



# FUNDRAISING FOR NORD

## Setting up your Fundraiser:

### 1. Decide on your fundraising Page

- Will you host an event? Will it be in person or virtual? Are you planning a social media campaign?
- Should an agenda or plan for the day be part of this? Please keep in mind that NORD has videos and other resources available for you to share online.
- Who in my community will help me?

### 2. Set a fundraising goal- When deciding on how much you will raise, consider the following:

- Will I be able to hit the goal in the time frame?
- Do I have a group of individuals helping me?

**Remember: You can always increase your goal if met early!**

### 3. Tell your story- Making your page personal will help get more supporters.

- Share your connection to rare disease.
  - i. **Example:** My friend/niece/uncle, etc has \_\_\_ condition, which only affects \_\_\_ in\_ people.
- Share the “why” behind your campaign. Why are you fundraising for NORD? What does it mean to you for your friends and family to donate?

#### Add statistics about rare disease

- ✓ 300 million people worldwide are living with a rare disease. Rare disease currently affects 5% of the worldwide population.
- ✓ Any disease affecting fewer than 200,00 people in the United States is considered rare.
- ✓ 25-50 million Americans are living with rare disease.
- ✓ Collectively the number of people living with a rare disease is equivalent to the population of the worlds 3<sup>rd</sup> largest country.
- ✓ There are 7,000 + identified rare diseases.
- ✓ 72% of rare diseases are genetic.

- ✓ 70% of genetic rare diseases start in childhood.
- ✓ Many rare diseases may result in premature death of infants or can be fatal in early childhood.
- ✓ There are an estimated 200 rare cancers. 1 in 5 cancers are rare.
- ✓ More than 90% of rare diseases are still without FDA-approved treatment.
- ✓ 5-year survival rate is lower for patients with a rare cancer than for those diagnosed with a more common cancer.

4. **Add your connection to NORD** – Why are you fundraising for NORD

- What does NORD do for the rare disease community that is meaningful and important to you
- Share NORD's Mission and Work

**This past year, NORD was able to support the community in groundbreaking ways:**

- ✓ NORD launched its Rare Disease Centers of Excellence (NORD RD CoE), a first of-its-kind network of U.S. medical institutions dedicated to diagnosing, treating and researching ALL rare diseases.
- ✓ NORD provided direct assistance to nearly 10,000 patients and caregivers so that they can access life-saving medication and treatment. NINE brand new assistance programs were established this year alone!
- ✓ NORD continues to advocate for federal and state policies that support the rare disease community. We supported 11 states in establishing Rare Disease Advisory Councils.
- ✓ NORD provide support, tools and empowerment to over 40 patient advocacy groups to mobilize their communities to accelerate research through the collection of patient reported data.
- ✓ NORD created invaluable opportunities for patients and families affected by rare diseases to come together each year to educate, inspire and support one another and provided financial support for patients and families to attend.

5. **Be the first contributor**- There is no better way to jump-start your fundraising than making the first contribution yourself.

## Now that your fundraising page is set up, it is time to spread the word!

6. **Email-** Spread the word to friends, family, & your community by sending out emails sharing your campaign and asking for donations.
  - Provide information about the event (Name, Time & Date, Location)
  - Add any specifics about the event and about your connection to NORD
  - Provide information on the organization and the work they do. Also, facts about the cause, mission statement and other relevant information for participants to share with their networks. This is not only good for fundraising but also for promotion of your organization.
  - Engage Donors by sending a thank you email

### [Email Templates available](#)

7. **Social Media-** Share your campaign page on all your social media channels: Facebook, Twitter, Instagram, Tik Tok, YouTube, Snapchat & LinkedIn.
  - Post about why you are supporting NORD and include information about your fundraising goals.
  - Share articles or videos about NORD and rare diseases so potential donors know where their money will go:
    - i. RDD video: [https://youtu.be/NNhY-v0\\_kzU](https://youtu.be/NNhY-v0_kzU)
    - ii. 10 Things You May Not Know About Rare Diseases: <https://youtu.be/7QKum6ihGyE>
    - iii. Show Your Stripes: [https://www.youtube.com/watch?v=NNhY-v0\\_kzU&list=PLMmYBWQscoiFCL5mFqSVq3d3VJ4a1Vt-i&index=1](https://www.youtube.com/watch?v=NNhY-v0_kzU&list=PLMmYBWQscoiFCL5mFqSVq3d3VJ4a1Vt-i&index=1)
    - iv. RDD thank you from Peter:
  - Remind your followers that no amount is too small- all donations help to push you to your fundraising goal
  - Engage supporters by liking comments, thanking them, and commenting on their posts
  - Add useful hashtags
    - i. **#ShowYourStripes**
    - ii. **#RareDiseaseDay**
  - Remember to share the link to your fundraising page in your posts
  - Post often to promote your event and fundraising goal. Make sure to include any updates to keep supporters aware of your progress.

- **Social Media Challenge:** Do a 24-hour challenge to your friends to support you. Ask for \$10 from 10 friends or \$20 from 5 friends and you raised \$100. \$10 from 20 friends you are at \$200 and so on! Post throughout the timeframe and share facts and information about the cause you are supporting. Be sure to include why it's important to you. Make it personal and be sure to thank those donors who do support you!
8. **Get Matching Gifts-** Encourage supporters to explore their employer's matching gift programs. Ask your company to match what you raise to double the effort.

