AT Society chAT





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

AT Society
Unit 54
Thrales End Business Centre
Thrales End Lane
Harpenden
Hertfordshire
AL 5 3NS

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

Disclaimer

The opinions expressed in the AT Society chAT are those of the individual authors and not ncessarily 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 ten hours of research in an AT laboratory

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.

Use this QR code to make an online donation





Dear friend

Welcome to our first edition of chAT, our new AT newsletter, bringing you the latest news, stories and events from the wonderful AT community.

In the newsletter you'll read about the recent AT Family Weekend (the first in four years!), important updates on the progression of clinical trials, stories about some of the children we have helped and information on specialist AT clinics.

Once again, we have been incredibly humbled by the lengths that our AT community has gone to, to support the charity this year. You can read about some of the recent highlights on pages 16 - 22.

We hope that some of this will inspire you to get involved again. In the lead up to the festive season, there are some easy ways to do this: you can take part in our Winter Raffle; buy some Christmas cards; or ask your local school or your work place to take part in our Christmas Jumper Day (see page 23). You can also volunteer your time, put us in your Will, come to one of our events, and you can donate. www.atsociety.org.uk/donate There are always lots of ways you can support the AT community!



Susie Norbury - Director of Fundraising & Operations

If you would like to discuss any of these options, please don't hesitate to get in touch – our contact details are on the opposite page, and we always love to hear from you.

I hope you enjoy reading the newsletter and, from us all, thank you for your fantastic support.

Susie

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







@ATSociety

atsociety

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Society News

AT Society on BBC TV



Louise Minchin on location with Susie and Kav

We were so excited when we heard that the AT Society had been selected as the charity for the BBC Lifeline Appeal in January. This was a fantastic opportunity for us to raise awareness for AT as well as vital funds towards family support services and our research. Louise Minchin (television presenter, journalist and former news presenter) kindly agreed to present the appeal for us.

The ten minute programme, which aired on BBC One on 29th January, followed three families who talked about their experience of living with AT and how the AT Society has supported them on their journeys, and Louise Minchin, the presenter, appealed for donations to support its activities.

The appeal raised approximately £35,000 as well as raising awareness around the condition and how it affects the lives of people living with it. You can still watch the video by scanning the QR code below.













The sky's the limit!

In September, a wonderful team of skydivers took to the cloudless skies in support of the AT Society. Huge thanks to all the individuals, Emily, Sam, Christian, Michael, Todd, Ying, Flavius, Caitriona and Sean, who joined the A-Team to raise in excess £9,500. Thanks also to Plowman Craven, Optimus Access Limited, Insmed and Travel Four Seasons.

Please contact sally@atsociety.org.uk if you are interested in our 2024 skydive on 7th September.



Break a leg!



Writer Nick Payne with actors and Director (right to left)

We were given the opportunity by The Abbey
Theatre, St Albans (who are a charity themselves) to
host the first night of the production of a play called
Constellations by Nick Payne. We discovered that
writer Nick, pictured left, grew up very close to our
office in Harpenden so we invited him along!

The evening was a great way to raise awareness about the AT Society and the play was really thought provoking. The evening raised just over £900 for the AT Society.

Wonderful volunteers

We have many volunteers; some who live locally to our offices and help with leaflet distribution, give talks at events, send out newsletters, prepare the folders for the Family Weekend and even give out ice lollies and marshall at events. We also have volunteers who do not live close to Harpenden but can help in other ways such as sourcing raffle prizes, taking collection pots and fundraising in aid of the AT Society. We are grateful to them all!

Volunteering at the AT Society was really fulfilling as I knew the work I was doing was having a positive impact on the lives of people with AT. There are a wide range of ways to help; from delivering fundraising leaflets to invaluable computer research data input and helping at events.

Stanley, Work Placement Student, St George's School, Harpenden





Lovely volunteers helping at the St Albans Half Marathon





Can YOU help by volunteering? Get in touch with:

sally@atsociety.org.uk

We would love to have you on the team!

Fantastic Family Weekend!



get to talk and hang out with On a cold weekend in October, 43 families got together in the East Midlands for the AT Society Family Weekend! This was very special as it was the first family event in 4 years.

