



Dr. Tobias Kruse | A-T-Survey.co.uk
Denninger Str. 30 | 81679 Munich | Germany

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Together against Ataxia-Telangiectasia

Trials24 GmbH

Dr. Tobias Kruse
Managing Director
Denninger Str. 30
81679 Munich
Germany

E-Mail: info@studiesforpatients.com
Telefon: +44 20 4600 6759

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Information about the Ataxia-Telangiectasia (A-T) Survey and the telephone interview

Dear Mom, dear Dad,

Thank you for your interest in our survey and the telephone interview on Ataxia-Telangiectasia (A-T). As the person responsible for the project, it is crucial that you are as well-informed as possible on the background of our survey and telephone interview.

What is the survey or telephone interview on A-T about?

A diagnosis of Ataxia-Telangiectasia (A-T) means you, your child, and your loved ones will face challenging times ahead. Unfortunately, there is no cure for the symptoms and consequences of this condition. This makes it even more important to find the right doctors and specialists who can offer the best possible support for you and your child in managing A-T.

Finding the proper support allows families to adapt their lives around A-T, meeting their child's needs while maintaining as much independence as possible. Medical research is working on developing treatments that could both improve the quality of life and increase the life expectancy of patients with A-T. The goal of this survey and telephone interview is to support these scientists in their important work.

Why is your participation so crucial?

Surveys and conversations with affected families are crucial for better understanding the course of Ataxia-Telangiectasia (A-T) and developing improved diagnostic and treatment options. We need your experiences and insights on living with A-T to gather valuable data and

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gain medically significant insights into this rare disease. Your participation is essential for advancing our knowledge.

Even if you do not benefit directly from the survey or the telephone interview for the time being, by taking part, you can make a valuable contribution to possibly improving the treatment of Ataxia-Telangiectasia in the future and thus help other people affected.

Who do we ask?

We are seeking parents from the USA, UK, and Germany whose child has Ataxia-Telangiectasia (A-T) to participate in an A-T survey and a telephone interview. Your insights and experiences with your child's diagnosis and management of A-T will be invaluable.

How does the telephone interview work?

If you have agreed to take part in the interview, we will contact you by email or phone to briefly explain the procedure and answer any questions you may have. We will also arrange an appointment for when we call you for the telephone interview. The interview lasts around 20 to 30 minutes. We will ask you questions about the path to your child's A-T diagnosis and your previous experiences with treatment and living with Ataxia-Telangiectasia.

Who conducts the survey or interview?

We, Trials24 GmbH, are conducting both the survey and the telephone interview on behalf of Quince Therapeutics S.p.A.

Do you have any questions? Feel free to contact us

If you have any further questions about the survey or the telephone interview, please get in touch with our Patient Information Service at:

Email: info@studiesforpatients.com

Phone: +44 20 4600 6759

Thank you very much for your help!
With best regards

Dr. Tobias Kruse

Dr. Tobias Kruse
Managing Director of Trials24 GmbH

And your Trials24 team

Patient Information Service of the Ataxia-Telangiectasia (A-T) Survey

Head: Dr. Tobias Kruse

Telephone: +44 20 4600 6759

Email: info@studiesforpatients.com

Web: <https://a-t-survey.com> (USA), <https://a-t-survey.co.uk> (UK), <https://a-t-umfrage.de> (DE)

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