing well. I wanted to follow up on our conversation about the CDRC/xCures Sarcoma Project and see if you had any further questions or if there's anything I can assist with. I'm here to help provide any additional information you may need and answer any questions you have.

Looking forward to hearing from you.

1-pager

TAKE PART IN CDRC'S SARCOMA PATIENT PARTNERED RESEARCH

Share your experience living with [SARCOMA SUBTYPE]

Sarcoma subtypes will be evaluated for a repurposing drugs initiative to advance treatment potential and options. We need you to help find better treatments and to learn from your experiences. We want to find out if there are any drugs, supplements, or natural products not prescribed for your sarcoma that make your life better or that might cause harm. We also want to help crowdsource treatment options that can be shared publicly with the community. If you want to know more about this project or have any questions, please send an email to cdrc@c-path.org.

WHY WE NEED YOU!

Our goal is to better understand the current therapies being used for rare and ultra-rare sarcomas. Your medical records and patient information is the best source to find out the drugs you have taken and the treatments you have tried. By collecting and sharing all this information, we will help patients make better decisions about treatment and identify more treatment options. In the future, we hope to study even more types of sarcomas.

xcures.com/cdrc

HOW DO I PARTICIPATE?

- Medical Records are helpful, but don't tell the whole story. We need your help! Your story can inform more treatment options for sarcoma patients.
- Share your treatments that you have received
- Sign up for xCures to help consolidate your medical records with your permission. Review and amend your records to share your story.
 - xCures will gather and provide access to all of your medical records, produce a visual summary of your care history and, when appropriate, provide information regarding clinical trials.

FOR MORE INFORMATION

- Check out the FAQ page [here](#)
- Visit xcures.com/cdrc
- Email cdrc@c-path.org for more information

PLEASE SHARE THIS INFORMATION WITH OTHER FAMILIES LIVING WITH ANGIOSARCOMA, EHE, OR PECOMA. THE MORE PEOPLE PARTICIPATE, THE MORE WE WILL ALL LEARN!

PARTNERS & COLLABORATORS

Goals:

- Collecting deidentified data on lived experiences
- Collaborating more effectively to ask the right questions
- Sharing insights gained to help identify treatments and to make better treatment decisions

- Ability to change out sarcoma subtypes!

Postcard, Patient Outreach

YOUR DISEASE JOURNEY CAN EXPEDITE SAFE AND EFFECTIVE TREATMENTS FOR RARE SARCOMAS

DEAR [SARCOMA CENTER]

Take Part in this Patient-Powered Research – Share Your Experience Today!

Visit: Xcures.com/cdrc

Website Language

You can expedite safe and effective treatments by sharing your journey with [rare sarcomas or insert subtype].

Drug Repurposing is a global effort that every person living with [a rare sarcoma or insert subtype] can contribute to. With the goal to identify drugs that are proven to be safe and effective in other diseases, drug repurposing can accelerate the availability of effective treatments for [rare sarcomas or insert subtype].

Your lived experience can:

- Help identify existing FDA-approved drugs used for other diseases that may be repurposed as a new treatment for [rare sarcomas or insert subtype] simply by donating your medical history (your data)
- Generate real-world evidence from your lived experiences, to support the expansion of a repurposed drug's label to include [rare sarcomas or insert subtype]
- Inform the design of clinical trials that can test a potential drug for repurposing in [rare sarcomas or insert subtype]
- Educate doctors and researchers about the natural history of your disease – if you have had treatment or have never had treatment.

Take Part in this Patient-Powered Research – Share Your Experience Today!

Visit: [Xcures.com/cdrc](https://xcures.com/cdrc)

This project is a partnership of the CURE Drug Repurposing Collaboratory (CDRC) and sarcoma patient advocates. 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.

For all Questions and Concerns please email: cdrc@c-path.org

Contacts and partner logos

- U.S. FDA
 - Heather Stone, Heather.Stone@fda.hhs.gov
 - When using logo, may need Heather to approve.
- NIH/NCATS
 - Ewy Mathe, ewy.mathe@nih.gov
- CURE Drug Repurposing Collaboratory (CDRC)
 - Marco Schito, mschito@c-path.org
 - Chandler Birch, cbirch@c-path.org
 - Claire Bassetti, cbassetti@c-path.org
- AntiCancer Fund
 - **CONTACT**
- ClearCell Sarcoma Foundation
 - Lennie Woods, lenniewoods@sarascure.org
- The EHE Foundation
 - Denise Robinson, deniserobinson@fightehe.org
- EveryCure
 - David Fajgenbaum, davidfa@pennmedicine.upenn.edu
- LMS Foundation
 - Mitch and Annie Achee, annieachee@aol.com
- Memorial Sloan Kettering Cancer Center
 - Bill Tap, tapw@mskcc.org
 - Assistant Ellen Cangialosi, cangiale@mskcc.org
- MIB Agents
 - Christina Ip-Toma, christina@mibagents.org
- University of Michigan, Rogel Cancer Center
 - Denise Reinke, dreinke@med.umich.edu
- Sarcoma Foundation of America
 - Brandi Felser, bfelser@curesarcoma.org
- xCures
 - Mark Sharp, msharp@xcures.com
 - Zac Cole, zcole@xcures.com



Patient Outreach Departments, Patient Learning Centers, Director of Communications

