

People Raising

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People Raising



- 1) What is your story?
- 2) Listening to patient needs
- 3) Getting patients and families to volunteer
- 4) Motivating volunteers
- 5) Acknowledging volunteers



**What is
your story?**

What is your story?



- What do you hope to achieve?

AKU Society Mission Statement:

“Transforming the lives of AKU patients;
through patient support, community
building and medical research”

What is your story?



- How will you achieve it?

AKU Society Mission Statement:

“Transforming the lives of AKU patients;
through **patient support, community
building and medical research**”

What is your story?



Patient Support:

- Provide reliable, up-to-date information about AKU
- Run annual patient workshops
- Offer individual home support visits
- Provide ongoing support at the National AKU Centre and for DevelopAKUre patients

What is your story?



Community Building:

- Encourage connections through our online communities
- Help raise awareness of AKU among the general public and healthcare professionals
- Establish and support AKU sister societies in other countries
- Unite AKU patients around the world through international patients workshops.

What is your story?



Medical Research:

- Form scientific partnerships
- Fund research to understand and treat the disease



Listening to patient needs

Listening to patient needs



Should be the foundation of your work.

Help to set objectives for your organisation.

Surveys, Questionnaires, even phone calls or conversations with representative members.



Getting patients and families to volunteers

Getting volunteers



1) What needs to be done?

Getting volunteers



- 1) What needs to be done?
- 2) Who are your options?

Getting volunteers



- 1) What needs to be done?
- 2) Who are your options?
- 3) Promotion



Motivating volunteers

Motivating volunteers



1) Regular Meetings

Motivating volunteers



- 1) Regular Meetings
- 2) Respect

Motivating volunteers



- 1) Regular Meetings
- 2) Respect
- 3) Be accessible

Motivating volunteers



- 1) Regular Meetings
- 2) Respect
- 3) Be accessible
- 4) Be flexible

Motivating volunteers



1) Regular Meetings

2) Respect

3) Be accessible

4) Be flexible

5) Have fun



Acknowledging volunteers

Acknowledging volunteers

- 1) Let them know how they have contributed

Acknowledging volunteers

- 1) Let them know how they have contributed
- 2) Involve them in planning new ideas

Acknowledging volunteers

- 1) Let them know how they have contributed
- 2) Involve them in planning new ideas
- 3) Recognise them publicly

Acknowledging volunteers

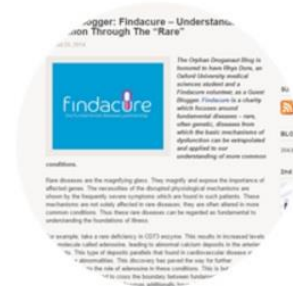
Meet Rhiannon

Rhiannon volunteered for Findacure from October 2015. Wanting to get experience to add to her CV, she volunteered from her home in London 2-3 days a week writing scripts for a video series on the physiology of rare diseases. She also volunteered on-the-day at our London-based workshops and conference. In March 2016, she was spotted by a recruitment agent who put her forward as a medical and video script writer – she got the job! Read [Rhiannon's blog](#) for more about her experiences.



Meet Rhys

Rhys had just finished his second year as a medical student at Oxford University when he joined us as a summer intern in 2014. Tasked with engaging more people in rare diseases and Findacure, he had a lightbulb moment: a [student essay competition](#)! Rhys spent the summer turning his idea into a full project, and his legacy has lived on: the essay competition is now a very popular and well-renowned part of Findacure's annual calendar. Rhys also scanned the scientific literature for examples of how rare diseases are fundamental. He summarised his findings in a blog, which can be [read here](#).



Meet Jane

While working part-time at a local biomedical company, Jane supported the preparations for our 2016 [scientific conference](#). Putting conference packs and name badges together for 100 attendees is a daunting and time-consuming task for a charity as small as ours – but Jane came to our aid! She made materials at home and put the packs and name badges together in the office, in addition to helping us in London on the day. Jane saved us a lot of time and stress!





Thank you!

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+ Alkaptonuria Society →

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