AT Society News

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INTERNATIONAL RESEARCHERS MEET VIA VIDEO CONFERENCE

ADULT ACTIVITY WEEKEND

2.6 FUNDRAISING CHALLENGE

AT society
awareness research care

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

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FUNDRAISING REGULATOR

Welcome

AN UPDATE FROM YOUR CHAIRMAN,
MIKE DETSINY

I am writing this piece in mid-April, in the middle of the coronavirus lockdown. It's a very strange time for all of us and a particularly worrying one for anyone who knows or cares for someone with AT.

People with AT have been identified as being in the 'extremely vulnerable' group. However it took a long time for this to become clear, and many families did not get included on the list until the AT Society took up their cause.

So far, the AT Society has continued to work at virtually full strength, with most people working from home and only one in the office – to answer the phone and so on. There has been a huge amount of work to do, trying to work out what was happening, to condense this into comprehensible information and guidance, to talk to the many concerned people and to deal with the many and various issues and problems that have arisen. We have also been ringing around families to make sure that we speak to everyone we know living with AT.

To date, the real success has been that no one with AT has, as yet, got the virus. I hope that this will continue. We know what a big strain shielding puts on families, but if we can keep it like this, it will be worth it. It's also been great to see the AT community pulling together on social media to cheer on and encourage each other.

My colleagues have done a brilliant job, working under difficult conditions. Kay and Anne supported by Emma have been at the forefront of dealing with families, but everyone else has been incredibly busy with equally valuable but less visible work. I know how much our support is valued by people out there and I am extremely proud of the whole team.

I also want say a big thank-you to the amazing Alan Staples, our IT guru, who quickly and quietly sorted the whole working-from-home issue. While he is not technically a volunteer, he does so much more than we pay him for and we are hugely grateful to him.

Of course, the pandemic and lockdown have had a huge impact on the organisation. As you will read elsewhere, we have had to cancel the Family Weekend and Clinical Research Conference not to mention a whole raft of fundraising events. As a result, our income too has taken a dive.

That we have been able to continue as we have, when many other charities are really struggling, is testament to the strong financial position that the Society reached last year helped by a very generous legacy. However, the fact remains that even in the very best of circumstances, we will have lost several months of key fundraising. There will also be a huge demand on the trusts and companies that we depend upon and more generally money is likely to be tight for many people across the country.

So, once we have got through the worst, and things start returning towards normality, we will all have to work together to see what we can do to build on this powerful sense of community. We will need to get the money flowing in again so that the AT Society can continue to be there at the side of families living with AT, supporting them through thick and thin.

I just have time to add a short item on the 2.6 challenge, which was due to take place on 26 April, when the London marathon should have taken place, but has been going on since then. The idea was taken up enthusiastically across the AT community and to date it has raised well over £15,000 for the AT Society (see page 26). Your response was amazing and we would like to say a massive thanks to all you stay at home heroes who took part and raised such a significant amount of money.

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.

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Disclaimer

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

Welcoming Emma Lukins to the Family Support team


From left: Anne, Emma, Kay

We are delighted to welcome Emma Lukins to the Family Support team. Emma joined the charity last May as a fundraising intern and she soon proved to be an invaluable member of the team. During her time in the fundraising team Emma worked alongside Sarah to support our fundraisers, organise fundraising events and she became the queen of social media for fundraising posts. Her positive outlook and willingness to 'get stuck in' became apparent at the Family Weekend where she was required to turn her hand to a number of tasks and she braved the scary rides at Drayton Manor theme park with Rachel.

Emma moved over to the Family Support team just before Christmas. She will be working alongside Kay and Anne 3 days a week in an administration role. Amongst lots of other things, Emma will be organising the AT Clinics, keeping our support section of the database up to date, providing admin and planning support for the Family Weekend, Activity Weekend and Live Well with AT project and liaising with families and professionals in applying for a Support Grant.

Having a much-needed and extremely capable, extra pair of hands on the team will allow Kay and Anne more time to focus on offering vital support to families such as filling out the time-consuming PIP and DLA forms, writing appeals for Educational Support in School, visiting more families all around the UK, attending meetings with Social Services and working on the Live Well with AT project, as well as liaising with local schools and professionals.

Family Weekend and Adult Activity Weekend 2020 cancelled

Though it is unlikely to be a very big surprise to anyone, we are nevertheless very sad to have to announce that the 2020 Family Weekend and Adult Activity Weekend that were due to take place together in October are being postponed to next year. We know how much our Family Weekends mean to our families so it wasn't a decision that we took lightly. The uncertainty about how long the coronavirus pandemic will go on and what the impact will be on travelling and getting together in groups and the loss of income over the coming months meant we just couldn't commit to the October dates – these are not events that can be organised in a hurry. On the positive side, we are still planning to hold the events together in the same venue, hopefully towards the end of June 2021 and will aim to make them bigger and better than ever!

Transitioning to Special Education

It is always difficult to find the 'right' school for your child but going up to secondary level brings new challenges. Some children do very well at mainstream secondary school, and some schools have special units for children with physical disabilities. However, some 'Special Schools' can also offer a wonderful environment for children who have AT. We would always advise visiting a school and asking lots of questions before applying.

Like many parents, Lola's mum agonised over the decision whether to move Lola from mainstream school into special education. Although Lola's primary school were doing all they could for Lola, it was becoming clear that they were struggling to meet her needs as her condition deteriorated and she was less able to keep up with her peers. Kay and Anne wanted to support mum as best they could along this emotional journey, so they accompanied her on a visit to a local special school last year. They were blown away with the enthusiasm and happiness that filled the whole school. They all felt that the school was a good fit for Lola.

Her school arranged for Lola to go to the special school for a couple of days a week and to have some of her lessons there. It was a gradual transition which helped Lola and her mum and they were made very welcome. After a year of discussions and making sure that this was the right move, Lola fully transitioned to her new school last September aged 10.

Kay and Anne were invited to revisit to deliver a talk to staff about AT and offer advice on how to best support Lola. Approximately 30 members of staff and local professionals stayed very late after school to attend Kay and Anne's session. It was one of the best turnouts they'd ever experienced and the genuine interest and enthusiasm in the room was a joy to witness. For Lola the move to the new school has been a very positive experience – she is being offered the most enriched school life possible and she feels cherished.

