ISSN: 1366-0209

AT Society News

AUTUMN 2021 / NO.60

NEW RESEARCH PROJECT

AT & COVID-19 – WHAT WE KNOW SO FAR

FANTASTIC FUNDRAISERS

FAMILY SUPPORT & COUNSELLING

AT society
awareness research care

www.atsociety.org.uk
Registered charity no:
1105528

Welcome

Our Autumn Newsletter is here! We're delighted to share your stories and latest developments – connecting everyone to the wider AT Society community.

The A-Team taking part in the Captain Tom 100 Challenge in April 2020

In this issue, we say hello to four new trustees who all bring vital expertise to our governance team. At the same time we say goodbye to Linda and Lynda who both resigned from the Board of Trustees in July after 17 years collectively; the skills, knowledge and dedication they brought to the charity were excellent and will always be appreciated.

We have been incredibly humbled by the lengths that our AT community has gone to support the charity recently, some of these highlights you can read about on pages 21-22. You are all at the heart of what we do, and we are here for you and because of you; thank you.

As you will be aware, most of our events were cancelled due to lockdown, but we look forward to building these up again very soon. In the meantime, look out for our virtual events in November and December, and for anyone interested in becoming a Hosting Hero, a Rudolph Runner, or taking part in the January Winter Walk do visit our website to find out more. www.atsociety.org.uk/events/.

As the impact of the pandemic continues to dominate our work there will continue to be difficult decisions to be made. Some of our AT families and our staff have contracted the virus and recovered. Friends and colleagues have lost loved ones. It remains challenging for all, and we're determined to ensure that everyone affected by AT has timely access to the right information and advice regarding the pandemic's impact. Please see page 8-9.

It is still the case that we are going to see the biggest reduction to our income in recent years. We have received some amazing donations from so many of you, for which we are extremely grateful. We still need more help right now to fund our vital research developments and our Family Support Team. For this dedicated team, we are launching our Fundraising Programme to help raise money to keep our Family Support Services going.

Please, if you can, make a donation to support the AT Society today. By donating to fund our Family Support team you will be helping to ensure that we can continue to be here for families who need us most; visit **www.atsociety/donate** or use our QR code on page 23.

For all the latest news and updates from the AT Society, don't forget to follow us on social media!

Thank you, from us all.

Susie Norbury
Director of Fundraising & Operations
susie@atsociety.org.uk

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About us

Ataxia telangiectasia, or AT, is a neurodegenerative, genetic condition which affects many parts of the body, causing increasingly severe physical disability.

The AT Society is a national charity providing information and support to people affected by AT and funding and promoting research. Our positive philosophy of Live Well with AT expresses our commitment to provide the information and support to enable people with AT and their families to live their lives to the full. At the same time, we work to improve treatments and to stimulate and fund research.

Contact us

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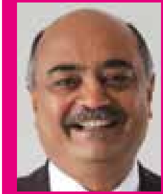
Disclaimer

New Trustees

We feel very lucky to have welcomed four new trustees to the charity this year. They bring with them a wealth of skills and knowledge which will be of great value to the governance of the AT Society, and we are all looking forward to working with them in the future.



Dr JayeshBhatt

Jayesh is a Consultant in Respiratory Paediatrics at Nottingham Children's hospital. He has been privileged to look after children and young people with Ataxia Telangiectasia for over 15 years.

David Macdonald

David is Managing Director of a European insulation manufacturing business with operations in the Netherlands, Spain and Ireland. David has a background in finance and is a member of the Chartered Institute of Management Accountants. David appreciates first- hand the importance of the wonderful support provided by the AT Society given the help provided to his family since his son was diagnosed with AT in 2018. David wants to help all those affected by AT maximise their quality of life and to support the development of treatments and ultimately a cure, in any way possible.

Rachel Poupard

Rachel is a Civil Servant who has worked in HM Treasury, the Cabinet Office, and the Financial Stability Board in Switzerland. She is passionate about the work of the AT Society, which is a charity that has been very close to her family for many years. She spent numerous school holidays stuffing envelopes for the AT Society newsletter and is excited to now join as a Trustee to help support the Society going forward.

