Fundraising Toolkit
EURORDIS is a non-governmental patient-driven alliance of rare disease patient organisations.

By fundraising for EURORDIS, you are supporting the 30 million people living with a rare disease across Europe.

Thank you for your support.

What's inside this toolkit?

- What we do
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- How to pay in funds raised
- What your money could help us do
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If you have any questions, please contact us at donate@eurordis.org
What we do

Rare diseases are largely unknown, seriously debilitating, chronic and often life-threatening. People with rare diseases face many challenges including access to diagnostics and treatments, financial burdens and isolation. People affected by rare diseases often rely greatly on the support of communities.

We work to build a strong pan-European community of patient organisations and rare disease patients, to be their voice at the European level and to fight against the impact on the daily lives of all those living with a rare disease.

Key figures 2015

- 695 Member patient organisations
- 63 Countries (All 26 EU Countries)
- 52 European federations
- 39 Staff members
- 320 Volunteers
- over 1000 Patient groups represented
- 38 National alliances

Here are just a few of our most recent achievements, which your funds could contribute to sustaining and improving:

- We have nearly 700 member patient organisations, in over 60 countries.
- Rare Disease Day 2015 events were organised in more than 85 countries, including all EU countries.
- There are more than 75 RareConnect online patient communities for people living with a rare disease.

Before you get started

Get online

Set up and create your own online fundraising page to track donations, update content and ask your family and friends to support your fundraiser.

There are many online sponsorship platforms available like iRaiser or BetterNow for example. Search online for a user-friendly platform that works in your country then sign-up and create your fundraising page.

Tips to boost your fundraising:

- Ask your employer to support you by matching what you raise
- Spread the word about your event and the cause that you are fundraising for; you may inspire others to do the same!
- Use social media and personalised emails to share your message - keep your content bright, snappy and informative.

Who can I contact with questions?

For questions about fundraising for EURORDIS, donations and tax receipts, contact EURORDIS: donate@eurordis.org
**Fundraising ideas**

**Active events**

Enter a local sporting event and challenge yourself, get fit and have fun, all while raising funds for EURORDIS! Get friends, family or colleagues involved and form a team.

Here are just a few types of events you could consider participating in:

- Sponsored run
- Sponsored walk or hike
- Sponsored cycle
- Sponsored triathlon
- Sponsored swimathon
- Sponsored ball games like netball, basketball, football or rugby
  - excellent for raising money with friends and family!
- Summer sports like tennis, cricket, or golf
- Something silly, like an obstacle course that children can easily take part in

**Quick and classic events**

Here are some quick and practical ways to fundraise; set a fundraising goal and use one of the following activities to reach it!

- Bake a difference — a fun and easy classic! Bake tasty treats to sell.
- Book sale — ask your friends and family to donate their unwanted books to sell.
- A close shave — set a fundraising target, if you raise enough money, get your head shaved or get something waxed!
- Run a sweepstake amongst your family and friends for a big sporting event and donate the takings.
- Let it grow — for men: get sponsored to grow your facial hair.
  - Let it grow until your fundraising target is reached.
- A close shave — ask friends and family to donate items to sell!
- Go pink, red or green — get sponsored to dye your hair one or several colours.
- Auction of promises — who will bid the highest to have someone else do the cooking all week?

Keep sporting events fun by gathering lots of people to cheer you on!

You could also include fancy dress and props.
 Donate your birthday gifts

Celebrating the day you were born is a special occasion; balloons, cake and presents present present presents.

Turn your birthday into a fundraiser and help people affected by rare diseases, and their families. It’s easy. Instead of presents, ask for donations.

• Create a Fundraiser

This part is really simple – create your birthday fundraising page on a social sponsorship platform such as iRaiser or BetterNow.

The process should be self-explanatory, and we can provide pictures for you if needed.

• Promote Your Fundraiser

Now that your fundraising page is ready, you have to promote it!

Post about it on Facebook, often! Facebook is a great way to share your campaign with people who might be interested. Anyone can see and contribute to it. It’s also a great place to thank your donors.

Send some emails! Friends and family (even distant family) are also good targets for email.

Fundraising at work

Many companies have Matched Giving or Top Up schemes which can double or even triple charitable contributions made by their employees.

Matched Giving is a system where your employer will match a sponsorship total or money raised at a fundraising event organised by employees.

There are many different schemes which apply to event sponsorship, fundraising or payroll giving. Ask your manager or HR department about schemes within your organisation or company. Even if there is not a recognised scheme, your employer may be willing to support you to raise more money for EURORDIS.

See our Fundraising at work toolkit for tips on organising a fundraiser at work.

Give it up for rare diseases

Give up a bad habit and raise money while doing it!

Choose any month of the year such as February (when Rare Disease Day takes place) and see how much you can raise by getting sponsored to give something up for the whole month.

