

Inviting Special People (Patients, Families, Healthcare Providers, Scientists & Advocates) to share their story at Rare Is Special™

ABOUT RARE IS SPECIAL

Qualiten Press is developing “Rare Is Special”, a social enterprise to raise awareness for rare diseases and ongoing research & development. “Rare Is Special” will be an interactive online platform to connect a variety of “special” people (patients, families, healthcare providers, scientists, advocacy groups and enthusiasts) who play major roles in research and improvement of healthcare for rare disease patients. The website will include disease information, recent research, case studies, eBooks, events, news, and special stories pages.

INVITATION

Currently, we are inviting different kinds of submissions including but not limited to personal stories, ideas, articles, case studies, books (fiction or non-fiction), picture books, memoir, collection of hobbies, animation, videos, music, etc. from our “special” persons.

Our dedicated special stories webpage will feature people with rare diseases or those who have overcome these diseases. We will be featuring their life stories, experiences, passions, careers, and more. We will also be featuring stories of family members, physicians, nurses, researchers, and advocates involved in study and advocacy of rare diseases. Thus, whether you are a rare disease patient, a family member, healthcare provider, researcher, advocate, or someone with special interest in rare diseases, you are welcome to share your stories that will motivate and support others to talk, connect and create a conducive environment to foster discovery and development of cure. Therefore, we invite you to submit your stories and articles of any kind for review and publication (if approved) at “Rare Is Special”.

SUBMISSION GUIDELINES

If you plan to submit books, videos and music then please write to us to get detailed guidelines. If you would like to submit short stories or articles, then you may find following guidelines useful:

1. **Audience:** Primary audience will be rare disease patients & families, healthcare providers, advocacy groups, and scientists working in rare diseases. All articles will be open access ([CC BY 4.0 - Creative Commons Attribution 4.0 International](#)) and available online to public to read without any restriction.
2. **Language:** We invite submissions in English. We welcome translated version in different languages as well.
3. **Word Limit:** There is no word limit, but 500 to 2500 words are ideal length for short stories and articles.

4. **Structure & Style:** There is no specific structure or style for writing the body of the story. We welcome stories that allow the readers to relate with the author's experiences and bring positivity & hope in their own lives. You may use headings and subheadings when shifting from one aspect to another in your story.

5. **Content:** There are no specific guidelines for content. But you may include following:

For Patients and Families:

- Early life, diagnosis, treatment, influential mentors, life changing events, and other aspects of professional and personal life.

For Healthcare Providers, Researchers, and Advocates:

- Early life, development of interest in science/advocacy, research/advocacy career, influential mentors, life changing events, and other aspects of career and professional life.
- What is your specific area of research/advocacy in rare diseases and how did you end up working in this field? What do you enjoy most about your work? What is the most important thing you have learned about your field and what needs to be investigated further? What are the key challenges involved in researching/advocating rare diseases and developing orphan drugs, and how to tackle them? What is most exciting about your field right now?

Common content:

- What are your major life events or philosophical influences that have impacted your life and career? Any personal/professional failures and/or achievements you would like to share? What are you passionate about and what are your hobbies and free time activities?
- What you think is needed to be done in rare diseases area by governments, advocacy groups, research centers, businesses, and public at global and local levels to raise awareness, advocate for those with rare diseases, expedite research and drug development for rare diseases? What advice would you give to people with a rare disease or family/friends of those with a rare disease? What career advice do you give to next generation of scientists, doctors, nurses, advocates, and students? What would you want healthcare providers to know? What lessons can someone extract from your life?
- It will be nice if you may include real-life examples and experiences while writing your story. Readers easily connect and get motivated by creative and personalized stories with examples and illustrations.

6. **Short Biography for Index Page:** Please include 80 to 100 words biography of yourself highlighting your education, current work, how you are advocating for those with rare diseases, your experience with rare disease, contact information, and any relevant website links (example: social media pages, websites, blogs, etc.). This short biography will be appearing in author section next to your picture at "Rare Is Special" website.

7. **Illustrations:** We highly recommend submission of illustrations as a part of your story. We accept all kind of relevant art, pictures, drawings, paintings, audio, video, etc.

8. **Photographs:**

- a. Submit at least 1 high resolution professional picture with face clearly visible. This picture will be published in author biography section.
 - b. Submit any number of relevant pictures which you think go well with your story. We recommend submission of high-resolution creative images.
9. **Number of Submissions:** There is no limit on number of submissions by each author.
10. **Deadline for submission:** Submission and publication is on rolling basis. However, we request you to please submit your story at your earliest convenience. Please do not hesitate to contact us if you have any questions, we would be happy to help you during the process of planning, writing, and publication.

POST-SUBMISSION PROCESS

What happens after submission of story?

The story will be read by “Rare Is Special” in-house production team and story committee for their feedback to improve the format and content. We will closely work with you while designing your story webpage and send a copy to you for your final approval before publication on “Rare Is Special” website.

Please note that the story submission and publication are parts of our social initiative to help and support rare disease patients and families. We do not provide monetary benefits to the authors of the stories, neither we charge readers to access and read the special stories published with “Rare Is Special”. Your story will empower those with rare diseases and the family and friends of those with rare diseases. Sharing your experience will motivate researchers, scientist, funding agencies, health care agencies, and advocacy groups to allocate more resources for rare disease research, treatment, community, and public awareness. These are few ways your story can make an impact on lives of others. Your support is crucial, and we greatly appreciate any contribution and feedback.

CONTACT RARE IS SPECIAL

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