Families with AT children, as well as adults who have AT and their extended family and friends, came along to enjoy a great weekend together. The main focus of these weekends is for the families to have a chance to meet with each other in a relaxed atmosphere, to chat and share ideas. This is a great opportunity to meet new people and form lasting friendships.

Families came from all over the UK and Ireland travelling many miles to be there.

The weekend kicked off with a welcome get together and 'street food' with stalls from Mexico, America and some mushy peas from the UK! Families were able to mingle and chat to each other and the

children could make new friends.

leave me (and my family) feeling less alone because we

others in the same boat

On the Saturday we had some talks about clinical trials. While these were going on we sent the children out on an exciting trip to 'Space' - well the Space Centre in Leicester! They had a great day and 100% of the children said it made them 'Happy'!

We introduced a new mascot to our team at the weekend, the competition to name him was won by Leah who suggested Boo Boo Bear! He put a smile on everyone's face!

We had activities for the adults with AT during the day on the Saturday. These included 'Virtual Reality' (where we had people experiencing all sorts of things, such as diving in the coral reefs and flying!) cake decorating for Halloween, sitting on a Harley Davidson bike and spring bulb planting were also enjoyed, as well as Boccia. This is a Paralympic sport where a ball is thrown onto the court with the aim of getting closest to a 'jack' ball. It is designed specifically for people with a disability affecting locomotor function, and is played sitting down. It was a serious competition and enjoyed by adults with AT as well as parents.

Relaxation was needed after all these activities and people could enjoy Yoga and a 'sound bath' (no getting wet, you are immersed in sound!). The weekend was rounded off with a Banquet Dinner and disco for all. Everyone left after breakfast on the Sunday exhausted but happy!

Science and Clinical Trials Updates

The 3-hour session took place for parents and carers to hear from AT experts about the AT trials and projects they are working on. It was superbly hosted by Professor Rob Dineen, Chair of the AT Society Scientific Advisory Board, and the speakers were all AT scientists from companies and institutions from the UK, America, Australia, and Italy – a useful reminder of the excellent international connections that exist within the AT community – and all demonstrated that there is hope on the horizon for AT individuals and families.



Scientific Update from the Family Weekend

New trial in 2024, for children:

At the AT Family Weekend, Guenter Janhofer, CMO of Quince Therapeutics, formerly EryDel, spoke about their work using EryDex for the treatment of AT and about the progression of their clinical program.

Erydel previously completed the largest global study of AT patients and the results have been positive in slowing the progression of AT. They now need to complete a 6-month international clinical trial, to substantiate their findings, before applying to the regulatory authorities in the US, Europe, and the UK, for market authorisation. It is anticipated that this final study will start to recruit children in April 2024 when they plan to enroll 86 children ranging from 6-9 years, and up to 20 additional children aged 10 or over. We can expect that around 20 will come from the UK to receive the monthly treatment in one of two UK hospital sites. The moment Quince is ready to start this trial, the AT Society will work with Prof. Whitehouse and Prof. Payle from Nottingham University Hospitals, to contact all families in the UK with eligible children.

Further information can be seen at www.atsociety.org.uk/research/clinical -trials. If you have any questions about this, please do contact us on 01582 760733.



Insmed's Synthetic Rescue Approach:

We heard from Tom Heightman, Senior

Vice President of Research at Insmed at the weekend, about their development of a new synthetic rescue medicine for AT. Synthetic rescue is a novel way of treating genetic diseases which aims to restore the function of geneticallyimpaired cells by blocking the activity of a different gene (a so-called "modifier gene"). Modifier genes have been shown to naturally protect people from the symptoms of a range of other genetic diseases. Insmed is developing an antisense oligonucleotide (ASO) approach to block the activity of the target modifier gene.

We will share more information on this when we can.



