

## Sample Social Media Posts:

- I am raising funds for a treatment to prevent vision loss. Odylia Therapeutics, a nonprofit biotech, is developing a gene therapy to treat vision loss caused by mutations in the RPGRIP1 gene. You can help, all donations make a difference. Visit: *(link to your fundraising page)*.
- Imagine a possible cure for a rare disease is discovered, but then 'shelved' because there is not enough profit to be made from it, because there are too few people in the world with that disease. Odylia Therapeutics champions these rare disease programs to prevent this from happening- using donations from people like you and me to manufacture treatments instead of depending on traditional business models. Your support will make a difference *(link to your fundraising page)*.
- Odylia Therapeutics is reinventing how treatments can be brought to patients with rare diseases. They are a nonprofit building innovative partnerships and unique solutions to fundamentally change drug development for rare disease. Join me in supporting their work at *(link to your fundraising page)*.
- Discovering treatments for rare diseases is not harder than any other disease. *But* developing them usually won't provide as big a financial gain. That is why Odylia, a nonprofit biotech, is working to change the story. With support from people like you and me, they can continue to develop a treatment for RPGRIP1, and move it to clinical trials. Would you consider supporting this work? *(link to your fundraising page)*.
- Did you know that in the USA 1 in 10 people have a rare disease and 50% of them are children? We must do all that we can to support the development of treatments for rare diseases. I'm raising funds to help a nonprofit, Odylia Therapeutics, manufacture a gene therapy to prevent vision loss caused by RPGRIP1 gene mutations. Will you join me in supporting their work? *(link to your fundraising page)*.
- 40 million people in the US have a rare disease. 80% of rare diseases have identified genetic origins, yet 95% of rare diseases do not have a single FDA approved treatment. This is not acceptable. Odylia Therapeutics, a nonprofit biotech, is working to change the way treatments are brought from the lab to clinical trials. Join me in supporting their work at *(link to your fundraising page)*.

## Sample Emails:

#1

Hello [name],

You might remember that my [relation] was diagnosed with a rare disease called [LCA6/ CORD13/ juvenile Retinitis Pigmentosa] that causes vision loss. It is caused by a mutation in the RPGRIP1 gene. I've just launched a campaign to raise [goal] to support the development of a treatment for this disease. Odylia Therapeutics is a nonprofit working to manufacture the treatment and complete the final studies required before clinical trials.

[LCA6/ CORD13/ juvenile Retinitis Pigmentosa] caused by mutations in RPGRIP1 is a rare disease, so there is very little commercial interest because the perceived profits are too low. It is frustrating to know that a possible treatment has been discovered but isn't being developed because there is a lack of funding. So, I'm writing to ask if you would consider joining me in supporting this program directly with a donation: ([link to your fundraising page](#)).

I know there are many fundraisers out there and I truly appreciate your consideration. Every bit will help and together will make a difference for people who have this rare disease. If you have questions, please let me know.

Many thanks,

#2

Dear [name],

Did you know that in the US, 1 in 10 people have a rare disease and 50% of them are children? That number surprised me, but not as much as when I found out that 80% of rare diseases have identified genetic origins, yet 95% of rare diseases do not have a single FDA approved treatment. Although the science and technology now exist to treat many of these genetic diseases, most pharma companies or biotechs do not find it profitable enough to develop these treatments. I want to change that reality, so I created a fundraiser to support Odylia Therapeutics, a nonprofit biotech working to change the way treatments for rare disease are brought from the lab to patients: ([link to your fundraising page](#)).

Funds raised will enable development of a treatment for vision loss caused by mutations in the RPGRIP1 gene. Your donation will directly support manufacturing and safety testing for clinical trials. People like you and me are coming together to support this program because there is no commercial interest. The future of this program depends on private support. Would you consider making a gift to this campaign? Every donation will support the RPGRIP1 Project and will make a difference.

Let me know if you have any questions and thanks for your consideration.

Sincerely,

*Got questions? Contact Odylia's Director of Development at [hgreene@odylia.org](mailto:hgreene@odylia.org).*