Joe Powell

Joe's son Winston was diagnosed with AT in 2016 where he and Winston began to benefit from the advice, support and expertise within the AT Society. Joe and his family are active fundraisers for the AT Society and are proud supporters of its mission to improve the lives of those with AT and their families. Joe is a senior manager within local government with a background in managing housing, homelessness and support services as well as a range of other council departments.

Back to school for Family Support!

From young children just starting nursery, to young adults transferring to specialist colleges, issues arising at school are a real concern for most of our families.

Our family support team work closely with schools to make sure this transition runs as smoothly as possible. Here is a snapshot of what they do.

As soon as we are in touch with a new family, we will offer a home visit and often visit the school at the same time. Most children go to mainstream school when they are young, but many go to specialist schools at secondary level – or sometimes sooner if their needs cannot be met at mainstream schools.

We help to support the family in their choices right through their journey and offer advice for the next stage in their child's education.

We work in partnership with parents to offer schools the following:

- Meet with SENCO and staff teams to talk through the needs of the child and give training about AT
- Provide supporting reports by coordinating with our clinical team at Nottingham to get the Education and Health Care Plan (EHCP) from the local authority and push for full time 1:1 support for the child
- Provide ongoing support, advice, and resources to staff teams at the school to enable them to meet the child's needs
- Visit the school premises to give advice on the environment and any adaptations that are needed to make the school accessible for the child
- Meet with other team members such as occupational therapists who are supporting the child within the school environment and offer advice on pastoral support as much as possible (access to play/art/music therapy when needed)
- Focus on the youngster's overall emotional wellbeing, inclusion, and ways to help them develop positive self-esteem, personal identity, and resilience
- Suggest ways for staff to help manage fatigue with various strategies
- Link schools up with one another so they can share ideas and swap success stories

"On the first day at my new school I felt very nervous but as soon as I started to meet my teachers and my friends I wasn't anymore... My form tutor was really kind to me and she keep asking me if I need a rest or not... Some of my primary school friends were in the same class as me and I also made new friends... Everything's looking good, thank god! 🙂" Melik

Meet Jane Flint

Jane Flint is the counsellor who works closely with our family support team and is known to many families living with AT. We caught up with Jane to ask her a few questions about her work.

Can you tell us a bit about your background?

I was born in Canada. My family moved to Chicago when I was school age and stayed there throughout my teens. I came to the UK in 1971 to meet my maternal grand-parents for the first time and never left except for 5 years back in Canada in the 1980s. I have an adult son and daughter and three grand-children ages 10, 12 and 20.

How many years have you been practicing?

I have been practicing since I completed my MA in Counselling Studies as a mature student at the University of Nottingham in 1997. I also later completed an MSc in Gestalt Psychotherapy at the Metanoia Institute in London.

How long have you been working with the AT Society and how did this connection come about?

During the 1990s I worked for Barnardos. My job was to set up a new project to support parents with children recently diagnosed with life limiting conditions. That's when I first became acquainted with the Children's Development Centre in Nottingham. Ten years later, while working as a counsellor in Primary Care I had a colleague who also worked as a Genetic Counsellor in Nottingham City Hospital. At that time he was the person who offered the psychological support sessions at the AT Clinics in the Children's Development Centre. He asked me to stand in for him a few times when he was on holiday. When he moved on to another job in 2010, I took his place at the AT Clinics.

Counselling Support Grants

We have funded counselling support grants for many families this year. Here is some of the feedback from families who have benefitted from this support.

> **"Speaking to a counsellor gave me an opportunity to speak in confidence openly and honestly about my thoughts and feelings."**

> **"My counsellor provided me a way to figure out what coping strategies work for me and how to best manage my stress, anxiety and worries."**

What is your role when you visit clinic?

My role at the AT Clinics is primarily support for parents and carers. They are each allocated a session during the AT clinic. The psychology session offers the opportunity to talk about and reflect upon the impact of AT on individuals and families, and to assess whether further psychological and emotional support would be helpful.

How can counselling help families with AT?

Counselling can be very helpful to AT families.

It can help you to increase your understanding of how to find your inner resources and empower yourself to move forward. It is an opportunity to express your feelings, unravel your thoughts, gather what is helpful and learn how to let go of what is not.

