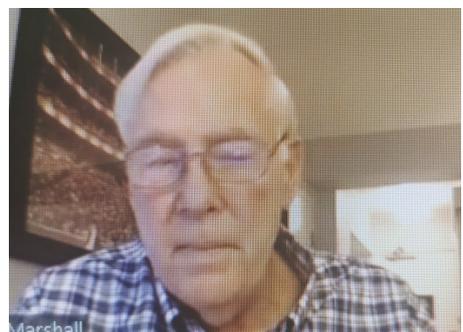


Alström Global Conference 3rd and 4th December 2021



Bringing the Alström Community Together

Be Inspired. Be You. Be Together

In true virtual style, we brought together families and professionals from 21 countries from around the world to learn from one another and share their stories together. Our aim was not only to bring the community together, but provide global insights through presentations from researchers, clinicians and families from across the globe. In our experience, often living with a rare condition can be a lonely place, feeling that no one really knows what you are going through. Events such as the AS global conference are a great opportunity to bring everyone together, to show the strength and resilience that is evident throughout the community and have some fun!



On **Friday 3rd December 2021**, we had cosy fireside interactive chats with families coming together for a pre-conference gathering to share stories and experiences. It was lovely to bring the AS community together on a platform which enabled us to all come together and chat no matter where we were in the world!

We had four sessions running at once:

Growing old disgracefully

In this session Melissa spoke about her work, life and the fun things she enjoys doing such as cooking and holiday time with family and friends.

Yes you can!

In this session, Lexi spoke about the different sports and activities she has tried and how she has never let the word 'no' stop her.

Braille in Business

In this session, Jamie shared her experience of the world of work. Describing how she has turned her knowledge and expertise of Braille, into a paid job. Jamie explained how she overcame many challenges and obstacles along the way, but these never stopped her from seeking work in what she loved.

New to Alström

This session with Kerry, focused on those who had been recently diagnosed with Alström and were seeking further information. Kerry is Mum to an adult with AS and is also Chief Executive of Alström Syndrome UK so has a wonderful insight and working knowledge of the condition and the services and support which may help.

Bringing the Alström Community Together



Alström Syndrome UK

Strength for today, hope for the future

Be Inspired Be You Be Together

Saturday brought together presenters from China, the UK, America, Italy and the Palestinian Territories. Our aim was not only to bring the community together but provide a global insight through presentations from families, researchers and clinicians from around the world.

The first sessions of the day, centred around research and discoveries. **Qianwen Zhang** and **Dr. Xiumin Wang**, Chief of Department of Endocrinology, from Shanghai's Children Medical Centre, discussed the continuing research across China. Exploring the onset of symptoms compared with the rest of the wider population throughout Turkey, America and Poland. She also discussed her research into facial features and whether this could be a diagnostic tool going forward.



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2021



Around the world with RESEARCH, SCIENCE & HOME HEALTH

RESEARCH UPDATES

50 ALMS patients recruited



CHINA



Qianwen Zhang
Dr. Xiumin Wang

14,000 - 12,600
ALMS patients
in China

INCLUDING facial analysis



specific to CHINESE population

GENETIC + PHENOTYPE ANALYSIS



international comparisons



mostly SIMILAR BUT SOME DIFFERENCES

auditory + olfactory function
specific odours



Achievements:

1st conference + party for patients

- ✓ literature
- ✓ 5 conferences
- ✓ Social Media

let's collaborate!

NEXT →

GUIDELINES • POLICY • DRUGS • RESEARCH

Bringing the Alström Community Together

Dr Pietro Maffei Consultant Endocrinologist from Padua University in Italy, was up next with his eagerly anticipated presentation about the first baby born to a couple, where the Mother is affected by Alström Syndrome. It was fascinating to hear about the pregnancy. Although as he explained often with AS, due to insulin resistance and fibrosis in the body, it can be challenging to become pregnant.



The Mother who had a mild phenotype, carried the baby until 35 weeks when health complications meant they needed to perform an emergency caesarean. The baby was born on the 22nd February 2021. Both Mother and baby are doing well and were discharged from Hospital after 6 days.



The family would like to remain anonymous but we hope one day we may get to see a picture. The only one we have currently is from the ultrasound (pictured left) which shows the baby developing at the regular rate with no health complications.

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Strength for today, hope for the future
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2021



Around the world with
RESEARCH, SCIENCE & HOME HEALTH

Welcome to the world,
new bambino!

