



\$31k in 31 Days Fundraising Kit



Dearest friends,

Welcome to the **\$31k in 31 Days Fundraising Kit** — and thank you for joining us in this important mission. Every October, our community comes together during **Joubert Syndrome Awareness Month** to shine a light on Joubert Syndrome (JS) and to raise critical funds that fuel hope, resources, and connection for families around the world.

This year, our goal is bold: **raise \$31,000 in just 31 days**. We know it can be done — because it's powered by you. Families, friends, and loved ones are at the heart of this campaign. By sharing your story, rallying your network, or simply spreading awareness, YOU are making a difference.

The funds raised through this effort directly support:

- **Grants for families** to use for mobility devices, physical therapy intensives, or home support
- **Resources for newly diagnosed families**, helping them navigate those first overwhelming months
- **Our biennial family & scientific conference** that brings hundreds of families together with JS experts and researchers
- **Awareness and advocacy** efforts that bring Joubert Syndrome into the global conversation
- **Educational webinars** for our community unable to connect in-person at conference or meet-ups

Inside this kit, you'll find everything you need to get started: email & social media templates, how-to's and ideas for your own fundraising efforts, as well as tips to make your fundraiser simple and effective.

We know asking for support can sometimes feel daunting — but remember this: **people want to support causes that matter to the people they care about.** By sharing why this campaign is meaningful to you, you give others the opportunity to join something bigger than themselves.

Our volunteer-led foundation would be nothing without your continued support. Together, we can reach \$31,000 in 31 days — and in doing so, ensure that no family facing Joubert Syndrome ever feels alone.

With gratitude and hope,
Melissa Fields, President



Key Facts About Joubert Syndrome

In the spirit of October being Joubert Syndrome Awareness Month, here are some quick facts about JS you are welcome to include in your fundraisers and awareness campaigns.



Joubert Syndrome is a rare genetic disorder that affects the brain, balance, coordination, and development. A distinctive brain malformation called the “molar tooth

sign” is seen on MRI.

Usually, Joubert Syndrome is inherited in an autosomal recessive pattern — meaning both parents carry one copy of the altered gene, though they typically show no symptoms. Rarely, it can also be X-linked.

Common features include low muscle tone, difficulty with balance and coordination, abnormal breathing patterns, abnormal eye movements, and developmental delays. Severity varies widely from person to person.

Joubert Syndrome is considered a ciliopathy (a disorder of the cellular cilia), and it can also affect the eyes, kidneys, and liver in some individuals, so early detection and frequent monitoring is recommended. Many families face a long journey to diagnosis, which typically involves both an MRI and genetic testing.

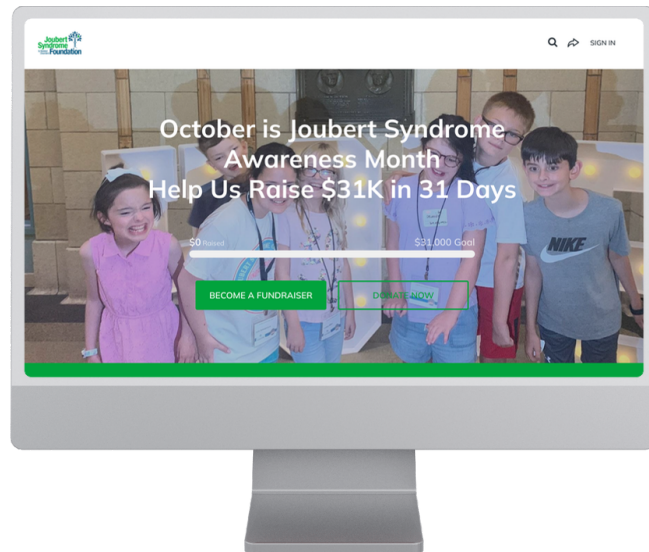
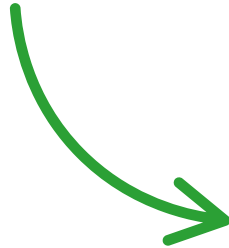
Successful Fundraising Tips & Tricks

- **Personalize your outreach:** Tell your story and why you're passionate about the cause.
- **Set a clear goal:** Having a specific fundraising target can motivate you and your donors. \$500 is the recommended individual goal.
- **Share updates regularly:** Keep your donors informed about your progress and the impact of their donations.
- **Thank your donors:** Express your gratitude to everyone who contributes to your campaign.



How To: Setup Your Fundraiser

Click here to get started!



1. Navigate to our \$31k in 31 Days Sign-up [page](#)
2. Click "Become a Fundraiser"
3. Choose whether to join an existing team, create a team, or as an individual. If unsure, starting as an individual may be best.
4. Click "Sign in" if you already have a Classy or GoFundMe account or "Create an Account" if you do not.
5. Set your goal for this campaign - we'd recommend between \$500 - \$1000, then set your landing page's headline - make it personal for your family!
6. Click Finish!
7. Now that your page has been created, click on Manage to add more details and personalize to tell your family's story and how Joubert Syndrome has impacted you.
8. Afterwards, you're all set! Make the first donation, then share the link to your page with family, friends, and/or coworkers.

