

PRESS RELEASE

Answering questions about rare inherited anaemia

A ground-breaking group of rare disease stakeholders have come together to form a Priority Setting Partnership (PSP) to find out what matters to patients, carers and clinicians in the field of rare inherited anaemias.

The group is calling on all stakeholders in the rare anaemias field to help them address an issue commonly found in the rare disease community.

Patients with rare conditions, and the clinicians that work with them, often have far more questions than they have answers. Research is often scarce in the rare disease community and patient can face a lifelong, life limiting condition without any hope of a cure, and little prospect of any treatment.

Patient groups report that when research is carried out, the issues addressed by researchers are not always in line with those that patients and clinicians feel are the most important.

The PSP on rare inherited anaemias has been set up with funding and administrative support from the NIHR Oxford Biomedical Research Centre. The goal is to ensure that all research seeks to address the questions that patients, their carers and the clinicians working with them, feel could have the biggest impact on their lives.

To this end the Priority Setting Partnership has launched a survey asking for people to consider which questions they think are the most important for researchers to be asking.

Who can get involved?

- The survey can be answered by anyone who has a rare inherited anaemia listed below;
- is a carer or family member of someone with it;
- is a health, or social care, professional caring for people with rare inherited anaemias; or
- is part of an organisation representing and/ or supporting people with rare inherited anaemias.

By Rare Inherited Anaemias, we mean:

- Diamond-Blackfan Anaemia
- Congenital Dyserythropoietic Anaemia
- Congenital Sideroblastic Anaemia
- Red Cell Membrane Disorders
- Red Cell Enzyme Disorders
- Transfusion-Dependent Unexplained Inherited Anaemias

Genetic Alliance UK

contactus@geneticalliance.org.uk
www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

We are calling on groups to disseminate the survey, and help us spread the word about the importance of Priority Setting Partnerships to rare disease patients.

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NOTES

Survey: go to website: <http://www.ouh.nhs.uk/research/patients/priority-setting-partnerships/rare-inherited-anaemias/default.aspx> and follow link to survey

Contact details:

Judith Rogers, Assistant James Lind Alliance Project Co-ordinator, NIHR Oxford Biomedical Research Centre,

Oxford University Hospitals NHS Foundation Trust Churchill Hospital | Joint Research Office | Block 60 | Headington | Oxford OX3 7LE

Tel/voicemail: (01865) 223298 | E-mail: judith.rogers@ouh.nhs.uk

The survey will be open from October 3rd for around 3 months

Facilitated by The James Lind Alliance, PSPs are groups which bring together stakeholders to set priorities for research in a particular disease field. They aim to facilitate the inclusion of patient voice at the centre of priority setting and have collaboration at their core. Template social media:

Tweet sheet

Include #anaemiahaveyoursay in ALL tweets, and @lindalliance & @OxfordBRC in tweets if/when possible and other useful # e.g. #JLA

Survey launch

The JLA Rare Inherited Anaemias PSP survey is now live. Take this short survey to improve research bit.ly/29iN9oU #anaemiahaveyoursay

Ongoing

Do you have a rare #anaemia? What are your priorities when it comes to research? bit.ly/29iN9oU #anaemiahaveyoursay

What questions do you have about rare inherited anaemias? bit.ly/29iN9oU #anaemiahaveyoursay

What questions do you want answered about your #rare #anaemia? Tell us by filling in this survey: bit.ly/29iN9oU #anaemiahaveyoursay

Help us understand what #patients with rare #anaemia want researchers to focus on: bit.ly/29iN9oU #anaemiahaveyoursay

Take this short survey to improve research into rare inherited anaemias bit.ly/29iN9oU #anaemiahaveyoursay

Have your say on future research into rare inherited anaemias bit.ly/29iN9oU
#anaemiahaveyoursay

Questions about rare inherited anaemias? Let us know here bit.ly/29iN9oU to help inform research
#anaemiahaveyoursay

Affected by rare inherited anaemias? We want to hear from you bit.ly/29iN9oU #anaemiahaveyoursay

Take part in our rare inherited anaemias survey – let us know what questions you need answered bit.ly/29iN9oU #anaemiahaveyoursay

What questions about rare inherited anaemias are most important to you? bit.ly/29iN9oU
#anaemiahaveyoursay

Use your voice to play a role in rare inherited anaemias research bit.ly/29iN9oU
#anaemiahaveyoursay

[Help improve research into rare inherited anaemias](https://bit.ly/29iN9oU) bit.ly/29iN9oU #anaemiahaveyoursay

Still time to ask your questions about rare inherited anaemias bit.ly/29iN9oU
#anaemiahaveyoursay

What would be on your wish list of research areas in rare anaemia? bit.ly/29iN9oU
#anaemiahaveyoursay

Survey closing

Rare Inherited Anaemias PSP survey closing soon - let us know what questions you need answered
bit.ly/29iN9oU #anaemiahaveyoursay

Still time to ask your questions about rare inherited anaemias bit.ly/29iN9oU
#anaemiahaveyoursay

Facebook Text

The James Lind Alliance is conducting a survey to find out what patients wish researchers could tell them about their conditions. Take the survey here, and help shape the future of rare anaemia research:
bit.ly/29iN9oU