- Rhabdo

ASCO Announcement

- ASCO Post

Pediatric Journals

Magazines, Podcasts, Newsletters

- **Cancer Today**
- CURE magazine
- Patient Advocacy Newsletters
 - SPAGN
- **Sarcoma Sisters-** podcast
- Let's Talk about Sarcoma- podcast
- osTEAo- MIB AGENTS podcast

Sarcoma Centers in America:

- [Sarcoma Cancer Treatment Centers Near You \(curesarcoma.org\)](http://curesarcoma.org)
- Alabama
 - University of Alabama at Birmingham
- Arizona
 - Mayo Clinic
 - Phoenix Children's Hospital
 - University of Arizona Cancer Center
- Arkansas
 - Arkansas Children's Hospital
- California
 - Cedars Sinai
 - Children's Hospital of Los Angeles
 - Children's Hospital and Research Center Oakland
 - City of Hope
 - Hoag Cancer Center
 - Loma Linda University Medical Center
 - Mattel Children's Hospital UCLA
 - Sarcoma Oncology Center
 - Stanford University Cancer Center
 - University of California, Davis Sarcoma Program
 - University of California, Los Angeles UCLA Sarcoma Program
 - University of California, San Diego – Moores Cancer Center
 - University of California San Francisco,
 - Helen Diller Family Comprehensive Cancer Center
 - University of Southern California,
 - USC Norris Comprehensive Cancer
- Colorado
 - Presbyterian/St.Luke's Medical Center

- Rocky Mountain Children's Hospital
- UHealth Cancer Care – Anschutz Medical Campus –University of Colorado Cancer Center
- Connecticut
 - Yale Cancer Center / Smilow Cancer Hospital
- Florida
 - Mayo Clinic
 - Sylvester Comprehensive Cancer Center Bone & Soft Tissue Sarcoma Program
 - Moffitt Cancer Center
 - University of Florida Shands Cancer Center
- Georgia
 - Emory Winship Cancer Institute
 - Georgia Cancer Specialists
- Idaho
 - Summit Cancer Centers
- Illinois
 - Robert E. Lurie Comprehensive Cancer Center, Northwestern University
 - Rush University Medical Center
- Indiana
 - Parkview Packnett Family Cancer Institute
- Iowa
 - University of Iowa – Holden Comprehensive Cancer Center
- Kansas
 - University of Kansas Cancer Center – Sarcoma Center
- Maryland
 - The Bone Cancer and Soft Tissue Sarcoma Service, Marlene and Stewart Greenebaum Comprehensive Cancer at the University of Maryland
 - The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
- Massachusetts
 - Dana Farber Cancer Institute
 - Massachusetts General Hospital (MGH)
- Michigan
 - University of Michigan Comprehensive Cancer Center
- Minnesota
 - University of Minnesota Cancer Center
 - Mayo Clinic
- Missouri
 - Siteman Cancer Center/Barnes Jewish Hospital/Washington University School of Medicine
- Nebraska
 - Nebraska Methodist Hospital
- New Hampshire
 - Dartmouth-Hitchcock Norris Cotton Cancer Center
- New Jersey
 - Hackensack University Medical Center
- New York

- Memorial Sloan-Kettering Cancer Center (MSKCC)
- Mount Sinai Hospital, Sarcoma Cancer Program
- New York-Presbyterian Hospital
- Roswell Park Cancer Institute
- University of Rochester, Wilmot Cancer Institute
- North Carolina
 - Atrium Health — Levine Cancer Institute
 - Duke University Cancer Institute
 - UNC Lineberger Comprehensive Cancer Center
 - Wake Forest Baptist Health
- Ohio
 - Cincinnati Children's Hospital
 - The Cleveland Clinic Taussig Cancer Center
 - The Ohio State University — The James Sarcoma Program
 - Summa Health System
 - University Hospitals Case Medical Center
- Oklahoma
 - Children's Hospital at OU Medical Center
- Oregon
 - OHSU Knight Cancer Institute
- Pennsylvania
 - Children's Hospital of Philadelphia
 - Fox Chase Cancer Center — Temple Health
 - Penn Medicine — Abramson Cancer Center
 - UPMC — Hillman Cancer Center
- South Carolina
 - Medical University of South Carolina — Hollings Cancer Center
 - Greenville Health System — Cancer Institute of Prima Health
- Tennessee
 - St. Jude Children's Research Hospital
 - Vanderbilt-Ingram Cancer Center
 - West Cancer Center & Research Institute
- Texas
 - Baylor University Medical Center
 - Mays Cancer Center UT Health San Antonio — MD Anderson
 - Texas Children's Hospital
 - MD Anderson Cancer Center
 - UT Southwestern Medical Center
- Utah
 - University of Utah Huntsman Cancer Institute
- Vermont
 - University of Vermont Medical Center
- Virginia
 - Virginia Commonwealth University (VCU) Massey Cancer Center
- Washington
 - Seattle Cancer Care Alliance

- Seattle Children's Hospital
- Washington, D.C.
 - Children's National Medical Center
 - MedStar Washington Hospital Center
- West Virginia
 - WVU Medicine Mary Babb Randolph Cancer Center
- Wisconsin
 - Aurora Healthcare
 - Froedtert & The Medical College of Wisconsin Clinical Cancer Center

International Cancer Centers: [International Sarcoma Cancer Treatment Centers \(curesarcoma.org\)](http://curesarcoma.org)