Give something up, such as:
- Smoking
- Alcohol
- Caffeine
- Fizzy drinks
- Unhealthy snacks
- Take away food
- An addictive hobby (e.g. Video games)
Other ideas

Once you have some experience with fundraising, why not aim even higher? Together with your friends and family you could try one of these fundraising events:

**Babysitting fundraiser** (level: easy)
Babysit for holiday shoppers and parents who want to go out on Valentine’s Day. Be sure to check that your insurance covers it!

**Pamper party** (level: medium)
Hold a pamper party for your friends, colleagues or women in your community! This is a great way to get to know people while fundraising. Ask people to pay per treatment or for the whole evening, and watch everyone relax and enjoy themselves!

**Dinner party** (level: medium)
Create an unforgettable evening! Host your own dinner party and ask your guests to donate what they would have paid for the same meal in a restaurant.

**Movie night** (level: medium)
Find a space in which you can host a crowd, ask someone to provide projection equipment (explain that it is for charity, you could ask your local cinema) and choose a classic film for people of all ages. Charge people for their tickets and gather your friends to help you provide snacks for a true cinema experience.

**Auction** (level: hard)
Donate your time, talent or treasures to be auctioned off to the highest bidder all for a good cause! This could be as simple as an auction of promises in your office, or something more challenging like an art auction:
Organise an art exhibition inspired by one or two prominent features (e.g. a city’s sea breeze and the vitality of its port life). Think about engaging local/international artists and art students, as well as people living with a rare disease who are interested in the theme of the exhibition.
Exhibit the artwork in galleries and cultural institutions during a certain time and announce an auction of the artwork pieces on the last day of the exhibition.

**Top Tips**

- Be as enthusiastic as possible and remember to have fun! The more fun the event, the more people will want to get involved now and in the future.
- Spread the word about your event in advance, starting with people within your own network and ask them to reach out to others to increase sponsorship. You could even inspire others to hold their own event!
- Think about all the different ways you can spread the word: word of mouth, social media, personalized emails, your company’s intranet, etc.
- Set up a suggested participant donation. Keep prices to round numbers but remind people that every little bit helps!
1. **Tell us about your plans**
   Contact us to let us know what you are planning to do.

2. **Choose your activity**
   A few questions to consider as you begin planning:
   1. Who do I want to support my efforts and what interests do they have?
   2. Who do I know who can help me fundraise and spread the word?
   3. What kind of campaign or event will my community respond best to?
   4. What event do I have the time and resources to hold?
   5. Are there people or organisations in my community who might like to partner my event?

3. **Set date, time and target**
   You might like to consider that the summer months and school holidays give you more flexibility for your events; people have more free time and sunny weather means that you can hold events outdoors. Evenings are the best time for movie marathons, dinner parties etc. Setting a target of how much you would like to raise will help to keep you on track and incentivise all those involved!

4. **Choose a venue**
   Think about what you have chosen to do and find an appropriate place to do it; explain to venues that you are organising a charity event, they might be very happy to be seen to be involved!

5. **Invite people**
   The key to success for any fundraising event is spreading the word.
   Start with inviting your family and friends and then move to your colleagues and acquaintances from other networks. You can use email and social media to invite your friends. If you are aiming wider you can put leaflets and posters in cafés, libraries, etc. Make sure people know that they are being invited to a fundraiser. Keeping things personal, simple and vibrant works best.

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### Top Tips

- Set yourself a goal of how many people you would like to attend, and how much you would realistically like to raise per guest. Start early and follow up with people; remind them of the event in the build-up. Make sure people know how to get to your event before the day!
- If people can’t come, ask them to make a donation and keep them on your list for the next event.
How to pay in the funds raised

Congratulations - you did it! Now you're ready to pay in the funds you raised to help improve the quality of life of people living with a rare disease.

Online by credit card or bank transfer

Through the EURORDIS donate page.

Online through a fundraising page

By setting up an online fundraising page you can be sure that donations will come directly to us.

You can also easily keep your sponsors up-to-date with your event.

By post

Send your cheques in EUR, made payable to ‘EURORDIS’, along with your paying in form to:

EURORDIS, Fundraising Department, Plateforme Maladies Rares, 96 rue Didot, 75014 Paris, France.

If you would like to support a rare disease patient organisation located in your own country or community, see the list of EURORDIS member organisations and contact them directly.

Please note: Your donation is tax deductible in all EU Member States and the USA

A series of rulings by the European Court of Justice set out a “non-discrimination principle”, according to which EU Member States must award equal tax concessions to charities based in other EU Member States where the foreign charities can be shown to be “comparable” to domestic organisations holding charitable tax status.

Hence, if you are a tax resident of an EU Member State making a donation to a charity having its seat in another EU Member State, you may benefit from a tax deduction equivalent to that which would apply to donations you make to a charity having its seat in your EU Member State of residence.

Please find a summary of tax deduction rules in EU countries here. In case you do not receive the expected deduction, EURORDIS commits to reimburse the corresponding loss. Donation receipts are published in the seven languages of eurordis.org.

In case you need to have a receipt in another language please send your request to donate@eurordis.org.

In case you need to have a receipt in another language please send your request to donate@eurordis.org.

