AT Society News

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AUTUMN 2022 / NO.61

FAMILY WEEKEND NEWS

FANTASTIC FUNDRAISERS

RESEARCH UPDATE

FESTIVE FUN

Registered with
FR
FUNDRAISING REGULATOR

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

AT society
awareness research care

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

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 to live well with AT expresses our commitment to provide the information and support to enable people with AT and their families to live their lives to the full. At the same time, we work to improve treatments and to stimulate and fund research.

Contact us

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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.

Giving Monthly makes a BIG difference

Your regular donations give us monthly income that we can rely on. It allows us to continue to be there for everyone with AT and their families.

£5 a month could provide help and expert advice to a family learning how to deal with AT

£10 a month could provide two counselling sessions for a child with AT or their parents

£20 a month could provide 10 hours of research in an AT laboratory

Richard's friend has AT and he gives £10 each month.

"It's so straightforward. £10 is gifted from my bank account just after I've been paid. I don't notice it, and without any effort I am giving a significant amount to a charity which really matters to me."

Sign up to become a regular giver and make a difference every month.

Thank you.

atsociety.org.uk/support-us/regular-giving

Welcome

In this Autumn's Newsletter, we're delighted to share your stories as well as the latest news and events here at the AT Society.

I have the pleasure of being a trustee for the AT Society. I am also thrilled to say that I have recently completed a skydive to raise money for this amazing charity. It has been one of the coolest things I've ever done!

You can see on pages 18–21 that many others have taken on exciting challenges this year in aid of the AT Society. If you would like to join in the fun, have an idea of how to fundraise or would like to speak to the team, please don't hesitate to get in touch!

As well as fundraising there are other ways to help, especially at this time of year. You can buy tickets to our eagerly anticipated annual 'Sparkle Draw' raffle, buy our Christmas cards, or get your school or office to wear Christmas jumpers to raise money, see page 23.

The charity's work is vital. As a beneficiary of the AT Society's services, I know from first-hand experience what a positive impact they make. We can't alter the fact that we have AT, but thanks to your support, we can definitely make life easier and happier, and we can provide hope for the future.

Thank you for reading this newsletter and for all your fantastic support. It really does mean a great deal to those of us with AT.

With very best wishes,

Shah

Jilly Shah
Trustee

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

@ATSociety
#atsociety
atsociety

Cheque mate!

Here at the AT Society HQ we simply love to receive a giant cheque! This year we would like to thank the following organisations for their 'giant' donations: The National Lottery Community Fund, Ashtons Estate Agents and The Concrete Society.

Family Weekend 2023 – Save the date!

After three years of COVID restrictions it is with huge excitement we are able to announce the date for the next Family Weekend! Here is what we know so far...

Who is invited

Everyone with AT and their families! And any professionals with an interest in AT.

Activities

Talks about the latest research into AT and advice, a supervised outing for the children, fun activities in the hotel, a chance to socialise with other families and much more.

Please register your initial interest in attending the Family Weekend by emailing support@atsociety.org.uk or call the office on 01582 760733. We will then contact those who have registered and provide further details in the New Year.

Date: Friday 30th June – Sunday 2nd July 2023

Duration: 3 days

Venue: Radisson Blu Hotel, East Midlands Airport, Derby DE74 2TZ

Contact us to register interest: **support@atsociety.org.uk** or **01582 760733**

A group shot taken at The Family Weekend at the Radisson Blu Hotel in 2019

Clinic on Camera!

> **"It was a real privilege to have been asked to shoot these clips for the AT Society. Our General Manager Craig has two children with AT so it's always been a charity very close to our hearts."**

One of the key components to our work at the AT Society is our involvement in the two unique, dedicated AT clinics in Nottingham and Cambridge, which bring together all the AT medical specialists in one place to offer professional care and advice. The COVID backlog has put increased pressure on our service and as a result we have been helping to run 2–3 extra clinics a year to ensure that young people with AT will continue to reap the benefits.

Recently some clinic attendees commented on the value of these clinics:

"They're a fantastic crutch and support to the whole family."

"We're so grateful to receive emotional, physical and mental support from professionals who understand about AT."