If you are considering changing schools for your child and would like to talk through your school choices, Kay and Anne would be happy to listen and offer advice. You can contact them via email **support@atsociety.org.uk** or 01582 760733.

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

Adult Activity Weekend

Our annual Adult Activity Weekend involves a fun-filled and social weekend for young adults living with AT. It provides an opportunity for these adults to push their own boundaries, try something new, build life-skills and develop firm friendships. Last November 17 adults with AT spent 3 fun, action-packed days eating, bowling, skiing, shopping and socialising with each other.

Anne Murray our Support Team Co-ordinator describes the work that went on behind the scenes to organise the activity weekend.

The complicated planning process for the annual activity weekend always begins several months prior to the event date, as the logistical factors to consider are endless! Things such as location of the event, activities over the 3 days, finding hotels with enough accessible bedrooms, food, transport, parking, sending out itineraries etc. not to mention all the costings – the list goes on! As the event date looms closer it's all hands on deck in the AT Society office and it takes a real team effort to ensure everything is in place for a jam-packed, fun-filled weekend.

In 2015 we worked in partnership with Disability Snowsport UK and offered a group of adults indoor adaptive ski sessions. As this activity proved a roaring success, we jumped at the chance when the wonderful team at DSUK offered us a date for another ski experience. The ski sessions would be our main Saturday activity, but we still had several evening and daytime activities to plan, so we determinedly set out to gather activity ideas from as many of the participants as possible. This involvement is vitally important to the AT Society because the foundation of all our work is embedded in the values of respect, inclusion and participation. None of which is ever easy to accomplish! Thankfully, our trustee Jilly Shah took on a leadership role and was a tremendous help to us before, during and after the event. Jilly researched potential restaurants for a group meal on the Friday night and possible venues for their now legendary 'Big Friday Night Out'. She used a Facebook messenger group set up for adults with AT and self-named 'AT Doesn't Define Me' to gather people's ideas and choices. The group eventually decided on Zizzi's so a booking was made for 42 people.

All Bar One was chosen and booked by Jilly as the post-dinner venue. After much online discussion, the group decided on a ten-pin bowling competition for their Friday daytime activity and even chose their own team names which we had printed on T-shirts; The Misfitz, The Cereal Bowlers, The King Pins and The Thunder Bowlers.

Of course, events like these never go exactly to plan and we had the usual last-minute scramble to avoid potential disasters!

Despite several issues finding enough accessible bedrooms in one hotel (we ended up using 2 hotels) and a last minute change of venue for the ski sessions, which meant we had to hire two coaches to transport everyone, we think the weekend was a huge success. So, a big thank you must go to all staff at the AT Society for a great team effort. We also extend our thanks to the following fabulous people: Katie Poupard and Kevin Atkins for their stellar volunteer efforts throughout the weekend, Ann Highley of Ann's Guiding Hand for all her hard work and constant listening ear, Jilly Shah for her continued support and smiling determination and last but not least, Team MK who presented gift vouchers to everyone in the group prior to our bowling competition.
We are very much looking forward to planning the next activity weekend in 2021 – that will be one amazing party!

We asked some of our adults how they felt about the weekend and what they enjoyed about it.

Mia was joining the activity weekend group for the first time – in fact the last time she attended any AT Society event was over 10 years ago, so she was understandably nervous. The group welcomed her with open arms and one of the older attendees, Leigh, took it upon himself to watch out for her during the weekend.

Mia

Before the weekend I felt very nervous because I hadn't been to one before and I did not know anyone. While I was there I was shy and I felt very overwhelmed but the acceptance I felt from everyone made me feel welcome. After I left to go home I was sad to be leaving my friends but overall I was happy.

Leigh

I had the time of my life at the activity weekend and I was pretty upset when we all had to go home. I did not want to leave as I was having too much fun!

Kayleigh

I was feeling really excited about the activity weekend, especially because I couldn't go to the previous weekend due to being heavily pregnant. My husband Lee and I were also looking forward to the break away with a couple of full nights' sleep! I had such a great time with my AT family, I didn't want the weekend to end! I always feel so comfortable with them and feel like my disability doesn't matter, I can relax because we're all in the same boat and have an understanding.

Ruzina

At first I felt a bit shy because I didn't know many people but as I got in with the crowd I felt so at ease. I feel like because we all have Ataxia or AT we can relate. I had so much fun. You really don't ever feel alone – that's what I love about these AT events! I made new friends and genuinely felt quite sad it was over.

George

I was really looking forward to meeting up with friends, meeting new people and also the skiing. As it was my first adult activity weekend I was a little nervous but also excited. Once I was there I felt quite relaxed once I'd met up with my friends. The best moments of the weekend were skiing, evening get-togethers and meeting new friends and still being in contact with them now.

Fantastic weekend

BY JILLY AND AMY

Every year Amy and I look forward to seeing each other at these weekends. We talk constantly via WhatsApp and Facebook, so meeting up in person is something we look forward to because it means we can finally have that long overdue catch up, face to face, preferably over some cake and hot chocolate!

But this goes far beyond us! Everyone that attends these weekends feels the same. Including the bit about cake and hot chocolate! At last year's weekend we got to see some new faces and we made new friends. These weekends are so important to us as they give us the opportunity to hang out with people who are going through similar things. We all understand each other and there is no judgement. So months and months before the weekend last year, Amy and I spent ages on swapping ideas for outfits, hair styles and makeup! Our itinerary was mapped out for us, so the only thing we needed to decide on was food and outfits.

Needless to say, we were both super excited and so ready for the weekend! The Thursday night of the weekend, we all gathered in the hotel for dinner. However, much to our disappointment, there was no dessert! So Amy joked, that I should go into the kitchen and whip up some dessert. At least I think she was joking... By this time, most of the room had cleared, and it was late, but there were 4 of us present, who were adamant on getting dessert. So me, Amy, Alecia and Katie (Alecia's PA), pulled up our own table and decided to order 2 chocolate fudge cakes and 2 chocolate brownies from the hotel bar (just as they were closing!) and split them between the 4 of us. It was amazing and we regret nothing.

Friday night was our night out. We were excited and so ready to get our drink on! However, the bar we were at wasn't really our scene. So we went back to the hotel bar and spent our night out there. A few of us who were chilling in the bar area including me and Amy decided to get a few rounds of shots in us, making the night both hilarious and enjoyable.