Please send the document from your fiscal administration refusing the deduction to donate@eurordis.org.

Please note: Your donation is tax deductible in all EU Member States and the USA

U.S.-based donors can support our activities in a tax-efficient way through a contribution to the American Friends of EURORDIS at the King Baudouin Foundation United States (KBFUS). Because KBFUS is a public charity, within the meaning of Sections 501(c)(3) and 509(a)(1) of the IRC, donors may claim the maximum tax benefits allowed by U.S. tax law for their contributions. If you wish to support us, here is how to proceed:

• Gifts by check
  Write your check to KBFUS, write “EURORDIS” in the memo section of the check, and send it to KBFUS, 10 Rockefeller Plaza, 16th Floor, New York, NY 10020.

• Gifts by credit card
  Go to www.kbfus.org, click on the ‘Donate Now’ button and select “EURORDIS (FR)” under “Giving Option 1: Nonprofit Partners Overseas.”

• Gifts by wire transfer or to contribute other types of property
  Contact KBFUS at email info@kbfus.org, phone (212) 713 7660.

What your money could help us do

Every donation helps to improve the lives of people living with a rare disease.

Your contribution enables EURORDIS to raise awareness about rare diseases; reduce the feeling of isolation by creating online patient communities, allowing people living with a rare disease to connect with others; and advocate for access to diagnostics, treatments and care for all rare disease patients.

Examples of how your support helps:
Keep it legal

Like every charity, EURORDIS is governed by different rules and regulations. Here’s how you can keep your fundraiser legal.

If you have any questions please contact donate@eurordis.org.

You and EURORDIS

Our supporters raise funds in aid of EURORDIS, but do not represent EURORDIS. We kindly ask that you do not talk about EURORDIS’ policies or positions on specific issues during the event or in any documents which you create.

Money collections

If you want to collect donations at your event, beware that for public collections you need specific permission and licenses depending on the venue. We don’t advise that you ever collect money door-to-door or as part of street collection as it is illegal to do so without license.

For your own protection be sure that you count the money collected together with another person who can verify the amount collected. Ask people who want to make a donation by cheque to make it payable to EURORDIS rather than to you personally.

Make sure any cents and euros are kept in a secure place and banked as soon as possible, then write a cheque made payable to EURORDIS for the amount, to avoid sending cash in the post.

Insurance

If you are planning an event that involves the general public you need a budget for public liability insurance (you can get this from any insurer). If you are planning your event in a place which has liability insurance, you can check with them if you can be covered by their insurance.

Food

At a one-off event you don’t need a license to sell food, but you should follow the food hygiene regulations that apply in your country - check with the environmental health department of your local council to see which food safety laws apply.

Alcohol

If you are selling alcohol as a part of your event you’ll need a temporary license. You’ll need to apply for it at your local magistrate’s court a couple of months in advance of the event. You can offer alcohol at your event without charging for it without getting a license.

If you choose this route, make it clear what is being offered and how much – for example, a free glass of wine with every ticket.

Take care that over consumption of alcohol is not part of your event and have a plan in place in case this does occur, in particular to ensure there is no drinking and driving.

Lotteries and raffles

Legally, lotteries and raffles are defined in the same way and the same rules apply to both.

For private raffles (at your workplace or club) or small raffles that are part of a bigger event, there’s no need to obtain a license. This is the type of lottery we recommend, since it is easy to run and isn’t legally complex.

For small raffles that are part of a bigger event, the results must take place during the event. If you hold a larger raffle that is open to members of the general public, it must be registered with the local council. Due to the legal issues and extra complexity, we suggest you refrain from organising this type of raffle.

Please note that EURORDIS cannot supply prizes for lotteries and raffles.

Health and safety

Please consider first aid, fire safety and the general well-being of your guests. If you need more information about your health and safety obligations then visit the health and safety executive website of your country.
Press release template

Please use the following template to alert your local media outlets about your fundraising efforts. Personalise this template by telling your story. This will hopefully generate publicity for your fundraising activity and support for EURORDIS in your community.

For a press release in PDF format please contact donate@eurordis.org

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Press release

**Title** [sum up your activity within the title]

Insert the date, location of event and your name/your organisation’s name and what you are planning to do here

Example: 21 February, 2015 – Paris. EURORDIS launches fundraiser to combat rare diseases (add any exciting info about your event that you think might grab the attention of journalists).

Insert a quote from yourself or a leader at your organisation here, explaining why you have chosen to support EURORDIS, and how much money you are trying to raise to support our work

EURORDIS works to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and to fight against the impact of rare diseases on their lives. Today, EURORDIS is Europe’s largest patient organisation in the field of rare diseases, representing nearly 700 patient organisations, in over 60 countries, covering more than 4000 distinct diseases. It is the voice of 30 million patients affected by rare diseases in Europe.

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting more than 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

Insert your contact details here so that journalists can ring you if they require further information

For more information please contact [insert contact details here]

Notes to Editors: For more information about EURORDIS and its work, please visit the website: http://www.eurordis.org/