



## Patient group pairing for the Student Voice Prize 2021- Terms of reference

The Student Voice Prize is an essay competition and collaborative project run by Findacure and Medics4RareDiseases (M4RD). The competition raises the profile of rare diseases among trainee doctors and scientists. It encourages them to consider rare diseases for the first time or share their personal experience of rare conditions. With the winning entry published in Orphanet Journal of Rare Diseases and the runners up in BioMed Central, the best essays have a chance to make a real impact on the work of medical professionals.

As part of this year's Student Voice Prize, we will be giving students the option to request a connection with a rare disease patient group in order to learn first-hand about the condition and patient experience and we encourage you to get involved if this is something of interest to your patient group and patient community.

Please note: **For 2021, the patient pairing application process will run from the 8<sup>th</sup> September to the 6<sup>th</sup> October and applications received after the 6<sup>th</sup> October may not be considered.** After the application process ends, the Student Voice team will be in touch with applicants with more information on the pairing and to connect them with their student pairs if appropriate.

Please read the Terms and Conditions below before deciding whether to get involved. If you have any questions, please email [studentvoice@findacure.org.uk](mailto:studentvoice@findacure.org.uk).

### What is expected of participating patient groups?

Participating patient groups will be expected to:

- Share basic information with Findacure for us to hold in a database to allow us to match students with groups.
- Allow Findacure to share a contact email address with any matched students.
- **Arrange to spend a time of up to one hour in phone or video call conversation with their paired student before 10<sup>th</sup> November 2021.**
- Share information with the student about their rare condition and their experience as a patient.
- Endeavour to answer the student's questions where possible.
- NOT seek medical advice from the student.
- Respect the students other time commitments when arranging calls.
- Ensure that only **ONE** patient representative from the organisation applies to take part in the pairing scheme on behalf of the organisation.
- Ensure that the individual who will speak to the student has a good level of conversational English.
- **NOT write the essay for the student, review or read it prior to submission.**

Patient groups may establish a more prolonged relationship with the student if it is the desire of both parties, but this is neither required nor expected.





## What are the benefits to the patient group?

- The patient group will have the opportunity to discuss their condition with a medical student or scientist, drawing their attention to rare diseases early in their career.
- The patient group will be able to read the essay after judging and share it with their wider patient community should they so wish. **It is permissible for the patient groups to publish the essays on their website or blog after the competition has finished and the winners have been announced, if the paired student is not a winner or runner up and the patient group gets the permission of the author. If the essay was written by a winner or runner up we ask that the patient group does not publish the essay in full but rather links to the published essay on the Orphanet or the Biomed Central website.**

## What is expected from the student author?

- The student will prepare a series of questions prior to their interview.
- They will arrange a time for the interview with the patient group in advance.
- They will respect the views and experiences of the patient representatives.
- They will agree to share an essay that features the disease of their paired patient organisation with that organisation after the competition winners are announced.
- They will maintain confidentiality and not disclose any details that haven't been agreed in advance with the person they are interviewing.
- They will remove any identifiable details about the person they interview - bearing in mind that in such small patient populations it can be easy to identify people with very little information.

## What is the role of Findacure and M4RD?

- Findacure and M4RD will hold your information as part of a database of patient groups interested in supporting the Student Voice Prize.
- When students request a patient group pairing for their essay entry, we will aim to identify a group that matches their broad areas of interest. We will then introduce the student to the patient group via email and leave you to arrange a discussion.

The Student Voice team cannot guarantee that you will be paired with a student and takes no responsibility for either the quality of the student's writing or the ideas or opinions they express in their essay.

To learn more about Findacure's approach to data protection and privacy, you can view our privacy policy: <https://www.findacure.org.uk/wp-content/uploads/2018/07/Findacure-Privacy-Policy-250518.pdf>

You can view Medic4RareDiseases' approach to data protection in their privacy policy: <https://www.m4rd.org/?s=privacy+policy>

