



Patient group pairing form

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

This connection should be used to conduct an interview of up to one hour, to learn about the organisation's rare condition, the patient experience of the disease, and to direct questions designed to aid your essay composition.

If you are planning to write an essay focussing on the patient experience of rare conditions, or would like to add this to your essay, this is a unique opportunity to increase your own knowledge of this area.

What is expected from the student author?

-  You will prepare a series of questions prior to their interview.
-  You will arrange a time for the interview with the patient group in advance.
-  You will respect the views and experiences of the patient representatives, and fairly represent them in writing.
-  You will agree that an essay featuring the disease of the paired patient organisation can be shared with that organisation after the competition winners are announced.
-  You will **not** ask the patient group to write the essay for you, or to review it prior to submission.
-  You are **not** expected to provide any medical advice to the patient representative.
-  You do **not** have to maintain contact after the interview, though you may if this is desirable to both parties.

What is expected of a participation patient group?

Involved patient groups will:

-  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.

What is Findacure's role?

-  Findacure will aim to identify a group that matches your broad areas of interest.
-  We will then introduce you to the patient group via email and leave you to arrange a discussion.
-  If you submit an essay based on your conversation, Findacure will share it with that organisation after the winners have been announced. The organisation may share the article with their patient beneficiaries but must seek your approval for wider dissemination.



Findacure cannot guarantee that you will be paired with a patient group and takes no responsibility for the quality of the information you are able to gather.

If you would like to be paired with a patient group to help with your essay, please complete the form below and return it to info@findacure.org.uk.

Patient group pairing form

Name	
University	
Essay question you are answering	
Areas of interest (please provide a brief summary of the types of condition or issues you would like to explore)	

Declarations – please tick as appropriate

- I hereby agree to take part in the Student Voice Essay competition patient group pairing scheme as outlined in this document.
- I agree for Findacure to hold the above information for a period of up to two years. Findacure may share that information with their partner organisation Medics 4 Rare Diseases to help with the organisation of the competition. They may also share that information with a patient group who is interested in talking to me about their rare condition.
- I agree that any essay submitted which includes reference to the disease represented by the group I am paired with may be shared with that group, and with their patient community.

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