Other activities of the weekend included skiing, bowling, and shopping. Amy is a big shopaholic so she was definitely in her element. We loved the weekend's activities. They were fun, challenging, entertaining, great for team building, confidence boosting and they got us all talking to and encouraging each other.

After this fantastic weekend, we all had to say goodbye. But Amy doesn't really say goodbye, she always says "until I see you again!"

Celebrating me

Charlotte is an inspirational young woman. She has completed over 50 Parkruns (helped by her half-sister Liz), taken on various volunteer duties at her local Saturday morning Catterick Parkrun and helped fundraise for her new sports wheelchair. In this article Charlotte describes what life is like living with AT and what she's learnt along the way. On page 17 she also gives us in insight into how her life has changed due to the coronavirus lockdown.

Hello, my name is Charlotte. I am 24 and live alone with my two chihuahuas in a 2-bedroom bungalow in North Yorkshire and yes, I am living with ataxia telangiectasia but even though I have this, it is not my life.

I live alone due to the fact I lost both my parents but my mum always taught me one thing that I have always lived my life by and I believe has made me who I am. I am feisty, stubborn, independent, resourceful and I am not afraid to say what I think or be who I am but I am also kind, considerate of others and believe it or not, I get scared and shy sometimes too.

If you don't mind, I would like to share this lesson with you.

My mum always taught me that we are who we are, your condition does not make you, the wheelchair, the medication, the physiotherapists, the doctors, the hospitals none of that makes you. Yes, you may think life will be easier without any of this and you may feel alone sometimes (I know I have) but we need to know we are never alone.

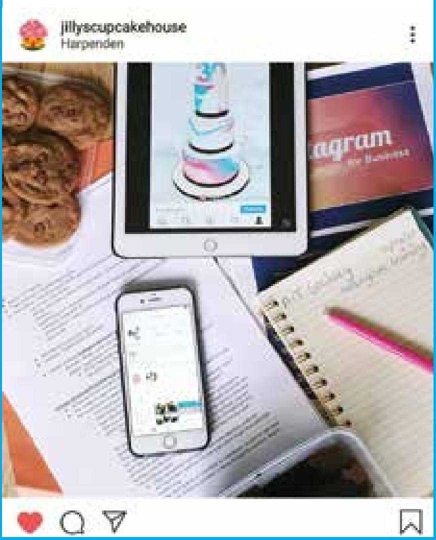
I love reading because it lets me escape reality for a while. I can immerse myself in the world of the book and the characters, imagine what they look like, what they sound like and how they interact. I love music and movies for similar reasons.

We have got to accept this condition we have but no matter what we are told, or how we feel, we need to believe we are strong and we can do this, but we will not let this or anything determine our lives and how we want to live them.

At the end of the day we all know we are ill to a different extent but there is one thing we all want no matter who you are, how old you are, or where you're from. We all want to be NORMAL. We don't want special treatment or to be singled out – just think how humiliating and embarrassing that must be for someone.

So if you meet someone different, don't call them names or be nasty just because you think it looks cool, just remember we are people too and we just want to be treated like any other person our age.

LET US BE.
WE ARE WHO WE ARE!!!



Follow us on Instagram

BY KATE MCELENEY
COMMUNICATIONS OFFICER AT SOCIETY

Everyone at the AT Society's offices looks forward to the quarterly board meetings as it's a day guaranteed to bring home-baked goods from trustee and Queen of Cupcakes, Jilly Shah.

We recently decided that we wanted to post more regularly on our AT Society Instagram account, and we called upon Jilly for help. Jilly uses Instagram successfully to showcase her edible creations as well as raise awareness about AT and she was happy to help.

At first, Jilly started out on our Instagram account by creating some of the content for posts and stories. Jilly's next challenge was to train Emma and me on how to use Instagram, so that we could start posting confidently and share our training with the rest of the team. Jilly certainly had her work cut out as Emma and I had very limited knowledge of Instagram – almost total novices.

Armed with cookies and cakes, an enthusiastic smile, oodles of patience and detailed tutorial notes, Jilly came to our offices in March to start our training. She spent the next 3 hours taking us through the intricacies of Instagram.

We learnt about the difference between an Instagram Story and a Story Highlight, how to add photos and emojis to posts, the tone of language to use when writing Instagram captions, and how to use hashtags effectively. Jilly also taught us the importance of Instagram etiquette, as well as how to engage with and follow people.

Jilly was a great teacher and Emma and I found the session so useful. It gave us the confidence-boost we needed and we felt ready to start posting (with Jilly on call to help if we need her).

Jilly said: 'When Kate and Emma asked me if I could show them how to use Instagram, I was delighted. I got the chance to help and share my skills, which is something that always brings a smile to my face.'

If you're on Instagram, please follow us **@atsociety.**

5 Ways to Wellbeing during lockdown

Here we celebrate some of the ways that our families looked after their wellbeing and kept their spirits up during the coronavirus lockdown. We have used the **5 Ways to Wellbeing** model, which was featured at our Family Weekend last year.

A group of our fabulous young adults showed us how they never give up, using exercise to stay strong and improve their sense of wellbeing. Using social media, they encourage each other to keep doing something they enjoy. **Jilly** practised her boxing skills in the garden and as **Henry** wasn't able to go to his local club to play boccia, he decided to carry on at home.

Brooke kept herself active in the garden by weeding some plant pots and then sowing some wildflower seeds. Brooke is very creative so she also made and sent Easter cards to her friends and family to keep in touch. Her mum Justine has been helping her in the kitchen and so far they have baked some amazing chocolate crispie nests and cheese and spinach muffins which were 'delicious' according to her family.

Ben practised holding a plank for 26 seconds in preparation for his family's 2.6 challenge which is an incredible achievement.

CONNECT

TALK & LISTEN,
BE THERE,
FEEL CONNECTED

Despite being oceans apart, connecting with others can help improve a youngster's wellbeing.

Last December, UK mum Jenna saw a post from Holly, a mum in Colorado, USA, describing how much her 8-year-old daughter **Hayley** loved sending Christmas Cards. Holly asked if Hayley could send cards to other youngsters with AT. Jenna excitedly wrote back to Holly, explaining that her daughter **Rose** was 8 years old too, has AT and would love to exchange cards with Hayley. Since then the girls have become pen pals and they both absolutely love receiving parcels and cards from one another!