Social Media Templates & Ideas

Diagnosis Story:

Our journey with Joubert Syndrome began when [child's name] was [age]. After months/years of searching for answers, we learned about JSRDF and found a community that understood.

This October, we're joining the \$31K in 31 Days challenge to help other families get the same support we did.

Will you give in [child]'s honor to make a difference?

💙 Donate here: [personal fundraiser link]

Simple Personal Ask:

This October, we're raising \$31,000 in 31 days for Joubert Syndrome Awareness Month. Every gift brings us closer to our goal and helps families like ours.

Will you join us?

💙 Donate here: [personal fundraiser link]

Program Impact Story:

One of the most meaningful experiences our family has had was attending the JSRDF Conference in [city]. [child's name] enjoyed [sibling camp/activity], we connected with families who understood our journey, and learned from leading medical researchers in the field of Joubert Syndrome and related disorders.

We'd love for more families to have this opportunity — so we're raising funds as part of \$31K in 31 Days as part of Joubert Syndrome Awareness month this October.

💙 Give here: [personal fundraiser link]

Challenge/Progress Update:

We're taking on [challenge: walking 31 miles, doing 31 acts of kindness, etc.] this October to raise funds for Joubert Syndrome.

We've completed [progress update] so far — will you help us reach our goal?

💙 Give here: [personal fundraiser link]

Make sure to add #31kin31days, #JoubertSyndrome, and #JoubertSyndromeAwareness hashtags and tag the JSRDF so we can re-share your stories!

Email Template

Subject line options (pick one):

1. Help me support families living with Joubert Syndrome 💙
2. Join me in raising \$31k in 31 days for Joubert Syndrome Awareness Month
3. Together we can make a difference for rare families this October

Body:

Hi [Friend's Name],

I'm reaching out because this cause is personal to me. As you may know, my [child/relative/friend], [Name], was diagnosed with Joubert Syndrome (JS), a rare genetic disorder that affects the brain, balance, and development. Families like ours often feel isolated, but the Joubert Syndrome & Related Disorders Foundation (JSRDF) has given us connection, hope, and support.

This October, I'm joining their annual campaign: \$31k in 31 Days. The goal is simple but powerful — raise \$31,000 during Joubert Syndrome Awareness Month to fund resources, conferences, childcare, and awareness efforts for families like mine.

Here's how you can help:

- 👉 Donate to my page: [Insert your fundraising link here]
- 👉 Share this campaign with your friends and family
- 👉 Learn more about Joubert Syndrome at www.jsrdf.org

Every gift, no matter the size, brings us closer to ensuring that no family faces Joubert Syndrome alone.

Thank you for supporting something so close to my heart. 💙

With gratitude,
[Your Name]



Remember to include photos in your email to make the message more personalized to YOUR family!

31 Fundraising Ideas for Every Family

Want to support JSRDF's \$31K in 31 Days campaign but not sure where to start? We've put together 31 simple, creative, and family-friendly fundraising ideas so anyone — anywhere — can get involved.

1. Ask 31 friends to give \$31.
2. Post a family photo with your fundraiser link.
3. Set up a birthday/anniversary fundraiser.
4. 31 Miles in 31 Days (walk, run, roll, swim).
5. Cookbook fundraiser — gather recipes from friends/family, sell as a PDF with proceeds to JSRDF.
6. Read 31 books in October (kids can join in).
7. 31 Acts of Kindness challenge with donation pledge.
8. Coffee for a Cause — donate the cost of your morning coffee for one week.
9. Matching gift challenge — ask an employer or family member to match donations up to a certain amount.
10. 31 push-ups a day fitness challenge with sponsor pledges.
11. Create a "31 Things I'm Grateful For" list and share one each day with your donation link.
12. 31 photos in 31 days challenge — share one each day with your fundraising link.
13. Host a trivia night.
14. Virtual paint-and-sip night with a donation to join.
15. Organize an online craft class.
16. Livestream a bake-along or recipe demo.
17. Bake sale or chili cook-off at school or work.
18. Backyard BBQ with admission fee
19. Host a board game night with suggested donations to play.
20. Yard sale with proceeds to JSRDF.

Quick & Simple

Asks

Fun Challenges

Virtual Events

In-Person Events

October Tie-Ins

21. Talent show (kids, teens, or adults — donate to perform or attend).
22. Awareness wear day (everyone donates \$5 to dress in blue or green).
23. Pumpkin carving contest or party – BYOP.
24. Spooky movie night with donation entry.
25. Halloween candy “buy-back” for donations.
26. Host a costume contest (in-person or online, \$5 to enter).
27. Pet costume parade — donations to enter or attend.
28. Silent auction — gather donated items, services, or crafts to auction.
29. Holiday prep workshop — teach wreath-making, gift wrapping, or cookie decorating.
30. Give up one luxury (coffee, takeout, streaming for a week) and donate the savings.
31. Share your Joubert story (or why you care) in 31 sentences across social media — with a link to donate.

Your fundraiser doesn't need to be big or complicated to make a difference. What matters most is showing up, sharing your story, and inviting others to join you in supporting families living with Joubert Syndrome. **If you have any questions, wish to get more involved with the foundation or have some new ideas, we'd love to hear from you! Reach out at info@jsrdf.org.**