

rare disease

# CROWDFUNDING

a how-to, lessons learned, and a case study

## ! WHY CROWDFUNDING?

**Crowdfunding can be a powerful tool in rare disease**

Crowdfunding can be used to help generate funds that can help open up doors for rare disease research and treatment. Examples of potential crowdfunded projects and breakthroughs include:

- Research studies
- Clinical trials
- DNA Sequencing

## TECHNIQUES

**How to reach an audience**

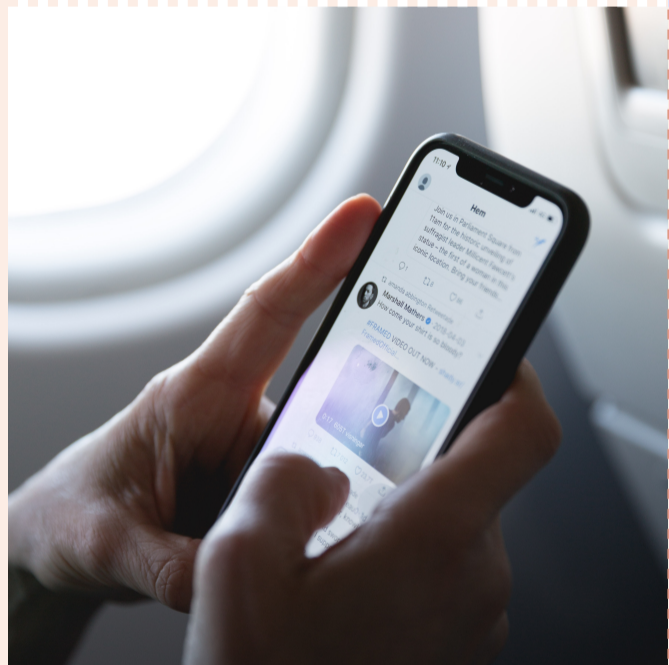
It's important to share and network in order to gain traction and attention to your campaign! Here are a few ideas:

- **Press:** Consider having coverage done in traditional media, such as radio, TV, magazine, or podcast
- **Social Media:** Share your campaign on Facebook or Twitter, and encourage friends and family to help you share it as well
- **Offline Fundraising:** Consider tabling or flyering at an offline event, or have an offline fundraiser such a gala or raffle

## LESSONS LEARNED

**Tips and Tricks to have a successful campaign**

- Make it easy for donors to give. Eliminate any extra steps and sign ups.
- Sharing more content over time allows more giving. Help the donors be engaged with the whole story instead of just one timeline
- People want to contribute. Providing small amounts give them the chance despite their current financial situation



## ✓ CASE STUDY: MAYA

**Using crowdfunding, Maya and her family are one step closer to an answer**

RGI was able to provide Maya and her family a crowdfunding platform to raise the funds necessary for whole exome sequencing. With these funds, researchers were able to start a research project that allowed them to report a novel genetic variant in Maya. More exploratory studies and therapeutic research are now being done as a direct result of this crowdfunded research project.



**SOURCES:**

<https://drjimmylin.com/presscov/2017/7/13/crowdfunding-rare-disease-research-one-family-at-a-time>

<https://www.causevox.com/blog/how-to-fight-rare-diseases-through-crowdfunding/>