Different issues come up during the psychology sessions at the AT clinics. Many people express feelings specifically about the impact of AT as individuals or the impact on their family. People often have different ways of expressing feelings which can be difficult for families where one person may become quiet and withdrawn, another may have the need to talk about the situation and be openly emotionally expressive. Still others will deal with their intense feelings through work or excessive business. Understanding and finding ways of all parties feeling acknowledged is important for families to be able to support each other.

Most parents at some point ask me how to talk to their children about AT. Children are not little adults and their understanding depends on their developmental stage. This means that we need to talk to children at a level that is developmentally right for them. Helping parents address their fears about difficult conversations is something that may come up during counselling.

Some siblings of children with AT find it difficult to process the impact AT has on them and their families. Parents often tell me that they have a sense of their children not talking about AT because they do not want to upset their parents. Children can benefit great deal from age appropriate therapy.

If you feel like you would benefit from speaking to Jane, please contact anne@atsociety.org.uk

> **“Being allowed to voice my thoughts out loud as opposed to having everything swirling around my head was a relief and helped give me some clarity.”**

> **“Talking with a counsellor was different from talking to friends and family because I was free to say what I needed and didn’t have to filter my words or worry about upsetting anyone.”**

COVID-19 and AT What we know so far

In May 2021, the AT Society organised an important international virtual meeting to focus on what we know so far about how people with AT have been affected by COVID–19. It was attended by over 30 clinical and scientific AT experts from around the world.

We would like to say a special thank you to Penny Jeggo and Cynthia Oviatt for contacting all of the AT experts and collaborating with the AT Society to make this event successful.

Prior to the meeting, an international survey was conducted to gather data provided by immunologists on individuals with AT who had been known to be affected by COVID-19.

All the survey results:

- 26 individuals across the world, with AT, were reported to have been infected by COVID-19
- Many countries reported no affected individuals with AT
- Of the 26 individuals affected, 6 were adults and 16 were under 18 years old. The remaining 4 did not have an age reported.

Symptoms reported:

- All had mild respiratory symptoms
- One individual required hospitalisation for 4 days because of acute neurological changes
- Some individuals had a cancer diagnosis. Several had immunodeficiency and lung problems, but none were severely affected by COVID-19
- The most common symptoms were cough and fever (as observed in the general public)

- Some infected individuals with AT were on the EryDel steroid trial. Their infections did not seem to be different to those observed in people not on the trial. (Please note that being on the EryDel trial should not affect the decision to use dexamethasone in treating anyone with AT showing significant symptoms from a COVID infection).

Key findings:
The good news is the data suggests that people with AT are not at greater risk of severe or life-threatening infection from COVID-19 than other people of the same age.

Vaccination is recommended for all individuals with AT since the risk from side effects is very low, compared to the danger of COVID-19 infections. There is no evidence that AT individuals should be at increased risk for any known vaccine side effects.

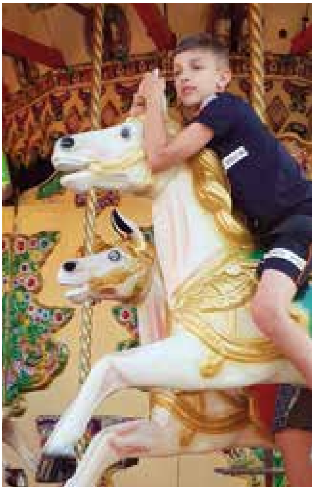
There is no evidence at this time that any of the licensed vaccines are better or worse than the others.

Individuals with AT should follow the local recommendations for COVID precautions, but generally do not need to be more cautious. Those with specific problems should seek guidance from physicians. They can also always contact the AT Society if they have specific concerns.

It is unclear if this data represents a lower prevalence of severe disease than in an equivalent subset of the general population, since the individuals are young and age is the major risk factor for severe disease.

Although parents will feel concerned about the lifting of restrictions, returning to normal life was viewed as being a good thing for the mental and physical health of people with AT and their families.

Butlins support grant



Mum Shannon said the family hadn't been on holiday for a few years, so when Mallaki and his siblings found out they were going to Butlins in Minehead they were beside themselves with excitement! On the run up to their holiday, the children made lists of all the fun things they wanted to do – fairground rides, swimming, making sandcastles and eating lots of ice cream! Shannon told us the support grant helped the family to make lots of very happy memories together.