We were delighted to receive a grant from the Vinci UK Foundation which we were able to use to raise awareness of the clinics.

Thanks to Craig and Ali at Erskine Arts and all the willing participants, we have been able to create a series of films showing our specialist clinics at Nottingham and Papworth. These will be used to help to show new families what to expect when they come to clinic.

Ali from Erskine Arts said: "Getting to interview the team and the families they are supporting gave us an insight into how valuable the service is. It's hard to comprehend the stress and heartache these families have to go through on a daily basis. The AT Society take a huge weight off, supporting with medical guidance, support for home care and, probably most importantly, are there to listen and ensure families that they are not alone.

These media clips are designed to be a first port of call for newly diagnosed AT families and carers, to help them feel familiar with the services and support available through the AT Society and we hope they give a small amount of reassurance for those that need it."

Watch our films here.

EryDex Clinical and Regulatory Update

EryDel
INNOVATION INTO BLOOD

> **“We remain confident in our clinical package and the benefit EryDex may provide to children with AT. Your support and patience are appreciated as we look forward to bringing this much awaited treatment to AT patients and fulfill a critical unmet medical need in the AT community.”**
>
> **Thomas Sabia**
> Chief Commercial Officer
> Erydel

EryDel is a global biotech company whose goal is to bring EryDex to the AT community as an approved treatment. To this end the first major clinical trial assessing their treatment to slow the progression of ataxia in AT completed in 2021 with positive outcomes.

The team is now working hard with the regulatory bodies in America (FDA), Europe (EMA) and the UK (MHRA), to identify the best approach to obtain the green light for market authorisation. The FDA has provided feedback that an additional clinical study is required prior to drug application submission and Erydel is working with them to establish an agreed approach for this. They continue to work with other regulatory agencies in the EU and will communicate updates as more feedback becomes available.

In the meantime, wherever possible, the treatment is still being provided to those children who participated in the trial – in the UK this is for 9 children – and Erydel is committed to ensuring this continues until the formal marketing authorisation is obtained in each country.

We continue to work closely with EryDel and will ensure we provide updates to families affected by AT as soon as they become available.

For further information, please scan the QR code.

The Natural History of AT (N-HAT)

As many will know, the AT Society continues to support this important study carried out by Dr William Whitehouse and Dr Emily Petley. Their primary aim is to better understand the AT process, its response to treatments and more accurately map the course of AT from childhood into adulthood. It is the first study of its kind in AT and has been funded jointly by the AT Society, BrAsh-AT and Action for A-T. A systematic review of both the clinical and scientific literature was published in March 2022. This data will be used to help recognise different patterns of presentation and progression of AT in individuals, anticipate complications more accurately (to keep one step ahead) and help professionals to design clinical trials in a more targeted way. It will also help to identify the best ages for treatment intervention.

The next step for the researchers is to involve parents and guardians in focus groups' discussions, to identify areas of primary importance to those affected by AT. This participation is an essential element of the research. Only through discussion and involvement of those living with the condition can progress be made and priorities in AT research discovered.

Focus groups invitation at the AT Society Family Weekend Saturday 1st July 2023

We want to know what you think of the N-HAT study results so far, and need your views for future research. To register your interest please email: **support@atsociety.org.uk**

Intrabio Trial Update

The IB1001-301 clinical trial with N-acetyl-L-leucine for AT is underway and progressing well. They are still actively recruiting adult patients aged 18 years + at Royal Papworth Hospital so if you are interested in joining this trial please contact Hannah Munday hannahmunday@nhs.net.

Intrabio had previously tried to open a paediatric trial site in the UK, but was unable to due to the lack of availability at that time. They understand the urgent medical need of children with AT in the UK, and by the end of the year, plan to re-evaluate the feasibility of opening a paediatric site in the UK.

At the same time a trial site in Giessen, Germany has offered to recruit paediatric patients from the UK, and plan to make recruitment available to UK patients early 2023. We don't have a lot of information on this yet, but anyone who is interested to know more is encouraged to connect with us at **support@atsociety.org.uk**.

