AT Society News

ISSN: 1366-0209

AUTUMN 2020 / NO.59

BACK TO SCHOOL

NEW RESEARCH PROJECT ON THE HORIZON

VISITING CLINIC FOR THE FIRST TIME

AT society
awareness research care

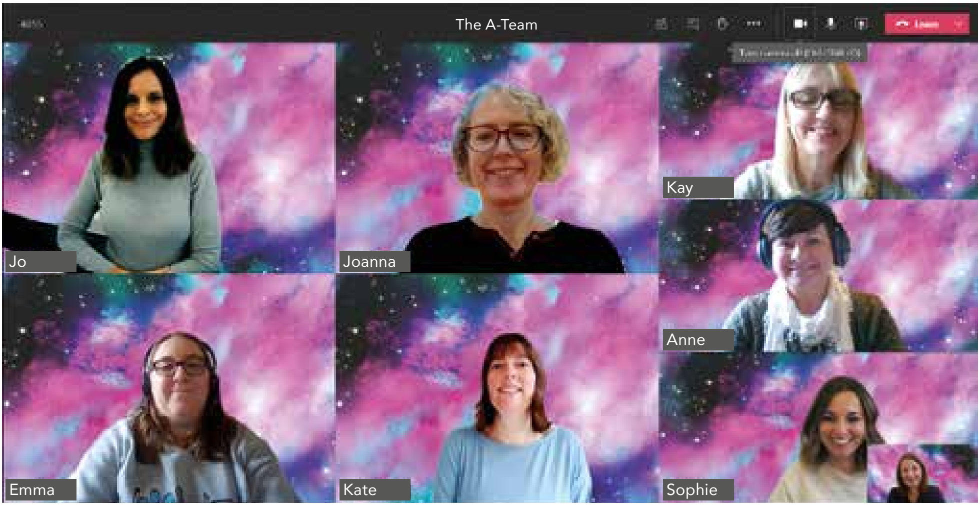
www.atsociety.org.uk
Registered charity no:
1105528

Registered with
FR
FUNDRAISING
REGULATOR

Welcome

AN UPDATE FROM SUSIE NORBURY, DIRECTOR OF FUNDRAISING AND OPERATIONS

Welcome to our autumn 2020 newsletter, six months on from our last newsletter, and what a six months! It's been a whirl of zoom calls, face masks, coronavirus updates, online events, policy changes, virtual meetings and cardboard boxes!



During this time, as the pandemic has continued, we're pleased that we've been able to adapt our services so that our schools training, advocacy work, NHS meetings, research calls and group social events have been able to take place online. It's not ideal, but it is possible, and does mean we can continue to make a difference to the lives of people affected by AT and provide the support, care and advice that is so crucial.

In amongst the changes, prompted by our landlords, we have had to move offices. The move wasn't without its hiccups, but with the help of all sorts of truly fantastic volunteers and corporate donations, we got there. We haven't quite unpacked the cardboard boxes yet as no sooner had we moved, we went into lockdown again! But we look forward to properly settling into our new premises soon and do hope you'll be able to visit in the not so distant future.

We've also taken the opportunity to have a mini restructure. Until we understand more about the long term effects of the pandemic on our finances, the charity will be managed in the following way: I am now Director of Fundraising and Operations, and am proud to be taking a more senior role at this very special charity; as Head of Services, Kay Atkins will continue to oversee the management and development of the support activities we provide; Penny Jeggo, who has been a trustee of the charity since 2014, and Chair of the Scientific Advisory Board, is leading on the exciting developments in our research work. Penny is undertaking this in an entirely voluntary capacity for which we are naturally enormously grateful. The brilliant Sophie, Jo, Anne, Emma, Kate and Jo make up our staff A-Team!

On behalf of us all, I'd like to say how grateful we all are to everyone who has supported the charity over these difficult months. We really couldn't do our work without you. So thank you all so very much!

I expect you won't be surprised to hear that we continue to need your support more than ever. There are various ways to get involved in the charity – whether by making a donation, taking part in fundraising challenges, or buying Christmas cards and face masks – there are still lots of ways you can help. And if you feel you are able to stretch to making a regular donation to the AT Society, it would make a huge difference to our work. I understand that's a big ask during difficult times, but if you are in a position to donate a regular amount each month, please do consider the AT Society as a beneficiary. You can read more about how to do this at **www.atsociety/donate.**

There is no doubt that we are operating in challenging times. But we are enthusiastic about the changes and are looking forward to finding creative solutions to the trials that may lie ahead. On behalf of the team, thank you to you all for all your support and we hope you enjoy reading our newsletter as much as we enjoy creating it.

Susie

susie@atsociety.org.uk

AT society
awareness research care

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

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

Call: 01582 760733
Email: info@atsociety.org.uk
www.atsociety.org.uk

Disclaimer

The opinions expressed in the AT Society News are those of the individual authors and not necessarily those of the AT Society.

A fresh start

Unfortunately, after 15 wonderful years at our beautiful offices, Red Gables on the Rothamsted Research Estate in Harpenden, we had to move.