£50 A £50 donation could pay for a much needed counselling session for an adult with AT, or a family member struggling to cope with the daily challenges of living with the condition.

Amy's standing frame

Amy's physio approached us about providing funding for a specialist standing frame that the local services declined to provide (we appealed twice but they wouldn't budge). The standard equipment local services offered to provide wouldn't fit through Amy's front door and even if it had, it would take up too much room in her new flat.

So, we provided a support grant, to which Amy contributed, for a specialist standing frame.

"Having the standing frame has improved my life. I'm so happy that I can stand, it's amazing! I'm sitting in my wheelchair all day, which is very tiring believe it or not!! I am able to transfer independently. While I'm standing I can help my carers with cooking and other activities, like FaceTiming mum, playing on my phone/iPad and doing puzzles. It's helped me get stronger in my legs. I'm able to do my standing and arm exercises too. Having the standing frame is good for my posture, I'm able to have a good stretch and relieve my BUM!"

A boost for Rose!

Rose has been provided with counselling sessions by the AT Society. Her mum told us that as a result her confidence has grown remarkably over the past few month. She is now embracing new challenges such as Boccia and horse riding where before she would have let her anxieties get the better of her.

"It has been a delight to watch her take up new hobbies and to see the enjoyment that taking part in them is bringing to her."

AT Society collaboration with Ataxia UK, by Dr Julie Greenfield

Three years ago the AT Society started a collaboration with Ataxia UK. This involves Ataxia UK's Head of Research Dr Julie Greenfield and her team providing support in furthering the research work of the AT Society. Ataxia UK is a support organisation for people with ataxias other than AT, and is a research active charity. The collaboration thus enables the sharing of this resource between charities.

Julie helped create and launch the AT Society's new research strategy, and organised a research symposium in Cambridge alongside Penny Jeggo, Chair for the Scientific Advisory Committee at the AT Society. As part of this initiative we then launched a global call for research proposals in 2020. The aim was to focus on understanding and treating the neurological problems caused by AT and the loss of the ATM protein. All research project applications received were peer reviewed by specific experts in the relevant fields, and then taken for discussion to the Scientific Advisory Board – to read more about the grants awarded see page 12.

Supporting the work of pharmaceutical companies in progressing their work in AT is important and Julie has been working with us in supporting the company Intrabio, who are doing a trial in AT with a UK site at Papworth. There were discussions on the design of the trial (which also resulted in a publication) and assistance in selecting the sites. Julie also attended a meeting at the European Medicine Agency, with Intrabio, in which they were assessing whether to grant orphan drug status to the Intrabio drug in AT. This status was granted, and it is important as it provides companies with privileges to assist in the research programme. Recently Intrabio announced positive results in alleviating the ataxia symptoms of two other conditions, which is encouraging for the AT trial.

A research webinar was organised jointly on Ataxia with Oculomotor Apraxia Type 1 (AOA1) and AOA2, for the latter we've created a closed Facebook group. This group will be used for peer support, to share experiences, and to connect with others with AOA2 and their families. If there is sufficient interest we will also create one for AOA1.

Please find the link to join the Facebook group here: **www.facebook.com/groups/285323423092568**

Professor Penny Jeggo ran the Science Simplified programme – Penny is a senior scientist at the University of Sussex and a trustee for the AT Society.

Pandemic research meetings

Keeping abreast of AT research during the pandemic has been challenging but like others, we have embraced virtual meetings.

During the early months of 2021, we ran an online 'AT Science Simplified' programme for families to learn the rudiments of what ATM does in cells. This has been paused during the summer but, if there is interest, we aim to initiate further virtual meetings this coming winter focusing on more clinical aspects.

We also held an online talk covering cancer in AT with Malcolm Taylor, Louise Izatt and Simon Bomken giving presentations. Transcripts of all these meetings are available on request.

