hello

angelman uk

support education research

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#67

summer 2022

Registered Charity 1021882

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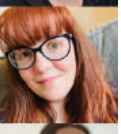

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hello

What an eventful two years!

We hope you all escaped relatively unscathed from the Covid pandemic. It has certainly led to many changes both within our families and the wider world. Many are now working from home on a regular basis, job roles have changed along with our perspective on life - as many of our loved ones have had to isolate for so long. Our mental health and well-being have been brought into focus with more people realising that quality of life is hugely important.

As parents and carers of people with Angelman Syndrome we must take our own well-being into consideration when discussing options for our loved ones. Take respite if its available. Ask for it if it's not been offered. Get support from your local carers' organisations. Seek out support for other children in the family from national organisations such as SIBS and Barnardos. And lastly, we must remember that people with Angelman Syndrome also have mental health and well-being needs of their own.

Lockdown has caused many carers to notice an increase in anxiety-related behaviour such as nail picking, hitting, increased attachment issues, etc. Our loved ones with Angelman Syndrome have found the last few years as hard and as confusing, if not more so than us. All lost time at school or college with friends, social activities, respite and routines which made their lives stable and enjoyable. Don't be afraid to reach out to professionals to seek help for ourselves and those we care about.

We hope you enjoy reading this newsletter, we apologise for not sending one out sooner but please remember we are all volunteers who have families and jobs which must take priority, especially during the recent international upheaval. To that end we have taken on some new board members who will be with us for the next part of our journey in supporting you. You can read all about them on pages 20-21.

We are also in the process of updating our database. At some point in the near future you will receive communication from AngelmanUK regarding this. Please make sure to follow any instructions given so that we have your up-to-date information.

And now something to look forward to! Our Family Conference is back this year at The Doubletree Hilton Hotel, Coventry on 26-28th August (see advert on r/h page and order your Conference T-shirts on pg 4).

We are so excited at the prospect of seeing you all again and we hope that you have an amazing time meeting friends old and new, sharing experiences and hearing from professionals and trustees about how we can create positive futures for our children and loved ones with Angelman Syndrome.

See you in Coventry!

angelman

useful information

Freepost address
AngelmanUK, Freepost
PO Box 4962, Nuneaton
CV11 9FD

Helpline 0300 999 0102
Email support@angelmanuk.org
Website www.angelmanuk.org
Shop angelmanuk.org/shop

Cover photo by Lottie Fox-Jones

get ready for another...

family conference

2022

angelman uk

Friday 26 - Sunday 28 August

how much?

Weekend – Full Board	
Adult	£150
Child	£75
Person with AS	Free!
Carer	£50
Under 3	Free!

where?

DoubleTree by Hilton Hotel
Paradise Way, Walsgrave
Coventry CV2 2ST

what's going on?

- Early Years advice
- Research Update
- Newlife
- Dad's Chat + Free Pint with PMH Support
- AS Clinic
- Communication with Rosie and Livvy
- Makaton Sing-Along with Sign-Out-Loud
- Parent-to-Parent Chat
- Sensory Room
- Swimming
- Free portrait photos by Rob Chadwick
- Yoga and Mindfulness
- Sibling Support
- Post-16 advice
- Family Fun Day
- Wills & Trusts
- Drayton Manor trip
- Disco
- Safety Sleeper and UrZone free loan beds for 5 lucky families
- ...and much more!

For booking, email: lisa.court@angelmanuk.org

conference 2022 angelman

t-shirts

We have two designs for you to choose from, available now for pre-order from our online shop until 1st August. Collection at the conference.

Adult sizes XXS - 3XL £20

Child sizes ages 2-12 £10

Take a look at the store on our website for details.
https://store20396178.ecwid.com

angelman uk

conference beds

We have 5 beds available for loan at the conference.

Murrays Medical are loaning us 2 of their Safety Sleeper beds and HKD solutions have also offered us the use of 3 UrZone beds for the Friday & Saturday nights of the conference weekend.
If you would like to apply to use one of these beds please contact: **lisa.court@angelmanuk.org** by 1st August and she will draw the first 5 names.

Previous winners will not be offered a loan bed.

The Safety Sleeper by Murrays Medical is described as a "an enclosed bed system: a safe sleeping space for those kids with no sense of danger and/or night time wanderers. This innovative product cocoons and relaxes poor sleepers and provides parents with peace of mind knowing that when your child goes to bed, they cannot leave without your knowledge. This helps the whole home to sleep and recharge for the day ahead". The design was revised and improved for 2020. It includes a hard-shell wheeled suitcase and air mattress – the package weighs 17kg, is fully portable and easy to transport, making it suitable for daily use and providing the possibility of familiarity for respite care, holidays, travel or hospital visits. The Safety Sleeper is spacious enough for an adult, sets up in 5-minutes, is easily assembled with no tools required. Waterproof padding is available for attachable sheets (Coverlet), which is removable for easy laundering.
Murrays Medical will be at the conference in August and the original designer of the Safety Sleeper will be on hand if you'd like to have a chat about your needs.

MURRAYS UK
www.murraysmedical.co.uk

The UrZone is a low sensory safe environment for sleeping or calming down. The all-around mesh allows for airflow and visibility for the occupant to see out (whilst having diffuse light coming in which soothes the brain) and for carers to see in. A see-through panel for camera or personal observation can also be included. The UrZone is very strong and durable (currently in use with several Angelman families), can be used on the floor, divan base, bed frame or profiling bed, it's easy to clean (washes and tumble dries) and fits into a suitcase for travel. It can be used as a daily home-use bed, or for travel, respite or hospital use. Features include access holes for feeding or oxygen tubing, very strong material, frame design features (including gas struts) to increase strength and durability of the frame, LED lights and zipped-in bed sheets for 100% anti-entrapment during seizures or high night time mobility. It can be assembled in 20-25 minutes with no tools but has been designed for quick partial assembly and disassembly in 2-3 minutes for emergencies or where full disassembly isn't required.

life in lockdown

When I left the office on the evening of Friday 20 March 2020 I had no idea that I wouldn't go back to work until 3 August. Boris put us into lockdown the following week and for the next 135 days I found myself confined to our little bubble with Charmaine, Martha (AS) and her smaller siblings Solomon and Norah.

For nearly 3 months we didn't leave the safety of our house and garden. Thankfully the weather was glorious throughout so the paddling pool got plenty of use. We clapped, played, drew, splashed, planted, home schooled, Zoomed, baked, argued, laughed, cried, hugged, hunted mini beasts, watched *Star Wars* and *Dr Who*, rocked out with *Andy & The Oddsocks*, attempted to keep up with Joe Wicks' workouts and even broke a world record for being part of the largest online art lesson.

The last few weeks were a lot easier with schools reopening so Solomon and Norah were able to get back into some kind of routine and we were able to venture out further to see family and friends and visit some of our favourite places. We decided to keep Martha home, even though her school had reopened because we felt she was in a safer environment staying at home. Her school were absolutely fantastic throughout lockdown. Her teacher set up a Teams group so Martha could keep in touch and she uploaded so many activities to help keep her occupied. A personal favourite was a frozen flowers messy play. Martha and I picked lots of colourful flowers from our garden then froze them in cups of water. Once they were frozen Martha really enjoyed watching and feeling them melt, although I had to stop her from eating the flowers once they were free from the ice!

The local Mencap group also organised Zoom activities which involved a lot of singing and dancing: we learned how to sign along to *Can You Feel the Love Tonight* from *The Lion King* as part of the signing choir. It was also nice to virtually meet up with other Angelman families on Zoom, see some familiar faces, meet new ones and see how they were all coping with lockdown.

It wasn't all fun and games though, Martha suffered her first seizure which really shook her and us up but thankfully it does seem to have been an isolated incident. Obviously, a lot of you can relate to the distressing experience of witnessing a seizure and having an ambulance come to the house but Martha managed to time it perfectly. She was taken out to the ambulance pretty much bang on 8 o'clock in the evening on a Thursday just as the neighbours were coming out for the weekly clapping and saucepan banging in tribute to the fabulous NHS staff and keyworkers so the paramedics were treated to their own personal round of applause!

A lot of the time they drove me up the flipping wall and I'm sure they felt the same but I feel extremely fortunate to have spent so much time with my family. Most days pre-Covid I was out the door before they were awake, home after they'd gone to bed and I really miss spending all day with them.

I know the lockdown months were terrible for a lot of people but my experience of lockdown was mostly positive. It was a chance to press pause on the stresses of work and reconnect with those that I love and I'm a bit sad it's come to an end.

Lee Taggart

congratulations!

ASA ANGELMAN SYNDROME ALLIANCE grant winners 2022

RESEARCH GRANT 2021

The best researchers on Angelman Syndrome in the world competed for the **4th Angelman Syndrome Alliance Research Grant.**

We proudly present the recipients and their research projects:

170,000 €
Dr. Ilaria Tonazzini & Dr. Laura Baroncelli, Cnr Nano, Pisa Italy
Innovative brain-targeting nano-tools and imaging methods for therapeutic development in Angelman Syndrome (InnovAS)
The goal of the InnovAS project is to improve future therapeutic pipelines for Angelman Syndrome (AS) by;

1. Working on a less invasive method to deliver antisense oligonucleotides (ASOs) to the brain, compared to intrathecal injections. The proposed brain-delivery strategy for ASOs targeting Ube3a, will be based on biocompatible nanoparticles that can be delivered non-invasively via intranasal administration.
2. Assess non-invasive imaging methods as an unbiased biomarker for monitoring brain function in AS.

175,000 €
Dr. Simão da Rocha & Dr. Evguenia Bekman, University of Lisboa
Stem cell toolkit for modelling cerebellar dysfunction in Angelman Syndrome
This research project will investigate the hypothesis that cerebellar dysfunction significantly influences the symptoms of AS, particularly ataxia. In a stem cell-based approach, cerebellar organoids will be generated using novel induced pluripotent stem cells (iPSCs) from patients and genetically matched controls. These "cerebellum-in-a-dish" models will help future drug discovery efforts to improve the lives of patients with Angelman syndrome.

We are happy to have these strong scientists working on Angelman research. They have our faith and support!

