Writing a Blog for M4RD

We believe that asking doctors to **#daretothinkrare** is fundamental to improving the experience of all people living with rare conditions and eliminating the diagnostic odyssey. Working closely with patients, patient advocates and patient advocacy groups to share the real patient experience is vital in enabling us to do this...creating content for the M4RD website and social media platforms is a fantastic way to share the lived experiences.



Top Tips for Content

- What are the key messages that you want to share?
- Provide 6 **key words** that are used regularly in the article, including in titles and subheadings.
- Keep it short! We recommend no more than 750 words. If it's too lengthy, we may edit your piece but will always ask you to review it before we publish.
- Focus on key elements and break the text up with subheadings.
- If you want to highlight a key **quote**, add this in red. It's always good to back-up your post with interesting facts and quotes.
- Include relevant background and context remember that although you're an expert on what you're writing, the reader may not be!
- It's true: less is more! Don't use too much jargon and try to keep your writing concise.
- People like learning about other people. Add a personal element to your story to make it easier for the reader to relate and engage.
- When you've finished writing, go back to the first point: 'What are the key messages that you want to share?' and check that you've achieved this.

If you're writing about your diagnostic odyssey, here are some questions that you might like to consider...

- When did you first suspect something was wrong?
- When was the first time you sought medical help?
- What was this experience like? (Your diagnostic journey/'odyssey')
- What went well?
- What went badly?
- Are there any consultations with doctors or other healthcare professionals that stand out in your mind? Either for positive or negative reasons?
- When were you finally diagnosed and how did it feel to finally have some answers?
- Have you received any consultations with specialist consultants? Can you describe this experience?
- What changed for you and your family after you received the diagnosis?
- What could improve your quality of life?
- Finally, what can we learn from you? What advice can you give to medical students and doctors that might help them diagnose a rare disease in the future?

- We may edit your post but if we make any significant changes we will send it back to you for approval before publishing.
- We will remove any text that promotes commercial companies.
- We will share a link to your guest blog on our social media, including Facebook and Twitter, and encourage you to do the same.
- We will not share your blog or photographs with anyone else to publish or use without asking your permission first, but please be aware that once they are in the public domain we cannot stop other people from sharing or linking to them from their websites and/or social media.
- Your privacy is important to us and we may edit your blog and photos to remove any personal details. You do not have to provide photographs if you do not wish to.
- A copy of the story and any accompanying photos will be kept securely in our password protected files in accordance and compliance with GDPR and your contact details will be held on our secure database. For more details, please see https://www.m4rd.org/m4rd-privacy-policy/ or email info@m4rd.org.

HOW TO SUBMIT

Please submit your blog and any images by completing this <u>form</u> which will also ask for consent to share.