Our new offices are located on an actual working farm, Thrales End in Harpenden, which we are very excited about. We will be fully embracing farm life by wearing our wellies (sometimes!)

As you can imagine, we had a lot to pack up and, as we were doing the move ourselves in order to keep costs down, it has been all hands on deck. So, we've all been busy carefully sifting through files, folders, paperwork, stock, etc.

However, although it has been hard work, it has also been quite therapeutic to be able to have a clear out!

We couldn't have done any of this without the ongoing help of our supporters. We would like to say a big "Thank you!" to some of the people who have helped us: Anne Hughes for her initial project management, and volunteers from Pizza Hut plus Kevin Atkins who gave up their Saturday to help us pack up and move. We want to say an extra special "Thank you!" to Derek Lukins (Emma's dad), who let us use his lorry free of charge, which certainly saved us a lot of car journeys!

We would also like to thank JPA Workspaces, a local company who have generously provided us with new office furniture. They helped us put together floor plans for our new offices, as well as kindly giving us a big discount, fitting our new desks, and donating a kitchen table and chairs.

Please rest assured that nothing will change in terms of our support and fundraising, and you will still be able to get in touch with us on the same telephone number. But the move has already re-energised the team, and we wanted to share with you the news about this exciting new chapter in the life of the AT Society.


Busy staff and volunteers


JPA Workspaces installing our new furniture

£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.

The AT Clinical Research Conference

The AT Clinical Research Conference was due to take place in October 2020 and unfortunately had to be cancelled due to COVID-19. The decision has been made to hold the conference in 2022 (and not 2021) partly because it is unclear if international travel will be realistic in 2021 and also because ATW, which is a meeting that focuses on the more non-clinical research aspects of AT, such as the function of ATM (the protein defective in AT), is scheduled to take place in Shenzhen, China from 4–7th November 2021. We aim to hold the AT Clinical Research Conference to overlap with the AT Society's Family Weekend in 2022. Currently, plans are being progressed to promote interaction of scientists and clinicians interested in AT during 2021 via virtual meetings.

A novel biomarker for assessing neurodegeneration

The ability to accurately assess the status and function of neurons in children with AT is a critical measurement or 'biomarker' required to assess the progression of the disease and to evaluate the efficacy of any clinical trials. In the UK at Royal Papworth and Nottingham Hospital, we are using MRI analysis to monitor the cerebellum and Purkinje cell layer. Another approach that appears to be progressing in the US is to assess levels of a neurofilament light chain (NfL) protein. This appears to be expressed at high levels in the axons of AT individuals compared to healthy children. Similar research is also now progressing in Europe.

More information on this can be seen at **www.atcp.org/a-biomarker-to-track-brain-cell-death-in-a-t-kids/**

ATTeST Trial update

ATTeST, the first multinational trial aimed at treating AT, was established by the Italian company EryDel. The randomised, double blind, placebo controlled trial will determine if the steroid, dexamethasone sodium phosphate, will delay the progression of ataxia in AT patients who are still able to walk. Red blood cells taken from an AT individual are loaded with dexamethasone, then infused back into the bloodstream. The dexamethasone diffuses slowly over 3–4 weeks, avoiding harmful side effects caused by a burst of the steroid. Recruitment to the trial has now closed. Globally there have been 175 participants in 22 centres with 11 UK AT children aged 6–12 years having progressed through the trial at Nottingham Hospital. We will share the results when they are available, but this may not be for a while yet.

Exciting new research project on the horizon

For the next few years, the AT Society is primarily focusing its research efforts on understanding and treating the neurological problems caused by AT and the loss of the ATM protein. This is the feature of AT which has the greatest impact on every-day life for people with AT. It not only affects movement and manual dexterity, but also speech, eating and nutrition, posture and it also contributes significantly to the development of lung disease.

This summer we invited researchers across the world to submit research proposals which will lead to major advances in being able to treat neurodegeneration in AT. We are really excited by the number of quality applications we received and have created a shortlist of proposals that we feel have the greatest potential.

The shortlisted applicants have been invited to attend a presentation day in January 2021 in London – either in person or by video link. Here, researchers will present their projects to the Scientific Advisory Board, as well as several other stakeholders, including representatives of pharmaceutical companies and people living with AT.

This is a great opportunity for the AT Society to fund a high-quality grant and we look forward to progressing this research initiative. We will post updates on this project early next year.

ASO gene therapy

ASO (antisense oligonucleotide) gene therapy is an approach that has been used to treat one or two neurological disorders where an aberrant protein is made. ASO treatment is an approach to diminish the cellular production of a harmful protein. Unfortunately most AT patients do not make any ATM, the protein that is lacking in AT, or at best small levels of an impaired but partly functional protein, so that the ASO approach has limited current applicability. However, one patient in the US has been identified who could benefit, since in this specific case, diminishing the production of a faulty protein could allow enhanced production of the normal and functional ATM protein. The AT Children's Project have helped to support this approach led by Dr Timothy Yu at Boston Children's Hospital.