Betty Willemsen
Chair of ASA

ASA ANGELMAN SYNDROME ALLIANCE

ASA Members
AS parent organizations from Austria, Belgium, France, Germany, Ireland, Israel, Italy, Japan, Netherlands, Portugal, Spain, Ukraine, United Kingdom and the Nina Foundation

ASA Associates
AS parent organizations from Argentina, Czech Republic Hong Kong, Hungary

ASA Board
Betty Willemsen, Chair of ASA
Peter Sel, Vice-Chair of ASA
Manuel Trocado Costa Duarte, Treasurer of ASA

Scientific Advisory Board (SAB)
Hanoch Kaphzan MD, PhD, MPH(PI)
University of Haifa
Prof. Dr. Martin Scheffner
University Konstanz
Univ.-Prof. Dr. Harald Sitte
University of Vienna
SAB contact
harald.sitte@meduniwien.ac.at

Community Advisory Board (CAB)
Pharmaceutical companies can consult the CAB, a joint force of ASA and ASF (USA) to represent the interests of the AS community.

ASA / CAB contact
Betty Willemsen
info@angelmanalliance.eu
www.angelmanalliance.org

Scientists funded by ASA
Ben Distel, PhD, Associate Prof.
Prof. Dr. Ype Elgersma
Prof. Dr. Ugo Mayor
Ben Philpot, PhD
Dr. Silvia Russo
Dr. G.M. (Geeske) van Woerden

The 4th Angelman Syndrome Alliance (ASA) Research Grant 2021 for best worldwide research into Angelman Syndrome has been awarded to two teams...

AngelmanUK would like take this opportunity to congratulate Dr. Ilaria Tonazzini, Dr. Laura Baroncelli, Dr. Simao da Rocha and Dr. Evguenia Bekman on their grant awards and give our personal thanks for their continued hard work in the field of Angelman Syndrome.

thank you!

research powered by parents

thank you Jill

retirement

Professor Jill Clayton-Smith MB ChB MD FRCP Consultant Clinical Geneticist and Honorary Professor in Medical Genetics came from a working-class Lancashire background and attended Bolton school from 1970 - 1977. As a teenager she was determined to be a science teacher however her aspirations grew and she graduated from the University of Manchester Medical School in 1982 with MB ChB Hons and trained in cardiothoracic medicine, obstetrics and paediatrics, obtaining MRCP in 1985. After specialising in paediatrics, she entered clinical genetics in 1986 and undertook an MD at the Institute of Child Health, London from 1989-91. Professor Clayton-Smith completed her training in genetics in Manchester and took up a consultant post in 1994. She became a Fellow of the Royal College of Physicians in 1999 and an honorary Professor of Medical Genetics in 2006.

One of her clinical specialist interests was in Angelman Syndrome and she had been involved in this field for many years prior to her retirement in 2022.

AngelmanUK would like to thank Jill for her support, input and knowledge over the last few decades, without which we would not be the community we are today. Research into Angelman Syndrome is not a new phenomenon – Jill and her peers were at the starting block, and it's thanks in part to Jill that we are in the position we are today: without her input we would not have the Dyscerne standards of care that are used clinically and the international Angelman community owes a huge debt of gratitude to her.

All at AngelmanUK wish Jill a happy and enjoyable retirement.

Rachel Martin

"We are blessed to have many amazing clinicians in the space of Angelman Syndrome: Professor Jill Clayton-Smith was one of the first. In 2003 she received the Claudia Benton Award for Research from the Angelman Syndrome Foundation for her outstanding work both clinically and in the field of research. She has been a pivotal part of this community and has aided with the creation of standards of care in Angelman Syndrome, research development and so much more. We are so thankful for the impact she has made in the community and it will be felt for years to come."

Amanda Moore, Angelman Syndrome Foundation

angelman clinic

meet the team

The Angelman Clinic was initiated by AngelmanUK and formed in 2013 under the leadership of renowned Consultant Clinical Geneticist Professor Jill Clayton-Smith. Professor Clayton-Smith has a vast knowledge of Angelman Syndrome and genetics and has been jointly responsible for many research papers which have influenced the organisations and researchers we have today. Dr Dan Hindley, Helen Jameson, Dr Eric Taylor and Jenny Pemberton have been long-standing clinicians who have attended and supported the clinic over the last few years. Other clinicians attend when available. Dr Eric Taylor no longer attends the clinic.

AngelmanUK is actively seeking ways in which we can expand the clinic geographically and we will share updates on this when we can. Be assured that we are working on it!

Professor Clayton-Smith has now retired and the clinic has a new lead clinician, **Consultant Clinical Geneticist Dr Catherine Breen**.

Dr Breen has been a Consultant Clinical Geneticist since 2017 – she graduated from the University of Manchester Medical School in 2004 and first trained in paediatrics before completing specialty training in genetics. Her main clinical interests are in genetic neuromuscular conditions and developmental disorders and she runs the specialist Rett Syndrome clinic.

Other team members include **Dr Dan Hindley,** a Paediatric Consultant and clinical lead in community paediatrics, he has interests in childhood epilepsy and neurodisability. Dr Hindley has seen many patients with Angelman Syndrome throughout his career and has attended many AngelmanUK conferences over the years.

Helen Jameson is a Specialist Epilepsy Nurse and is also based in Bolton. She has been a valued member of the team since its inception and along with Dr Hindley has attended several AngelmanUK conferences.

Claire Abbott is a new addition to the team and is also a Specialist Epilepsy Nurse in Bolton. She alternates clinics with Helen Jameson.

Jenny Pemberton is a Speech and Language Therapist who has been with the clinic since 2016. Jenny has clients who have Angelman Syndrome and has also attended the AngelmanUK communication conference.

The clinic was being run on a face-to-face basis in Manchester, but Covid restrictions have imposed virtual consultations. This worked well for some although connectivity has sometimes been an issue! We are very happy to announce that the clinic is now back to face-to-face consultations and has re-opened to referrals. Virtual consultations are still available to families who are unable to travel. If you have a clinical need to see the doctors at the clinic please ask your GP, Paediatrician or Consultant to refer you to:

Dr Catherine Breen,
Manchester Centre for Genomic Medicine
St Mary's Hospital,
Oxford Rd, Manchester, M13 9WL

changing the future

Treatments for Angelman Syndrome

When I was asked to write this article about the current situation of Angelman Syndrome research and clinical trials, I felt a bit overwhelmed. There is so much going on. How do I do this topic justice? The fact is that the landscape is moving so rapidly that it is difficult to keep up. We are at the forefront of ground-breaking scientific advances that the vast majority of people wouldn't have imagined seeing in their lifetime.

These advances aren't just relevant for AS, but for all genetic conditions. If you are scientifically minded and want to learn more about the latest types of genetic treatments being developed, I would recommend a recent review of gene-based therapeutics (Davidson et al., 2022). Alternatively, for non-scientists, we have worked with Laurent Servais and Dora Markati from University of Oxford, to host a couple of webinars which you can watch online through the AngelmanUK website.

Fortunately for our community, drug companies interested in using new genetic technologies to create therapeutics seem to have latched on to AS as a good target to start working on, with over 10 companies currently involved in clinical trials for patients with AS and a further four having registered their intent to market a drug for AS in the USA or EU. I have provided links below for you to find the details of these.

In terms of directly treating the genetic cause of AS, there are currently three stage I clinical trials taking place world-wide, KIK-AS (GeneTX/Ultragenyx), TANGELO (Roche) & HALOS (Ionis). All three trials involve a similar class of drug that aims to activate the paternal copy of UBE3A. These drugs, called antisense oligonucleotides (ASOs) have to be injected via a lumbar puncture directly into the fluid that travels along the spinal cord and into the brain. ASOs are only effective while they remain in the body, so the current trials aim to work out how frequently treatment needs to be given. Early estimates are about 3-monthly intervals, with each treatment involving a general anaesthetic and lumbar puncture injection.

It is also likely a gene therapy clinical trial will start in the UK within the next 12 months. Gene therapy involves a different class of drug, which permanently alters the DNA of a person's cells, so while the delivery method is the same, it would not need to be given as regularly. It seems likely a company called PTC Therapeutics will be the first company to announce a clinical trial using gene therapy for AS, although others are also working on this technology.

In the UK we currently have two clinical trials recruiting. The KIK-AS trial described above, in Oxford, Cambridge & Great Ormond Street Hospital London and the Natural History study in Oxford which is described on page 9 of this newsletter. If you are interested in taking part in any clinical trial please see the NHS site; https://bepartofresearch.nihr.ac.uk/

So what does all of this mean? As parents/carers and as a community, what do we need to know, do, or even think about all of this? Of course I can only give my perspective on this here, but hopefully I can provide some ideas to think about.

As a scientist, I am excited by the progress taking place. However, as a parent I have to be honest and say it is more complex and can feel like an emotional roller coaster at times. My daughter was diagnosed in 2008, when a diagnosis of Angelman Syndrome was absolute. You simply had to learn to understand and accept a diagnosis of AS. But now it is so much more complicated. Should you hope for life-changing treatments, or should you continue to accept the diagnosis we have grown to understand over the past few decades? I am not sure if it is easier or harder for those diagnosed more recently, or longer ago. Change can be difficult and the unknown frightening. Ultimately, I think the best approach is to try and remain as open minded as possible, try not to let fear hold you back and be respectful of others' views.

If you are thinking about taking part in a clinical trial, there are significant considerations. What are the safety implications of the trial? How do you think you, your child and the rest of the family will cope, physically and mentally? How much of your time will it take up, will you have to ask for time off work? How much school will your child miss? Financial reimbursement is often offered, but how much is it, and will it cover everything you need it to? For example time missed from work, or childcare for your other children? It is also important to realise that you shouldn't share any information with others about how the trial is going. One reason for this is that you could jeopardise results by putting preconceptions in people's minds. Will you be able to do this without feeling isolated?

So what should we be doing as a community? Now, more than ever, it is really important that we come together and unite. Combining data and information on our patient population in one place can prove invaluable for drug companies. Expanding our AS clinic is another area that could help, both for trials, future treatments but also patient care in general.

Most people taking part in trials, especially those involving invasive procedures, do not want to be in a placebo group (a group not given the drug). However, when a child is taking part in a trial it is inevitable that expectations may change, you might start subconsciously making a bit more effort with their AAC device, or physiotherapy. So a question I have is whether as a community we should be encouraging drug companies to include placebo groups?

It is certainly important that we support trials into biomarkers. Biomarkers are biological indicators that can be used to show if a drug is having an impact. For example EEGs, or movement patterns (measured by wearing sensors). Having a good range of biomarkers will improve the accuracy and outcome of a clinical trial. So it is well worth the long-term effort to take part in these kinds of trials.

