

Alström Syndrome Telemedicine Clinics
Birmingham Women's and Children's Hospital

What is a Telemedicine Clinic?

A Telemedicine Clinic is a way of using technology to deliver healthcare at a distance to children, young people and their families.

How will I be invited to take part in a Telemedicine Clinic?

Birmingham Women's and Children's Hospital will send you a letter, email or text message confirming the date and time of your appointment. This will include a link to Zoom with an Identification number and a unique password.

What is Zoom?

Zoom allows people to meet virtually by using a computer or mobile device. Follow the link provided by the hospital to download the Zoom software if you do not already have this set up on your device. It is free and quick to install.

Who will be taking part in the Telemedicine Clinic?

Professor Tim Barrett or Dr Melanie Kershaw will lead the virtual clinic and they will be joined by other members of the Alström team. This may include Dr Ashish Chikermane or another cardiologist, Catarina Leal or another dietician, Marie McGee Transition Coordinator, Kirsty Mobberley our Diabetes Nurse Specialist if available. A member of the Alström Syndrome UK Family Support Service will also join.

How can I prepare for the Telemedicine Clinic?

There are a few things you can do to help you prepare for the clinic

- Download the Zoom software onto your device
- Make sure your device has a camera, microphone and speakers (mobile devices and laptops often have these built in)
- Make a note of your child/young person's most recent weight, height and blood pressure
- Put together a list of your child/young person's medication
- Make a note of any new health professionals involved in your child/young person's care
- Make a note of any questions or concerns you may have

- Complete the food diary and send it to the Dietitian or ASUK and they will pass this on for you
- Decide if you would like anyone with you during the clinic. If possible, it may help to have someone with you to help keep your child/young person occupied
- Some children/young people may like to ask their own questions. Please take time to discuss this with your child/young person and practice their questions with them beforehand, so they feel confident to speak up for themselves (Self Advocacy)
- It is important that your child/young person is with you for the Telemedicine Clinic appointment

How will the Telemedicine Clinic work?

Follow the Zoom link and enter the identification number and password provided by the hospital.

This will take you to a virtual waiting area.

At your appointment time or soon after, you will then be taken to a new screen and members of the clinic team will all appear via video link on the screen.

You will be introduced to everyone on the call and the team will have a discussion with you about your child/young person.

You can ask questions at any time during the Telemedicine Clinic

If for any reason you are not able to connect to Zoom, Professor Barrett or Dr Kershaw will contact you by phone.

If you need to spend longer with an individual member of the team, then they will organise for you to go into breakout rooms.

What happens after the Telemedicine Clinic?

You will receive a clinic summary letter in the post and a copy will also be sent to your GP and other health professionals involved in your child/young person's care.

What if I have further questions after the Telemedicine Clinic?

You can contact any member of the Alström Syndrome team at Birmingham Children's Hospital via the Clinic Coordinator on 0121 3339267



Alström Syndrome UK

Strength for today, hope for the future



**Birmingham Women's
and Children's**
NHS Foundation Trust

You can also contact your Family Support Worker at Alström Syndrome UK



Jane Biglin
Senior Family Support Worker
(for patients living in the South of England)
Email: jane.biglin@alstrom.org.uk
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