

The Linux Foundation Hosts Project to Decentralize and Accelerate Drug Development for Rare Genetic Diseases

OpenTreatments and RareCamp creator Sanath Kumar Ramesh built the project to address his son's rare disease, now that work will be available to all in an effort to accelerate treatments

SAN FRANCISCO, Calif., March 31, 2021 – The Linux Foundation, the nonprofit organization enabling mass innovation through open source, and the OpenTreatments Foundation, which enables treatments for rare genetic diseases regardless of rarity and geography, today announced the RareCamp software project will be hosted at the Linux Foundation. The Project will provide the source code and open governance for the OpenTreatments software platform to enable patients to create gene therapies for rare genetic diseases.

The project is supported by individual contributors, as well as collaborations from companies that include Baylor College of Medicine, Castle IRB, Charles River, Columbus Children's Foundation, GlobalGenes, Odylia Therapeutics, RARE-X and Turing.com.

“OpenTreatments and RareCamp decentralize drug development and empowers patients, families and other motivated individuals to create treatments for diseases they care about. We will enable the hand off of these therapies to commercial, governmental and philanthropic entities to ensure patients around the world get access to the therapies for the years to come,” said Sanath Kumar Ramesh, founder of the OpenTreatments Foundation and creator of RareCamp.

There are 400 million patients worldwide affected by more than

7,000 rare diseases, yet treatments for rare genetic diseases are an underserved area. More than 95 percent of rare diseases do not have an approved treatment, and new treatments are estimated to cost more than \$1 billion.

“If it’s not yet commercially viable to create treatments for rare diseases, we will take this work into our own hands with open source software and community collaboration is the way we can do it,” said Ramesh.

The RareCamp open source project provides open governance for the software and scientific community to collaborate and create the software tools to aid in the creation of treatments for rare diseases. The community includes software engineers, UX designers, content writers and scientists who are collaborating now to build the software that will power the OpenTreatments platform. The project uses the open source Javascript framework NextJS for frontend and the Amazon Web Services (AWS) Serverless stack – including AWS Lambda, Amazon API Gateway, and Amazon DynamoDB – to power the backend. The project uses the open source toolchain Serverless Framework to develop and deploy the software. The project is licensed under Apache 2.0 and available for anyone to use.

“OpenTreatments and RareCamp really demonstrate how technology and collaboration can have an impact on human life,” said Brett Andrews, RareCamp contributor and software engineer at Vendia. “Sanath’s vision is fueled with love for his son, technical savvy and the desire to share what he’s learning with others who can benefit. Contributing to this project was an easy decision.”

“OpenTreatments Foundation and RareCamp really represent exactly why open source and collaboration are so powerful – because they allow all of us to do more together than any one of us,” said Mike Dolan, executive vice president and GM of Projects at the Linux Foundation. “We’re honored to be able to support this community and are both confident and inspired

about its impact on human lives.”

For more information and to contribute, please visit:
OpenTreatments.org

About OpenTreatments Foundation

OpenTreatments Foundation’s mission is to enable treatments for all genetic diseases regardless of rarity and geography. Through the OpenTreatments software platform, patient-led organizations get access to a robust roadmap, people, and infrastructure necessary to build a gene therapy program. The software platform offers project management capabilities to manage the program while reducing time and money necessary for the development. For more information, please visit:
OpenTreatments.org

About the Linux Foundation

Founded in 2000, the Linux Foundation is supported by more than 1,000 members and is the world’s leading home for collaboration on open source software, open standards, open data, and open hardware. Linux Foundation’s projects are critical to the world’s infrastructure including Linux, Kubernetes, Node.js, and more. The Linux Foundation’s methodology focuses on leveraging best practices and addressing the needs of contributors, users and solution providers to create sustainable models for open collaboration. For more information, please visit us at linuxfoundation.org.

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