A final point I would like to mention is that AngelmanUK recognises the growing need to support our members in this new landscape, so we are looking at how this can be best achieved. Please contact us if you are interested in helping the charity in this area.

Dr. Katie Cunnea
katie.cunnea@angelmanuk.org

research natural history study

A Natural History study is research looking at a particular group of people who have a specific medical condition (in this case Angelman Syndrome). It examines and collates data which can be used to provide potential future treatments and support.

FAST UK are currently funding a Natural History study led by Professor Laurent Servais at Oxford University and we have been asked to share this study with you.

The study will recruit 40 participants affected by Angelman Syndrome and their one or two primary carers (up to 80 carers in total). Each individual will be followed-up for two years at six-monthly intervals. The study will run for four years, including a study setup and a data analysis period. It will be undertaken by the Specialised Translational Research Oxford Neuromuscular Group (STRONG) team of the Muscular Dystrophy UK Oxford Neuromuscular Centre (MDUK), Department of Paediatrics, University of Oxford.

This is a Natural History Study, which means that the research team is planning to assess and observe participants affected by Angelman Syndrome over time with the aim of identifying and designing specific assessment tools tailored to the needs of Angelman syndrome patients; it does not include any therapeutic interventions.

If you would like to take part in the Natural History study please contact:
Laurent.servais@paediatrics.ox.ac.uk

or:
Theodora.markati@st-annes.ox.ac.uk

...to discuss requirements and reimbursement.

research update

CEREBRA
Working wonders for children with brain conditions

Aston University
BIRMINGHAM UK

A new research project at Aston University, in collaboration with the Cerebra Network for Neurodevelopmental Disorders is launching this summer. The project is exploring anxiety and separation distress in people with Angelman Syndrome (AS). Based on feedback and discussions with parents we know that this can be an area of concern for some families, yet there is very little research capturing families' experiences of what this looks like in people with AS and the impact of anxiety on the individual and families. To address this, the team at Aston University are developing a questionnaire to assess anxiety and separation distress as well as an interview which will look at the presentation of anxiety, associated characteristics, and specific triggers. The questionnaire will be part of the larger BEOND study that is being run by the Cerebra Network. Because we are interested in learning about why some people with AS do or don't experience anxiety, the person you care for doesn't have to experience anxiety for you to take part.

As part of the BEOND questionnaire study launching later this year, we are also investigating sleep and daytime behaviours in children diagnosed with rare genetic syndromes, including AS. Via the BEOND study, we aim to examine the association between children's sleep difficulties, health and daytime behaviours within and between syndromes. Later next year, children recruited via BEOND who have poor sleep and complex health conditions will be invited to take part in a direct ten-day assessment of sleep within the home setting alongside a same-household sibling, to explore the association between ill-health and poor sleep and identify priorities for support within the wider family.

We will be providing more information about these studies later in the year, but if you would like to register your interest early for either the questionnaire and/or interview study, please email:
j.waite@aston.ac.uk

Dr Jane Waite

We are very happy to announce that Jane will be attending our family conference in August to discuss this research with our families.

letter from UKRAINE

90 days of war in Ukraine. I do not know when the war will end, especially since we are unable to explain why it began. The great Ukrainian nation has become hostage to the painful, insatiable thirst for power of one man. At one point, life was divided into before and after February 24. The worst was that night, three months ago. When a phone alarm rang at night, when I woke the children with the words "Get up quickly! We are being bombed!" The eldest daughter Diana was extremely collected, reacted instantly, gathered herself and her youngest sister Alisa and anxiously grabbed a suitcase. Alisa, a happy little daughter, was sleepy but happy as always. Diana tried to pull on a warm sweater, thinking I was frozen. I ran from corner to corner, trying to figure out how it was possible for my fellow man to shoot me. Then it was not scary. There was and remains universal anger and hatred for the aggressor country. Three months that have gone down in human history. Three months since the birth of the new nation.

Before the war, our Ukrainian community of people with Angelman syndrome had just begun its activities. Step by step we searched for our families, registered them, created a website, learned to communicate with each other. Parents' sentiments were divided into two categories: those who were completely desperate and had no hope for a better future for their children, and those who sincerely believed that a desirable and long-awaited treatment would soon be found. It is very difficult to unite people who have different living conditions, different personalities, levels of education and upbringing. It was even harder to find medical facilities and doctors who understood how to identify, register and accompany our children. The hardest part was finding the right path to Europe and the United States, where there are experienced patient organisations that are able to support, advise and offer hope.

I am always asked the exact number of people with Angelman Syndrome. A difficult, very difficult question. When I started working with families, I thought it was 60 families. When the war broke out, it turned out that many families did not have a confirmed diagnosis, only clinical manifestations, some do not see the difference between Angelman and Prader Willi Syndrome, the main thing is that chromosome 15 was damaged. Some families do not get in touch at all for reasons I do not understand. On the contrary, there are those families that I had no idea about, and they found themselves.

The story of every family is a tragedy. Our children who spend the night in the bomb shelters it is horrible. Women who are forced to flee bombs with a sick child who has an epileptic seizure... Now we can safely say that children with Angelman Syndrome do not always laugh. We refute this scientific fact. When the sirens howl, they cry. When they hear explosions, they tremble and go to the bathroom, thinking that they can hide there. In three months, our children have become adults for life. Many children went with their parents to other countries. Frankly, this is a tragedy for us. Our children have nowhere to go. Wherever they are, they are refugees. In Ukraine, they are at home. We dream of creating comfortable conditions for them in their native country. We want our actions to have a future. We want our children to have access to clinical trials, quality diagnosis, treatment, education and rehabilitation.

We will definitely win. Glory to Ukraine! Glory to heroes!

Anna Kyrychenko

ukraine
crisis appeal

Global Angelman Community Ukraine crisis appeal

In response to the war in Ukraine, AngelmanUK created a fundraiser in order to raise money to support Angelman families in Ukraine. This fundraiser was quickly joined and supported by our partner organisations FAST UK, Angelman Syndrome Foundation (USA), FAST (USA), Angelman Syndrome Association (Australia) and The Angelman Network (New Zeland). To date we have raised just over £10,000 and it is still increasing. This money will be sent to families in Ukraine once we have worked out how to use it with the greatest benefit and with the furthest reach. We are considering offering a grant to families who need financial support during the ongoing crisis and this will be decided by the organisations involved once the fundraiser is closed.

The fundraiser is still open for donations at:
www.justgiving.com/fundraising/angelmanukrainecrisis

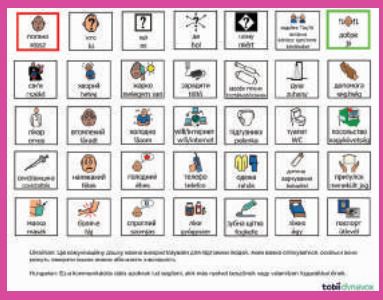
Ukrainian & Russian communication resources

AngelmanUK has also been busy behind the scenes supporting families who have been affected as much as we can. We have worked with other International organisations both in the Angelman community and in the Pitt Hopkins community to help families with disabled children escape the situation they find themselves in. We have also ensured that communication boards both in Ukrainian and Russian have been made available to families and border control.

Thanks to Smartbox and Tobii Dynavox for making these valuable resources available.

https://thinksmartbox.com/news/ukrainian-communication-boards

https://www.tobiidynavox.com/pages/ukraine-refugee-communication-resources



INTERNATIONAL COMMUNITIES

DUBAI – International Angelman Day Raising awareness

On the 15th February, in coordination with Heroes of Hope athletes and coaches, International Angelman Syndrome Day was marked with a walk through the beautiful and car-free Sustainable City development, and followed by an afternoon of arts and crafts, cakes and laughter. Dozens of participants were highly visible in blue and the very well supported event promoted awareness and inclusion in the community. It also gained traction in the regional daily publication Gulf News.

Collaborations and family support
Souzie and Alia, a fellow Angelman mum, are currently coordinating ASF supported educational webinars to bring much needed world leading expertise within reach of the regional Angelman community. For the first time this invaluable information was translated live into Arabic and thus far the webinars have discussed clinical trials, research, the role of pharmaceuticals, behaviour and anxiety. The next webinars will cover neurology, AAC and literacy, OT and sensory processing to name a few. If any Arabic speakers would like to enrol please contact Souzie on **souzie.mackay@yahoo.com**
There are bigger projects in the pipeline to support the Angelman families in the region which will be announced very soon.

Souzie Mackay

siblings

James meets his nephew (again!)

We never really thought that James understood the concept of me being pregnant, but when he met Benjamin for the first time in hospital, he proved us all wrong! Each time I visited when I was pregnant with my eldest son, I would explain to James that I had a baby in my belly but he didn't really show much interest. I used to put his hand on my belly so he could feel the kicking but we never thought he fully understood that there was a real baby in there.

Once I'd had Benjamin, I remember sitting on the hospital bed with him in my arms and James came through the doors and he instantly smiled. He came up to me, sat down next to the bed and put his arm round me. He then stroked Benjamin's head whilst looking at me, as if to say "this is your baby!" It really seemed like he was so proud of me.

Unfortunately, James wasn't able to meet Tobias straight away because of lockdown but he loved meeting him when we were eventually home.

James absolutely loves both his nephews! Every time they visit, he plays with Benjamin and is really gentle with him! We all know James can be a little heavy handed at times, but he is so different with both Benjamin and Tobias. He does however get a little fed up with them at times and is quick to tell them to go back home when he's had enough!

He is an amazing Uncle to both my boys and we certainly underestimated how amazing and gentle he would be with them.

Alex Edgar – sibling trustee

when my brother left home

It was hard to see Samuel leave home (see pages 18-19), as being the younger sibling meant he had always been in my life. On the other hand I was very pleased for him, his move would be a huge and exciting milestone in his life. It was a long and bumpy journey getting Samuel the right care he needed in his adulthood. Going through lockdown and witnessing how much Samuel struggled without school etc. reinforced why keeping him at home wasn't in his best interests. He has settled really well into his new home and I still get to see him twice a week, which is lovely.

Willoughby Coffen, age 16

babies around people with AS

This year is very exciting as I'm expecting a baby boy with my fiancé, Jack. We can't wait for him to arrive and hopefully bring him along to the conference!

When Gareth (24, Angelman Syndrome) and I were younger, our mum used to childmind a family friend and Gareth absolutely loved playing with her. There were plenty of times when he was a bit too rough with her and pulled her hair, but everyone was amazed at how gentle he could be, so I'm interested to see how he will react, now he's much older, to a new baby in the family. We've shown him a couple of the scan pictures, which he had a good look at and he was interested in some of the baby grows we'd bought – and of course he tried to put his own arm in one!

