



RettGive Crowdfunding Guide

Rett Syndrome Awareness Month is an opportunity for families to share with the world what Rett is and its challenges. Raising awareness is important, but it doesn't automatically translate into raising funds for the research. However, if we combine awareness building with raising funds for research, **it makes a big difference.**

For Rett Syndrome Awareness Month, we're encouraging Rett families to start a crowdfunding campaign on RSRT's platform, **RettGive**. A RettGive campaign can be done from anywhere in the world, it's easy, and it's an extremely effective way to raise money.

This guide will walk you through the steps to run a successful RettGive crowdfunding campaign, including examples that you can use to talk with everyone you know about your loved one and the progress for a cure. On the following pages this guide covers these three critical steps:

- / The Materials You Need to Set Up Your Campaign
- / How to Deliver Your Materials for Your Personal Campaign Webpage
- / How to Spread the Word About Your Campaign to Your Network

This guide has many examples of materials and outreach, and you can check out current campaigns in the **Browse Campaigns** section of the **RettGive website**.



THE MATERIALS YOU NEED TO SET UP YOUR CAMPAIGN

1 A Campaign Title

The campaign title will be the headline of your personal campaign page, so it's important to craft a title that inspires your community to give. Typically families use their child's name in their campaign title. Here are some examples:

- / A Cure for Eleanor
- / Grace's Race Against Rett
- / Empower Erykah
- / Help Us Cure Laura
- / Let's Fight with Aida!

2 A Short Description of Your Child and Her Story

A short description of your child and her story that briefly explains what Rett is and how it affects her will help your donors to understand why a cure is so important. We find that personal details about aspects of her life are particularly effective. Your paragraph doesn't have to be long – typically 200 to 500 words is more than enough to get donors engaged, and it can be in any language or more than one language.

Some examples of things to share in your description:

- / What makes your loved one so special
- / What it was like getting the diagnosis
- / The activities your loved one enjoys
- / Why you are hopeful about progress for a cure

SAMPLE DESCRIPTION

Shortly after her third birthday, we realized that Shanay no longer uttered the words she could easily express a year before. She was first diagnosed with autism, but her doctor informed us that she had Rett syndrome when the genetic test results returned.

Devastation and deep sorrow for us followed the news, yet, Shanay kept smiling, laughing, and playing around. And it was her energy that made us recuperate and start the search for possible courses of action. Hours and hours of consultation with doctors helped us gain a new perspective on how to engage and help children with Rett syndrome.

Meanwhile, Shanay has been the happy kid she has always been. Indeed, her energy and joy of life keep us all motivated and hopeful. Motivated in making sure that she remains joyful no matter what the syndrome might cause; hopeful that the Rett Syndrome Research Trust's incredible achievements and all the researchers involved in finding treatments or a cure for Rett syndrome will come to fruition.

Shanay has opened our eyes to a new world with fantastic possibilities. A world in which her smiles and movements tell us volumes about its corners and wonders.

3 Four Photos of Your Child

Photos are one of the most effective ways to communicate the joy, life, and hope within your loved one and among your family. It's up to you what kind of photos you'd like to share. We recommend a mix of your loved one alone and with family or friends.

SAMPLE PHOTOS



4 A Fundraising Goal

A fundraising goal is important because it gives you something to aim for and helps donors think about how they can support you and your family to achieve that goal. Most campaigns have a goal between \$5,000 and \$25,000. Your goal should be ambitious and achievable. Remember, it's okay if you don't reach your goal – a goal primarily helps to motivate your supporters.

5 Your Campaign Giving Levels

Campaign giving levels are suggested donation amounts that help your donors decide how much they can give. RettGive campaigns usually have five giving levels, and each level typically has a motivating name that you choose.

SAMPLE GIVING LEVELS

/ \$1,000 VIP

/ \$750 Champion

/ \$500 Hero

/ \$250 Star

/ \$100 Supporter

Instead of selecting one of the offered giving levels, your supporters can always choose to give whatever amount they want.



HOW TO DELIVER YOUR MATERIALS FOR YOUR PERSONAL CAMPAIGN WEBPAGE

- 1 Email your materials to RSRT Chief Development Officer **Tim Freeman** at tim@rsrt.org.
- 2 We will then set up your personal campaign webpage and send you a link. Easy!



HOW TO SPREAD THE WORD ABOUT YOUR CAMPAIGN TO YOUR NETWORK

Spreading the word about your campaign is the most important step. Email and social media outreach are the two primary ways, and you should plan on doing both to reach as many people as possible.

1 Craft an outreach email to send to potential donors.

Email outreach is usually the most effective way to raise funds. You likely have the email addresses of hundreds of people. You surely have family and good friends you can reach out to, but consider others as well: colleagues, neighbors, acquaintances from your child's school, etc. Get creative about who you reach out to, and have fun going through your email address book to find folks you think would be responsive to your ask for a donation.

And here's the great news: If you've already written your short description for your webpage, you have practically written your outreach email.

