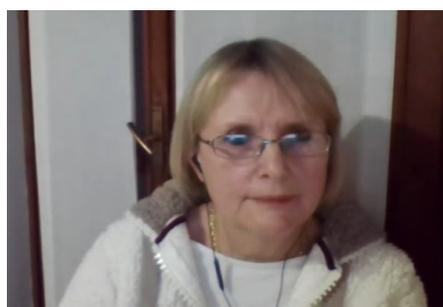


# Alström Global Conference 4th and 5th December 2020



Bringing the Alström Community Together

## Let's Bring the Global Community Together

This year's conference, was somewhat different to the usual face to face gathering and networking, that the Alström Community enjoy so much. Due to the pandemic, this year the global community joined together at the first virtual conference, a truly global Alström collaboration.

Our aim was not only to bring the community together, but provide a truly global insight through presentations from researchers, clinicians and families from across the globe.



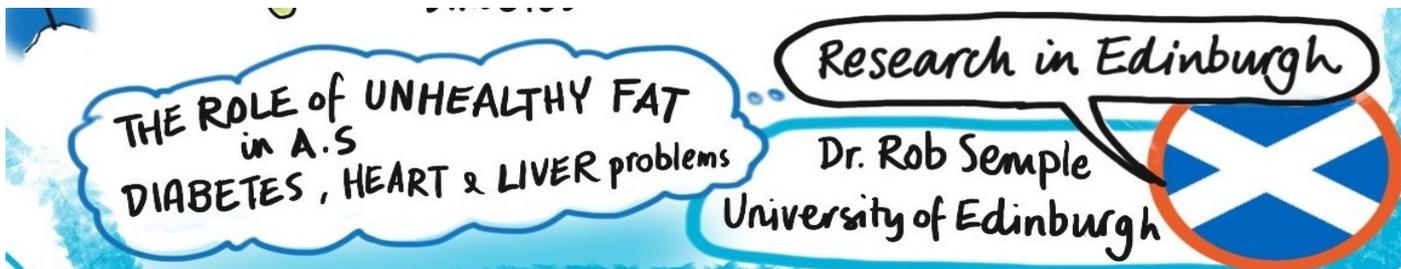
## Global Science and Research Day 1

The **Scientific Symposium** began with a look at research and clinical insights from **Qianwen Zhang** and **Dr. Xiumin Wang**, Chief of Department of Endocrinology, Genetics and Metabolism at the Shanghai Children Medical Centre in **China**. Qianwen explained about their work and how they have found 57 patients in China, who are mainly under 18.



This presentation was followed by **Dr. Vincent Marion**, Team Leader at National Institute for Health and Medical Research Hôpitaux Universitaires de Strasbourg, **France** who talked about current research developments. Dr Marion, gave an insight into their current academic research looking at the gene identifications and clinical studies. Explaining the pathological make-up and the importance of gene coding. This coding can mean symptoms can be targeted and managed through specific treatments.

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**Dr Rob Semple**, Chair of Translational Molecular Medicine Centre for Cardiovascular Science from the University of **Edinburgh**, gave an insight into the research study he is starting which is beginning to look at the role unhealthy fat tissue plays in diabetes, heart and liver problems, seen in AS patients.



AS clinical experts **Dr Tarek Hiwot** and **Prof. Tim Barrett** from the **UK** and **Prof. Pietro Maffei** from **Italy**, gave their overview of the recently updated clinical guidelines and its use in the treatment and management of the condition.

**Marina Valenti**, European Reference Network Patient Representative, AS Italian Association, Italy. Marina joined us from the AS Italian Association in **Italy**, to update us about the European Reference Networks. Marina gave an overview of why ERN's are important as no Country alone has the knowledge and expertise to treat rare and complex conditions. Working together in this way, ensures patients have access to the best expertise available. ASSAI and ASUK were delighted to work together on the Early Years research.



**Kerry Leeson-Beevers**, National Development Manager from ASUK provided an insight into the AS multi-disciplinary specialised clinics in the **UK**. Explaining how throughout the pandemic clinics have continued as tele-medicine clinics, enabling patients and families to meet with the AS Clinicians virtually, maintaining regular health checks.

## AS Global Conference, Living Well—Day 2

The **second day** began with **Robin Marshall**, Alström Syndrome International's Executive Director, who reflected on the journey of Alström over the years. The collaboration between organisations and research initiatives which were developed by his late wife, Jan Marshall whose passion to help and support the AS community has driven this research forward. We also took a moment to reflect and remember all those we have loved and lost along the way.