Many families found new ways to keep in touch with their friends and families.

Charlie celebrated his 24th birthday virtually! He invited his friends and family to pop by and celebrate online with him. Charlie and his brother Owen selected a playlist and everyone was encouraged to bring their own food and drinks and sing along and have a dance. By all accounts it was a great party!

Charlie and his girlfriend Heidi also organised a country and western virtual party where they both dressed up. Charlie's family have been doing some virtual quizzes with extended family members too which they have all enjoyed.

George has been enjoying sitting out in the sunshine and keeping connected with his friends via his mobile phone. He has also started using Wii Fit as part of his daily physio exercise programme – boccia and baseball seem to be the current favourites. George used to struggle to do 15 minutes of his normal physio programme because he found it boring but he's found doing the Wii Fit games much more motivating. He even managed to do 3 hours of Wii Fit in a day which is a great achievement.

TAKE NOTICE

REMEMBER THE SIMPLE THINGS THAT GIVE YOU JOY

Mia decided to self-isolate in style and enjoyed her nail and make up pamper sessions, whilst AT mum **Tania** has re-found her love of painting.

KEEP LEARNING

EMBRACE NEW EXPERIENCES, SEE OPPORTUNITIES, SURPRISE YOURSELF

AT mum **Jo** discovered hula hooping as a way to look after her mental health and keep fit too. Jo said “It’s an uplifting, motivating, feel-good feeling with an added bonus of burning loads of calories. It’s cheap to buy and you can do it anywhere in your home and when you like! Lola likes to dance in the background.” Jo loved her newfound exercise so much that she set up a Facebook group encouraging others to take up it up and join her in her 50-day hula hooping challenge and over 400 ‘hoopers’ have joined her so far.

Rachel has been Skyping her friends and is continuing to write her children’s fiction book called ‘Magic Meg’. Rachel has planned it all out and has nearly finished chapter 8. We can’t wait to read it once it’s finished. Meanwhile Rachel’s mum, **Joy,** has been busy baking and trying out some new recipes. She’s been sharing her bakes on Facebook and making everyone’s mouth water – her lemon meringue cake looked delicious.

Jake learnt some TikTok moves to Blinding Lights by The Weeknd and practised to perfection.

Give

Your time,
your words,
your presence

Alecia posted an upbeat video message to Facebook thanking us all at the AT Society for working through the coronavirus crisis.

What's your news?

We'd love to hear your news and feature more AT families in our newsletters.

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

Our next newsletter will be out before Christmas so please send before 1st October if you'd like to be featured.

Many rainbow images appeared in windows all around the UK. These colourful rainbows were popping up to spread joy and hope in these strange times. We decided to make our own AT version with a different picture each week which we encouraged people to colour in to sprinkle a little happiness across the AT community and beyond. Here's just some of the pictures we received.

£50 A £50 donation could pay for a play therapy session for a child with AT or their sibling. Play therapy enables a child to express their feelings and talk about their worries and concerns through play.

Two of our young adults with AT gave an insight into what it was like living in complete lockdown and not being able to leave the house.

The Virus

BY ALECIA

There was a young lady called Alecia, she lived at home with her family. Alecia had a rare condition which meant that she needed to use a wheelchair at all times. She was a very sociable person and loved to go out, she accessed many clubs and regularly met with and enjoyed spending time with her friends.

In early 2020 she was going about her fun-packed life when an evil virus struck. It was a scary time; people were becoming very unwell and the government had to put in very strict rules to stop this virus from spreading more. This meant that everything came to a standstill and the whole of the UK went into "lockdown."

Alecia went from being extremely active all week, going out most days, to being stuck indoors and isolated away from her friends. This was very difficult for Alecia and it made her feel upset and frustrated. And emotional!

Alecia was lucky to have close family with her who supported her, she did baking with her sister and even went on a family bike ride on her specially adapted trike and managed over 2 miles. However, she was still very sad that she was not able to party with her friends.

Nobody knew how long this would last, Alecia hoped that she would soon be able to get back to her normal life.

£150 A £150 donation could cover the cost of our support helpline for a day, ensuring expert advice is given to parents, children and young people living with AT.

My life in lockdown

BY CHARLOTTE

Since lockdown or social distancing was put in action I have mainly been working through Netflix series and a few Netflix movies but I have also been helping the AT Society with a few things, as well as looking after my 2 dogs (my babies) ironically called Baby and Prince who I quite happily look after every day.

The dogs keep me company as the three of us live alone in a bungalow but we do normally see my half-sister Liz on a Saturday, when she takes me to do Parkrun with her, we then go shopping afterwards for any bits I need. I haven't seen her or been out with her since the 7th March.

I have carers coming in three times a day to help me with whatever I need doing, but since the coronavirus outbreak they now they have to wear gloves and aprons. I sometimes see my brother but this is now if and when I need his help. He stands a good distance away from me and I am not allowed to see his children (my niece and nephew) which is hard.

My boyfriend used to finish work and come to see me; he'd then spend some of his day off with me but this has also been put on hold due to this lockdown. We do speak nearly every day and we are making plans for a holiday together as well as looking into me moving closer to him once this is all over.

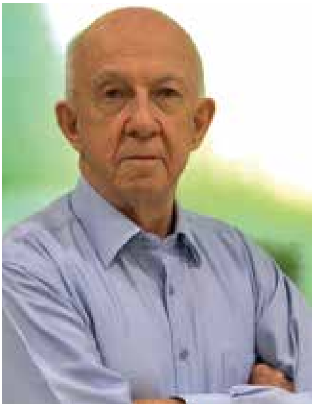
On Netflix I have been watching a series about Ted Bundy which was really interesting, a new series of Vampires, and I am currently working my way through the Vampire Diaries series where most girls like Stefan or Damon but I actually prefer Klaus (go figure!). I have also watched Glee again. As for movies I have watched a few such as Twilight, Fifty Shades Of Grey, What To Expect When You're Expecting, and P.S. I Love You.

I imagine like all of you I am bored, fed up and frustrated with being stuck inside and not being able to go anywhere or see anyone. I have come to the realisation that life's too short so if you want something in life then you need to go and get it because no one can do it for you and you will always wonder "what if". Of course, we'll have to wait until the lockdown rules are relaxed to be able to go out and do this but we can plan ahead.