We recommend incorporating the following elements in your outreach email:

1 / A reference to Rett Syndrome Awareness Month as your reason for reaching out. For example:

"October is Rett Syndrome Awareness Month, which is why I'm reaching out to you now. Not only is October an important time to educate folks in our life about the realities of Rett syndrome, it's also a time when you can get involved in the research that is giving our family so much hope for a cure."

2 / A summary of your child's story

3 / Why you are hopeful about Rett research and why you are fundraising for RSRT

4 / A direct ask to donate with a link to your campaign

5 / A "thank you" in advance of a donation. For example:

"I want to express my deep and heartfelt thanks for any amount you can give."

These elements will make clear the who, what, when, why, and how of your email outreach. Here is an example, using the description sample from above, to give you some ideas.

SAMPLE EMAIL

Hello [First Name],

I'm writing to share with you why the month of October is an important month for my family, and to ask if you can support a cause that is so near and dear to my heart. October is Rett Syndrome Awareness Month, and my daughter, Shanay, was diagnosed with Rett syndrome when she was 3 years old.

Shortly after her third birthday, we realized that Shanay no longer uttered the words she could easily express a year before. She was first diagnosed with autism, but her doctor informed us that she had Rett syndrome when the genetic test results returned. Rett syndrome is a rare neurological disorder that affects mostly girls. Girls lose acquired skills like speech, the ability to walk, and the use of their hands. As girls with Rett age a variety of symptoms can emerge, including seizures, breathing and digestive problems, and scoliosis.

Devastation and deep sorrow for us followed the news of Shanay's diagnosis, yet, Shanay kept smiling, laughing, and playing around. And it was her energy that made us recuperate and start the search for possible courses of action. Hours and hours of consultation with doctors helped us gain a new perspective on how to engage and help children with Rett syndrome.

Meanwhile, Shanay has been the happy kid she has always been. Indeed, her energy and joy of life keep us all motivated and hopeful: motivated in making sure that she remains joyful no matter what the syndrome might cause; hopeful that the [Rett Syndrome Research Trust's](#) incredible achievements and all the researchers involved in finding treatments or a cure for Rett syndrome will come to fruition.

To celebrate Rett Syndrome Awareness Month, we have started a crowdfunding campaign, [A Cure for Shanay](#). All of the money we raise goes directly to the Rett Syndrome Research Trust, which uses the funds to advance research for a cure.

Can you help Shanay and all of the 350,000 people across the globe with Rett syndrome? We are so grateful for anything you can give: <https://rettgive.org/campaigns/a-cure-for-shanay/>

Shanay has opened our eyes to a new world with fantastic possibilities. A world in which her smiles and movements tell us volumes about its corners and wonders. We hope you will join us on Shanay's journey.

Thank you,

✦ **TIP: Create a few versions of your email to speak more personally to different people.**

For example, you might have a slightly different message for people you know from your child's school (who may have experience interacting with your loved one with Rett) than for your colleagues who may not know about the diagnosis and might need more explanation.

In addition to tailoring your message, you may also want to send out emails that have suggested giving amounts based on what you know about how much a person can give. If you think your neighbor can afford a larger contribution, ask them directly for a donation of \$100. It would be a missed opportunity if you only ask them for \$20 but they could easily give \$100.

✦ **TIP: Don't stress about asking for money.**

Asking for money – even over email – can seem like a difficult thing to do. Speaking from experience, however, people connected to Rett families want to help, and asking them to make a donation is an easy way for them to know they are making a difference.

✦ **TIP: Don't get stuck writing a unique email for each person.**

This is time consuming and can be discouraging if people don't respond. (It's true: some people won't give or respond to your email. This doesn't mean that they don't care about you or your child, or that you're not doing a good job of outreach, it's just what happens sometimes.) Write a standard email and then make a few variations based on people's familiarity with Rett syndrome and how much you think they can give.

✦ **TIP: Before you hit "Send," consider your subject line.**

There are many ways to craft a strong subject line, and you should choose the approach that's right for you.

SAMPLE SUBJECT LINES

- / *Can you help make a difference for Eleanor?*
- / *Laura's struggle with Rett syndrome – and how you can help*
- / *Reaching out about fundraising for a Rett syndrome cure*
- / *Grace has Rett syndrome, but a cure is possible*
- / *Please help make a difference in Rett syndrome research*
- / *You might not know that my daughter has Rett syndrome*

2 Create social media content to ask your followers to donate.

If you're active on social media you have a built-in audience that is ready to support your efforts to fundraise for Rett research. If you've already written your short description of your child and her story, again, great news!

You have practically written your social media posts.

Pull tidbits of your child's story and package them for social media. Using the sample description from above, here are a few ways you could create social media posts.

SAMPLE SOCIAL MEDIA POSTS

Post #1

Shortly after her third birthday, my daughter Shanay no longer uttered the words she could easily express a year before. Eventually she was diagnosed with Rett syndrome, a devastating neurological disorder that robs her of many basic functions. To celebrate Rett Syndrome Awareness Month this month, I've started a crowdfunding campaign to support research into a Rett cure. Can you join Shanay and me in our journey by making a contribution? Thank you so much.