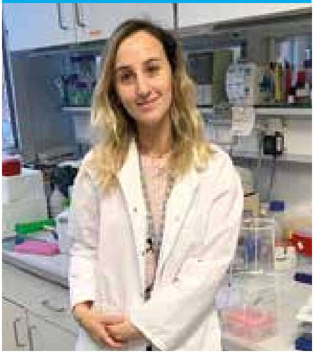
If successful, it could represent an important milestone to verify that progression of AT can be halted. Current progression of the treatment of a young child using this approach can be viewed at: **www.atcp.org/a-t-aso-gene-therapy-trial-continues/**

£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.

IntraBio Clinical Trial IB1001

One of the researchers working in the lab on the IntraBio Trial



If you would be interested in finding out more please contact Hannah Munday, Senior Clinical Trial Coordinator. Email **hannahmunday@nhs.net** or ring **01223 639716**

A trial involving the drug N-Acetyl-L-Leucine (IB1001) is being undertaken by IntraBio Inc at Royal Papworth Hospital. A small-scale study involving different hereditary ataxias, including AT, provided preliminary evidence that IB1001 could provide a significant and clinically meaningful improvement in symptoms for ataxia patients.

A parallel trial with IB1001 for Niemann-Pick disease type C (a related cerebellar degenerative disorder) recently reported positive data, demonstrating that IB1001 met its primary and secondary objectives and was safe and well-tolerated.

The current clinical trial at Royal Papworth is for adults aged 18 and over with AT. Although patients were ready to be screened for recruitment in 2019, progression of the trial has been slowed due to COVID-19 but recruitment is now being progressed. The trial will consist of three study phases: a baseline period, a 6-week treatment period where the drug will be administered to patients orally, and a 6-week post-treatment washout period. For each individual participant, the study will last for approximately 3.5 –4 months during which 6 visits to the Royal Papworth Hospital will be required.

Remembering Helen

This lovely photo is of 'Our Helen' (Helen Carter).

Sadly Helen died in August. Helen was without doubt one of the most fun-loving, smiling, adventurous young adults with AT, that we have ever known. The photo was taken last year at our Activity Weekend, where Helen had just been 'sit skiing' in the very cold snow!

Helen would try anything once and was always up for an adventure. She loved her holidays in Mexico and particularly her 'cocktails' where she would have a competition with her mum to see how many they could have between them during the holiday – their record is 64! Helen was a massive Ed Sheeran fan and in 2018 she went to his concert two nights in a row!

Helen will be so very missed by her mum Joy and dad Simon, all her family and friends and all within the AT Society.

Introducing Sandra from the AT children's clinic at Nottingham City Hospital.

My name is Sandra Hufton, and I am the Lead Nurse for the National Paediatric Ataxia-Telangiectasia (AT) Clinic based at Nottingham City Hospital. I have been a nurse for thirty years and currently work in the Genetics department and have been coordinating the Nottingham AT Clinics for the last 5 years. I work closely with Dr Mohnish Suri who is the Clinical Lead and we are supported by Louise Snow, Clinic Administrator. My role has expanded over the years and as well as coordinating the clinics, I have formed links with local clinicians and am promoting the importance of parents and clinicians getting in touch when they have any concerns or issues around the children's medical care. The Nottingham Clinic is an essential reference point for all the local clinicians and my role is ensuring that they have all the support and advice that they need to offer the best ongoing care.

The clinic is a fantastic opportunity for children and their parents/guardians to meet professionals from Genetics, Respiratory, Neurology, Immunology, Physiotherapy, Occupational Therapy, Speech and Language and Dietetics. Psychological support is also offered at the clinic should families wish to speak to a trained psychotherapist.

The clinics have previously run for two days every alternate month, with 6 children attending. Due to coronavirus, in March the clinic changed and children were 'seen' via online video consultations. This was successful, but not as effective as meeting face to face. The clinic format changed again and in July and September the children attended face to face again, but to keep everyone as safe as possible, it has been for one day rather than two half days. Although this makes for a long and tiring day, it involves fewer stopovers in Nottingham and less time off work and school. We have been, and for the foreseeable future, are operating a one child/one parent policy and all the national guidelines around PPE and cleaning are strictly adhered to. There are no waiting room facilities and children are now allocated to one room for the duration of the day. The last two clinics have been successful and it is very important that the children are seen and examined so that their overall progress can be monitored.

We are always striving to improve the service for the families and are currently in the process of looking at how we will run the clinic going forward, so please watch this space.

If you or your local clinicians have any medical queries about your child, then please contact me on our dedicated email address:
nuhnt.atnottingham@nhs.net

Adapting our support

As Sandra mentions, COVID-19 measures meant quite drastic changes had to be made to the clinic format this year. These changes prevented our support team, Kay, Emma, and Anne from offering their usual face to face support to families within the clinic setting. But did not stop them from being creative and planning to meet each family in a COVID-19 safe hotel environment!

To make these alternative plans, negotiations began with the local Holiday Inn regarding using one of their breakout rooms to meet families. However, before the hotel management would agree to these new arrangements, the support team had to undertake hospitality cleaning training and be deemed competent in meeting the hotel's stringent COVID-19 standards! Appropriate PPE also had to be at the ready.