> “ I imagine like all of you I am bored, fed up and frustrated with being stuck inside and not being able to go anywhere or see anyone. ”

The adults living with AT have a Facebook Messenger group called "AT doesn't define me" which we use to stay in touch with each other, a couple of months ago I had the idea to create an "interaction" post for the group to generate conversation and so we could get to know each other better.

Forty years AT the front line – a profile of Martin Lavin



Professor Martin Lavin, a biochemist whose laboratory is in Brisbane Australia, is one of the foremost researchers in the world seeking to understand and develop treatments for AT. He and his team have explored many different features of the condition. They always have new and interesting data to present at AT conferences, and are helping to push forward our understanding of the condition and how we can hope to treat it.

Martin has been researching AT for over 40 years. He was initially interested in DNA damage more generally, but in the mid-70s a paper by Malcolm Taylor and his colleagues on the radiosensitivity of people with AT drew his attention to the condition.

From that moment on, AT has been central to his work, particularly once he had set up his own group in around 1980. Aiming to try and explain this sensitivity to radiation, he began to work on cell samples taken from people with the condition and their families. He realised from cell studies that relatives of people with AT had some sensitivity themselves.

His interest led to his being part of the international consortium, led by Yosef Shiloh of Tel Aviv, which described the ATM gene following its discovery in 1995. At that time they knew that AT was caused by loss of the ATM protein, but they needed to work out exactly what the protein should do.

This turned out to be a very complicated task, as it became evident that the protein does an awful lot of different things. Indeed, we now know that it interacts with over 1,000 different proteins within the cell. Very early on, Martin's group showed that ATM activated another protein called c-ABL, which plays a role in the cell's cycle and in response to stress and is linked to cancer. The important insight that resulted from his and other work was an understanding of how the ATM protein signalled to other proteins in order to maintain the genetic integrity of the cell.

Then it became clear that ATM interacted with a series of particular proteins involved in repairing damage to DNA, the loss of which results in other conditions with similar characteristics to AT. As with AT, cancer predisposition was common to some of these syndromes. Gradually a picture of a whole network of interactions in the cell emerged, controlled by ATM.

A crucial finding was that the ATM protein itself has to be activated and this was shown to be through the presence of breaks in the DNA. However, Martin feels the role of ATM is not just about responding to breaks in the DNA. He sees ATM as having a broader role in protecting the cell. More recently he has become particularly interested in the role of ATM in dealing with oxidative stress. The normal activity of cells produces various substances containing oxygen radicals known as ROS (Reactive Oxygen Species), which if allowed to build up can damage the cell through a mechanism quite distinct from the response to DNA breaks. Together with a leading American researcher Tanya Paul, Martin showed that ATM was activated by a build-up of ROS and so absence of ATM would lead to increased oxidative stress in cells. This leads to the important question of how these different types of unresolved damage might give rise to the neurological features of AT.

> “ Recently, Martin’s team have been looking closely at problems in mitochondria and have identified a drug that appears to correct them. ”

Much of the ROS in cells comes from the mitochondria, small units within the cell which produce energy to power it. Lots of previous studies have shown that there are problems in the mitochondria of people with AT. Recently, Martin’s team have been looking closely at these problems and have identified a drug that appears to correct them, at least in cell cultures in the laboratory. This is a drug that has been used previously to treat epilepsy and metabolic disorders.

The next stage is to test it in humans, and an application for funding for a clinical trial has already been made to the Australian National Health and Medical Research Council. If all goes well and funding is approved, a trial could be started by the end of the year. While this is potentially very exciting, there is still a long way to go, and it is far from certain at this stage that what works in the laboratory will also work in the body.

Over the years, Martin and his team have been involved in many other areas of AT research projects. One key issue is the lack of a good ‘animal model’, that is animals, usually including mice, that show the characteristics of a particular condition. These are extremely valuable in helping understand the condition and in showing whether particular drugs have the potential to be effective in humans.

Martin’s team has tried to generate ATM animal models, that show the same symptoms as humans. They produced a strain of mice that showed many of the features of AT in people but not one of the most obvious and important symptoms – the movement disorders. They also produced a strain of rats which did show some movement disorder, but this was very different to that in people with AT. To date there is still no good animal model – and this remains a problem for AT research.

Martin’s team has also worked a lot with stem cells in collaboration with Professor Ernst Wolvetang, also of Brisbane. They were the first team to produce stem cells made from the cells of people with AT and later were able to produce a number of different cell types, including cerebellar neurons. This is very difficult work and the team are now working along with others to try and produce specific cells like Purkinje cells.

Given the extent and range of Martin's AT research work, it is no surprise that the Australian AT clinic, now under the co-directorship of Drs. Coman and Sinclair, was established in Brisbane. Martin has a close relationship to the clinic, both clinicians and families.

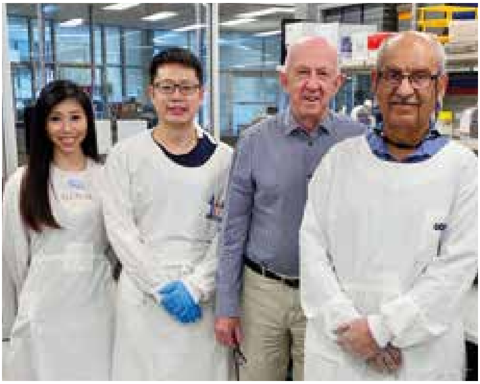
> “ Martin has been described by a leading researcher as ‘an international AT treasure’. His deep insight into all the multiple aspects of AT research underlies the breadth of his contribution. ”

They inspire his work and also provide materials in the form of cells and samples. And the work of his team has received strong support from BrAshA-T, the Australian AT charity.

After so many years on the research front line, he remains up-beat about the future. He sees the number of different clinical trials that are now emerging – their own planned trial, EryDex, Intrabio and the ASO study in the USA – as a very positive sign, not to mention the breakthroughs made in other rare conditions.

When asked about retirement, he replies that though it will inevitably happen, he hopes it won't be for a while to come. The work requires a lot of travel, but that suits him as travel is one of his passions. Living in Queensland – he was originally born in Reading UK – also suits him perfectly, as he enjoys the wide-range of outdoor activities and quality of life on offer there.