I think the biggest challenge is that we've now moved a couple of hours away from our families to Liverpool, so it's not as easy for anyone to pop over and visit. I'm not sure how we're going to navigate the first few weeks or months when having a new baby plus Gareth in the same room could be quite overwhelming. We're in the process of finding a suitable provider for supported living which will hopefully mean that my mum will be able to come and stay with us sometimes, but I'm sure it'll all work out one way or another.

I'm sure Gareth will be a fantastic uncle and I think our little boy will grow up to have a great understanding of how some people are different but still a lot of fun to be around. Roll on July!

Sian Allen – sibling trustee

Sibs

For brothers and sisters of disabled children and adults

Sibs exists to support people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.

Young siblings

Children and young people growing up with a disabled brother or sister often get less attention from parents and have more worries and responsibilities than their peers. Many young siblings experience daily challenges in their lives such as public prejudice and finding it hard to get schoolwork done. They also need recognition for the positive aspects of their family lives, such as learning new skills and being supportive of their brothers' and sisters' needs.

Supporting your sibling child with their feelings

Acknowledging your sibling child's feelings about their disabled brother or sister, or about family life and school, is one of the most important things you can do to support them. You may not be able to change what is happening at home, but you can respond to how your child feels about things in a way that makes them feel you really care and understand.

Acknowledge your sibling child's feelings

As a parent your life is busy and it can take time to listen carefully, however it really makes a very positive difference to your relationship with your sibling child.

Siblings' complaints and upsets

It is a normal part of family life for siblings to get angry, sad or worried about things that happen. When a sibling tells you about one of these things this is an opportunity for you to listen to their feelings.

What to avoid with feelings

We will use the example here of a sibling coming indoors to say "He's broken the Swingball." If you want your sibling child to share their feelings with you, then avoid these:

Blaming – e.g. "Why didn't you call me outside when this was happening?" If the sibling has done something to cause the problem, it is better to talk about helpful strategies at another time – not when the sibling is upset or angry.

Solving – e.g. "Don't worry, we can buy you a new one." It is best to discuss a solution to the problem at another time. Although the problem may be easy to sort out, your sibling child still needs to have their feelings acknowledged.

Explaining – e.g. "He can't help it because he's got a learning disability." Siblings particularly dislike it when parents explain away the problem because of the disability or illness. Most siblings already know why the problem has happened but that does not change the fact that they feel upset or angry.

Your sibling child may still feel the upset or anger strongly for a while. You can encourage them to use some of the tips for dealing with feelings on YoungSibs.

For more ideas on acknowledging children's feelings a really useful book is *How To Talk So Kids Will Listen & Listen So Kids Will Talk* by Adele Faber & Elaine Mazlish

Adult siblings

Adult siblings, in particular those with a brother or sister with a lifelong learning disability and/or autism, provide support, advocacy and care for their brothers and sisters, at the same time as juggling support and care for their elderly parents, their own children, and their work. They rarely receive any acknowledgement of their role or expertise, information about service provision, or support for their own needs. As a result many adult siblings experience isolation, reduced wellbeing and negative effects on their work and finances. Many adult siblings just want to enjoy social time with their brother or sister rather than time together being focused on care tasks.

Our eBook for adult siblings

Are you an adult sibling who grew up with a disabled brother or sister? Do you ever feel that other people just don't 'get' what life as a sibling is like? Do you find it hard to make time for yourself? Then our eBook *Self-Care for Siblings* is for you.

Chapters include

- Being a sibling
- Your feelings
- Your mental health
- Childhood experiences
- Thinking about the future
- Your relationship with your parent(s)
- Your relationship with your disabled brother or sister(s)
- Having your own children
- Your own family life
- Being a sibling carer
- Siblings and work
- Bereavement
- How to find a counsellor

Get in touch for more information or advice on sibling issues and to request a copy of the eBook.

Sibs.org.uk

vanLIFE

Motability is a widely used scheme by UK Angelman families and for good reason. It's generally considered a good value scheme and is largely worry-free motoring. It's not the only option though, especially when catering for a wheelchair user.

Vehicles are currently in short supply with some brands now unavailable through Motability and others raising advance payments. Waiting times can also be long, largely due to the worldwide shortage of semiconductors which are used in modern vehicles in their thousands.

When we were coming towards the end of our Motability lease, we took a look at the costs. We had paid out around £11,000 over three years when counting advance payment and mobility contributions from DLA.

With lockdown limiting our movements over that period we had only put around 10,000 miles on the vehicle and with only a relatively small 'good condition' bonus coming back to us when handing it back (currently around £600),we felt it was time to look at other options. We considered buying a used vehicle but prices are high on those too in the current market and we would still have needed a loan to finance it. Then we discovered the VAT relief on adapted vehicles for disabled people.

With Jasmine using a wheelchair, we also wanted to make the whole process of travelling easier. We looked at wheelchair accessible vehicles but I have always wanted a camper van and decided to look into how we might combine the two things. We had no trouble finding a good company, Revolution Campers* who really wanted to help us and placed our order for a brand-new VW camper conversion *(*see panel on the right for more options)*.

It meant re-mortgaging the house but month-to-month we are now no worse off (mobility payments cover the extra on the mortgage) and have our dream vehicle, which not only suits our day-to-day needs but allows us to do so much more - including days out, weekends away, holidays and festivals.

We opted for a good specification and made sure we added all the extras we thought we would want right at the start to maximise the benefit of zero-rated VAT.

With camper vans holding their value better than most vehicles, we should be able to largely avoid the depreciation experienced by many when buying a new vehicle. You can only purchase a vehicle using this method once every three years but at the end of that period our camper should be worth somewhere around what we paid for it, enabling us to replace for little or no cost and certainly a lot less than we were paying over a three-year period on Motability.

The conversion companies also have stock coming in all the time as they order them well in advance. This can help to avoid the long waits experienced by others. It's certainly not for everyone but something to consider for those who feel they're

not getting value out of the scheme or want something a little different.

Happy travels.
Dan & Cherry Moir

https://www.gov.uk/guidance/vat-relief-on-adapted-motor-vehicles-for-disabled-people-and-charities-notice-1002

Christyan Fox adds... *because we're also due for Motability renewal in the next few months I was genuinely interested in this approach so (because Dan is a trustee and happy to help other families) I emailed for some more advice:*

You would need a long wheelbase if using it for Harvey in the arrangement that we have. We just about manage with short wheel-base (SWB) because Jasmine is only 6 and we usually just lift her in rather than using the telescopic ramps. You might want a better ramp system and lowered as much as possible (probably air bag suspension which adds about £5k) as the ramp angle is quite steep for us (only lowered 40mm). Cherry wanted SWB as it's her daily drive but I'm working on convincing her to go LWB when we hopefully replace it for new after 3 years. Of course you could also look at alternative layouts with rear access and perhaps a fold-down bed. Some of the conversion companies (including the one I used) work to standard designs so you would have to find someone more flexible if that was the case.

The company we used were very good. We had a bit of snagging which we have had to go back to them for but they dealt with it quickly and are really friendly. The owner is in a wheelchair himself and really wanted to help us. Lots of companies will do it with a basic wheelchair conversion but I found good people who wanted to help at a very competitive price. I'd be happy to pass you their details if you're interested. They're based in Cambridgeshire, so you may prefer to look closer to home but we felt it was worth the travel after going to see them and getting confidence in them.
Dan Moir

paint your wagon

Dan & Cherry Moir chose a very tasteful modern interpretation of the camper theme, with subtle orange accents to offset the grey paintwork.

But how about recalling the glory days of the 1960s and 1970s VW campers with your new van?

You might have seen Volkswagen's new retro-themed 'Buzz' in the news recently and been horrified by its starting price of £57,000(!).

But a quick Google search reveals lots of other companies who can give a more modestly priced van a fun twist.

The retro-themed vans shown below are from a conversion company called 'Jack's Shack' (instagram: jacksshackuk), but once you start searching you'll reveal lots more companies in the market who can help you realise whatever van dreams of your own.

the challenges of afte





Daniel left his SEN school setting behind at the age of 19 – this was July 2021, after all the restrictions and lockdown rules we all had to contend with.

We had an idea of what we wanted for Dan after he left school but found it extremely difficult to access anything suitable within our local borough, Dudley. We realised that 16 hours a week at a college without the correct support wouldn't work and that a few days in day centres here and there really wouldn't benefit him. We felt he had so much more potential, as long as he had the correct package put in place.

We opted for a residential college (term time only), so he would still come back to family life during college holidays. We had to do a lot of research, ask questions and email the correct people because there was very little help (if any) offered to us with regards to transition.

The first college that offered us a place was National Star in Cheltenham and everything seemed to be going fine until we had to rely on our local authority for funding. Not having a social worker was crucial and after a lot of moaning we were eventually allocated one in March 2021, after asking for 6 months – needless to say this was too late and we lost the place in Cheltenham.

So we started looking around again (using NATSPEC – which is a list of colleges up and down the country). We had some rejections that couldn't meet Dan's needs, there were some that were too far away etc. – so we kept looking.

We eventually found Seashell Trust near Manchester. They had a place, could meet his needs and were a couple of hours away – so we went for it.

Then the battle of emails, Zoom and phone calls started. It was like a having a full-time job. Education, health and social care were all going to panel to battle it out over who would pay for what in Dan's package that was put together by the college. I was often asked if he really needed an 'educational setting' and that he could learn life skills in a day centre (obviously the cheaper option).

Plodding on through the summer of 2021 there always seemed to be excuses of paperwork missing or being unsure who to speak to. It even got to the point of contacting MPs and getting SENDIASS involved to help put a case together for tribunal. All the ins and outs of an EHCP and what needs to go in which section and what jargon or 'buzz words' to be used. (Just take note that the views and aspirations of parents are not really taken into account on an EHCP.)

We were nearing the end of August and Dan had had no transition or stayed at his new college and we were told he could start late September, so a weekend could be squeezed in during early September for a visit. Seashell Trust were brilliant and we were shown his new house – shared with two other young adults. We saw the grounds, park, petting area, sensory garden, gym, college... the list goes on. We met all the professionals who would be involved with Dan. SLT were great and worked really hard to help with Proloquo2go on Dan's communication aid.

