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hello

Issue #1 - 2023



We hope you enjoy reading these regular updates - keeping the AngelmanUK community connected.

If you require information or support please email support@angelmanuk.org or click on our logo which takes you to our website.

It's our 30th birthday!

To celebrate we'll be hosting trips to local zoos for families registered with AngelmanUK. We'll announce more information on this very soon.

Why not host a birthday tea party and raise money for AngelmanUK? Our fundraising party pack will be available from March onwards.

INTERNATIONAL
ANGELMAN
DAY FEB 15



February 15th 2023

IAD is an initiative started 10 years ago by international organisations who saw an opportunity to unite; to celebrate and recognise the achievements of people with Angelman Syndrome and to remember those who are no longer with us. This year we are encouraging families to contact local councils and attractions to see if they can 'light it up blue' for Angelman Syndrome.

Some families also contact their local news stations to share information about AS. Let us know if you are successful and don't forget to send us a photo to share on social media. You can read more about #IAD2023 by clicking the button below.

[More info](#)

family

Matthew is 14 1/2, he lives in Yorkshire with his parents Steve & Rachel and siblings Ryan (13) and George (6).

What are his likes & dislikes?

He loves watching live shows and his favourite musical Frozen! He enjoys spending time with his Nannan & Grandad and going to places where there are lots of people.

Can you name one of his most recent achievements?

He's doing really well using his iPad for communication and can now put three or four words together e.g 'mummy - i need - the toilet'.

His mum says he's improved so much because he's in a class with others who also use AAC devices.

Is there anything you'd like to share with our families?

"The fear of the future and the unknown is less scary than you think. In reality everything is better than we imagined. I'd also say we've met a new set of friends, some who have become like family and our lives feel enriched having Matthew and the special times we all share together because of him." ~ Rachel.

If you'd like to be one of our featured families, contact

sian.allen@angelmanuk.org





Save the date!

Stepping into AAC is a new project coming in 2023. It is an exciting and innovative collaboration between the **Angelman Syndrome Foundation** and **PrAACtical AAC**.

“We are developing a sequence of resources to support families and teams on their AAC journey. It will inspire and inform those just getting started with AAC, those seeking momentum, or anyone wanting to learn more about AAC to become a more informed member of their AAC learner’s team. This project will be a free, public resource to be released in 2023.”

We are very proud to announce that we are offering the only face to face training in using these resources, open to both professionals and parents/carers. This event is supported by the ASF, PrAACtical AAC and **Assistiveware**.

27/10/23 - Professionals
28-29/10/23 Parent/Carers

Booking opens in March, with subsidised rates for families registered with AngelmanUK.

Angelman clinic waiting list now open!

If you would like a consultation with the multidisciplinary team at the Manchester clinic, please ask your G.P, paediatrician or consultant to refer you to

Dr Catherine Breen
Consultant Clinical Genetics
Manchester Centre for Genomic Medicine

St Marys Hospital
Oxford Road
Manchester
M13 9WL

The clinic is open to people with AS of all ages.

research

AngelmanUK is proud to have supported many research projects since its formation 30 years ago. These have varied from small collaborations with UK researchers such as Prof Jill Clayton-Smith, Professor Chris Oliver and the CEREBRA Research team to joining forces with international organisations to support global research.

Angelman Syndrome Alliance

AngelmanUK is one of the founding members of the **Angelman Syndrome Alliance**.

The Angelman Syndrome Alliance (ASA) is a partnership of small organisations from around the world that are focused on supporting people with Angelman Syndrome, their loved ones, carers and clinicians. By combining resources, knowledge and a relentless dedication to initiate change, the ASA is uniquely positioned to drive advances in scientific knowledge about Angelman Syndrome. As a rare disease, funding for scientific research from major funders is limited. The ASA is breaking new ground, utilising limited resources from around the globe in a smarter manner. By combining financial resources we can fund research that individually our organisations could not.

Our mission is to grow and support scientific knowledge about AS that can create fundamental and lasting changes in therapy for people with Angelman Syndrome; so that parents, therapists and clinicians can improve the quality of life of those with AS.

Together we identify research that challenges our knowledge of AS today, to enable us to develop solutions for future therapies. The alliance focuses its investments on innovative science, with our ultimate goal to find therapies for patients with Angelman Syndrome.

Angelman Clinical Trials is a shared resource between the major players in Angelman research. It is not affiliated with any specific organisation, it is a shared space where the Angelman community can find relevant and unbiased information about clinical trials.

If you'd like to know more about Angelman Syndrome research and clinical trials, please contact Dr Katie Cunnea at **katie.cunnea@angelmanuk.org**

thank you

Without your fundraising and your donations there would be no AngelmanUK to offer support to your family. Whether big or small, every penny really does make a difference. Click here to read about some of our **fabulous fundraisers**.

fundraisers

David Darrock - London Marathon 2022
Michael Kilgannon - London Marathon 2022
Chris Mason - London Marathon 2022
Yuksel Selvi - London Marathon 2022
Sean McKeown - London Marathon 2022
David Netherwood - London Marathon 2022
Luke Ryan - London Marathon 2022
Chris Foden - London Marathon 2022
Michael Kennedy - London Marathon 2022
Steph Lewin - Great North Run
Ste Bray - Great North Run
Joseph Skelton - Great North Run
Mark Thompson & Team - Great North Run
Nikole Alexander - Great North Run
Andy Stephenson - Great North Run & Loch Ness Marathon
Graeme Carr - Great North Run & Loch Ness Marathon
Nick Payne - Triathlon
Richard Strickland - Joberg2C Challenge
Bruce Strickland - Joberg2C Challenge
Hannah Way - Cardiff Half Marathon
Niamh Gibson - Colour Rush
Michelle Jupp - Great Manchester Run
Nyra Bakrania - Waendel Walk
Lucy Hewlett - Royal Parks Half Marathon
Sarah Brown - London Classics Challenge
Paul Brown - Ride London-Essex 100
Niall Wall - Tough Mudder
Eoghan Wall - Tough Mudder

donations

Deborah Welland
Mrs Hazel Tait
A Taylor
David Wilson Homes
Gail Whisker
Eaton Lodge No. 533
Mr & Mrs Murphy
Sharon Hurcombe - 60th birthday celebrations
ShareGift Foundation
Barclaycard Finance Change
Star Cabaret Ltd
In memory of Mr John Southan
Knights of St Columba
Louise Dobbie
Mr & Mrs Thorpe
Deborah Gundle
In memory of Faye Daphne Froud
Christie Lee
Michael Houghton & Wedgewood Cricket Club
Noel Protheroe
Dan Heerey
Brett Porter
Rob Milsom
Clive Ingram
Inner Wheel Club of Huntingdon
Koris365 / JLA Resourcing Ltd
In memory of Peter Doherty
Mrs B Page
In memory of Jacqueline Shread
Clare Jonas
Carol Lee
Royal Sussex Lodge

Christmas card entries now closed

We have received some wonderful designs for our 2023 Christmas cards!
Thank you to everyone who took part, we will announce the chosen designs soon so keep your eyes peeled.

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