AT research is an international endeavour. While Martin may be Australia's "Mr. AT", he has been described by a leading researcher as "an international AT treasure". His deep insight into all the multiple aspects of AT research underlies the breadth of his contribution. Few have contributed to as many different areas of AT research as he.



Given how much he has achieved over the years to take forward AT research, we must all be glad that he plans to keep working for now. And it would be a fitting climax if he were able to close his career by bringing an effective treatment for AT successfully through clinical trials. But however it goes, as an AT community we can already be hugely grateful that over 40 years ago, Martin chose to devote his great talents to AT research.

AT Legacy

Over thirty years of life-changing support

Help it continue with a gift in your Will

Every year the AT Society supports nearly 200 children, young people and adults living with AT, and nearly 800 siblings, parents, grandparents, aunts and uncles, all who are desperate to be able to do the very best for their loved ones. With increasingly more pressures faced by them, from continued cuts in local authority and NHS funding, it becomes harder and harder to access the essential support needed when living with this life-limiting condition.

Leaving a gift in your Will to the AT Society helps to change lives by ensuring we are here for people affected by AT, now and in the future. It will enable children, young people and their families, to receive the help required, from starting with a reassuring, friendly, independent and impartial chat on issues that matter to them, to undertaking critical research to move nearer towards finding a cure.

In fact the major investment in research featured on page 22 was made possible by a recent very generous legacy from an AT family.

How can I start legacy giving?

No matter the size, a gift made in your Will can help families who need our help in the future. Through legacy planning, even 1% of an estate can make a big difference to the families we support.

Adding a gift to your Will is simple. All you need is the charity address and registered charity number:

AT Society, Rothamsted, Harpenden, AL5 2JQ
Registered charity number: **1105528**

Where exactly does your money go?

Your money is always important to us and we promise to spend it wisely. For every £1 the AT Society spends, 51p goes directly to supporting children, young people and families affected by AT; 21p on undertaking vital research to improve treatments and find a cure; 4p on governance, and the remaining 24p on fundraising. For every £1 we spend on fundraising we generate £3 in additional funds.

Your Will

Why do I need a Will?

Making a Will secures a future for your family and loved ones. It is one of the most important things that everyone has to consider at some point in their life. If you pass away without a Will, you won't get a say in who inherits your property, possessions and money. We are developing a Will Guide which will include information on how to value your estate and what to consider when deciding what you would like to leave to your loved ones. If you would like to receive a copy of the Guide when it is published, please email **info@atsociety.org.uk** with the subject WILL GUIDE.

A gift in your Will helps to provide healthier, brighter and happier futures for people with AT.

Research call

The AT Society has put aside a significant sum to invest in research and was on the point of asking for applications when the uncertainty of the coronavirus pandemic got in the way. We have postponed the call for applications until the situation is clearer both in terms of the practicalities of life and work and the Society's financial situation.

However, we fully intend to go ahead with this and indeed one of the purposes of the video meetings described opposite is to try and identify the most promising areas for research with the potential to lead to rapid developments in treatments.

Conference postponed

One of biggest impacts of the coronavirus pandemic on the Society's work has been the forced postponement of the AT Clinical Research Conference 2020. This was being planned to take place at the same venue and to overlap with the AT Society's Family Weekend, in October.

The uncertainty of how things would develop meant that it was impossible for us to go ahead with the existing bookings. However, we are currently organising both the events together in June 2021.

The AT Clinical Research Conferences are the primary meeting place for clinicians and researchers from around the world with an interest in improving care and developing new treatments for AT. This will be the fifth conference in the series, which is organised jointly by the AT Society and the AT Children's Project.

An international group of researchers and clinicians from around the world has already done a lot of work to put together an innovative and challenging programme. While the more traditional topic areas, such as the neurology, immunology, lung-health and cancer in AT are included, there will be a major focus on a holistic approach to managing AT, with two different sessions on enabling and supporting quality of life. Mental health, relationships and sexuality and assistive technology all feature in the programme as does discussion of how AT can effectively be addressed in poorer countries.

Organising the event together with the Family Weekend gives the opportunity for joint sessions and for clinicians, researchers and families to meet and socialise together.

£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.

Taking advantage of the lockdown

The lockdown has not been entirely negative, though. As many researchers around the world have been sent home from their laboratories, it means that they have more time on their hands to think and talk about broader issues.

Taking advantage of this, the AT Society recruited leading researchers from within and beyond the AT research world to focus on a number of key issues. Video conferencing facilities made it possible to bring the scientists together in discussion.

The three subjects chosen for the first groups were:

1. **The mechanisms underlying the neurodegeneration in AT** – if we could only understand why it is that some cells in the brain die in the absence of ATM but not others, it would help us develop treatments.
2. **Developing vectors for gene therapy in AT** – the ATM gene is so big that current gene-therapy vectors (the mechanism for carrying the corrected gene) don't have enough capacity. It is important that we overcome this hurdle to enable gene-therapy approaches to treating AT.
3. **Establishing induced AT Purkinje cells and cerebellar organoids** – the first ATM-deficient Purkinje cells have been produced in the lab, see below, but this is cutting-edge science and much needs to be done to maximise the potential of such cells to help understand and develop treatments for AT.

These are three of the key issues in AT research today. The researchers involved were from the UK, Europe, the United States and Australia. While some were well known names in AT research, others were not involved in AT but had valuable experience in related fields.

As we write, only one of the groups, that discussing mechanisms of neurodegeneration, has met but the discussions were very engaged and constructive. The outcomes are being written up and there is the possibility that the group's discussions could form the basis for publishing a new paper.

Purkinje cells research project

Last year we reported on a project funded by the AT Society to grow Purkinje cells in the laboratory using stem-cells derived from people with AT. The project at the IFOM institute in Milan was led by Domenico Delia and Marco Foiani. The team successfully produced the Purkinje Neurons, though initially the yield (the number of cells produced) was quite low. However, they have continued to improve their processes and as a result have both increased the yield and the structural complexity of the cells produced.

While they continue this work, they are also in a position now to start doing analyses and screenings of the cells to try and understand how they are different from 'normal', non-AT, cells.