Gene therapy for specific mutations:

Dr Anke Hensiek, Assistant Professor at the University of Cambridge and Consultant Neurologist, spoke to us at our Family Weekend about 'Designing gene therapy trials in AT'. Gene therapy is the use of genetic material to treat or prevent disease. ASO is a form of gene therapy and has been used to treat a child in the US with AT without serious side effects. for the last three years. The use of it depends on the specific AT mutation, and the genetic screening of individuals with AT in the UK is needed to find out who would be amenable to this (it is estimated that approximately 10% of screened patients would be suitable). Anke's study 'Trial REadiness in Ataxia Telangiectasia' with Dr Rita Horvath at Cambridge University is working on whether this will be a plausible route for treatment.

New trial for all ages, in discussion:

Professor David Coman spoke to us, live from Australia, about his Triheptanoin study to treat the mitochondrial dysfunction in AT. The one-year study, involving daily oil-based food supplements, found positive outcomes in relation to speech and fine motor skills. Improved energy levels were also reported for some. The Australian group are keen to progress an international Phase III clinical trial to take the findings forward and we are in contact with them about this.

Ongoing trial for 18 yrs+, awaiting news of extension to under 18's:

Intrabio have progressed trials using IB1001, their lead compound, which is a derivative of Acetyl-DL-Leucine, to improve symptoms, functioning, and quality of life. Currently, there is a multicentre Phase IIb clinical trial (IB 1001-203) at trial sites in the US. UK and Europe ongoing. For the UK, only patients aged 18 years and older can participate and enrolment has ended. However, based on recent positive findings there are discussions about the possibility of developing a paediatric site in the UK and we hope to communicate more with you very soon about this.

MRI Study:

Professor Rob Dineen, Chair of the AT Society SAB, and his team have been looking into whether an MRI scan of the whole body, together with a blood test, is a good way to find hidden cancers in children and young people with AT. He's also hoping to start a study in 2024 using MRI in babies and toddlers diagnosed with AT following newborn screening, to look at the earliest stages of brain changes in AT. Please contact Rob if you'd like to find out more: Rob.Dineen@nottingham.ac.uk

To look out for:

The common food supplement, Nicotinamide Riboside, affects mitochondrial dysfunction with no known side effects, and one AT trial in the Netherlands has had encouraging results, independent of age and the type of AT. A Norwegian group have also conducted a trial on this with positive findings. There is a plan by the Dutch group to progress a Phase II trial, but this is not yet underway.

Still under discussion:

Omaveloxolone, which is used to treat Friedrichs Ataxia has been discussed for use for AT, and Cerebellar tCDS, a trans cranial current stimulation, used for other ataxias, has also been discussed for use for AT.

Yoga & mindfulness with AT:

A collaboration of people who have a special interest in AT, have coproduced an online programme of yoga, breathing and optional mindfulness exercises for children with AT. This offers an alternative to conventional physiotherapy exercise and can be done with parents, friends, or siblings at home.

If anyone is interested in finding out more, please contact Dr Lisa Bunn at Plymouth University: lisa.bunn@plymouth.ac.uk







VR study to help AT:

Nottingham Trent University's Medical Engineering Design Research Group are investigating the use of Virtual Reality to design and assess a bespoke interactive and immersive system that could provide tangible benefits for paediatric AT patients for use within the home or clinic.

For anyone interested in being part of the study, please contact Priten Chauhan, Research Assistant, at priten.chauhan@ntu.ac.uk



Clinic Update

The specialist AT clinics take place regularly in Nottingham for children, and in Cambridge for adults, and are now booked until the beginning of January 2024. We continue to meet with families twice a month when they attend the AT paediatric clinic. We meet at the Holiday Inn with psychotherapist Jane Flint, the day before the child's clinic appointment, and use the time to offer therapeutic support, information, and advice. For those attending the adult clinic, we regularly communicate with Natasha Everett at the clinic, and offer support for individuals with AT and their families with transport arrangements and follow up calls as required.

For those attending their first child or adult clinic, watch our videos to learn what to expect



REMINDER!!

to everyone attending the AT clinics:

Please ensure you complete and take with you any forms prior to the clinic appointments (e.g. diet sheets). This information helps the team better understand everyone's needs and offer individualised advice.