He would be in a small class of five with one-to-one staff at college. When he was dropped off in late September he was

er-school life

obviously a bit homesick (especially not having mom around) and he would drop to the floor or not cooperate transitioning from A to B. But the staff in house and at college persevered and kept me updated.

We also did lots of FaceTiming and Zoom calls. Friends and family also called him and he loved seeing their familiar faces, especially his brother Joel – Dan is non-verbal and his favourite sign is 'brother'.

In just 8 months at Seashell he has conquered some huge milestones and his progress is ongoing. He is hardly using his wheelchair and walks to and from college (which is all on-site), he loves working with peers his own age and going off-site for trips.

Hopefully he will get funding for a second year as we can clearly see it has benefitted him and we're glad we made the right choice for Daniel as his journey into adulthood continues.

** Edit: Dan has now received funding for his second year at Seashell.*

Jane Walker and Rob Hill (parents to Daniel Hill)

'Angel' Man at 50!

Here is John recently celebrating his 50th birthday. His birthday picture sums him up perfectly... no change in his love of pulling decorations down! He is still the same happy ('adorable' his teenage nieces and nephews call him) person he always was, with the added bonus he now sleeps better! He lives at home with parents, John and Sheila. His dad was in the army so John was well-travelled: he was born in Germany and lived in Hong Kong. Since the age of 19 he has lived in Chester and has always attended the day centre 5 days a week 9am - 4pm. He does all the things he loves: swimming, trampoline, going out on cafe visits and spending time with all the people there. He loves the sunshine, especially from his garden swing. He is still a people watcher. Age has made him a lot calmer – nowadays he's a lot more aware of things going on around him – so he's learning all the time.

These photos illustrate the full and happy life that John has led so far.

Note: This 1970s photo is John with his older sister and younger brother. His brother is now a physicist working on the Large Hadron Collider in Geneva and his sister is a teacher living in Somerset.

Sheila Thompson

Samuel's move into supported independent living

We thought it might be useful or interesting for us to share with you the experience of our son, Samuel, leaving home to start a new independent life in supported living. We totally appreciate that every Angelman family is different and we want to stress that this is just our experience and what we felt was best for us and Samuel.

We live in Dorset and have Samuel, 19 (Angelman Syndrome Deletion) and Willoughby 16. Samuel was diagnosed at 15 months old and, as you all know, although having a child with AS can be extremely rewarding in lots of ways, it is also incredibly difficult in more ways than you can comprehend at the start. We have been supported by AngelmanUK from those early days after his diagnosis.

Over the years we fought and fought for respite and gradually got this increased from just 3 hours a week when Willoughby was a baby right up to, in the end, getting 108 nights a year (plus we always kept our original 3 hours a week).

At one of the ASSERT/AngelmanUK conferences a few years ago we attended an invaluable session by a parent of an adult AS child who had recently left home and we always remembered a key bit of advice from that session: to fight for as much respite as you can possibly get so that when the time comes it's not such a leap into full time supported living.

We knew the respite we so desperately relied on wouldn't continue once Samuel reached 18. We were barely coping with the respite we had, so we absolutely knew we wouldn't be able to carry on with it at a reduced level. Right back when Samuel was 14 and the 'transition' process started during his annual person-centred reviews at school with Social Services, teachers, health care, respite company, etc. we started firmly saying that the plan was for him to be able to move out of the family home at 18 into suitable supported living, locally with 'meaningful activities'. We consistently gave the same message during every meeting from then onwards.

At this point we must stress that we absolutely love Samuel and of course we have experienced every possible emotion throughout the transition experience, but we knew 100% that this was the best course of action for us and more importantly for him – to be able to live as independent a life as possible and we knew in our hearts that, although we did as much as we could with him and looked after him to the best of our ability, we weren't going to be able to sustain that forever. Also, knowing how long the process took for other parents, we didn't want to leave it until it was too late. We were adamant that we had to create the best situation for Samuel's future.

When Samuel was 16 we officially started the process of transition to adult Social Services from children's Social Services with the clear goal that we needed suitable supported accommodation and care for Samuel asap. This involved various meetings and reviews and the inevitable form filling. Samuel's children's social worker and new adult Social Worker were very friendly and both said the right things, but things moved extremely slowly with lots of *'My hands are tied as I can't control adult Social Services'* decisions' or *'My hands are tied until Samuel is 18 and is fully under adult Social Services'*. We were often stuck in the middle which was extremely frustrating.

We soon discovered that neither social worker was going to seek out or suggest suitable options for Samuel so we started our own research by speaking to other parents and care providers. We ended up going quite a long way with two different possibilities: both shared houses with 2 or 3 other young adults and full-time carers. But after a lot of consideration they weren't quite right for Samuel.

All this had taken nearly 2 years and many hours of phone calls, meetings and lengthy emails to more and more senior people. Samuel was now hurtling towards his 18th birthday and we were desperate to get things sorted, but we wouldn't compromise as this was such an important decision and it was imperative that we got it right for Samuel.

Eventually in February 2020 (less than 3 months before his 18th birthday) a possible property was identified by Social Services – it sounded perfect, then lockdown struck! As you can imagine this caused numerous delays and made everything so much harder, especially as poor Samuel was home from school turning stir crazy and his behaviours were worsening by the day.

However, the property was perfect: a lovely new-build 2-bedroom bungalow with a small garden and driveway in a small, special needs housing development right in the centre of Dorchester town, about 25 minutes from us. We'd driven straight there as soon as we heard about it and knew it was ideal for Samuel, so we immediately phoned Social Services and said *'Go, Go, Go!'*

Everything had to be approved by various committees, which took several more weeks, but then we moved onto the next stage where we had to get to know the proposed care company, iDirect, and, more importantly, they had to really get to know Samuel. This was a detailed process with numerous meetings, copious forms and paperwork, but we were pleasantly surprised, and quite frankly shocked, how efficient the care company was in pulling

everything together in contrast to the years of delays with Social Services. Whilst this was going on we were dealing with several other essential strands to the process – sorting out Samuel's benefits, furnishing his bungalow from an empty shell, sorting out a new Motability vehicle, attending court to establish that he lacked mental capacity and to take control of Samuel's finances and personal affairs, completing the Adult Continuing Healthcare Assessment (as his care is part- funded by them alongside Social Services), getting court approval for his Deprivation of Liberties (including the reason why his front door has to be locked, why he wears a onesie in public under his clothes, why he needs straps on his wheelchair etc.), setting up accounts for water, electricity, gas, broadband, Council Tax exemption and so on. All made so much harder by still dealing with the guilt and having to sort it out during lockdown, with no sleep and no respite, with Samuel sat next to us naked having 'personal time' interspersed with weeing and/or pooing on the settee or floor. Looking back we honestly don't know how we survived!

iDirect are a small private care company and we liked their ethos in putting Samuel first. We were involved in the interviewing process for his proposed new team members via Zoom. He was to have a big team of about 15/16 people as he has 2:1 care 9am-9pm and then 1:1 with another carer in the spare bedroom who can be woken up if needed during the night. Once the team was established we got to meet everyone either on their own or in pairs with Samuel, at our house or in a nearby town where we spent time getting to know them and Samuel gradually got used to them. It was a good opportunity for us to impart as much information as we could and build up a good relationship with his new team. In the weeks before the move they spent more and more time with him until he was ready to spend some weekends on his own with them at his bungalow. (We'd taken him several times to visit his bungalow beforehand and walk around Dorchester, his 'new home' as well.)

We'd made sure we'd furnished the bungalow as nicely as we could as we were conscious that, as well as being lovely for Samuel, we wanted it to be comfortable for his team as they were going to be spending so much time there and we wanted them to be happy. We made sure Samuel had familiar things there and we chose lots of steam train-themed things too, as they are his favourite.

Samuel's four transition weekends started in the July of 2020. Pre-lockdown he'd previously been used to staying away for the weekend twice a month and loved it, but we were sick with worry about this. As it turned out the first time we dropped him off he panicked for literally about 30 seconds as we went out of the door and left him with two of his new team, but before we'd even had a chance to sneak up to the window to see how he was, he'd shot through to 'his' lounge, sat up at 'his' table and was asking for a snack, happy as anything! We rang each night to check in and he was very happy. We were completely blown away.

All went well, so a month later on 7th August, we dropped him off for his proper move. We were so emotional and desperately trying not to cry so as not to upset him. However, when we arrived his new neighbour rushed out to greet him and invite him to her birthday BBQ that weekend, which was so lovely. After all these years he was finally getting a social life and we couldn't be more thrilled. We drove away understandably feeling sad, but also extremely positive for Samuel's future.

We obviously still want to be a big part of Samuel's life and always will be. We briefly ring each evening to say hello and find out what he's been up to from his team and we visit twice a week. We take him out for a drive and a meal each Tuesday evening and out every Saturday morning or lunchtime. He gets to see us and his team get to do his housework etc. while he is out.

To start with we were really anxious how he would react to our visits, or more specifically how he would react when we took him back. We needn't have worried though, he is always so excited to see us and flies out of the house like a cork exploding from a bottle and jumps into our car, but when we take him 'home' he gives us a big hug and kiss, pushes us back into the car, waves goodbye and goes off happily inside with his team. He knows it is his home. We were so relieved and still can't get over how quickly and how well he has settled into his new life. We feel privileged that he still wants us to be a part of it.

Samuel left home 18 months ago. We won't lie, not everything has gone smoothly, there have been numerous changes to his team and there have been various hiccups along the way, some more serious than others, and we have to keep an eye on how things are going, intervening where we feel necessary. Overall, we still know that this was definitely the best move for Samuel and he is positively thriving and living his best life.

Our advice to anyone thinking of going down a similar route in the future is to start early, fight, fight, fight and do as much research as you can. We are more than happy to chat to anyone about our experience. You can either contact us through AngelmanUK or via Facebook.

John and Amelia Coffen

meet the tr

Rachel Martin, Chairperson is a single mum and has been a trustee since 2005 and Chairperson since 2012. She lives in North Wales with James 20 (AS), Zac 16 and Beth 15. Rachel also has an older daughter Alex who lives in Bolton. James is well known to many families in the Angelman community because of his amazing bear hugs! Rachel is responsible for overseeing AngelmanUK moving forwards and has been instrumental in initiating many projects which benefit the community as a whole. Rachel has a clear vision for the future of AngelmanUK and is working hard to make sure that the board of trustees is able to accomplish its goal of supporting our families to the best of our abilities.