Once all these COVID-19 standard boxes had been ticked, a meeting room large enough to ensure safe social distancing was booked at the hotel and meeting invites sent to each family before they travelled to Nottingham. These planned meetings gave each family the time and opportunity to sit, chat and ask the support team lots of questions prior to their clinic appointments the following day.

Kay, Emma, and Anne hope that being there helped all the families who attended clinic – especially as 4 of the 6 families were arriving at clinic for the very first time.

Just proves that even COVID-19 will not stop our support!

£30 A £30 donation could pay for an hour of advocacy support from our highly experienced support team.

Visiting clinic for the first time

We asked two new families to share their experience of visiting the AT children's clinic in Nottingham for the first time in July. It was the first face to face clinic since lockdown, so their clinic experience was slightly different to normal due to COVID-19 measures being in place.

Bryce's family

How did you feel when you were invited to attend the AT children's clinic at Nottingham?
Delighted. We had struggled to get specific advice about the rare form of Ataxia that Bryce has and relished the thought of hearing from experts who know much more about the condition than we do.

Before entering the clinic for the first time how did you feel?
Positive and hopeful for answers, more information and advice.

How did you feel after attending clinic?
Enthused and exhausted in equal measure! Lots of information to take in and process. I couldn't wait to tell my husband, who hadn't been able to attend due to COVID-19 measures in place at clinic, everything I'd learnt. I felt optimistic for Bryce's future both longer term and also short term because he now has the medical network who understand as much as anyone can about AOA1.

How were you feeling once you had been introduced to Ethan's family?
Emotional and excited to build a relationship with them! I can't describe how amazing it felt to meet another with the same condition as Bryce. It was like seeing a mirror image of Bryce when I watched them together albeit briefly. We hope they will be able to become friends and both help each other manage this condition.

Equally as parents it is amazing to be able to have another couple who fully understand what we are going through and with whom we can exchange views and ideas as well as sometimes frustrations. It feels less isolating somehow.

What advice would you give to a family due to go to their first AT clinic appointment?
Prepare all your questions in advance so you can optimise the time you have with all the different medical disciplines.

We've subsequently received the report from the clinic and we now have a comprehensive set of results from which to measure Bryce's progress as well as many ideas and lots of advice to follow up on. We are really impressed with the level of detail and the many medical disciplines we got to meet all in one go which, whilst exhausting on the day for Bryce and myself, was an efficient use of our time. Thank you AT Society!

Ethan's family

On arrival to the clinic, what were your first impressions?

I knew that this was not going to be a normal visit to a clinic appointment as it was just me and Ethan, there were surgical masks everywhere and everyone was social distancing. We had never been to this part of the hospital at Nottingham before and were quite surprised to find free parking. When we found the clinic entrance we were met by Sandra, who was very apologetic about the whole set up, but these were all necessary precautions given the ongoing circumstances.

After Ethan had his initial observations carried out and bloods taken, we were shown to the room which would be our home for the day. All the specialists who came and saw us spoke directly to Ethan which, for me, is always a good sign, as everyone will agree there is nothing worse than being spoken about when you are in the room. The specialists that stood out to me were respiratory, dietician, physio and occupational health as they all brought something new to the table.

How did you feel after the clinic experience?

Apart from very tired and a bit of information overload for Ethan (he slept all the way home), pretty positive with a definite solution regarding food supplements vs a PEG, new direction and support from physio and occupational health and confirmation regarding AOA1.

How were you feeling once you had been introduced to Bryce's family?

To be honest it was like Ethan was looking in a mirror, Bryce and him are like two peas in a pod. It made me feel like we were not alone as it can often feel like people just don't understand with AOA1 being so rare. Being in the same room with another boy with the same condition was a little humbling. We haven't managed to meet up yet, unfortunately work and the crazy situation we are in at the moment is getting in the way. Ethan is also still a little apprehensive about mixing with the general population, he is a big fan of 10 pin bowling but I couldn't even sell him on that idea.

What advice would you give to a family due to go to their first AT clinic appointment?

Take a note pad and prepare questions and make sure you ask them.

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

Caring for yourself during the pandemic

Sitting at the very heart of our support work is the belief that taking care of our emotional and mental health is as vital as managing physical health.

We've long wanted to develop a section on our website dedicated to this important aspect of health, so during lockdown we made use of these extraordinary times, seized the day and started up a website page titled 'caring for yourself' **www.atsociety.org.uk/living-with-at/caring-for-yourself**. All the resources and activities within this section of the website have health benefits – you just need to find what's right for you!

At the moment, the information on the caring for yourself page mainly focuses on how to stay well and healthy during the uncertain times caused by the pandemic. But as we slowly find our 'new normal' we will reshape the content and focus on other more broader topics relating to good emotional and mental health.

Why is caring for yourself and your wellbeing so important?

We know from our own personal experiences and research evidence that emotional health and wellbeing affects how we think, feel and relate to both ourselves and others, plus how we interpret the world around us. Having good emotional health improves our ability to manage, communicate, form and sustain positive relationships. It also helps build resilience to cope with change and stressful major life events, such as loss or bereavement. But it isn't just about feeling happy and confident! It's also about having skills to engage positively with the world and to develop strong self-esteem.

