



## Patient group participation form

As part of this year's "Student Voice" Essay competition we will be giving medical students the option to request a connection with a rare disease patient group in order to learn first-hand about the condition and the patient experience.

### What is expected of a participating patient group?

Involved patient groups will:

- 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 conversation with their paired student no later than one week prior to the essay competition deadline of Monday 12th November 2018.
- Share information with the student about their rare condition, and the patient experience of it, as well as answer their questions for their essay.
- NOT seek medical advice from the student.
- 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 trainee medic 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.

### 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.

### What is Findacure's role?

- Findacure will hold your information as part of a database of patient groups interested in supporting the "Student Voice".
- When students request a patient group pairing for their essay entry, we will aim to identify a group that matched their broad areas of interest.
- We will then introduce the student to the patient group via email and leave you to arrange a discussion.
- If an essay is submitted based on your conversation, Findacure will share it with your organisation after the winners have been announced. You will be allowed to share the article with your patient beneficiaries but must seek the authors approval for wider dissemination.



Findacure cannot guarantee that you will be paired with a student and takes no responsibility for the either the quality of the students writing or the ideas or opinions they express in their article.

If your patient group would like to be involved in this project, please complete the form below and return it to [info@findacure.org.uk](mailto:info@findacure.org.uk).

## Patient group participation form

Name of patient organisation	
Rare condition represented	
Name of person who will talk to the student (contact)	
Email of contact	
Position of contact	
Contact's experience of condition (please tick as appropriate)	<input type="checkbox"/> patient <input type="checkbox"/> parent <input type="checkbox"/> carer <input type="checkbox"/> clinician <input type="checkbox"/> advocate
Brief summary of major disease symptoms	

### Declarations

- I hereby agree to take part in the Student Voice Essay competition as a patient group participant as outlined in this document.
- I agree for Findacure to hold to above information for a period of up to two years. Findacure may share that information with their partner organisation Medics4RareDiseases to help with the organisation of the competition. They may also share that information with a student who is interested in learning more about the rare condition my organisation represents.

To learn more about Findacure's approach to Data Protection and privacy, you can view our [privacy policy](#).