Lisa Court, Treasurer, lives in Nuneaton and is a single parent to Ella 19 (AS), Jacob 17 and Thomas 15. Lisa has been a trustee and treasurer since 2005. She is usually the first point of contact for many families who email us at the start of their Angelman journey. She handles most of the admin side of the charity as well as running a tight ship financially. Her spread sheets are legendary!

Diane Fox-Jones has been a trustee since 2015 – taking over from her husband Christyan. Diane oversees the charity's website, shop, media output and videos. She lives in Surrey with Christyan, sons Harvey 24 (AS) and Milo 16. Their older daughter Lottie lives nearby and is involved with AngelmanUK films & photography. They are currently in the process of finding a supported living arrangement for Harvey.

Sian Allen is one of our sibling trustees and helps with our creative design. She has a brother, Gareth who has AS. Sian lives in Liverpool with her partner and is expecting her first child this summer.

Dr Katie Cunnea has been a trustee twice, she likes it that much! She is the Science and Research advisor for AngelmanUK. Katie lives in Hampshire with her husband Dave, son Finley and daughters Ruby (AS) and Amber. As a Biochemist in real life, Katie is very helpful at explaining the technicalities of science and research to both the board and our families. Katie has attended international scientific conferences with Rachel for many years and is an integral part of the Angelman Syndrome Alliance (ASA) community.

Emma Goodson lives in Essex with her husband Andy and sons William (AS) and Eli. She and Andy are keen runners and enjoy fundraising for various charities including AngelmanUK. Emma helps with social media and is often the first point point of contact for newly diagnosed families who find us through Instagram or Facebook.

Dan Moir became a trustee in July 2020, a time when we had no other male trustees. He wasn't sure how he would be able to help but wanted to give back to the community that has been so useful and supportive. Dan assists with supporting dads and anything else he can get involved with, including being active on our social media and helping out with the technical side of things. Dan lives in Worcester with his wife Cherry, daughter Jasmine 6 (AS), son Max 3 and naughty beagle Bella.

Gemma Munsey lives in London with her husband Julian and two daughters Ava and Anna (AS). Gemma is a long-standing member of AngelmanUK and has come on board specifically to help us move into the future with our new database and digital upgrade.

ustees

angelman uk

trustee little helpers

Alex Edgar, Secretary became a trustee in 2022. She lives in Bolton with her two young children Benjamin and Tobias. Alex is taking on the role of secretary and will also be working with Sian Allen to support siblings. Alex grew up as the oldest sister of James (AS), Zac and Beth as well as being the daughter of a busy trustee. She is very aware of the needs of siblings and hopes to use her skills and interests to help develop the role of sibling support.

Dr Richard Strickland lives in Surrey with his wife Larisa, son Matthew (AS, born 2009) and a very supportive and loving younger daughter Petra. Richard has been a GP in Surrey for just over 20 years. As well as his clinical work, he is very involved in organisational leadership and pathway redesign in the NHS. The ambition is always to create services that are easier for patients to navigate, but also free up clinicians to focus on their patients.

Dr Ben Warne specialises in infectious diseases and adult medicine and is a researcher on viral/bacterial genetics. As you can imagine he has been very busy over the last 2 years! He lives near Cambridge with his wife Claire and children (his daughter, Tess, has AS). Despite being so busy Ben volunteered to come on board to help us in a professional capacity and he joins Dan, Richard and Christyan in our team of superdads!

Mairi McGaw is our Scottish Trustee. She lives in Laurencekirk with her three children Jon (AS), Ritchie and Molly, a few sheep and a couple of horses. She is the first point of contact for some of our new Scottish families and is responsible for sharing information relevant to Scottish law and guidelines.

Kate Pickering is the person you'll often hear at the end of ourtelephone support line. Kate is mum to Livvy, 25(AS), Will and Hannah and lives in Rutland with her husband Jeremy. Kate spent several years as a trustee but now prefers to help us as a volunteer.

Souzie Mckay is our 'Family Champion' from the United Arab Emirates (UAE). She has been based in Dubai for nearly fifteen years with her husband and two children. Souzie is an AngelmanUK Community Ambassador in the UAE and ASF Family Champion for the region. She offers support and guidance to newly diagnosed and long established Angelman families, and introduces them to the regional and global Angelman community. Souzie liaises with government bodies and commercial entities to raise awareness of Angelman Syndrome and the challenges it can present.

A lot of you might have bumped into **Christyan Fox** at one of our previous conferences. He's been involved with the charity for so long he's in danger of taking root: attending conferences since 2000, was a trustee between 2005-2015, then came back as media advisor in 2018 to oversee the rebranding from ASSERT to AngelmanUK. During that time he's done whatever he can to raise the media profile and awareness of the charity. Christyan is an author-illustrator-lecturer, all-round busy-body, designer of the newsletter you're reading and father of Harvey 24 (AS).

communication

multi modal communication

People with Angelman Syndrome are multi modal communicators. They use a variety of ways to communicate such as AAC, gestures and vocalisations. It's important to recognize all these modes of communication as valid, while using the mode you are trying to teach.

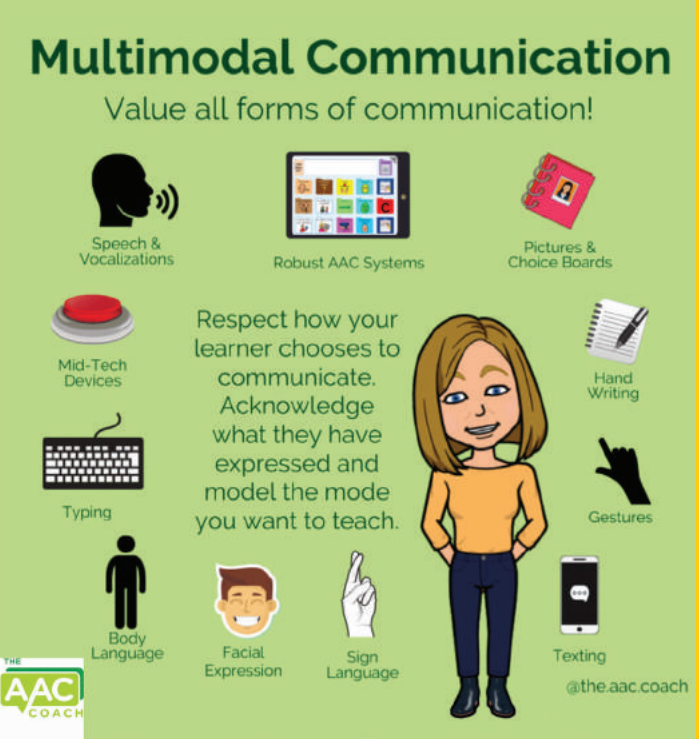
If you are part of the Angelman community, chances are you've heard the quote "Although I may not speak, I have much to say." Anyone who has got to know someone with Angelman Syndrome will tell you that they understand so much more than they can express. There is a discrepancy between their receptive and expressive communication.

This is not a lack of communicative intent, but likely due to a 'speech production impairment'. For this reason, we must presume potential that the individual is able to communicate, but needs support in overcoming complex communication needs.

A multi modal approach that includes the use of robust augmentative and alternative communication (AAC) can help bridge the communication gap and give individuals with Angelman Syndrome the power to express themselves more fully.

You can find an article on Communication in Angelman Syndrome here: https://pubmed.ncbi.nlm.nih.gov/31074506/

Kate Ahern



research

What is the Medical model of disability versus the Social model?

...and why does it matter?

For too long people with disabilities have been treated as second-class citizens. They have repeatedly been bombarded by messages that their bodies are defective, that they need to be fixed or cured, and that their inability to participate fully in society is because of them and their disability. Carol Gill at the Chicago Institute of Disability Research wrote a paper that strove to see how people with disabilities are seen by society, as well as how people with disabilities see themselves. Gill believes that there has been an overemphasis on the medical model of disability, which has kept people with disabilities from being able to fully participate in society. Following is a description of the five key differences between the two models.

1. The medical model says that disability is a deficiency or abnormality whereas the social model says that disability is a difference, just as a person's gender, age or race is a difference.

2. The medical model says that having a disability is negative whereas the social model says that having a disability is neutral. It is a part of who you are.

3. The medical model says that the disability is in you and it is your problem, whereas the social model says that disability exists in the interaction between the individual and society. Disability issues stem from someone with a disability trying to function in an inaccessible society.

4. The medical model tries to remedy disability through a medical cure or by trying to make the person appear less disabled or more "normal", whereas the social model says that the remedy is a change in the interaction between the individual and society. When society changes the issues of a person with a disability disappear. If a building is fully accessible it doesn't matter if a person walks in, runs in or comes in with a wheelchair or walker.

5. And finally, the medical model says that the fix is found with a professional. The only person who can help a person with a disability fit into society and be accepted, is a professional. The social model, however, says that the fix can be found within the individual with a disability or anyone who wants people with disabilities to be equally included in society, including you, the person reading this right now.

For too long people with disabilities have been told that there is something wrong with them, that they need to be fixed and that they shouldn't be surprised that they are not fully welcomed or able to participate in society. These negative messages are often internalised by people with disabilities, which creates even more barriers to participation. However, more people with disabilities are finding their voices and asserting their rights, all the while challenging the perceptions, definitions, and models of disability that currently exist. They are stating that we must move away from the medical model, which states that the person with the disability is the problem, towards the social model, which emphasises that society itself has a responsibility to create inclusive communities. As the differences in the models are being shared and explained, people with disabilities are gaining support and understanding from others in society, be they politicians, city employees, advocates, non-profit organizations, medical professionals, and/or individuals within the community. People are joining together to state that disability, like gender, age, and/or race should not be a barrier to participation. Carol Gill's paper on the two differing models has helped to move that dialogue forward.

You, too, can be part of the move away from the medical model and towards the social model. You can help to work towards an inclusive society whereby the disability no longer ostracises and where one no longer sees a person with a disability as less than their fellow community members.

Heather Mcain

Absolutely PHAB!

Phab inspires and supports disabled and non-disabled children, young people and adults to make more of life together - breaking down community barriers, reducing social isolation, and creating opportunities for all involved to enjoy the same activities and challenges side by side.

Around 130 Phab Clubs across England and Wales, with 8,000 members, enable disabled and non-disabled children, young people and adults to get together with friends and family for all kinds of activities and social events.

Rosie Clarke is well known to many of our families who have attended our family and communication conferences. She is a head teacher as well as one of the UK PODD trainers. Rosie has recently set up a mini PHAB club which promotes inclusion of all babies and toddlers including those with additional needs.