This skill development starts early in life. So, an important part of our role is to help parents to take better care of their own wellbeing and to support young people with AT to develop healthy self-management strategies.

This page will continue to evolve and we plan to build up these resources over time. For now, we hope the tips, suggestions and stories featured inspire you and provide ideas on how to take better care of your own and your family's overall health and wellbeing.

Here are a few stories to demonstrate what people are doing to help improve their overall health and wellbeing…

Hello, my name is **Amy**. I'm a fun, friendly and outgoing person. I care about people's feelings and am a good listener. I have a BA Honours degree in Health and Social Care. I am currently studying for a Masters degree in Psychology. I lived independently for three years whilst I was studying for my BA degree, I'm not going to lie some days were harder than others. I've had my difficulties and no one to talk to, yes there was mum and dad and friends but they are not in the same boat as you and me and there are some things we don't want our parents to know, for example that we are being bullied or peer pressure. So, if you're worried or not sure about anything – study, school, friends etc. I am here to talk to or offer advice or, if you just want someone to talk to due to COVID-19 then you can email me via **support@atsociety.org.uk**. If you tell me anything, I will keep it confidential. I would love to talk to anyone. I'm happy to help and it will give me great experience for my future career.

In April 2018 our daughter **Rose** was diagnosed with AT. It was a very difficult time with lots of questions and unknowns as it is such a rare condition. We were visited by Anne and Kay from the AT Society and their knowledge, compassion and honesty helped us prepare for what may come. The condition affects her balance and immune system and has thrown up many challenges in life including having to make the decision to move house to give her easier access. At all the hurdles we have come across, the AT Society have been on hand to help with things from making visits to school, liaising with occupational therapists to arranging hotel accommodation for hospital and clinic visits. At every difficult step they help make the way a little easier. This is why we decided to run the 2020 Brighton Marathon to raise funds to aid the wonderful work that the

AT Society do and the support that they provide to families all across the country.

We really wanted to give back to the AT Society by fundraising, but in the process of training for and completing the Brighton Marathon, David and I also found that running helped us to cope better with everyday stress and it has really improved our overall health and wellbeing.

Hannah's lockdown started before everyone else's as her school sent her home due to the government shielding guidelines. So, for the first few days Hannah enjoyed being at home by herself while her brother was still attending school. The fun started when all the schools closed down. We were so thankful for the good weather. We have a good sized garden so the pool was out and Hannah enjoyed spending the afternoons with her brothers in the pool.

We planned every day what we wanted to watch on Netflix. Every day we chose one movie of every family member's choice.

It will be a lie if I don't say that most of the time the children were spending time on their gadgets, so we tried to do different things as a family indoors. Cooking was one thing. Hannah can't cook or help me cook so Hannah's brothers helped and she told them what to do. Hannah had her hair dip dyed a purple/pink shade but in lockdown it faded away so, I decided do her hair at home. I bought the things we needed and thanks to YouTube we did purple stripes in Hannah's hair. She really loved it and so now Hannah doesn't need to go to salon anymore!! The first thing we did when Hannah was allowed to go out in public was have her nails done as she really wanted acrylic nails. She loved them.

When lockdown eased, Hannah received an offer from a local hospice to come and stay with them. She went for 3 nights and, even though she couldn't do normal activities, she still enjoyed her trip there.

I thought it would be very hard for us all to be at home all the time but it was the opposite actually. The children had a great time being with each other. I saw them bonding and caring for each other as well. They did a lot of bickering between themselves too, but I think we had good time and Hannah and Ryan became close. Hannah missed her prom but she is really looking forward to going back to college.

We would love to hear from people of all ages living with AT.

Please send your news, stories and photos to **kate@atsociety.org.uk**

Love is in the air

Mia's story

I met Leigh in 2019 at the AT Society Activity weekend. Leigh persuaded me to attend whilst talking on Messenger as I was very apprehensive. I'm glad I went as I thoroughly enjoyed myself and Leigh and I are now girlfriend and boyfriend. It's been tough through lockdown as we haven't been able to see each other so, once the restrictions were lifted, we arranged a few days to meet up. We attended a family barbecue and all my family love him as much as I do. We went to Woburn Safari Park and saw loads of animals – it was really fun. We also had a water fight in the garden as at the time he came to stay there was a heatwave. I look forward to many more dates with Leigh. I couldn't be happier.

Leigh's story

Given the distance between us we have seen each other 7 times including birthdays since we first met. After a year we are still very much in love as we should be really. It started off as me trying to convince Mia to come back to the AT weekend after she had not attended for 10 years, which she eventually did. I am so proud to call her my girlfriend. It just goes to show if you are patient enough you will achieve your dream. Better late than never! LOL.

Congratulations to Charlie and Heidi

Charlie shared their good news with us:

Me and Heidi first met on a dating website and then we started to chat on Facebook Messenger in January this year. So then I asked Heidi what kind of relationship she was looking for and she replied "a romantic one" and as we kept talking, we started to fall in love with each other.