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

Clinic attendee



Gracie's Animal Therapy



We provided a support grant earlier this year so Gracie could start animal therapy. We have loved hearing about her journey and how beneficial she has found being with animals. At the therapy centre Gracie was able to gain qualifications in horse care as well as build some lovely relationships with the other students attending the centre.

Her family are so proud of her and everything she has achieved.

Funding therapy of all different types is one of the many ways the AT Society has helped support families with AT.

"Gracie has been a wonderful student and has thoroughly engaged throughout every session.

She has grown in confidence and has become popular with everyone who meets her.

She has completed and passed her RDA levels 1-3 and is working on grade 4 this term."

Trauma and Mental Health Practitioner/Mentor







Family Fun for Ferne



Like many youngsters we meet, Ferne was first diagnosed with cerebral palsy when she was 3 years old. It was only when her parents found out Ferne had problems creating antibodies that further investigations and genetic testing were carried out. The genetic test results arrived in May 2022 and of course Ferne's parents were not expecting a diagnosis of AT. To say they were in shock is an understatement. Thankfully, the family quickly reached out to the AT Society support team and since then we have been able to offer a wide range of support to the whole family.

Ferne is always described as being kind, strong, brave, gentle, loving, and just simply amazing!

"The AT society has had a huge impact over the last year for us as a family. As well as being a support system and a fountain of knowledge, they've organised medical trips and even helped us with a grant towards our holiday! After a tough year following Ferne's initial diagnosis, this holiday was much needed time away. It allowed us to make precious memories as a family. The girls have had some fantastic bonding time and it's something we will talk about for years to come."

Anne, Ferne's Mother

Ferne's father, Sam, did the 2023 skydive, raising over £1500



Support with Schools

George's mum, Cheryl, contacted the AT Society support team this year as George was due to transition to secondary school. The family wanted a placement at a special needs school for children with a physical disability, to meet all of George's needs. However the local authority, although agreeing George needed a special school placement, named a completely inappropriate school on his Education and Health Care Plan, (EHCP).

We appealed against the decision to the educational tribunal on behalf of the family sending many supporting letters, reports and evidence and representing the family through the proceedings.

Eventually at the end of July the Local Authority contacted Cheryl to say they had conceded and would like to offer George a place at the family's preferred school. This was such a relief for everyone and George could finally look forward to going to his new school.



secondary school! George is really enjoying his new school

(as you can see in his photo!). We are continuing to support him in this setting by offering training to the team so they can learn more about AT and how best to support George, and by joining the annual review to work on his EHCP so we can ensure it is meeting all of his needs.

"The school system is so challenging to navigate, without the AT Society advocacy support it would have been impossible as I would not have had the emotional resilience to fight and appeal." George's Mum, Cheryl

The whole training was extremely beneficial for staff they were provided with a clear insight into AT and information about how best to support our student with the condition. Thank you!

A Head Teacher

So far this year, we've provided training for 26 schools and attended 53 meetings. Training covers information about AT, advice on nutrition, disability equipment fatigue management, and psychological support.

100% of participants said the training was very useful and that their knowledge of AT had improved. 90% said they felt confident that their working practices will improve.

5 Minutes with Anne Murray

Being a young carer as a teenager heavily influenced my career pathway. I first qualified as a registered learning disability and community nurse and worked in the NHS as a nurse manager for 11 years. After moving to the USA, I was lucky enough to study social communication, sensory integration, and positive behaviour support with some of the world leading experts of that time.

We moved around a lot in the USA, so I had numerous jobs including therapeutic recreation supervisor and 1:1 autism therapist. On our return to the UK, I studied occupational therapy at Brunel University.

Before joining the AT Society, we lived in Southeast Asia for almost 6 years and that opportunity led to my increased interest in equality, diversity, and inclusion. I draw on all these life experiences in my role at the AT Society, and hopefully add something positive to this amazing charity!

My OT career increased my passion about the importance of creating supportive environments to enhance quality of life and promote wellbeing.