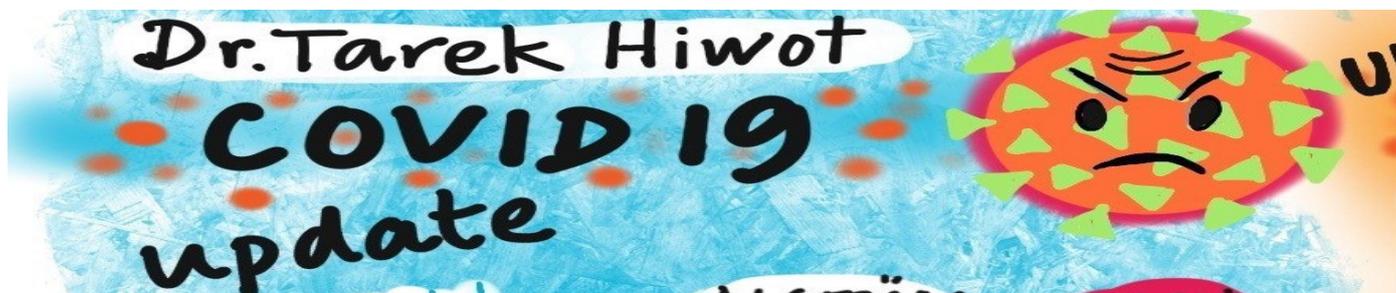


**Ann Chivers**, ASUK Chief Executive chaired the conference and began by giving a brief update about the Scientific Symposium from the day before. Ann highlighted the focus of day 2, which was on health and wellbeing and emphasised the Alström community works together collaboratively. Ann encouraged everyone to complete the **AS patient registry** to help inform researchers of the global picture of Alström Syndrome.



The scientific presentations can be found on the ASUK website

<http://www.alstrom.org.uk/ASUK-conference/>

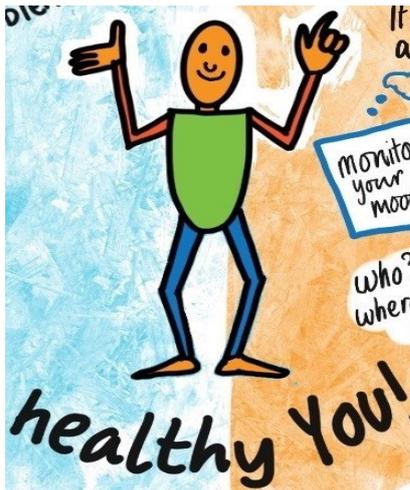
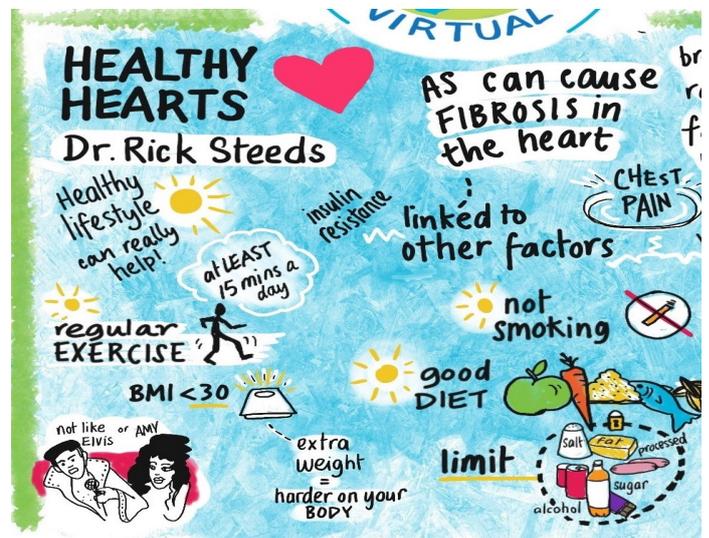


The first sessions of the day centred around Covid-19. **Dr Tarek Hiwot** and **Prof. Tim Barrett**, AS Clinical Leads from Birmingham NHS Trusts, joined us to give their observations of Covid-19 from their own experience and what they have encountered in their clinical practice. Dr. Hiwot, reminded us that we are all new to this virus but the scientific community and Clinicians are learning very quickly. The main risk factor in adults is age but also obesity, heart disease, diabetes and people who have serious underlying health conditions, this makes adults with AS clinically extremely vulnerable.

Prof. Barrett explained that the main risk factors for children are those; who have received a solid organ transplant and taking immunosuppressant medication, children undergoing cancer treatment, those affected by severe asthma or chest infections and those with severe disease such as severe kidney disease. For children in the UK, the current information is more reassuring, even with underlying health conditions, children have recovered well from Covid. The benefit of attending school outweighs the risk of getting Covid. Both clinicians said how reassuring it is that vaccines are now available, and AS patients in the UK should be in one of the priority groups, but we need to be led by the UK Government on this.