To see if you have a local club, contact PHAB: **www.phab.org.uk**

Mini Phab Epsom and Ewell

EPSOM AND EWELL MINI PHAB GROUP

Starting 17TH JUNE | ST JOSEPH'S CHURCH HALL, IN EPSOM FROM 9.30-11 am

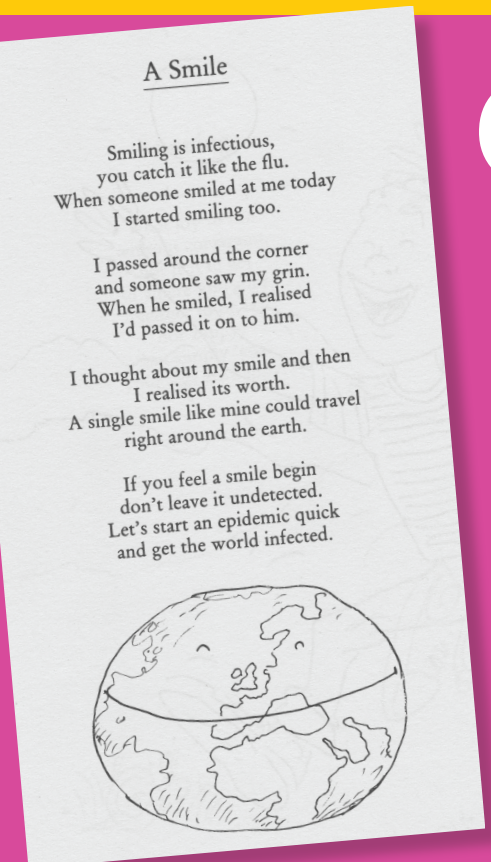
THIS EXCITING NEW VENTURE IS BEING SET UP AS AN INCLUSIVE TODDLER GROUP, OPEN TO ANY FAMILIES WITH CHILDREN FROM BIRTH TO SCHOOL AGE.

The group will be run on a Friday morning in term time, in Epsom, by volunteers with extensive experience of supporting children with complex learning, physical and medical needs and will aim to will offer activities that will enable babies and toddlers with and without additional needs to join in and have fun in a relaxed and fully supportive environment.

Volunteers will be on hand to offer advice if needed and give parents the chance to sit and have a coffee a biscuit.

There will be a range of activities to support the toddlers' physical development, play skills, social skills and early learning skills, as well as developing a range of communication skills including the use of signing and symbols.

To find out more information please see our Facebook Group - Epsom and Ewell Mini Phab or email rosemaryvclark@hotmail.com



a smile

A Smile is a poem that will appeal and resonate with lots of Angelman families. It was written by children's book illustrator and author Jez Alborough – creator of the *HUG, DUCK IN THE TRUCK* and *WHERE'S MY TEDDY* series of picture books. On his Facebook page Jez Alborough recently had this to say:

*In 1990 I wrote a little poem called **A Smile**. Here it is as it appears in my 1991 collection SHAKE BEFORE OPENING.*

A few years after it was published, a friend told me they had seen it reproduced, but mis-attributed to Spike Milligan. Perhaps because its style seems faintly Milligan-esque, someone assumed it was by the late great poet and this untruth has spread all around the world – just yesterday my stepdaughter, who lives in Denmark, told me there's a poster of my poem, mis-attributed to Spike, on the wall at the nursery where she works.

*Amazingly, there are quite a few other people online claiming that they, or their relative, wrote my poem. As you can imagine, it feels very odd to see other people claiming that the sacred moment of inspiration which produced **A Smile** happened to them. Not only does it feel like they're calling me a liar, but they're also trying to steal ownership of my creation.*

Please help my 'GET MY SMILE BACK' campaign by:

- *Liking and sharing my Facebook page*
- *Letting me know either by posting, commenting or sending me a private message if you see **A Smile** appearing on Facebook, posters, websites or videos mis-attributed to anyone else.*

Many thanks for your help – it will bring a smile to my face!

Jez Alborough

funding

ASF family fund

The ASF Family Fund was created in 2019 to provide financial assistance to families supporting individuals with Angelman Syndrome (AS) Family members can apply for funds that are needed to improve the quality of life for an individual with Angelman Syndrome.

The fund is opened twice per year in April and October. The application process was created to be as streamlined as possible to support families that are already buried with other paperwork.

Since it was opened in 2019, we have funded over 300 grants totalling close to $400,000. In 2021 we were very excited to partner with AngelmanUK, who share the same values and mission of supporting families through the journey of Angelman Syndrome This partnership allows AngelmanUK and the ASF to work together towards that mission. We are honored to work with the AngelmanUK board of trustees who work tirelessly to support their community.

Amanda Moore, Angelman Syndrome Foundation

AngelmanUK is very excited to join with the ASF in bringing this grant award to our UK families. We are a tiny charity compared to the ASF and because of this we have to limit our UK awards to a maximum of £500 per applicant. However, should your request exceed this amount, the ASF has the discretion to top-up funds if agreed by the board. So far, items we have funded or contributed towards include iPads and communication apps, travel beds, specialist wheelchair buggies, car seats etc. **Importantly, we would like to stress that this grant is open to people with Angelman Syndrome of all ages including those over 18 years old.** We understand that charitable funding is hard to find once you are an adult so we hope that by extending the age range to include everyone benefits our community as a whole.

For UK families to be considered for a grant you must be registered with AngelmanUK. You can register on the website for free! https://www.angelmanuk.org/about/join/

Please note that we cannot accept requests for permanently installed enclosed beds, however a contribution towards a travel bed such as the Safety Sleeper or UrZone will be considered.

The next cycle will open on 1st October 2022. For more information you can go to the AngelmanUK site or the ASF site to learn how to apply and to access the application.

Rachel Martin, AngelmanUK

thank you!

A huge thank you to AngelmanUK for the grant to enable us to buy Sophie a lightweight all terrain chair and freewheel which enables us to go off road and on the beach! The freewheel converts a normal chair into jogger/three-wheeler as it lifts the front castors and with the all-terrain rear tyres it creates an awesome piece of kit! We live in Cornwall, England and are surrounded by beaches, coastline and moors, all of which bring challenges for the normal heavyweight wheelchair users and we find ourselves constantly yearning to take Sophie to the water which she absolutely adores being in and next to - it has not only given us access to the country and coast, it has given us the freedom of choice - thank you, Sophie's smile says it all!

Noel & Tracy Dunne

funding

Child Trust Funds

Child Trust Funds are long-term savings and investment accounts granted to every child born in the UK between 1 September 2002 and the end of 2010. The scheme aimed to ensure that UK children had savings at the age of 18 and to encourage them to develop good financial habits. Children were issued vouchers by the Government that their parent or guardian could deposit with a financial services provider to grow until the child can take ownership at 18 and decide what to do with their money.

Child Trust Funds came of age in 2020 when the first generation of Child Trust Fund account holders – born in 2002 – reached the age of 18 and were able to start managing their money. But it emerged that as many as 200,000 children with learning difficulties would potentially be unable to claim their Child Trust Funds. Parents or guardians were expected to apply to the Court of Protection in order to manage the money on their teen's behalf. While the rules help to safeguard vulnerable people from fraud or abuse, it means parents and guardians spending hundreds of pounds in order to help their teens enjoy their money. In December the Ministry of Justice waived court fees for parents or guardians applying to the Court of Protection seeking access to a Child Trust Fund for this reason. There may be other legal costs such as solicitors' fees to cover and we believe these funds would be far better used to support the child's needs.

Please contact your Child Trust Fund provider or bank to discuss how you can access this fund on behalf of your child.

AngelmanUK is aware of several families who have been successful in getting the money withdrawn with no charges. If you would like to speak to someone who has managed to do this please email **support@angelmanuk.org** and we will endeavour to connect you with someone who can help.

turn 2US Tackling financial insecurity together.

Turn2us is a national charity providing practical help to people who are struggling financially, including carers, disabled people and those who may have become recently unemployed. They provide advice, financial support through grants and awards and have an excellent benefits calculator to ensure that you are receiving what you are entitled to. **Turn2us.org.uk**

free Wills

Alan Brown is one of 'The Will Guys' who also happens to have a brother with Angelman Syndrome. Alan therefore understands the difficulties faced by parents when deciding who to leave their estate to when the inevitable happens. Alan has kindly offered our families the chance to write a basic Will in return for a donation to AngelmanUK.

If your needs exceed the requirements of a basic Will, Alan can discuss further options with you. We'd like to thank Alan very much for his offer of support for our families and we look forward to meeting him at our family conference this year.

The Will Guys

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Phone, video and face to face appointments available at a time to suit you

For all your estate planning needs contact

alan@thewillguys.co.uk
07885 740 017
www.thewillguys.co.uk

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angelman uk

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Contact The Will Guys quoting 'ANGELMAN'

T 0333 012 4308
E info@thewillguys.co.uk
W thewillguys.co.uk

The Will Guys

fundraising

angelman uk

Fran Porter – skydive

Fran Porter very bravely agreed to do a skydive for AngelmanUK in memory of her cousin Lugh Baker who sadly passed away in April 2021. Fran raised the fantastic sum of over £725.

Rachel Hosgood – St Edwards Church, Roath

After receiving a diagnosis of Angelman Syndrome last year for our daughter Bella, our involvement in the Angelman community has given us strength and a positive focus which has been incredibly important. We wanted to raise funds and awareness for the two charities which support the condition, AngelmanUK and FAST UK. They have provided amazing support to us and also help people understand more about disability.

For International Angelman Day in February, we worked with AngelmanUK and contacted Cardiff Council who agreed to light up Cardiff Castle and City Hall to help raise awareness of the condition and honour all those affected by it. *Cardiff Life* magazine did a spotlight article on the day – which we were so pleased with as it reached out to so many people.

We have also held a piano concert coffee morning in our local church St Edwards in Roath, which was a massive success. We raised just under £2,000 with the help of a number of local tradesmen who saw our plans and wanted to be involved to raise as much money as possible. Lots of our wonderful friends and family helped set up the day and ran the stalls.

One of my oldest friends, Gary, is an amazing musician and organised lovely live music for everyone. He asked his piano pupils to perform, as well as many of his contacts in the singing world so it was a musical extravaganza!

St Edwards church in Roath was amazing in helping us run the event and providing all the bits we needed to run the day smoothly.