Find out about advocacy and contact Anne for advice

Anne Murray - Advocacy & Support Manager

SCAN

I believe the advocacy and support service is an important part of the AT Society. The service provides practical, emotional, and financial support to anyone affected by AT in the UK. We also frequently offer advice to overseas families and professionals. Our input covers a wide range of topics such as education, benefits, housing, social care, equipment, community activities etc. Kay, Emma, and I also remain determined to continue to offer home visits to newly diagnosed families. Feedback from families tell us this personalised support is hugely appreciated. We also offer AT training for professionals, fund counselling support and advocate for families to ensure they have access to the support they need.

Fundraising Stories

Ride, Paddle, Ride -London to Paris

Amazing fundraiser alert!:

In September, David, whose son has AT, and his two friends Shaun and Howard, took on an EPIC fundraising challenge. David, who is one of our extremely supportive Trustees who gives up so much of his time to help steer the AT Society 'ship', successfully steered his own kayak all the way across the channel - to raise money and awareness for the AT Society. We were quite blown away by his support!

This fab team embarked on a journey over three days to Paris.

We are so grateful to them for taking on this crazy challenge and we all loved following their progress along the way.

The team raised a staggering £11,000 for the AT Society and will, no doubt, have raised awareness of the condition along the way.

Day 1: Cycle the 85 miles to Day 2: Kayak across the English Channel from Dover to Calais. Day 3: to Day 5: Cycle the circa 200 miles from Calais to Paris.







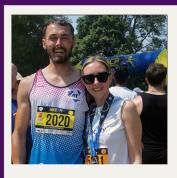
St Albans Half Marathon

We were delighted to be selected as the Charity of the Year for the St Albans Half Marathon in June. Huge thanks to everyone who took part in the event and those who volunteered on the day.

Kelly, whose daughter has AT, joined the walking half marathon with her friends, and her brother Charlie ran the half marathon. Rose, who has AT, and her friend Polly took part in the family Fun Run joined by mum Jenna, sister Layla and Polly's mum Zoe, while Rose's Dad, David, ran the half marathon course. Jilly, who also has AT, took on the 1.5 mile Fun Run with her Dad. Robert Johnson, from Insmed Innovation UK, with whom we have been working collaboratively on research, also ran for us on the day.

It was a beautiful, sunny and very hot day and loads of fun was had by runners and volunteers alike. The event was a huge fundraising success raising £9000 and also helped to raise awareness in the local area.













Rachel Writes a Magical Children's Book

We're so fortunate that you all do so many wonderful, fundraising activities for the charity. You give up your time to jump out of planes, run marathons, climb mountains, you organise dinner parties, your companies sponsor golf days, you bake delicious cakes, and you generously donate in all sorts of ways – financial donations, donating your time, and donating prizes and gifts. All of which is truly fantastic and allows the charity to keep going. So thank you to you all for everything you've done this year and in previous years – it really makes a difference.

In recognition of this, we want to introduce an award. There are so many excellent contenders, and so the fine tuning of the criteria is still work in progress. However, there is one very special and kind young lady who we think has been remarkable, and fully deserves a mention.





Rachel Ferguson comes from true fundraising stock - her family, friends and contacts are constantly organising events to raise money for the AT Society. Rachel has worked incredibly hard in the face of significant challenges to fulfil her dream of becoming a published author! She has written a story, 'Magic Meg Goes to School', has had it published and it is now selling on amazon, the profits of which are donated to the AT Society. We all know this won't have been easy to do and we think it's a pretty amazing achievement.

So we're delighted that our very first, and well deserved, AT Society Special Achievement Award goes to Rachel Ferguson.

After a long but determined battle, Rachel sadly died shortly after receiving her award. She was so proud of this achievement, as are we and her family and friends.

Fantastic Fundraisers

A huge thank you to all our amazing supporters who have collectively raised a staggering £62,962 to date this year.