For further information about the trial please visit: **clinicaltrials.gov/ct2/show/NCT03759678?term=IntraBio**

36p

For every £1 we spend, over 36p goes on vital research to improving treatments and moving us closer to finding a cure. Thank you for helping us do this!

We are so pleased to announce that Professor Rob Dineen has become the new Chair of the AT Society Scientific Advisory Board (SAB).

Meet Professor Rob Dineen

Rob is an academic and clinical neuroradiologist based in the Division of Clinical Neuroscience at the University of Nottingham. He has experience of leading on lots of AT scientific research projects and joins the SAB with a wealth of knowledge in this area.

The SAB exists to provide independent scientific advice to the AT Society on our research priorities. Rob said:

"The SAB brings together independent scientists and clinicians specialising in a range of research areas of relevance to AT including Molecular Biology, Biochemistry, Immunology, Cancer Research, Clinical Pharmacology, Physiology, Neuroscience, Neurology and Genetics, as well as people with lived experience of AT. I look forward to working with this impressive group to help ensure that research funded and supported by the AT Society can continue its path of advancing our understanding of AT and improving treatments."

We are currently funding four AT research projects, and are increasing this by another seven in coming months.

> **"We recently committed to co-funding five new research projects with our AT Global Alliance partners, Action for A-T, Brash-AT and AEFAT."**

We're delighted to be contributing to these projects, all of which promise to make significant inroads to improving what we know about AT and to keep moving us closer towards finding a cure.

More information about the research we are funding is available on our website www.atsociety.org.uk/research and updates about all projects will follow in due course.

Nick's Boccia journey

Following Nick's nomination for Boccia Coach of the Year we asked his wife Michele to tell us a bit about how Boccia, and Nick's AT Boccia team, has become such an important part of his life.

"Nick first became interested in Boccia when George (who has AT) joined a local club. He first decided to train as a referee and did this through Boccia England on one of their training days. He passed straight away and started to referee at Boccia competitions. After about a year Nick decided to train as a Level 1 Coach, he did this with Boccia England over two weekends and passed first time! He became the coach for Prince Arthur Boccia Knights team, who George played for. We arranged extra training at a local school, and the team got stronger and more competitive.

After the last AT Family Weekend, we invited Henry, Leigh and Charlie to join us – they did, and thoroughly enjoyed it. We started to go out for a meal afterwards, so our social circle was created. It gave the lads something to talk about and get involved with. They have become extremely close. A few months later Mia came along and joined us, and has become part of the team. Their bond has become so strong that George, Henry, Leigh and Mia are all going to Las Vegas next February (the parents are tagging along too!).

Around December last year Nick decided to form his own club, so The AT Warriors was formed! Henry designed the logo and the AT Society purchased some equipment to help start off their training. We are an all-inclusive club as per Boccia England guidelines, so we now have four new members who are registered disabled but don't have AT, one being Henry's Mum! We have competed in a couple of team competitions in Kent and Nick has high hopes for next year. Several players entered the singles competition for Boccia England at Crawley and Leigh won a silver medal, only losing in the final to an England player. Not bad for his first ever competition!

Nick gets a buzz out of coaching them and enjoys seeing the improvement in them all. Also, it's so nice seeing the enjoyment the team get out of coming to Boccia."

Left to right: Henry, Leigh, Nick, Mia, and George

Rose and Jenna connect with other AT families

Jenna, mother of Rose, shares her story

"When AT came into our life, the first thing we wanted to do was run in the opposite direction. Rose was diagnosed with AT and didn't really present with any symptoms, so naively we probably didn't believe everyone around us.

We didn't know any other families with a rare genetic condition let alone AT. When Rose started saying that she felt different from other people and wanted friends that had disabilities I didn't really know where to start. Anne and Kay, from the AT Society, advised me to go on to the facebook pages and they were so right. I found an international AT Mums support group and joined it. It felt good to get to know families in the same situation and I desperately wanted Rose to feel happy and included.