Post #2

When my daughter Shanay was diagnosed with Rett syndrome at age 3, my family and I were devastated. Yet although she had a debilitating disorder, Shanay kept smiling, laughing, and playing around. And it was her energy that made us recuperate and start the search for possible courses of action. Since then we have discovered the Rett Syndrome Research Trust, which is driving progress for a Rett syndrome cure. If you can donate to my Rett Syndrome Awareness Month crowdfunding campaign, Shanay and I would be so grateful.

Post #3

Ever since my daughter Shanay was diagnosed with Rett syndrome at 3 years old, she has remained the happy kid she has always been. Her energy and joy of life keep us all motivated and hopeful. And we are also motivated by the incredible achievements researchers have made to understand and treat the disorder, many of which have been spurred by the work of the Rett Syndrome Research Trust. October is Rett Syndrome Awareness Month, and I'm raising money to ensure that research progress continues for Shanay. Please join me by making a donation.

Post #4

With my daughter Shanay's diagnosis of Rett syndrome, she has opened our eyes to a new world with fantastic possibilities. Even though she can no longer speak to us, Shanay still says volumes with her smiles and movement. I want nothing more than a cure for Shanay and the 350,000 people around the globe with Rett syndrome. This month is Rett Syndrome Awareness Month, and in addition to raising awareness I'm also raising money to cure this devastating disorder. Any amount you can donate to my crowdfunding campaign will make a difference for Shanay and everyone with Rett.

★ TIP: Create content that is specific to the social media platform you're posting on.

- / **On Facebook:** Craft a compelling message and post the link to drive people to your campaign.
- / **On Instagram:** Post your best pictures, tell people in your post why you're fundraising and that they can find the link to your campaign in your bio. And then don't forget to put the link in your bio!
- / **On TikTok:** Create a video that breaks down an aspect of your and your loved one's life, including why you're fundraising, letting viewers know they can find the link to your campaign in your bio. And then don't forget to put the link in your bio!

3 Follow up over email and on social media.

Sometimes we all need a reminder or a little nudge to do something, even if we want to do it. Some people in your network will need a couple "asks" before they make a donation. The good thing is that **you have the entire month of October** to remind people about your campaign and how their dollars make a difference for Rett syndrome research.

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- ★ **TIP: Create an “outreach calendar”** to remind you when to follow up through email or on social media. Setting dates for your outreach can help keep you on track to follow up with potential donors.

SAMPLE OUTREACH CALENDAR

- / **October 1 – email & social media:** Send outreach emails to list of potential donors and put social media post #1 on Facebook and Instagram.
- / **October 8 – social media:** Put social media post #2 on Facebook and Instagram.
- / **October 15 – email:** Send a short reminder email to everyone who hasn’t made a donation yet. Seriously, keep the reminder short. Forward the original email with the note:
“Hi! Just wanted to make sure you saw this message I sent a couple weeks ago. Rett Syndrome Awareness Month is going strong, and if you’re able to make a contribution to my campaign I would be so grateful. Let me know if you have any questions, I’d love to talk more. Thanks!”
- / **October 18 – social media:** Put social media post #3 on Facebook and Instagram.
- / **October 27 – social media:** Put social media post #4 on Facebook and Instagram.
- / **October 31 – email:** Send out the final “thank you” and “reminder” email to everyone on your email list (see more on this in next section).

4 Thank your donors.

Your donors will appreciate a “thank you” after donating – most everyone likes to be recognized when they do something generous! In addition to thanking people individually over email or text, consider creating one or more social media posts and/or sending an email thanking everyone who has donated so far. **Making your “thank you” public can encourage people who haven’t given yet to take the action and donate.**

Everyone who makes a donation to a RettGive campaign will receive an automated email from RSRT acknowledging their gift and thanking them on behalf of the organization.

- ★ **TIP: Tag the people you’re thanking who are on that platform in your “thank you” post.**
This will alert them that they’ve been recognized.

- ★ **TIP: Send out a final “reminder” email that includes your “thank you” to encourage last-minute donations.**
At the very end of Rett Syndrome Awareness Month, send an email to everyone you emailed at the beginning of the month. This email serves the dual purposes of thanking your donors and giving others one last shot to donate. For example, this email can include:

- 1 / **A message of thanks** to everyone who donated to your campaign (you can name people or just say thanks in general).
- 2 / **A final message** to those who haven’t donated yet:
“Rett Syndrome Awareness Month isn’t over yet, so if you haven’t donated to my campaign there is still time! Even \$10 makes a difference.”
- 3 / **A final message** about why you are so hopeful about Rett syndrome research.

IN CONCLUSION ...

RSRT is singularly focused on a cure for Rett, and success requires funding. The more funds we raise as a community, the faster the research gets us to a cure. We hope this guide to crowdfunding on RettGive helps motivate and excite you about the possibilities for YOU to fundraise and join hundreds of other Rett families in our progress.

If you have any questions or want to talk through any aspect of your RettGive campaign, please reach out to RSRT Chief Development Officer **Tim Freeman** at tim@rsrt.org or 609.309.5676.

Thank you for all you do. Together we will cure Rett syndrome.