

**WABB Community Webinar**

**(Wolfram, Alström & Bardet Biedl Syndrome)**

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# Getting to grips with home monitoring equipment



# Welcome

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- We will try to answer all of your questions but if there is anything we are unsure of, we will get back to you after the webinar
- You will not be seen or heard during the webinar
- Please type your questions in the chat box

# Introduction to the Panel

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- Professor Tim Barrett, Birmingham Women & Children's Hospital
- Kirsty & Matilda Mobberley, Birmingham Women & Children's Hospital
- Rachel Nice, Royal Devon & Exeter NHS Foundation Trust
- Tracy Lynch, Wolfram Syndrome UK
- Kerry Leeson-Beevers, Alström Syndrome UK
- Tonia Hymers & Amy Clapp, Bardet Biedl Syndrome UK



# Home Monitoring Equipment

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Why are you being sent home monitoring equipment?



# Demonstration

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## **Wolfram Syndrome**

- ❖ Blood pressure monitor
- ❖ Blood glucose monitor – training will need to be provided by a local healthcare provider

## **Alström & Bardet Biedl Syndrome**

- ❖ Blood pressure monitor
  - ❖ Talking weighing scales
  - ❖ Tape Measure
  - ❖ Height measure (Stadiometer)
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- Kirsty & Matilda will demonstrate how to use the equipment
  - Your equipment will be arriving shortly in the post
  - Information and instructions will be sent out with the equipment and added to charity websites

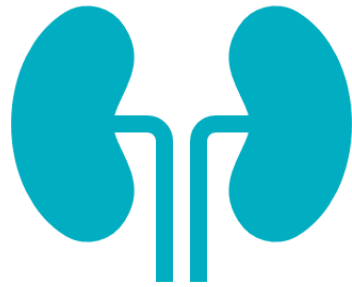
# What To Do With Your Results

- Please take all measurements monthly and record on sheet enclosed with equipment.
- Please take a photo, scan or post your sheet every three months to the medical Team.
- If you are concerned about your blood pressure reading please relax and then repeat.



# Support

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How will you know if your blood pressure / blood glucose is ok?



What type of feedback and support can you expect?

# Home Blood Sample Kits

- It can be difficult to organise local blood tests before clinics
- We now have a new service where blood sample kits are sent to your home
- Full instructions are provided in the kits
- A link to a short video explaining how to take your blood sample will be added to charity websites

<https://www.exeterlaboratory.com/instructions/>

- The sample needs to be taken from your child/young person's finger
- You will need to post your blood sample back in the envelope provided





# Questions

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# Keep in touch!

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Wolfram, Alström and Bardet Biedl Syndrome UK are open and we are here for you

- You can call or email us
- We can arrange a video-chat
- FAQ's and resources from today's webinar will be posted to our websites

- <https://wolframsyndrome.co.uk/>
- <http://www.alstrom.org.uk/family-support/>
- <https://bbsuk.org.uk/>