A summary of the issues discussed was relayed to AT Society families and can be seen here if you missed it **www.youtube.com/channel/UC7qEfHXOfFJYOMF7RE-tqpA**

Further research supported by the AT Society

Following the AT Society call for research proposals in 2020, we agreed to fund Dr Svetlana Khoronenkova at Cambridge University, so that she can examine the contribution of aberrant microglia function to progressive ataxia. Microglia are immunogenic-type cells, which aid clearance of aberrant neuronal cell bodies and neurites. Sveltana has evidence that AT deficient microglia can aberrantly clear healthy neurones and will investigate the underlying mechanism. Svetlana has appointed a post-doctoral fellow who will commence this work at the beginning of November 2021.

Although the AT Society was only able to fund one new research project in full, we were pleased to jointly fund a second

INNOVATIVE*

*Ataxia Telangiectasia

Encouraging findings from the ATTeST Trial

ATTeST is the first major clinical trial assessing a potential treatment to slow the progression of ataxia in AT.

The trial was undertaken internationally by EryDel and involved the enrolment of 175 children with AT from different parts of the world, 11 of whom were from the UK. The trial is now completed and findings from 6 months were reported in June showing very positive outcomes.

Assessment of ataxia using a modified International Cooperative Ataxia Rating Scale (mICARS) showed significant improvements after treatment compared to the placebo. Patient self-assessment of quality of life and other monitoring supported these findings and analysis also found that the treatment was well tolerated. The final analysis of the trial should be available in November. We will share them with you when we have them.

These interim findings are extremely encouraging and significant in representing the first treatment providing benefit to individuals with AT.

The AT Society has been a partner in this study, via an EU-funded project. We have established a registry of AT individuals from different parts of the world, and surveyed patients' experience of participating in the trial. Participation is demanding and time consuming involving regular travel commitments and blood infusions; Erydel are considering how to use this information to improve experiences of future treatments.

project with Action for A-T, BRASHAT (Australia) and AEFAT (Spain). This work commenced in June 2021 in the laboratory of Tanya Paull at the University of Austin, Texas following the appointment of a talented PhD student, Phillip Woolley. Tanya's initial findings based on protein analysis showed that components of a well-established signalling pathway are deficient in both the cerebellum and cortex tissues of AT individuals compared to healthy individuals. Phillip has consolidated this finding by RNA sequence experiments and observed changes specific to the cerebellum.

Phillip Woolley, PhD student

£5,000

Research is the key to unlocking a cure for AT. It costs £5,000 a month to fund a researcher. Please donate whatever you can to help fund projects seeking new treatments.

COLLABORAT*ING

*Ataxia Telangiectasia

Additional clinical trials for AT

It is an exciting and dynamic time with additional clinical trials aimed at slowing the progression of AT either progressing or on the horizon. In some cases, these trials have been undertaken on disorders with features overlapping with AT and can thus be considered as of potential benefit for AT.

These trials include the use of Tempol, a drug reducing oxidative damage. This is under planning by Matrix Biomed in the US but is not yet in progress.

A trial involving Triheptanoin to treat mitochondrial dysfunction in AT is close to being initiated in Australia by the University of Queensland.

A trial involving IB1001 (N-Acetyl-L-Leucine), which we have previously reported on, is still under progress by Intrabio Inc. Following delays due to the pandemic, this trial is progressing in the UK at the Royal Papworth Hospital for adults over 18.

Very recently, potentially exciting results have been reported from a small trial involving the use of nicotinamide riboside (NR).

NR enhances levels of nicotinamide adenine dinucleotide (NAD+), which is a factor required for many cellular processes. There is evidence that NAD+ deficiency contributes to the manifestation of AT in mice, although mice do not show the progressive ataxia observed in patients. This trial was small involving only 24 patients with a range of ages. However, improvement using two ataxia rating scales was found. Although this was an open-label study rather than a randomized placebo-controlled trial, and the patient numbers were small, the findings are encouraging. Currently, however, the treatment period was short (4 months) and further work will be required to assess if improvement is sustained or enhanced after longer treatment.

Finally, a treatment involving cerebellar transcranial direct current stimulation has been undertaken for patients with other forms of ataxia and is being evaluated for treatment of AT individuals. The AT Society is aiming to have a clinical research meeting to evaluate these treatments and assess their potential utility for AT individuals in December. We will report back to families in January.

£100

A £100 donation could pay for an overnight stay in a family room for a child attending the AT Clinic in Nottingham.