Fertility, pregnancy
and phenotype
issues: ALMS

! we know that
Severe Insulin
Resistance can
AFFECT

- testicular health
- polycystic ovaries
- ovulation
- pregnancy

SO WHAT HAPPENS WHEN...

case study

Prof. Pietro Maffei



Bringing the Alström Community Together

Next we welcomed **Dr. Reham Khalaf-Nazzal, MD, PhD** (pictured right), Physiology and Medical Genetics from the Faculty of Medicine from Arab American University/ Jenin and **Dr. Emma Baple** (pictured below), Clinical Senior Lecturer (Genomic Medicine), Consultant in Clinical Genetics from the Royal Devon and Exeter Hospital, England. They discussed the partnership between Exeter Hospital in England and the community work happening across the Palestinian Territories. They have found clusters of families affected by AS in a small village in the Palestinian Territories and they are using the facilities at Exeter Hospital, to implement diagnostic genetic testing.



This community work between the two organisations continues as they work together, to educate people on the ground, in the communities and clinicians in the Hospitals. They would like to work with ASUK to promote the patient registry, translate the medical handbook and work with the clinicians in Birmingham to look at further testing and training for health care professional and look at ways we can help these communities going forward.

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2021  GLOBAL VIRTUAL CONFERENCE



Bringing the Alström Community Together

Prof. Tim Barrett, Professor of Paediatric Endocrinology, AS Paediatric Service Lead from Birmingham Women's and Children's NHS Foundation Trust, talk was titled **'Do you know your BP from your BMI?'**



Prof. Barrett explained about how we can monitor our own health at home and what the readings mean for us. He gave some top tips throughout, about how we can lower our blood pressure, such as reducing our salt, eating lots of fruit and vegetables, avoiding saturated and trans fats and tobacco, reducing our alcohol intake and having regular exercise.

He also suggested that you take your blood pressure first thing in the morning as this is when we are most relaxed, rather than when we have just finished a meal or taken part in exercise. Everyone has their own targets, so always talk through specific readings with your local health care provider.



Alström Syndrome UK

Strength for today, hope for the future

Be Inspired Be You Be Together

2021



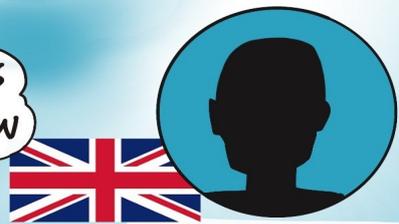
Around the world with RESEARCH, SCIENCE & HOME HEALTH

average for ADULTS lower for children

Do you know your BP from your BMI?

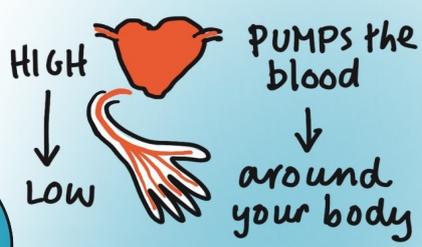
a rough measure of BODY FAT

increases as children grow from 4 yrs



Prof. Tim Barrett

BLOOD PRESSURE



SYSTOLIC

120

70

DIASTOLIC

(between the beats)

AIM FOR 18.5

you CAN make a difference!



take it in the morning!

what to do! ? worried?



preventing HIGH blood pressure



we are providing



home monitoring KIT!



Bringing the Alström Community Together

The next three talks were a real highlight, with families from our community sharing their stories.

First up was **Marina** from Italy who shared her own family journey of acceptance and resilience. Marina spoke about 'reframing':



Reframing is a way of changing the way you look at something and you change your experience of it. It can turn a stressful event into something either: traumatic or a challenge to be overcome. It can depict a really bad day as a mildly low point in overall wonderful life. It can see a negative event as a learning experience.

Marina explained to try and see life through new eyes, by accepting, seeing the funny side of situations, finding your new norm and sharing together with others.

She encouraged everyone to be the change you want to see:

1. Complete the patient registry to build a worldwide picture of Alström Syndrome
2. Sticking together, Internationally and globally to learn more and support one another

It was great to hear her top tips and uplifting quotes and phrases she has picked up along the way.