I was scrolling through the Facebook page just before Christmas in 2019 and I saw a post saying that a little girl the same age as Rose loved sending and receiving Christmas cards, so if we wanted to give our address, they would send a card. I sent a message to Holly, the Mum, and two weeks later Rose received the biggest box of American Christmas treats from Hayley, the little girl. We were so surprised, and Rose was beyond excited. We sent her back a box of goodies and that started our friendship – we have been pen pals ever since. I will be forever grateful to Holly for bringing kindness, excitement, and joy into Rose's life when she needed a boost.

At the start of this year, I saw a post on the UK Facebook page asking if anyone wanted a chat. My initial thought was gosh, I wish I was as brave as that lady. Then I thought, I love to chat! It was Steph and she had a daughter, Poppy, who was new to this AT life. We set up a small WhatsApp group and started chatting. Steph and I hit it off immediately and our families met at Easter. We had an absolute blast. We were facing the same challenges and it felt really good that there was another family going through the same things. Poppy came down and supported us with an AT Society fundraising event, which we appreciated so much. We were invited back to their house and the girls spent the whole time in the paddling pool. We plan to have a Christmas Party this year and go on holiday together next year. I think it works because they 'get' AT.

My advice to other AT parents is to get involved in the disability community. It can be trial and error, but Rose has gained confidence in speaking to people and has found hobbies that she loves. AT is rubbish but our life has definitely been less challenging since making our wonderful friends."

> **"When I think about the AT Society, I feel emotional. They were there, right at the start of our AT journey. They have helped with renovating our house, schooling and will listen to the endless calls. They show sympathy, compassion and advise when I feel at my worst. I think they are amazing."**

Emily's Housing Success Story

Emily's old residential home was no longer meeting her needs. COVID related delays and a battle to get a funding agreement meant Emily had to wait patiently for several years to move to her preferred residential setting. The great news is she finally moved into The Halcon Centre in May, and now has a lovely big bedroom with access directly into the beautiful garden, plus lots of activities to join in with. It took a coordinated team effort to get everything in place. Emily, her Mum, brother, social worker, and the AT Society worked together to push this move forward – a bit like pushing a juggernaut with one hand tied behind your back!

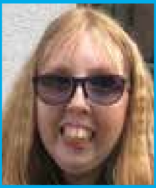
Emily told us she's still getting used to living in her new home, but so far, she's really enjoying life there. She said The Halcon Centre's ethos is that life should be fun, and she's already booked on a short break to Torquay next month. We think her smile says it all!

In Memory

We pass on all our love and thoughts to those families who are grieving. We will miss all our young friends very much.

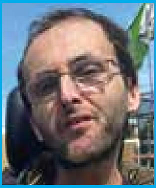
Tina

Tina was a fun and loving person who was always on the go. Whether Tina was snuggling up to a furry friend like Tilley, drinking in the Freshfields bar or singing along with the choir, she always did it with a smile on her face.



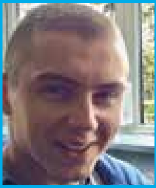
Mollie

Mollie loved her animals and would always be willing to help out with feeding the goats, she loved them. Mollie was never worried by the bitter wind and was always smiley and positive.



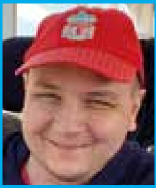
Tom

Tom had a wicked sense of humour and could get away with almost anything. He attended our Activity Weekends and was such a character, everyone knew when Tom was there!



Robert

Robert, despite all his problems, was always happy, positive, caring and a very calming guy to have around. His mum commented, "Life is never going to be the same, but we all have the most amazing memories of Rob to hold on to."



Charlie

Charlie lived and breathed Liverpool FC! He was able to make some amazing memories with his family, one of which was witnessing LFC bring home the FA Cup, miracles do happen. Whether it was playing wheelchair football, watching football on TV, or running his Fantasy Football League, Charlie always had a positive outlook!

Bereavement and grief

Sadly, we all experience bereavement and grief at some point in our lives and it can affect us in different ways. The loss of a loved one is both devastating and life-changing for those left behind, with no right or wrong way to cope.

Talking about our grief or loss can be helpful but is not for everyone. Some of us can speak with close friends and family about how we are feeling, but others find this difficult. Sometimes speaking to a professional outside our family and friends' network, can help us to work through our thoughts and feelings and enable us to find ways to cope in day-to-day life.