Charlie's Willow Foundation experience

We caught up with Charlie to find out about his cricket trip, this is what he had to say.

"At one of the AT Society family weekends, my mum got some information about the Willow Foundation. My mum applied before COVID-19 hit, so it delayed the time to authorise a special experience. Originally, I wanted to meet the Liverpool Team, but due to COVID, they had suspended those experiences. In the summer my mum heard from Willow saying I had reached the top to receive my wish, but they had limited availability. We saw that Hampshire Cricket Club had a hotel at their ground which meant we could isolate. We managed to watch Hampshire beat Somerset in a T20 match. It was really good as my family were able to come along. We stayed the night in the Hilton Hotel.

In the morning we had our breakfast delivered to our room. It was a great experience!"


Charlie with his family

Kaid hits the gym!

Kaid's mum, Jo, wanted to help Kaid to get physically stronger, build stamina and also self-confidence. She set about finding a personal trainer to help her on her mission and selected Jay Wright from Challenge Life Fitness. The results have been fantastic for Kaid, and Jo has seen a marked improvement.

Jay said, 'As a personal trainer my usual clients tend to have goals of weight loss, strength and condition or cardiovascular fitness but when I was approached by Jo to discuss personal training with her son Kaid I had to rethink the approach.

Having never heard of Ataxia Telangiectasia I took Jo's lead and really enjoyed the challenge and journey with Kaid.

What an incredible young man! Our time together was about confidence, core stability, range of movement and mental health and well-being. We had fun doing a bit of boxing, weight training and functional and coordination movements.

I knew that ultimately, I wasn't going to change Kaid's world, but I did watch his confidence grow as we engaged in positive banter. I am so proud of Kaid and what he achieved, it has been an absolute pleasure personal training with him and I hope to do so again in the future.'


Kaid with Jay, his personal trainer

Ivy's little pony

Animal lover Ivy goes horse riding every two weeks with her local Riding for the Disabled Association (RDA) group at Saddleworth Stables, located way up on the Pennine moors.

Before she started riding, Ivy said she was nervous – not about the horse, but about falling off! Now she's been a few times, Ivy has overcome these nerves.

Mum, Dayle, helps lift Ivy onto the horse (her favourite is a lovely black pony called Dylan) then the RDA helpers walk alongside Ivy as she carries out tasks in the stable arena, before going off into the countryside for a short hack. Dayle started taking Ivy's moving and handling vest for the helpers to use to help keep Ivy safe whilst riding. The vest was such a hit the RDA group have now bought their own equihandee harness vest for other riders to use.

Ivy told us that riding and going to the gym every other week has helped strengthen her whole body – especially her legs and core muscles. She does sometimes have sore legs after her work outs, but a regular body massage helps to ease those achy muscles. Dayle said lockdown has had a negative impact on Ivy's strength, stamina and foot position, but regular exercise and stretching have helped improve these problems.

Ivy's advice to anyone thinking about taking up horse riding is 'Just give it a go!'

Regular physical activity can improve your muscle strength and boost your mental health. Exercise also helps your cardiovascular system work more efficiently.

There are over 500 RDA centres across the UK, to find out more visit **www.RDA.org.uk**

INSPIRAT*IONAL

*Ataxia Telangiectasia

London mini break for the girls

Alecia and Mia talked to us about their weekend away with their mums Lian and Louise in London.

"During one of our lunches, I told Mia that I was planning a mini break to London and Mia said she would love to come along, so we decided make arrangements.

"We stayed in a Hotel in Waterloo with our mums, which was nice and central for all the adventures that we had planned. We booked a disabled room, which was very accessible and had its own kitchen. We had lots of fun exploring London, shopping in Oxford Street, a trip to the theatre to see Hairspray (we felt like royalty in our own box and we were very close to the stage), meals out, and Madame Tussauds.

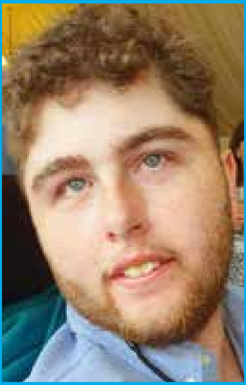
I am really happy that Mia and I have become such good friends, we have so much in common and always have a good time when we get together."