As the romance grew we decided to get engaged so I went off and got her a lovely ring with a pink stone in the middle, as that is her favourite colour. I proposed to Heidi in a local war memorial park on a sunny day in July and I couldn't be happier. Heidi was very happy and excited too.

We normally meet up every Friday to spend a few hours together. We FaceTime each other every night for a couple of hours and we play Ludo together and with family.

We have discussed wedding plans but both agreed that we would wait a couple of years until we actually get married.

Back to School

Most children with AT returned to school in August/September after a long break. For many parents there were mixed emotions about them returning – happy that they would be seeing their friends but also apprehension as to how they would adjust to the 'new normal' at school. Some of the families have kindly shared their experience.

▲ **Eric's** 1st day of school was August 11th. He began getting really excited the night before as we were getting his school uniform and school bag ready. As you can imagine it took a while for him to settle to sleep that night! He woke just before 5am and ran into our room shouting it was time to get up for school! For the next 4 hours all we got was 'mammy, daddy can we go to school yet?' He was so happy and excited to be seeing his friends again and his one to one teaching assistant Charles. Eric had no worries about starting back, he was just so happy about being a big boy now and starting P1 and seeing his friends and the school staff again.

Eric Snr and myself were a bit more anxious than excited. Even though the school had lots of new procedures and cleaning procedures in place, it still sits in the back of your mind 'what if' as not everyone has taken COVID-19 as seriously as they should! At the same time we were relieved the schools were re-opening as, after 5 months shielding, Eric needed to have some routine back and start to see other people again in a safe environment. 2 months later and Eric is still excited walking out the door for school!

▶ **Orla** has been awarded a resilience award for having to shield for longer than most but still attending zoom sessions with a smile and positivity. The award is from the charity and support group, Friends for Leisure, who have been utterly brilliant. It was winners all round today as Orla's brother, Finbar, won his class raffle.

▶ The kids went back to school after a long holiday break (well that's what we call it!), where we not only enjoyed loads of fun homework sent by school, but countless activities and movie nights. They were excited to go back and finally see their friends (I was bit worried about them settling in and being safe).

We can't thank school staff enough for their hard work, not only during lockdown but when they went back to school. The school tried their best to make sure they provided the safest environment for the kids, in the friendliest way, without bringing too many changes to help settle them back into a routine.

Zara has been really happy as she loves Miss Yates to bits and they have been chilling out. When the kids have to isolate due to a positive case in their class, well for us, it has been an opportunity to spend more time with them and we can't complain. The lockdown has given us the chance to create some wonderful memories with the children so we are trying our best to stay positive and safe.

▲ **Melik** has gone back to school happy. He's in his final year at primary school so next year he'll be heading off to secondary school. He's very sociable so he's loved being back at school and especially seeing his friends. Melik's younger sister, Emna, has started at preschool and was very happy to go. She didn't even miss me!

▶ We've been shielding for nearly 5 months and **Kristian** was missing all his friends from nursery, he couldn't wait to get back there. When he finally got back it was only for a few weeks as then he started school. He loved going to school from the very first day. They learn to count and he loves it, now he counts everything – cars, houses, trees etc. and he is learning the letters of the alphabet so he always looks for letter K like Kristian.

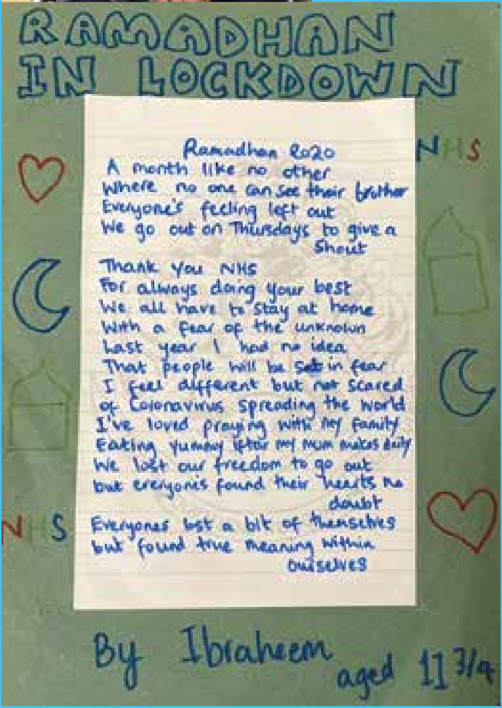
Last Friday Kristian turned 5, I made him a rainbow cake as that's what he wanted. There were no guests unfortunately (strange times), but he got a lot of presents.

On Saturday we went to pumpkin patch, what a fun time he had, then to the car themed restaurant. I haven't seen him smiling so much for a while. He had such a great day. Sunday was a bit quieter but we went for a bicycle ride in the afternoon.

Kristian didn't get an Aston Martin like he wanted (not a toy he said), but he said that he was very happy. At the end of the weekend he said 'Thank you mummy and daddy', so that was nice and emotional.

◀ **Ibraheem** returned to school in September after being off since February 2020. He was a bit nervous about going back but had an amazing first day as it was a PE day. He loves PE!