We are so grateful to everyone who came and donated money, cakes and raffle prizes, bought cakes and enjoyed the music. It was a wonderful morning and an amazing atmosphere. We feel very privileged to be able to raise funds for AngelmanUK and FAST and to be a part of this amazing community.

Linda Holmes
Alton Towers-SplashLandings IAD short break

A massive thank you to all the families that attended the 2022 IAD 9th annual Alton Towers SplashLandings 'big weekend'.

We had an absolutely fantastic meet-up for our Angelman families, totally enjoyed seeing each other after being apart for 2 long years and in doing so we raised £621!

This was divided between AngelmanUK and FAST UK with raffle prizes generously donated by the families and Name-the-Teddy competitions with bears donated by the Alton Towers resort hotels. Everybody thoroughly enjoyed themselves, meeting up with all the pirates and princesses at this much needed get together.

Jackie Anderson
BT Fundraising

Having worked for BT for 26 years I've been involved in many of the fundraising events in which the company participates. In 2021 we were asked to nominate some charities for this year's event. I nominated AngelmanUK due to my 4-year-old granddaughter, Maia, having Angelman Syndrome (AS). There were many worthwhile and well-known charities nominated but after the ballot results, it was announced AngelmanUK had won! I was extremely happy and touched that this little-known condition (to many people) was now being brought to the attention of all the people involved and those who sponsored us. I think it was probably the write-up I sent with the reasons why I had nominated AngelmanUK that touched those who voted. Here are some snippets of my nomination:

My granddaughter, Maia, was born in August 2017 and was developing as a typical baby until around 5 months of age when we, as a family, realised her development was slowing down and she wasn't achieving her milestones.

After conversations with the doctor and health visitors we were told Maia had possible global development delay. We were referred to a paediatrician where Maia was diagnosed with Angelman Syndrome (AS) a month before her 2nd birthday.

As you can imagine, our world fell apart – we knew very little of this condition and feared the unknown. My daughter had an appointment with a geneticist a few days later, who gave her information about the genetic part of the condition, handed her a leaflet and told her to go online and join AngelmanUK for any further information. That same night, I was extremely upset, not only for myself, but trying to find a way to help and support my daughter and her partner who were completely heartbroken.

I contacted AngelmanUK and spoke to a lovely lady who really helped to calm me down. They're a support group entirely run by volunteers of people who are related to, or carers of people with AS. My initial upset and concerns were a mixture of the unknown: what kind of life would Maia have? Who would look after her in her adult life? How would we deal and cope with her seizures? How would we deal with the fact she may never walk, that she would be non-verbal – how would we communicate with her, and grieving for the life we thought we'd have with our first grandchild.

The lady on the support line was very calming, shared experiences of her own 23-year-old daughter and how she had handled her emotions over the years. She told me not to worry about things I was unable to change or look too far into the future worrying about what may or may not happen: "Don't miss out on the 'now' by worrying about what may never happen in the future", and she was exactly right. We now live and enjoy every moment with Maia, she is developing into a cheeky, mischievous, lovable toddler who brightens up our darkest days and anyone who meets her says the same.

AngelmanUK are like a little family community of people who know exactly how we are feeling, they have children of all ages into adulthood so have experienced everything we are going through. The online support group are always able to answer any questions or concerns ranging from behaviour, health matters, special equipment, mobility requirements... basically anything and everything to do with caring for an Angelman child.

I have been in touch with other grandparents from across the UK as well as the US and Australia. This is also lovely and supportive for us, because we are not only worried about our grandchild with AS but also our own children who are trying to handle a physically and emotionally draining situation they never expected to be in.

Maia can now bum-shuffle and crawl and has started to climb. She is unable to stand alone (unless she is against something) or walk – but we are hopeful this will come in time. Although Maia is non-verbal she certainly has her own ways of letting us know when she is hungry or unhappy with something, but most of the time she is a very happy, cheeky and lovable child.

The planning teams across BT, EE and Plusnet raised over £5,713 by participating in various events which mainly took place on 25th June 2021. The events were held across many locations in the UK and were things like 50 mile bike rides, walks, runs/marathons.

angelman uk

fundraisers

You've read about the efforts of our fabulous fundraisers – why not get involved yourself and organise an event to raise money for us! Contact **lisa.court@angelmanuk.org** and she'll send you a fabulous fundraising pack with all the details of how you can get involved.

Cameron Smith	The Kiltwalk 2021
Freddie, Max, Sofia, Beau	4000m swimathon
Lisa Warrington	Fire Walk
Bindu Bakrania	Nyra's Journey
Chris Docherty	FQM Free Training
Gavin Smith	2.6 Challenge
Hiten Bhundia	4 Round Challenge

Sian Allen	Challenge20
Dan Moir	Challenge20
Vanessa Jones	Challenge20
Rich Williams	Challenge20

Adam Hearnden	Lands End to John O'Groats
Leanne Davidson	Team Oliver Walk
Camilla Turton	Christmas Market
Yuksel Selvi	Hackney Half Marathon
Blue Blush Events	Charity Ball
Namos Solutions	Various Events
Shelby Bajramovic	Squats
Jonathan Chapman	50 Mile Run
Roisin Gabell	5k Run
Natasha Read	Skydive
Flawed Tomato	24-Hour Live Stream
Claire Lynch	Daily Walk
Hollie Smith	75km Walk
Jackie Anderson	BT Fundraising Events
Jenna Hamilton	EMF Virtual Half Marathon
Kevin Pannett	155 mile walk
Mark Biddulph	Street Party
Frannie H	Suzuki Alto Road Trip
Frannie H	Cycling
Yuksel Selvi	London Landmarks ½ Marathon
James Nicholson	24-hour darts marathon
Paul Evans	Eden Valley Ultra
Calvin Moffat	Movember
Jack Blackburn	Movember
Rachel Hosgood	Bella's Birthday

Jim Bacon	Virtual London Marathon 2020
Sarah Brown	Virtual London Marathon 2020
James Drake	Virtual London Marathon 2020
Jim Bacon	Virtual London Marathon 2021
Shelley Brown	Virtual London Marathon 2021
Leigh Collins	London Marathon 2021
Tracey Nessling	London Marathon 2021
James Drake	London Marathon 2021
Mark Lisssaman	London Marathon 2021
Tony Mardon	London Marathon 2021
Suksun Hutangkabodee	London Marathon 2021

Bethany Pye	Great North Run 2021
Elise Ling	Great North Run 2021
Rachel Cowell	Great North Run 2021
Andrew Stephenson	Great North Run 2021
Mark Thompson	Great North Run 2021
Marc Lockwell	Great North Run 2021
Chris Brady	Great North Run 2021
Glen Richardson	Great North Run 2021
Graeme Maddick	Great North Run 2021
Gareth Ancrum	Great North Run 2021

...and we'd also like to thank all our fabulous Facebook fundraisers!

help us to help you keep

smiling

donations

Without your contributions there would be no AngelmanUK to offer support for your family. Whether big or small, every penny really does make a difference. A very big thank you to...

Mrs Hazel Tait

Mr A J Taylor

Mrs Jean Girling

KBC NV London

Duffy family and friends

Gail Whisker

Davey House at Halstead School

Anne Barrett

Jackie Snow

Kendal South Westmorland Rotary Club

In memory of Kathleen Gavan

Fantha Tracks

Abersychan Dental Practice

Mr & Mrs Fox

Abii Coe - Rouxs Bookcorner

Neale Turk LLP Solicitors

In memory of Brody Cave

FCE

Mrs J Tolley

Collier Row Catholic Club

In memory of Doreen Reader

Mr Rodney Freeman

Rhys, Sarah, Kaiden and Cody Thomas

In memory of Mr John Russell Savory

Mrs Gillian Ibbotson

Mrs Marguerite Chisti

Lynn & Jim Keeley

Ruth Curbishley

Inner Wheel Club of Huntingdon

The Rotary Club of Norwich St Edmund

Mr R J Brook

Mrs Jane Clarke

Carol & Joshua Lee

Issa Medical Centre

Eaton Lodge 533

Pete's Plaice

CMS Nabarro Olswang LLP

Leeann Barnett

Kirkleatham Hall School

Mr and Mrs Barkley

In memory of Jane Carpenter

Helen Fielder

Clare Jonas

In memory of Graham Sloper

Namos Solutions

Mrs Brenda Page

Huntingdon Inner Wheel

Baillie Gifford

In memory of Lynne Wright

Fran Porter

The Lions Club of Maidenhead

CMS Cameron McKenna

Becky Holmes and all at the Fox & Hounds, Cookridge

Mrs Anne-Marie Jones

In memory of Mr Alan Ottley

In memory of Mrs Mary Green

Mrs I Carpenter

George Eliot Over 50s Club

Opinion Health

In memory of Philip Roberts

In memory of Maureen Jobling

Ruth Curbishley, friends and neighbours

New Inn Darts & Dominoes Team

Mrs Val Sloper

In memory of Mr Roger Shipman

Mrs Jane Clark

The Harrow Pub

Linda Holmes - Alton Towers / SplashLandings IAD GetTogether

In memory of Mr Daniel Lavigillante

Mr & Mrs McArthur

The Lions Club of Maidenhead

The Thirsty Farmer

In memory of Mrs Catherine Smith

In memory of Mr Harold Goad

ISSA Medical Centre

Rickmansworth Lodge L2218

St Pauls Church, Chichester

In memory of Ken Fox

In memory of Danny Eves

Stephen Roberts

Charlotte Walker

Elize Lomas

Craig Brown

Adam Mee

Kate Fox

Jim Griffith

Robert Brashier

Maria Moralee

Abby Waldron

Athena Wu

Anna Marshall

Felicity Bennett

Gwen Elliott

Tim Yates

Stephen Roberts

Josep Alvarez-Perez

Jordan Dearn

Andrew Goodson

James Donaldson

Carol Mackay

Martina Longueira

Sally Hogg

Judy Knapp

Ian Holmes

Catriona Mackay

Stacey Banbery

Carlie Scott

Carol Elberg

Aoife Doyle

Ellie Horsburgh

Phillipa Newton

Angela Brown

Janet Davidson

Helen Hughes

David Beausang

Anne Chester

Stephen Brown

Angus Watt

Peter Williams

Annabelle Partington

Zeyu Zhao

Vicky Bone

Tracy Janes

Mundeep Purewal

Christina Munsey

Sarah Jordan

Dawn Bunn

Carol Owens

Kevin Palmer

Dan Heerey

Brett Porter

Mary Skellam

In memory of Mrs Deborah Bowditch

Christie Lee