2021 GLOBAL VIRTUAL CONFERENCE

Accepting and Connecting

You only live once? OR... **Live every day!**

it's like a **LABYRINTH**

Things aren't always what they SEEM

You have to **WALK THROUGH IT**

it's full of **OPENINGS**—you're just **NOT SEEING** them!

our 'limited edition'

REFRAMING

CONSCIOUS DECISION

acceptance

lightheartedness

equilibrium

sharing

A•L•L•I•A•N•C•E•S

ACTIVE Around the world

BE THE CHANGE

learn to WANT what we HAVE

parole buone = GOOD WORDS

A CURE? find your PURPOSE

NEW NORMAL

IT IS WHAT IT IS

Then we heard from **Jennifer** from America, about her three Amigos—sharing her family story of her three boys being affected by AS.

Their fun loving, get up and go attitude, showed through; especially as Chad has recently faced one of the toughest years of his life. Chad went into heart failure and spent 111 days in cardiac ICU, but after rehab he is now doing well with a heart pump.

Jennifer's top tips are to embrace everyday, remember that you are the expert, your kids can accomplish anything they put their mind to and take advantage of all the resources and support available to you.



Alström Syndrome UK
Strength for today, hope for the future

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2021



The THREE AMIGOS!



ACTIVE
Around the world

our journey with 3 boys affected by AS

NOLAN (10)

is blind & hearing-impaired, diabetic with liver dysfunction

HE loves the pool!



2021
our MOST challenging year



CHAD (17)

is most affected by AS, is blind with lots of health issues.



HE also loves the pool!

MATTHEW (13)

is blind, with scoliosis, respiratory & liver issues.



HE is a funny guy!
plays SAX
is ACTIVE

it was HARD WORK!

Chad had severe heart failure
Spent **111** days in HOSPITAL
+ **51** days in REHAB

now has a HEART PUMP & VAD BAG

He's home, doing well
LISTED for a heart transplant

KEY TAKEAWAYS...

You are the AS expert!

IF YOU THINK

Something's WRONG...

IT PROBABLY IS!

Embrace every single day

even the HARD ONES

our children can accomplish ANYTHING!

BRaille MATTERS!

TAKE ADVANTAGE of resources available to you

Be a CONSTANT, STEADFAST ADVOCATE for your child

Lexi our own ASUK Vice Chair was up next. Showcasing how she overcame Covid-19 and became a dressage champion.

Lexi explained about her journey of riding and her love for horses and how with lots of practice, anything can be achieved. Lexi has recently come 1st, 2nd and 3rd place in Dressage Championships—showing us all how it is done.

Her motto



'If I can do it, anyone can do it!'



Alström Syndrome UK

Strength for today, hope for the future

Be Inspired Be You Be Together

2021



Horsing Around

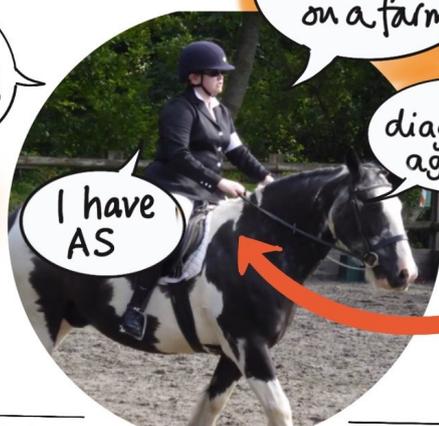
HOW TO BE A DRESSAGE CHAMPION... WHILST RECOVERING FROM COVID

ACTIVE Around the world

Listened to me & advocated for me

I hate SPECIAL SCHOOL!

My parents and grandparents were DETERMINED to give me OPPORTUNITIES



I grew up on a farm



HORSES

- an OBSESSION! -

diagnosed age 10

I have AS

I WAS DIFFERENT on a horse

Able-bodied riding was INACCESSIBLE and DANGEROUS for me.

Lexi Griffiths-Rayson

HOW I RIDE independently
by feel
Counting strides
markers called



DECEMBER

2020

I was hospitalised: HEART FAILURE

Riding for the Disabled: I was 'too able'

I'd ISOLATED but vaccine not available yet

I'm alive

Now I only go out with a sighted person.

to NATIONAL LEVEL!

I have competed in virtual dressage competitions

We were delighted to welcome **Archana Kulkarni**, Consultant Ophthalmologist, Paediatric Ophthalmology and Adult Strabismus from South Warwickshire NHS Trust, Warwick Hospital and Birmingham Women and Children's Hospital.



Archana discussed sight, support and beyond, looking at the different lenses, tints and support aids which can help people affected by vision loss.