During his time at home shielding Ibraheem entered a competition. Ramadhan was particularly different this year so this kept him busy and he aired his feelings.



RAMADHAN
IN LOCKDOWN

Ramadhan 2020
A month like no other
Where no one can see their brother
Everyone's feeling left out
We go out on Thursdays to give a shout
Thank You NHS
For always doing your best
We all have to stay at home
With a fear of the unknown
Last year I had no idea
That people will be Sat in fear
I feel different but not scared
of Coronavirus spreading the world
I've loved praying with my family
Eating yummy food my mum makes daily
We lost our freedom to go out
but everyone's found their hearts no doubt
Everyones lost a bit of themselves
but found true meaning within ourselves

By Ibraheem aged 11 3/4

▲ **Jack** started primary school after leaving his preschool on 22nd March 2020. After almost 6 months he was very excited to meet his teachers and make new friends. Jack is really settling in well and enjoying playing with the other children. He has an excellent TA who helps him daily but he is still keeping independent. Sometimes he is a little tired but embracing school in every way.

If you would like to discuss your child's school needs, please contact the Family support team, Kay, Anne and Emma. They can give advice to schools/colleges on the issues that children with AT may have and can arrange to give a talk about AT to the staff, (which includes an overview of AT and health issues). **Email support@atsociety.org.uk**

£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.

Celia's story

Hello! My name's Celia and I have AOA2. I have been in a wheelchair for 25 years but I'm a newcomer to the AT Society. Here's a bit about me and my experience of lockdown.

What are your hobbies?

I have varied interests. Music is a big part of my life, be it listening to it or singing it. Westlife were a huge part of my musical life and Take That before them. My mum used to say that if I paid as much attention to my schoolwork as I did to songs and lyrics I'd be a genius. I belong to two choirs, both quite different in genre and discipline. One of my hobbies that has taken a bit of a back seat of late is jewellery making. Years ago, when I first set foot – or wheel – into a day centre, I came across a silversmith/jewellery making class. I loved those classes; I learnt a lot and carried on with them when the centre closed. Making jewellery is often really fiddly, intricate work but very enjoyable and satisfies the magpie in me!

What did you miss the most during shielding?

Shielding, pah! Not gonna get the better of me! In 'normal life' I'm lucky – or unlucky depending on your viewpoint – to not go out too much anyway, so it wasn't too much of a shock to the system, and I live with my parents and our pooch so I wasn't on my own. I missed my friends though, I've built up quite a social life with friends from choir and, during the summer months especially, I was usually quite a busy bee. There's normally 3 or 4 choir performances during those months so I've had a very quiet summer this year. I've filled it in other ways though. I really missed my Grandad too.

What emotions did you go through during shielding?

To be honest, although it was an anxious time, it was easy to close the door on the world as I was doing it to protect myself and, as far as I could, my family. It's opening that door again that's the hard bit. There was no boredom. I'm pretty good at finding something to do to entertain myself. But there was, midway through, frustration at not being able to go anywhere or see anyone. Video calls are nice but not the same as human interaction. There was, unfortunately, sadness too. When I was initially diagnosed with Friedreich's Ataxia I was buddied up with a guy called Matt, and he helped me through the first few years. Unfortunately, as so often happens in life, we lost touch. I found out that he contracted COVID-19 and died. It was a huge shock for me. Sadly, it didn't end there, my Grandad passed away too.

Where was the first place you went once shielding was over?

The crematorium for my Grandad's funeral, not a nice place to go at any time, but first place out of shielding was rough. It was the hottest day of the year and everybody was melting. Wearing all black didn't help and the mask was horrendous, all sweat and tear soaked. It definitely added to the feeling of nausea. I think we did him proud though.

Fantastic Fundraisers

During these rather strange times many public fundraising events have been cancelled. This means we are more grateful than ever for our individual fundraisers. Here are just some of the amazing, imaginative ways you have supported us in the last six months. Huge thanks to all our fantastic fundraisers for your support!

Waitrose & Partners in Harpenden supported us with their green token scheme

Luca Baricella smashed his 10k personal best raising money at home and at school

Rachel and Ste Arrowsmith tackled a virtual 10km instead of the cancelled Manchester 10k!

Steven McGowen valiantly climbed Pendle Hill in Lancashire

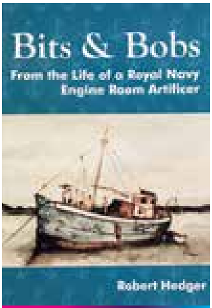
Laura Yarlett generously donated the money she made from her homemade facemasks

Charlie kindly donated the money from his Fantasy Football League

Claire Metcalf organised a very successful online raffle

Mary Russell raised money teaching spinning classes

Although the Brighton Marathon was cancelled Alicja Blount valiantly ran the marathon alone



Bits & Bobs

From the Life of a Royal Navy Engine Room Artificer

Robert Hedger

Robert Hedger is generously donating all the proceeds of his book *Bits and Bobs*

AT Society Face masks

Our lovely new AT Society face masks are flying off the shelves! Thank you to everyone who has bought one so far.

