



We are running a new survey to find out what research questions are the most important to patients and their families.

This leaflet contains more information about:

- the survey,
- why we need your help
- what happens with the results,
- and how you can take part.

Taking the survey

You can complete this survey online:
www.bit.ly/2nd-mito-survey

More information

Web: www.bit.ly/MitoPSP

Phone: 020 7831 0883

Email: amy.hunter@geneticalliance.org.uk

Funded by:



Patient organisations involved:



**HELP SHAPE THE
FUTURE OF
MITOCHONDRIAL
DISEASE RESEARCH**

**November 2019
#mitohaveyoursay**

Who is this survey for?

This survey is for you if you are:

- a patient with a mitochondrial disease,
- a carer (either now or in the past) for someone with a mitochondrial disease;
- or a healthcare professional with relevant experience.

www.bit.ly/2nd-mito-survey

How can I help?

We have collected lots of research questions that patients, carers and healthcare professionals would like to see answered. Now you can complete a survey and tell us which of the questions are the most important to you.



Why do we need your help?

Despite growing research activity in the UK and across the globe there are many unanswered questions about mitochondrial diseases.

Resources for research are limited.

So that future research can be targeted appropriately it is important for research funders to understand which are the most important questions from the point of view of patients, carers and healthcare professionals.

What happens next?

The results of this project will help shape the future of mitochondrial disease research in the UK and beyond.

The project consists of three stages:

- 1.** The first survey, which is now closed, and which collected questions from patients, carers and healthcare professionals.
- 2.** The current survey asking people to rank the questions in order of importance.
- 3.** A workshop to agree the final 'top 10' most important questions.

You can be kept informed about the project by leaving your email address at the end of the survey.