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



Juan, Octavio and Manuel took part in the Great North Run in support of the AT Society raising £1748



Sarah ran the Royal Parks Half Marathon raising almost £1500



Mother and Son, Emma and Jack, both ran the Brighton 10K representing the Hastings Hulks Team and raising £425



Shelley, who did a bungee jump in memory of her sister Nicole who had AT, raised almost £500



Sarah and Timo sold nearly 500 raffle tickets at their band night and raised around £600



Emma, Simon, Robert and Robert all took part in the Endure 24 raising a massive £1830 in the process



The team from Bilton Grange raised over £2500 completing the Three Peaks Challenge



Orla added to her already amazing fundraising total at Saint Mary's Presbytery's Summer Fair which raised a fabulous £111.50



The fantastic Hulks team ran the Hastings Half Marathon and raised £838. Huge thanks to everyone involved with this over the years



Annette and Beverley, who run the Concordia Ladies Choir held a wonderful art exhibition and raised £400



Rachel who held an auction on Ebay, selling her amazing collection of Sylvanian Families, raised £700



Francesca, Rhiannon, Rachel, Ellie May and Rachel, hosted a womens day brunch and raffle in aid of the AT Society, raising over £2700



Emma Roe who raised a fabulous £332 at a charity cake sale at her work adding to her already superb fundraising total



The Harpenden Lions Club hosted a fab barn dance donating all funds raised to the AT Society!



Cripps House Rowing Challenge - 50 boys rowed a total of 950km with 25 continuing through the night! They raised a massive £2500



The Concordia Ladies Choir in Bridgnorth continued to add to their impressive fundraising total and have more events planned in December



Brooke dyed her hair some crazy colours in her 'hair-raising fundraiser' and raised £270.

Father Stefan ran the London Landmarks Half Marathon raising £200



Friends Helen, Charlotte and Elaine raised £378 by walking as many steps as they could in July. They managed just short of a million steps!



Mike's singalong in Harpenden raised an impressive £2858.31



Katrina hosted a Quiz night evening - lots of fun was had and she raised £350



Suzanne set herself the challenge to walk/run 250 miles in May raising £1100

If you have any fundraising ideas (big or small), we'd love to hear from you!

Get in touch:
sally@atsociety.org.uk

Golf Day



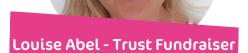
In April we were excited to hold the AT Society's first ever golf day. We had wonderful support, advice and help organising the event from golf-loving AT family members. The day was sunny but cold and saw 72 golfers in teams of 4 from local businesses, supporters and AT families and friends, set off around the fabulous Harpenden golf course. We fundraised an amazing sum of approximately £7500 from the day.

The golf day in 2024 will be even bigger and better and will be held on Thursday 18th April at Luton Hoo.

Could you help with corporate contacts?

If you or a family member works for a fantastic corporation or retailer, we'd LOVE to know! Why? Because having an inside connection at these companies can turbocharge our efforts to secure essential charity funding through corporate trust applications.

Your name, the company's name, and contact details for your corporate contact can be our golden ticket to unlocking more resources for AT families!



Please don't wait call today (01582 760733)
or email
louise@atsociety.org.uk
and help us write the next
chapter in our AT journey!

Louise

Festive Fun



Our annual, much anticipated, Winter Raffle is back and has some great prizes including £500 CASH, Amazon vouchers and short breaks!

Buy tickets from our website and share the details with ALL your friends!

Buy raffle tickets here -



Proudly wear your Christmas jumper or top in exchange for a suggested donation of £2

Find out more about Christmas jumper day







Dates for your diary

Thursday 7 December 2023

Christmas concert 7.30pm St John's Church, Harpenden

Thursday 14 December 2023

Winter raffle to be drawn by the cast of Cinderella at the Eric Morecambe Centre, Harpenden

March 2024

Lead On (Dog walking challenge)

Thursday 18 April 2024

The AT Society Golf Day at Luton Hoo

Sunday 9 June 2024

St Albans Half - walk or run

Saturday 9 September 2024

Skydive (North London Sky Dive Centre)





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for only

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Thank you for supporting the AT Society by purchasing our 'Ho ho ho' card.

- Each pack contains 10 cards with envelopes
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- Message inside reads 'Season's Greetings'

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| Contact tel/mobile number | AT SOCIETY and return to: AT Society Unit 54 |
| Number of packs required | Thrales End Business Centre Harpenden Hertfordshire AL5 3NS |
| YES, I give the AT Society permission to communicate with me about their work and | |



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below) - we will not sell your details to third parties.

Phone



how it can be supported. I am happy to be contacted by (please tick all that apply

Text



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