"Alecia and I are great friends, and we try to meet up whenever we can. I love it. I would definitely recommend a break in London. It was so wheelchair friendly. I recommend you plan your day and route beforehand."

£175

A £175 donation could pay for a specially adapted joy stick and computer keyboard. Having access to specialist IT equipment means a young person with AT can continue to do school work alongside their peers.

In Memory



Jordan

It takes a lot of courage to push through hard times and to believe better days are coming. But 'Never Give Up'.

Jordan 'never gave up', instead with the unfaltering, unconditional love of his devoted family and friends, Jordan gave it his absolute all – an absolute 'true warrior'. By Jordan's mum Adelle

Graham

The AT Society supported Graham ever since the start, he lived the best and happiest life. He was funny, caring and didn't let anything stop him from doing what he wanted to do. His mum and family were the ones that gave him the best life and will be forever remembered for that, he loved family, friends and importantly cars. Some of his best times were on holidays (with family or friends).

He kept us laughing every single day without fail and made everyone happy. My favourite memories would be Christmas days. Everyone misses him very much.

By his sister Kiara

John

Despite all the odds being against John, he fought through to lead as normal life as possible.

I think most people couldn't cope with a problem like John's and I would find it extremely difficult. I think John was the most courageous person I know, a true soldier in the battle of life.

By his brother Stephen

Fundraising stories

The high flyers club

We currently have 19 skydivers booked in to (willingly!) jump out of a plane for the AT Society. The initial date for the dive was in September, however, the UK weather didn't play ball so everyone had to rebook. In early October Daisy, Gavin, Owain and Nikki decided to take a chance on the weather. We all arrived at the Skydive Centre for 8am, and it was then a waiting game to see if the weather would be kind. After a few hopeful breaks in the cloud – at one point Nikki even donned her skydive outfit! – the dive was called off yet again. Everyone was, of course, very disappointed.

However, we'd like to say a massive thankyou to all our skydivers and their supporters. We wish you luck in your forthcoming jumps.

We still have spaces to book more skydivers in and will be returning to the skydive centre in the spring! If you would like to join our skydive team please contact **jo@atsociety.org.uk**

Brighton rocked for Hannah

A big thankyou to Hannah who ran the Brighton Marathon in September.

"On the 19th April 2020 I was set to run the Brighton Marathon, however COVID happened and so I took on this challenge on Sunday 12th September 2021 to raise money for the AT Society.

In the early part of 2019, a close family friend of mine was informed that her daughter had been diagnosed with AT. For me, this really is about raising as much money as possible for the AT Society so they can continue to keep focussed and carry out the fabulous work necessary to research and attempt to find a cure!"

Fantastic Fundraisers

We have been both humbled and delighted to see that fundraising has continued to go ahead despite so many events being cancelled. Here are some of the wonderful and imaginative ways that our fantastic fundraisers have rolled their sleeves up and got involved.

Thank you for your immense support!

A fantastic team – Alan, Gary, Adam, Jackie, Julia and Laura completed a 10K run in London

Julian took the Brighton half marathon in his stride

Daniella and her team of friends ran, jogged, walked and crawled an amazing 1,112.6 miles which is the distance between Hastings to Italy!

St Patrick's Academy, Ireland joined a 5K walk to raise money. Extra thanks to Finn, Cassie, Aoife, Peter and Ryan who organised the event

Jenny and Declan smashed the 10K 'Run for All' Marathon in Leeds

Justine and Brook held a gorgeous garden party

Joe bravely shaved his hair and his beard off to raise money

Chris took on a smashing challenge, inspired by his nephew, Winston, he ran 4 miles every 4 hours for 48 hours

Zoe, Gareth and Cabhan took to the skies for an exhilarating sky dive

Captain Tom 100 fundraisers

Mimi made 100 delicious cupcakes

Thea, Freya & Phoebe took on a fantastic trampolining challenge

Claire & Jo got hula hooping to raise money

Jilly took on an impressive cupcake challenge

Flo & Eliza shot 100 hoops!

Staff at the AT Society Head Office cycled 100km

If we have inspired you to organise your own fundraising challenge then do get in touch with **sophie@atsociety.org.uk** and she'll help get you started.