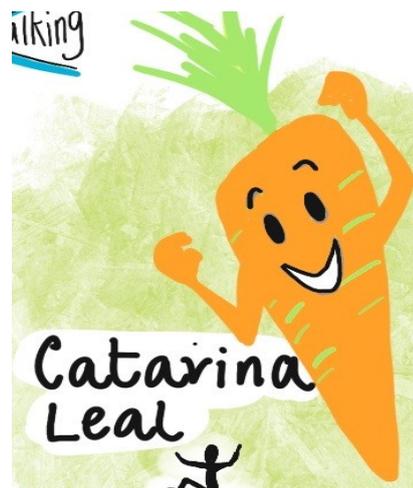
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**Dr Rick Steeds**, AS Adult Cardiac Consultant, from University Hospital Birmingham, highlighted how we can keep you and your heart healthy; how following a healthy balanced diet and taking regular exercise, can manage the condition more effectively. AS is linked to fibrosis in the heart, which can also be attributed to other lifestyle factors such as smoking and following an unhealthy diet with no exercise. Dr Steeds, emphasised that just 15 minutes of regular exercise a day, alongside a healthy diet can help keep you and your heart healthy.



## Live Life on the VEG!

Staying on the healthy theme, **Catarina Leal**, Paediatric Diabetes Dietitian from Birmingham Women's and Children's NHS Foundation Trust, presented 'Live Life on the Veg!' explaining how important a healthy balanced diet is to our overall health, including our weight, diabetes and blood pressure. Catarina told us about healthy snacks and ways to exercise to support our overall wellbeing.



**Robin Watts**, International Safeguarding Expert and Trainer, gave his overview of how we can keep ourselves safe online. Reminding us, that we should think before we share anything and be aware of how to keep our information safe, through strong, unique passwords and checking our privacy settings.



The rest of the afternoon had us all glued to our screens, with members of the AS community sharing their insights and experiences.



**Lexi** (pictured right) shared her insights into useful technologies and gadgets that support her to live independently. Lexi explained that above and beyond all the technology and gadgets in the world, her guide dog 'Unique' is her number 1 support, that she wouldn't be without.



**Jamie Seegar**, from America began by describing her personal perspective of her Journey to Independence.

Jamie reminded us to “find something you love to do and do it. For me, it is playing something that has 88 keys some black and some white also known as the piano. For you, it could be reading, making pottery, playing an instrument, or watching college football. This Syndrome is rough and we need something we can turn to when times get tough.”

## Interactive Workshops

The conference concluded with attendees heading off into separate virtual rooms. ASUK Senior Family Support Worker **Carrol** and her son **Chris**, told us about useful kitchen gadgets, ASUK Trustees, **Lexi and Melissa** gave their insights into growing up with AS and answered parent's questions and ASUK National Development Manager, **Kerry** explored the support and information available for those families and individuals who have been recently diagnosed.

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## I did it my way!

The conference concluded with an emotional display of family photos from around the world, whilst Jamie (pictured right) played her piano rendition of 'My Way'.



## Help us, with the next steps...

- ◆ Stay in touch
- ◆ Join the Patient Registry
- ◆ Join the AS campaigns
- ◆ Join us for the next Global conference
- ◆ Fundraise for ASUK so we can do this again!

*“Today was great!! Understandable for the parents and patients. If we can't be there in person, this is the next best thing.”*

## Thank you

From Ann and the team at ASUK, we would like to say a **HUGE THANK YOU** to everyone who is part of the Alström community. Thank you to those who shared their knowledge and their lived experience of Alström, offering insights and understanding to help us know more.

A big thank you to the Clinicians, Researchers and Presenters for giving their time so generously and making this a truly memorable event. **See you at the next one!**

Why not listen again? — you can find further information, including the conference recordings on the ASUK website: <http://www.alstrom.org.uk/ASUK-conference/>

***“Thank you for all your hard work, not only to enable the conference, but to be a source of information and support for Alström families!!! We loved it all from listening to the Doctor's and Dietician to listening to Lexi and Jamie.”***



**Strength for today, hope for the future**



# The numbers!



**183** attendees



From **23** Countries



**15** Presenters



**7** Family 'experts by experience' speakers



**4** Interactive workshops



**13** Hours of collaborating knowledge & experience

**100%**

Would attend another AS Global Conference



**9/10**

Average score for how much you enjoyed the conference