There is no easy answer and grief is something that we never 'get over'. But in time, maybe we can learn to 'live with it' in a way that we can still function, whilst holding onto wonderful memories of our loved ones, to keep us going during our difficult days.

The AT Society can offer bereavement counselling for those families affected by AT. We would source a qualified bereavement counsellor near where you live and arrange an introductory session to see if you feel it would be beneficial.

If you are interested in this please contact the Support Team on 01582 760733 or email kay@atsociety.org.uk or anne@atsociety.org.uk. Please do also contact us if you just want to talk things through. Be assured that any correspondence is confidential.

Here is a list of charities who specialise in bereavement and grief and have resources that may help:

childbereavementuk.org
Child Bereavement UK help children, parents, and families when a child is grieving or when a child dies.

childdeathhelpline.org.uk
The Child Death Helpline is run by bereaved parents. They can support parents who have lost a child of any age and however long ago. They also support grandparents, siblings, and extended family.

cruse.org.uk
Cruse support anyone who has suffered a bereavement of any kind, in any situation.

Organ Donation

Although this can be a difficult subject to talk about, some people wish to donate their organs when they die, and some want to donate organs or tissue samples to AT Research.

If this is something you would like to discuss further, please do contact us and we would be happy to talk it through with you.

kay@atsociety.org.uk

Fundraising stories

50 Marathons for Lola

An idea formulated by two friends after one too many birthday drinks evolved into one of the most impressive fundraising challenges we have ever seen!

Martin ‘Marv’ Hine and his friend Ian Corns, set themselves the goal of running 50 marathons each in the year before Martin’s 50th birthday which was this July.

The two have been friends since their days together in the RAF, and in honour of their former colleague’s daughter, 13-year-old Lola Bloomer, they raised a massive £1,932 for the AT Society.

Ian said “At my 49th birthday this idea sprang out after a couple of drinks”.

“Instead of just forgetting about it the next day, we just got on with it” said Martin.

“We both enjoy running and we’ve done a couple of marathons here and there but nothing like this.”

We would like to say a huge thank you and congratulations to Ian and Martin for completing this epic challenge. They completed the last marathon together and did six laps around their village, each in a different fancy dress costume!

They said: “The courage and determination shown by Lola and other children with AT, every single day of their lives, puts our 12 month challenge into perspective. By the time we are 50, our struggle will be over, theirs won’t.”

If you would like to create a crazy fundraising challenge, we’re here to support you – please email **sally@atsociety.org.uk** with your ideas.

> **"We are delighted to have been involved in this great cause. Working with Pizza Hut, a fellow local business, we were able to save a number of carbon emissions going to landfill, by repurposing and reusing their furniture for Sky's new studio in Elstree. This is a great example of how local business can work together today, for a better tomorrow."**
>
> **Blaze, Furniture Consultant**
> JPA Workspaces

Pizza Hut Furniture Sale

We were thrilled to receive £16,000 from Pizza Hut Europe who used JPA Workspaces to repurpose and sell their old office furniture to Sky and then donated the proceeds of £16,000 to their chosen charity – the AT Society.

May's Mega 100Km Challenge!

May Yung-Tiet is a Neurology Registrar studying for her PhD in ataxia-telangiectasia. As if that doesn't keep her busy enough, she is also a super-star fundraiser! Having run the Cambridge Marathon for the AT Society in 2020, this year May took on the Thames Challenge for us in September where she ran a staggering 100km and raised a wonderful £1,390.

On completing the challenge, May told us,"It was so hard but ordinary people do amazing things and this is nothing compared to what people with AT go through. I hope I've managed to raise awareness about AT at the very least".

Young Adult's Greek Getaway!

In May this year a group of young adults with AT and their carers had a wonderful break at the Courti Estate located on the Corfu Riviera. The holiday was organised by Elizabeth Vlassi and included an evening fundraiser in this beautiful setting which raised over £2,500 for the AT Society.

After the trip Elizabeth commented: "It was absolutely amazing to meet everyone, we learnt so much from each other – we love them all and have made friends for life! I have never seen Andreas so confident and animated, and this was my reason for organising all this!"