Fundraising stories

Orla cycled her socks off!

Orla, who has AT, took on the challenge of cycling for 100 minutes and made everyone proud. Here is what her Mum said about the challenge.

"The cycling challenge was physically tough for Orla but she persevered with music blaring. Orla's motivation was to help others with wobbly legs/AT and to raise money for the AT Society who have provided support.

Orla is now thinking about her next fundraising challenge. She didn't moan once that her legs were tired or about how difficult it was, she just kept on going and loved seeing the fundraising goal get completely smashed!"

Denise triumphed at the London Marathon

Having always wanted to run the London Marathon, Denise was over the moon to receive a ballot place for the 2020 event which was postponed until 2021.

"I know people often have a personal connection to a charity but for me it was a chance meeting that I think was meant to be. I was locked out my office and a kind lady from the next door office came for a chat. She told me all about AT. I was really taken by what Susie said and I knew there and then I was going to run for the AT Society."

"I asked on the AT Society Facebook page for names of people with AT so I could write them on my hand, and when the going got tough, I could look at them and feel inspired to keep moving forward."

"I finished! It was so hard, harder than I'd imagined. I really struggled after 15 miles. I just had to hang in there. I had a mantra in my head to keep me going: Lola – Alicia – Charlie – Kaitlin – Jack – Mollie. I even tried to put them in alphabetical order!"

"I smashed my target for you guys and I am so happy about that! Thank you to all the parents who donated. I feel humbled and will forever feel a personal connection to this charity."

Ways you can help us this Christmas...

YOU HAVE TO BE IN IT TO WIN IT!

SPARKLE DRAW VIRTUAL RAFFLE 2021

TICKETS £1 EACH FROM:

www.atsociety.org.uk/product/virtual-christmas-raffle

Draw takes place Thursday 16th December

Registered with FUNDRAISING REGULATOR

Registered Charity No. 1105528

AT society

1st Prize:
4 Nights UK Holiday Break*

2nd Prize:
£500 Cash

3rd Prize:
PlayStation 4

Jilly's Cupcake House vouchers

Pizza Hut vouchers

And many more fabulous prizes!

To buy your tickets go to:
www.atsociety.org.uk/product/virtual-christmas-raffle

*T&C's apply (see website)

AMAZON SMILE

AmazonSmile is a simple and automatic way for you to support us every time you shop, at NO COST TO YOU. Just go to www.smile.amazon.co.uk

amazonsmile
You shop. Amazon gives.

HOSTING HEROES

Organise your own 'mulled wine and mince pies' evening and ask everyone to give a donation to the AT Society!

Support the AT Society on Christmas Jumper Day!

Do your bit in a festive knit!

Donate £2 to join in the fun on Friday 10th December

To donate please visit:
www.atsociety.org.uk/donate/

CHRISTMAS JUMPER DAY!

Ask your friends and colleagues to wear their favourite Christmas jumpers on Friday 10th December and make a donation.

SCAN TO DONATE

Simply scan the QR code on your phone to donate.

AT society
awareness research care

10 cards
with envelopes
for only
£4

Christmas card order form 2021

Thank you for supporting the AT Society by purchasing our 'Waiving to Santa' card.

- Each pack contains 10 cards complete with envelopes
- Card size is 124mm x 124mm
- The message inside the card reads: 'Season's Greetings'

Order online at **www.atsociety.org.uk/product/christmas-cards/** or fill out this form.

Please send to: (BLOCK CAPITALS)

Name

Address

Postcode

Contact Tel/Mobile Number

Number of packs required

Postage & Packing:
1–2 packs = £1.21
3–8 packs = £3.00
9–16 packs = £5.10

Total packs £

Total p&p £

Grand total £

Please make cheques payable to the AT SOCIETY and return to:

AT Society
Unit 54
Thrales End Business Centre
Thrales End Lane
Harpenden
Hertfordshire AL5 3NS

☐ YES, I give the AT Society permission to communicate with me about their work and how it can be supported. I am happy to be contacted by (please tick all that apply below) – we will not sell your details to third parties.

☐ Email ☐ Phone ☐ Text ☐ Post