 **Alström Syndrome UK**
Strength for today, hope for the future
Be Inspired Be You Be Together

2021



Around the world STAYING SAFE AND WELL

SIGHT SUPPORT



! Photophobia *
! Light sensitivity *
short wave → SCATTER *
+ mid wave *

Mrs. Archana Kulkarni



your G.P. can refer you!

ask for TRIAL lenses

Yearly optician visits



reading electronics

EDGE FILTER

TIPS

choose your SETTINGS!



good light

try a magnifier

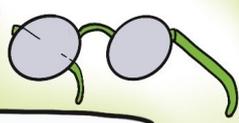
try a CAP



theBlindlife

AIM for 99-100% UV protection
75-90% visible light

SPECS



Tinted lenses

stay the same colour

polarised

make the most of residual vision.

TRY them to see what works for you

photochromic

react to light-darken can be SLOW

reduce glare off horizontal surfaces

— crisper, clearer — less GLARE

— but do reduce light getting to the eye — NOT good at night!

Cathy Chadwick-Rayner from our Breaking Down Barriers project brought us a quick snapshot of scams and how to keep you and our loved ones safe.

She highlighted the different forms of scams and top tips to keep safe. Reminding us all to take 5 before acting, take a moment to think, is this legit or could it be a scam.

You can all view her top tips and the video from the conference on this important topic via the link below:

<https://youtu.be/XU58YOBBzbw>





Alström Syndrome UK
Strength for today, hope for the future

Be Inspired Be You Be Together

2021



Around the world STAYING SAFE AND WELL



I've won the lottery - AGAIN!

SCAM-BUSTING

£5 TRILLION LOST to scammers each year!

JUST 13% is REPORTED!

WHY?

- embarrassed
- unaware
- loss of independence
- fear of repercussions
- Miracle?
- FREE TRIAL
- Medicine FAKE
- unbelievable?

please pass this on!

EMAILS:

- look carefully:
 - where's my name?
 - Don't click links or call numbers
 - DELETE + block sender

SOCIAL MEDIA TIPS:

- profile pic: with family or friends
- check your PRIVACY settings
- stay on SAFE SITES

YOUR PERSONAL DATA

- change passwords
- create STRONG passwords!

ROMANCE SCAMS

- exploit loneliness
- asking for £?
- hard for you to contact them?

TIPS

ONLINE: look for the SECURE SITE symbol in the web ADDRESS

TELEPHONE + TEXT:

- don't give REMOTE ACCESS to a caller
- call blocking / filtering
- PAUSE before you speak
- Don't click a link
- Google the caller's number

Call blocking device

Reverse image search

Block + report

Forward scam texts to 7726 (UK)



Thank you

On behalf of ASUK, ASI and ASSAI we would like to say a big thank you to all the presenters who contributed in making this second virtual conference such a success; and of course a huge thank you to everyone who attended, the more we know the better the treatment and management of Alström Syndrome. **Alone we are strong, together we are stronger!**

A HUGE THANK YOU to AS Canada who kindly supported the conference and future AS Global work and to the Clinicians, Researchers and Presenters for giving their time so generously and making this a truly memorable event.

Why not listen again? — you can find further information, including the conference recordings on the ASUK website: <http://www.alstrom.org.uk/as-global/#AS-Global-Conference-2021>

What's next?

Well, we will be collaborating with our friends, families and professionals from around the world to host webinars throughout the year on topics to bring the AS community together. From discussions around eye health, to staying healthy, through to ways to stay independent and ways to keep everyone connected around the globe. If you would like to be involved, present or send us an article then please get in touch with **Catherine by email catherine.lewis@alstrom.org.uk**

We look forward to seeing you all again soon!

“I think the global collaboration is wonderful! A dream come true, really.”

“I thought the last global conference was good but today's was exceptional, full of information and stories from inspirational people from the Alström families around the world. Well done Team!”

It's all about team work!





The numbers!



82 attendees



From **21** Countries



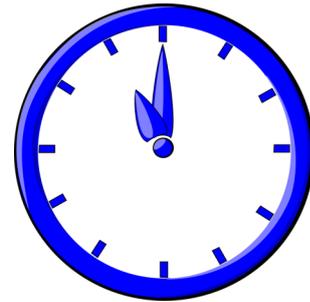
16 Presenters



6 Family 'experts by experience' speakers



4 Interactive workshops



10 Hours of collaborating knowledge & experience

100%

Would attend another AS Global Conference



9/10

Average score for how much you enjoyed the conference



