

# TELL YOUR RARE DISEASE STORY



The most important thing to keep in mind is that your story is unique to you and gives readers a sense of how your rare disease has affected you and your family.

## THE BASICS:

- We like our blogs to be quite short – no more than 750 words. Don't worry – we won't cut you off mid-sentence, but we may edit your piece and ask you to review it.
- Try to include sub-headings if you can – it breaks the post up a bit and helps draw attention to key elements.
- Blogs can be as conversational as you like. We encourage bloggers to write in their own voice – after all it's your personal experience!
- Please send us a picture or two with the blog. We would prefer a high-resolution image if possible, and landscape images work best on our website.
- At the end of your post, please include your name and a short biography – a few lines about who you are and what you enjoy. We are happy to publish stories using your first name only or a pseudonym– just let us know your preference. You can also include your website and Twitter handle if you have one.

## WHAT TO WRITE ABOUT:

- What period of your life would you like to focus on? It can help to stick to specific events, such as the time just before diagnosis or joining a support a support group, rather than trying to cover too much.
- What happened then and how did it affect you? Did something happen that changed what you felt was important in your life?
- Has anything changed for you now? What advice would you give to someone going through a similar experience?

## OTHER INFORMATION:

- We may edit your post but we will send it back to you for your approval.
- We will remove any text that is promoting or advertising commercial companies.
- We will only include the names of pharmaceutical companies if we see it as a benefit to patient readership.
- We will share the link to the blog post on social media including Facebook and Twitter, and will encourage our supporters to do the same.
- Please do get in touch with use before writing as we might not be able to publish everything and are happy to offer further guidance.
- You don't have to use your real name if you don't want to.
- By telling us your story for publication on Rare Disease UK's blog, you are confirming that the rights to any materials are yours, and that the sources are credited as necessary. You are also granting Rare Disease UK rights to the copy. We may reproduce your blog, or quotes from your blog, in other materials.

*Rare Disease UK would like to acknowledge that this document draws on the guidelines written by Mind.*