

Ataxia UK: COVID-19 survey of ataxia patients in the UK

Ataxia UK is always looking for ways to better support the ataxia community. The COVID-19 pandemic has raised significant new challenges for all of us. COVID-19 affects patient groups in different ways, and your experiences will help us to understand the particular impact on people with ataxia.

Ataxia UK and their Medical Advisory Panel are interested in understanding whether there is a long-term impact of contracting COVID-19 on patients with ataxia, to provide a focus for future care. **We hope to hear from anyone with ataxia that had confirmed or suspected COVID-19 (“Coronavirus”) since 1st March 2020, and has recovered (by ‘recovered’ we mean feeling that you have recovered or largely recovered from most COVID-19 symptoms).** We would like to know the effect of COVID-19 on your ataxia symptoms, and about your recovery from the virus.

What we learn from this survey will help Ataxia UK and our Medical Advisors to better understand the long-term impact of COVID-19 on the ataxia community. We would be grateful if you could spend a few minutes completing this questionnaire. All data will be stored in accordance with the Data Protection Act 2018 and all responses will be anonymous. The data collected will be pooled and shared with our Medical Advisory Panel, who will be involved in analysing the data. Although Ataxia UK’s medical advisors may be able to recognise individuals from their responses in the survey, they are still bound by doctor-patient confidentiality.

Data will be shared with the *CoroNerve* Studies group. The *CoroNerve* group exists to investigate the neurological symptoms of COVID-19 in the wider community (see more here: www.coronerve.com). Data may also be published in scientific journals and shared with other interested parties, such as other researchers.

In this survey, we are only collecting information from people that have recovered from COVID-19. We are aware that unfortunately some people with ataxia have passed away after contracting COVID-19. If this is the case for your family member or friend then please know that Ataxia UK is here to support you however we can. Our helpline is open Monday-Thursday from 10:30-14:30 and can be reached by calling 0800 995 6037 or emailing help@ataxia.org.uk.

By completing and submitting the survey you consent to taking part. As responses are anonymous, once your responses have been submitted it will not be possible to withdraw your consent or your responses. Anyone aged 15 or under should complete the survey with a parent, carer or guardian.

If you find answering these questions upsetting in any way then please contact the Ataxia UK helpline (0800 995 6037, Mon-Thurs 10:30-14:30, or email help@ataxia.org.uk), or discuss this with your GP or neurologist, or someone in your support network.

How to complete the questionnaire

- Please answer all questions, unless indicated otherwise, by ticking the relevant box or by writing in your answer.
- If you are completing this survey as a carer please answer all questions on behalf of the person with ataxia.
- All information should be about a single patient. In families with more than one affected individual, please complete a separate form for each person.
- If you need help completing the questionnaire, please ask a friend or relative to help you, or to fill it in on your behalf.
- If you have any questions regarding the survey please email research@ataxia.org.uk.

To complete the survey follow this link or copy into your browser:

<https://www.surveymonkey.co.uk/r/BCNDRKN>