The group had a fantastic time in this magical location, and we are very thankful to them for fundraising for us at the same time!

"It was such a wonderful evening. The room was full of love and support and was enjoyed by everyone. Looking forward to organising the next gala for 2024!"

Kelly's Dinner Dance

We were so grateful to Kelly Saponaro who gave up her time to organise a very successful dinner dance in Harpenden this May. An elegant drinks reception was followed by a delicious three course dinner and all the guests were dressed in their finery! Everyone had a wonderful evening and an amazing sum of £8,548 was raised for the AT Society. Many thanks to Kelly and everyone involved.

Team Green!

In March, the Pemberton-Powell family once again coordinated a team of enthusiastic Incredible Hulks and Mini-Hulks to run the Hastings Half Marathon.

Sara and Joe Pemberton-Powell commented "Since diagnosis, we have continued to fundraise for our son, Winston. At the half marathon in 2019, we grew our team from 9 to over 60 Hulks (Win's favourite superhero) who ran to raise money for the AT Society. This charity took us all under its wing from the moment of our son's diagnosis – not just for the daunting practical tasks like navigating the welfare system and fighting for support and equipment in education, but, even more importantly at that time, they allowed us the space to talk about our feelings. It felt like they helped us become part of a bigger family – one who understood exactly what we were going through. Five years on, I am thankful every day that we have them."

This year the team of Hulks continued to grow, and we would like to say a massive thank you to the team and everyone who joined them to make the day such a huge success. They have raised more than £10,000, this year alone, for the AT Society and we have been overwhelmed by their wonderful support. They are all Hulk heroes!

Tell us you're fundraising

We'd love to hear your fundraising ideas and stories, tag us **@ATSociety** and let us know your plans by emailing **sally@atsociety.org.uk** and we can support you on your next fundraising journey.

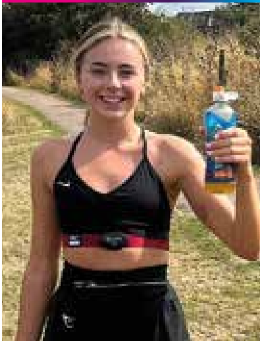
Fantastic Fundraisers

A huge thank you to all our amazing supporters who have raised from £50 to £5,000, and collectively raised a staggering £58,866 to date this year.

Including those of you who kindly donated on Facebook Fundraisers.

Here is just a selection of some of our fantastic fundraisers.

Alice bravely took on the Bedford Autodrome Half Marathon



Christian smashed it at the London Marathon

Jon triumphed at the London and New York Marathons

The Concordia Choir have sung their hearts out to raise money

Mike asked for 70th birthday gifts to be donated

Sally donated the money raised from her Yurt Yoga classes

Sinead and Orla held a summer fete amongst other fundraising

Kayt, Ali and Tina trekked up Snowdon

Adam, Alan, Alicja, Gary, Jackie, Julia, Laura, Michael and Tommy took part in the ASICS London 10k

Andrew, David, Jenna and Rose organized the wonderful 'Rose Garden' festival

A massive thanks to everyone else too!

Andre set up a JustGiving page in memory of Mollie

Caroline walked 100 miles 'in their shoes' for all those affected by AT

Ed raised money at his gig at the Stag in Hastings

Emett hosted a hilarious comedy night

Jilly hosted a Jubilee cake decoration event

Marmalade Cat Nursery took part in a sponsored wheelie

Mary kindly donated the money from 'Mary's Spinning' spin classes

Mike completed the Trans-Pennine Trail

NG Dance Collective hosted dance parties to raise money

Owen coordinated a fundraising fantasy football league in memory of his brother Charlie

Sara organized a magical dinner dance

The Little Squirts Swimming Club hosted a brilliant summer BBQ to raise money

Tea and 'the tinies' bravely climbed Cader Idris and Pen Y Fan

Zara swam like a fish in a swimming challenge

Jackie smashed it at the swimathon in Hastings

Alex completed a '24-hour slog' running, walking, cycling and rowing

Emma has been swimming, walking and cycling her way to 210 miles

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

Sensational Skydivers

An incredible 19 brave fundraisers took to the skies this year and raised a whopping £26,610 between them. It takes a huge amount of courage to jump out of a plane and we were humbled to see so many of you take the leap!