At £5 for one mask or £12 for 3 including postage and packaging, they would make a great stocking filler if you're stuck for Christmas present ideas!

If you'd like to purchase some masks, please visit the shop on our website. **www.atsociety.org.uk/product/at-society-face-mask-3-pack**

Thank you to Sinead and Orla who sent us a photo wearing our masks

We need your help now, more than ever before, so please consider fundraising for us. We might have to rethink some of the more traditional ways to fundraise and use our imaginations but we believe it can be done!! Contact Sophie Arnold **sophie@atsociety.org.uk** with any ideas, big or small!

Fundraising stories

Home Half Marathon

Anne Saunders didn't let the coronavirus get in the way of her fundraising plans. She managed to travel 21.1km (a half marathon) just by doing circuits of her own garden and raised an amazing £1,000 in the process. Anne used social media to make a real 'event' of her half marathon, updating her supporters with live feeds and updates along the way. Due to coronavirus runners can't have the usual fanfare and cheering crowds, but Anne showed us all that there is another way!

Charity of the Year and a Fundraising Superhero!

Harpenden Golf Club chose us as their Charity of the Year and in spite of the coronavirus hindering some of their original plans they were undeterred and went on to organise a host of wonderful and inventive fundraising activities raising a total of £29,316!

Congratulations to one of our most inspirational fundraisers, Peter Hart. In April, Peter, who was Men's Captain at the golf club, set out to lose 26lb in 3 months for the 2.6 Challenge. We were amazed to see the difference between the before and after pictures and to hear he lost a grand total of 28.2lb!

Not only did Peter meet his weight loss goal but he hit his fundraising goal of £12,000! Thank you for all your support Peter and Cathy Gosling, Women's Captain, you really are fundraising superheros.

Local Cycling Challenge

Local sixth former Hugh Halsley cycled the distance from Lands End to John O'Groats around Hertfordshire. Cycling in all weathers throughout the summer, Hugh travelled an average of 30 miles a day to cover the total 942 miles. He raised an incredible £1,500 which is especially impressive during these challenging times. A big thank you to Hugh for being a super supporter!

Thank you Fantastic Facebook Fundraisers!

A huge thank you to these lovely people who used Facebook to invite friends and family to help celebrate their special days by donating money to us.

Christine Baird
Gem Byrne
Debbie Cutts
Linda & Harry Downie
Angie Eley
Mia Everitt
Joy Ferguson
Sam Hemmings
Julie Heil
Kate King
Lisa MacDonald
Luciana Maltez
Sally McGill
Ash McKnight
Mollie Midwood
Adam Price
Shamraz Razzaq
Eric Ritchie
Justine Sprawling
Amber Tahir
Beth Tighe
Cris Werley


Joy Ferguson

"This year I obviously wasn't going to be able to hold my 'open house' event so instead I've had to adapt. When it was my birthday Facebook asked me if I wanted to create a fundraiser, a couple of clicks later and it was all set up. I didn't expect to raise much but was completely bowled over by raising over £500, I have an amazing set of friends!"

It couldn't be easier to set up your own fundraiser on Facebook to help raise money and awareness:

1. Click **Fundraisers** in the left menu of your Facebook News Feed
2. Click **+ Raise Money**
3. Select **Nonprofit** or **Charity**
4. Select **AT Society**, fill in the fundraiser details and choose a cover photo
5. Click **Create**
6. You're all set to go

One in a Million!

Stephen Johnson is another of our 'Home Fundraising Heroes', he completed his One Million Step Challenge a month quicker than expected and has raised £800 to date.

"Knowing you are helping people and making a difference is a great motivation to get up in the morning" Stephen told us.

He found the challenge a fantastic way to explore his local area at a time when many other activities were unavailable.

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

AT society
awareness research care

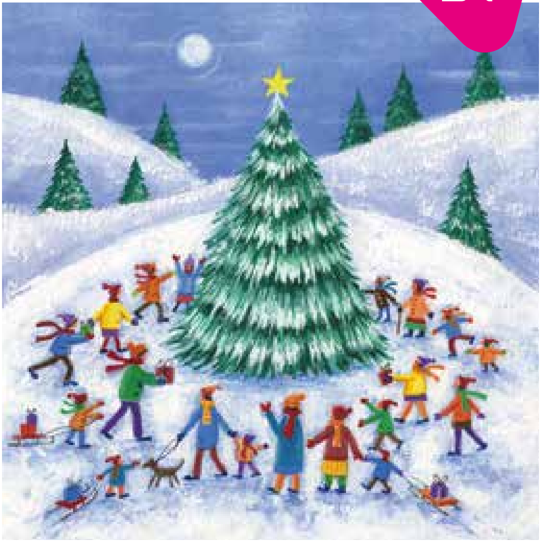
10 cards
with envelopes
for only
£4

Christmas card order form 2020

Thank you for supporting the AT Society by purchasing our 'Oh Christmas Tree' card.

- Each pack contains 10 cards complete with envelopes
- Card size is 123mm x 123mm
- 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 = £1.16
3–8 packs = £2.95
9–16 packs = £5.05

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