Fantastic Fundraisers

FUNDRAISING

Here are some of the amazing ways you have supported us in the last six months. Huge thanks to all of our fantastic fundraisers for your support!


AT volunteers collected in St Albans with the Round Table Santa Sleigh


Jilly Shah, our trustee, continued to raise money with her delicious and spectacular cakes

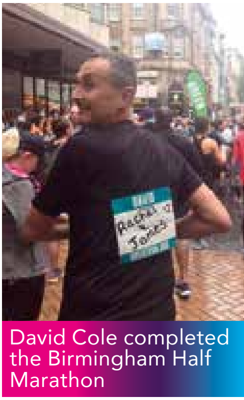

Joy Ferguson's annual fundraiser was another big success


Concordia Choir sang carols at Much Wenlock Christmas Fayre

Flo and Eliza hosted a spooky Halloween party


HSBC's Natasha Jones organised a fun day to raise money

Carol Giles organised a wonderful coffee morning


David Cole completed the Birmingham Half Marathon

Jiggy Childcare held a Christmas cake sale

Hazel Stancliffe cracked the Leeds 10K

The Hertfordshire Chamber Orchestra delighted their audience with a rousing classical music concert in Harpenden

Helen Higham ran the Manchester Half Marathon for beautiful Orla

Another tasty cake sale from St Patricks Academy

Rosemary Macartney asked for donations instead of gifts for her 70th birthday

Vikki and Mike Climpson held a Christmas Fayre in Hastings

AT Society staff hosted a fun-filled quiz night at the King's Arms in Berkhamsted

Have we inspired you to fundraise for us?
Contact Sarah Ajder
sarah@atsociety.org.uk
with any ideas, big or small!

2.6 Fundraising Challenge

Our ever-inventive supporters rose magnificently to the 2.6 challenge! Here's just a selection of the challenges that have raised **£15,000** and counting! Huge thanks to our stay at home heroes.

Hats off to Alecia who came up with the most stylish and fun 2.6 fundraiser – wearing 26 different hats in 26 seconds. Thanks to Alecia's family for lending a helping hand.

Superheroes Spiderman and Captain America (aka Jack and Harry) completed 26 jumps on their trampoline for their brilliant 2.6 challenge.

Their grandma, Nora, completed 26 laps around the block to support us. Thank you Nora – your neighbours must have been intrigued.

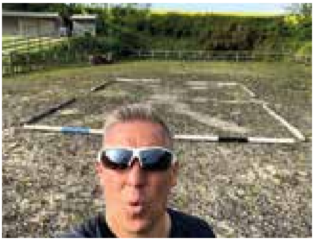
Zara, Iqra and Maria are happily reading 26 books for their challenge. They're enjoying escaping to another world and we suspect the rest of the family are enjoying the peace and quiet!

Lilly deserves a big round of applause for completing her 2.6 challenge. She managed to walk 26 steps for the challenge which, as any parent with a child with AT knows, is a massive achievement.

Merry chose to walk 26 steps a day for 26 days which is a real marathon effort for her. Well done Merry – we knew you had the determination and will power to do it!

Fiona Bell ran 26.2 miles over 7 days, turning her daily exercise into a fantastic fundraising opportunity. Fiona has known Merry for over 12 years and having Merry as her motivation for this challenge spurred her on.

In support of Lola, super fit Jonathan ran a full marathon in a 40 x 20 metre sand paddock at an equestrian school, completing this gruelling challenge in 4 hours and 7 minutes!



In support of her nephew, Winston, Tea Killick and her family virtually walked 26.2 miles on the Inca trail. It was a real family affair with Tea carrying her youngest on her back so that they could all take part.

Head of fundraising, Susie and her daughter Amelie ran 2.6 miles in 26 minutes in the heat. Wow great effort you two!

Trustee Jilly made us all a little hungry in her latest fundraising endeavour. Jilly iced 26 cupcakes in 26 seconds and she still made every single one of them look pretty which is no mean feat!

Fantastic Fundraiser Eliza pogoed 263 times in 2.6 minutes. Her mum, Jo, coordinates the AT Registry so Eliza knows how much of a difference every single penny makes.

Charlotte challenged herself to read 262 pages in 5 days. Charlotte chose The Scarlet Letter by Nathaniel Hawthorne and was very determined to finish on schedule!

Ben completed 260 ping pong bounces with no drops – super skills Ben! Ben's mum is our Fundraising Coordinator so he was keen to raise as much money as possible to support our families.

AT mum Jennifer and daughter Chloe walked 26 miles over 4 days and finished with 26 body weight squats lifting Ben, who then held a plank for 26 seconds!

"We wanted to contribute to the AT Society at such a difficult time – you've all been an incredible support to our family over the years.

It was really important to Chloe to do something for Maria and Ben and she didn't want it to be easy but a real challenge! Ben was very keen to take part and use his amazing strength and determination. He felt an incredible sense of pride, as we all did – it was an amazing moment to share."

Fundraising stories

Cambridge Half Marathon

A new event in our fundraising calendar, the Cambridge Half Marathon was a huge success on a sunny Sunday at the start of March, just before lockdown. Our A-Team really proved to be the magnificent seven by raising over £5,500 between them!

All runners had a special connection to the AT Society. Pete McEleney and Joe Ganley are husbands of AT staff, Dr Nick Oscroft and Natasha Everett are key staff at our Adult AT clinic at Royal Papworth Hospital and May Yung Teit had just started a PHD in AT research.

The team enjoyed a well-earned celebration at a pub near the finish line and were all delighted that Ruzina and Jusna came to join us.

Just in time...

A-Team Brighton Marathon runners Hannah Knipe and Megan Davies organised a sparkling fundraising event which luckily went ahead the weekend before lockdown began. With so many events being cancelled since, the funds they raised have become even more valuable to us than ever. Thanks to everyone who helped make the evening such a huge success. With Ava as their inspiration we know Hannah and Megan will stay the course to the end, whenever that may be.

Our Brighton Marathon runners have all made a huge effort with their fundraising and we are grateful to everyone in the team for sticking with us and continuing to fundraise. Thanks to Ava's dad Vito, Rose's mum and dad, Dave and Jenna Wright and Alicja Blount for being the best Brighton A-Team!