If you've ever fancied skydiving join the A-Team in 2023 for a day of fun, laughter and an amazing adrenaline rush!

David raised £3,883

Tyrone raised £520 and Beth raised £445

Alec and Harry raised £800

Mia raised £535 and Ebony raised £715

Gemma raised £1,045

Arjun, Jilly and Vimal raised £1,666

Christie raised £10,066

Thanks also to

Simon, Stacy, Gilly and Tod who raised £1,600

and still to jump...

Gavin raised £730
Peter raised £410
Owain raised £220
Daisy raised £425

James who raised £487 dived with Gianluca (Plowman Craven)

Ashley, Nick, Jocelyn and Gianluca all from Plowman Craven raised £1,983

Nikki raised £1,080

Over thirty years of life-changing support

Help it continue with a gift in your Will

Every year the AT Society supports around 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 increasing pressures faced by them, from escalating costs of heating their homes to continued cuts in local authority and NHS funding, it becomes even 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. 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 us nearer towards finding a cure.

Much of what we do today has been made possible by a very generous legacy from an AT family. Without it, we wouldn't have been able to develop our support and mental health work in the way that we have.

Why do I need a Will?

Your Will is the safest way to protect those closest to you and lets you choose what happens to your money and possessions. It also makes it easier and less stressful for your family while they try to sort out your affairs after you're gone. If you don't write a Will, the law decides how your estate is passed on – and this might not be as you had wished.

How can I start legacy giving?

We know Will writing can seem confusing and daunting. We recommend using a professional solicitor to write or update your Will, as this ensures everything is valid. You may have your own that you want to use, or you can contact The Law Society to find a qualified solicitor.

No matter the size, a gift made in your Will can help families with AT. Even 1% of an estate can make a very big difference to the families we support.

If you would like to leave a gift in your Will to the AT Society, all you need is the charity address and registered charity number:

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

Registered charity number:
1105528

Please contact Susie on
01582 760733 or email
susie@atsociety.org.uk

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, last year 40p went directly on supporting children, young people and families affected by AT; 36p on undertaking vital research to improve treatments and find a cure; 6p on governance, and the remaining 18p on fundraising. For every £1 we spend on fundraising we generate nearly £4 in additional funds.

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

Join us, there's loads going on!

YOU HAVE TO BE IN IT TO WIN IT!

SPARKLE DRAW VIRTUAL RAFFLE 2022

TICKETS £1 EACH FROM:

www.atsociety.org.uk/product/raffle

Draw takes place 15th December

Prizes include:

£500 Cash!

An Away Resorts 2023 break of any duration worth up to £500* in value

Bespoke designed necklace in white gold and diamond

Dinner, Bed & Breakfast for 2 at the Radisson Blu

An overnight stay and a hamper at the Holiday Inn

Jilly's Cupcake House voucher

+ more fabulous prizes!

Buy your raffle tickets now!

*T&C's apply (see website)

Support the AT Society on Christmas Jumper Day!

Do your bit in a festive knit!

Donate £2 each to join in the fun

on

Friday 9th December

(or a day of your choice!)

www.atsociety.org.uk/donate/

CHRISTMAS JUMPER DAY!

Ask your friends and colleagues to wear their favourite Christmas jumpers on Friday 9th December and make a donation.

SCAN TO DONATE NOW!

Simply scan the QR code to donate.

AMAZON SMILE

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

amazonsmile
You shop. Amazon gives.

Virtual Christmas Bingo Evening

Back by popular demand!

For more info please contact **emma@atsociety.org.uk**

AT society
awareness research care

10 cards
with envelopes
for only
£5

Christmas card order form 2022

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

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

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

Please send to:

Name

Address

Postcode

Contact Tel/Mobile Number

Number of packs required

Postage & Packing:
1–2 packs = £2.15
3–8 packs = £3.85
9–16 packs = £6.95

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