Hastings Hulks Half Marathon

We were really disappointed that our team of Hulks couldn't run the Hastings Half Marathon this year but thanks to Anna and Chelsea the event went international when they ran their own half marathon in Berlin! Now, that's what we call incredible!

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

Solo runners stepping out

After months of training in preparation for running events that have been cancelled or postponed several runners took to the streets where they live to run their event distance solo. Showing total commitment to their sponsors and the AT Society we applaud them all. It's tough going without a crowd to cheer you on.

Unable to run the postponed Manchester Marathon, and just two weeks after running the Cambridge Half Marathon, May Yung Teit ran her first full marathon solo around Leicester just days before postponing her PHD in AT to work in the hospital. We hope May will soon be able to return to her research and stays safe and well in the meantime.

To quote from a post on Marianne Insley's Facebook page, 'My charity run was cancelled, but my human portable water station and I did it anyway!' Marianne still hopes to run the postponed Lulworth Cove Trail Half Marathon in September. Fingers crossed!

Alicja Blount celebrated her 36th birthday by running a full marathon! She will deserve two medals when she eventually crosses the finish line in the Brighton Marathon!

Charity of the Year

Nominating us as your company's Charity of the Year is a unique opportunity to unite your staff behind an inspiring cause and demonstrate your company's commitment to making a difference.

Here's a few examples of some of the super companies and clubs we've been working with. A big THANK YOU from us all.

Our long term partnership with Pizza Hut continues to amaze us. As well as raising money, donating prizes and volunteering at fundraising events, they helped us to spread a little joy during the coronavirus crisis by donating pizzas to some very lucky AT families during lockdown! What's not to like about that!

"Thank you Pizza Hut for the pizzas. It was such a treat for Orla. We would normally take her to Pizza Hut and the cinema at least monthly so for her to be able to have this treat, which is in her comfort zone, was wonderful and much appreciated by us all."

Based in Harpenden, brand design and marketing agency Gosling have adopted the AT Society as their Charity of the Year. They have organised the most amazing cake sales and are busy preparing for their Thames Bridges Trek challenge in September.

We have welcomed the support of the Concrete Society NW who have, in total, raised a wonderful £3,769 through their two annual Society Luncheons. Amazing! Thanks especially to Peter Cowan, Chairman, for his fantastic support throughout the year.

Nationwide in Harpenden donated a lovely cheque for £652 after their raffle and book sale in their branch. Thank you Nationwide and thank you Harpenden!

100
BEAVERBROOKS
Your Family Jewellers For 100 Years

Beaverbrooks Jewellers' Bluewater Branch have chosen us as their Charity of the Year and so far raised a magnificent £2,601 through various fundraising initiatives, including a very successful Tuck Shop and bake sale! Many thanks to you all!

DBpixelhouse have been raising money for us in a variety of ways from spooky Halloween events, selling Christmas cards, corporate quizzes and taking part in our annual Christmas Sparkle Draw raffle! Thank you everyone for all your support and great fundraising ideas!

If you, your friends and families work for companies that support charities please let us know. There are all sorts of ways they can get involved and we are constantly looking for more corporate support. Please contact **susie@atsociety.org.uk** for more information.

Harpenden Golf Club have been amazing. They have chosen us as their Charity of the Year and have organised a host of wonderful and ingenious fundraising events for the charity, from selling car parking spaces, Captain's dinners and raffles. Whilst the coronavirus lockdown has now thwarted some of their original plans it has not deterred them. Peter Hart, Men's Captain, has challenged himself to lose weight for the charity – 26 pounds in 2.6 months – and at the time of going to print, has raised a staggering £4,500. Good luck Peter, we know you can do it!

WEAR JEANS CHANGE LIVES.
JEANS FOR GENES DAY

We're delighted to have been awarded a £5,000 grant from Genetic Disorders UK, the national charity that supports individuals and families affected by a genetic disorder. The grant will be a great help towards the costs of running our Family Support work.

The charity are responsible for Jeans for Genes Day, which is their annual fundraising campaign where schools and workplaces are encouraged to wear jeans for the day and to fundraise. This year the campaign is due to run from Monday 14th – Sunday 20th September.

In addition to the grant, as a partner, they will share 50% of the income raised by schools and workplaces on Jeans for Genes Day with us, just from those organisations that we can sign up. Nearer the time we'll be sending further information out about it, in case you know schools or workplaces who will be interested in getting involved, so do keep a look out and get your jeans at the ready!

www.jeansforgenesday.org

Easy ways to get involved...

VIRTUAL PUB QUIZ

Virtual quizzes are becoming more and more popular as a fun way to socialise whilst not leaving the house. Why not set one up and get each participant to make a small donation?

AMAZON SMILE

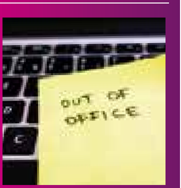
The AT society is registered with AmazonSmile. It is a simple and automatic way for you to support us every time you shop, at NO COST TO YOU. It is amazingly simple, just go to Smile.Amazon.co.uk next time you are using Amazon, and they will give 0.5% of every purchase to us.

amazonsmile
You shop. Amazon gives.

FIND ITEMS TO DONATE LATER

If you are spending more time at home, the chances are you will find time to have a clear out of items in your house. You could put some items aside to sell and donate the money.

OUT OF OFFICE EMAILS/ EMAIL SIGNATURES



Here is an opportunity to let people know, not only that you are working remotely or out of the office, but of a charity that is close to your heart. You can link up to a JustGiving page or link to our website to help raise awareness.

DONATE YOUR COMMUTE

If you are saving money on your daily commute to work, or if you have been granted a refund as a season ticket holder, perhaps you could donate some of what you have saved.

HOME CHALLENGES

If you are at home with the children, setting them a challenge and asking people to sponsor them could be a fun way to get them active, learn a new skill or make something creative. You could even set them cooking or cleaning challenges to raise money!

DONATE YOUR BIRTHDAY

If you can't go out to celebrate or your family or friends can't come over to join you on your day, why not invite them to make a donation in your name. You can create a birthday fundraiser on Facebook in just a few easy steps, select the AT Society and every penny will come to us!

DONATE WHATEVER YOU ARE NOT SPENDING MONEY ON

Your daily coffee shop budget, money spent on haircuts, cinema, or nights out... the list goes on. If you are in a position to donate then please go to www.atsociety.org.uk/donate/ and donate now.