

THE TSA
**VOLUNTEER
HANDBOOK**
FOR SUPERHEROES



ALL VOLUNTEERS ARE SUPERHEROES

In this Volunteer Handbook

3. Welcome

4-5. About the TSA

6. Volunteering Opportunities
Ways To Get Involved

tssa
tuberous sclerosis
association

6-7. Volunteer Charter
(What can you expect from us /
What we can expect from you)

8-11. Volunteering Information

12-14. The Essentials
(Policies & Procedures)

15. Recognition and Reward
How much you mean to us

16. Useful Information



WELCOME!

Thank you for choosing to volunteer with TSA, and for helping to reach and improve the lives of people affected by TS.

Volunteers are vital to the heart of our organisation, you can help us spread the word about the TSA and its services.

You can join us in raising funds to support continued research in pursuing a cure and better treatment for Tuberous Sclerosis, and your voice can help us promote TSC awareness and support across medical, educational, and social care groups.

We want anyone who gives their time to us feel valued, understood and proud to be part of the TSA.

This handbook is here to explain the things you need to know about volunteering with us.

We hope you find it helpful. If you'd like more detailed information on any of the subjects covered, please speak to your main TSA contact. They'll be more than happy to help you.

Thank you once again for deciding to make a difference.



Thanks

Tanya Darnton
Volunteering Manager

ABOUT THE TSA



History

Launched in 1977 with a membership of 50 families and funds of £25, the Tuberos Sclerosis Association (TSA) has grown from a round robin support letter, to a professional organization providing support to families affected by TS across the UK.

Purpose

The TSA has 3 main objectives:

- 1 To support individuals affected by TSC, together with their families or carers.
- 2 To encourage and support research into the causes and management of TSC.
- 3 To provide education and information.

OUR MISSION:

**“To provide care for today
& hope for tomorrow”**

Your TSA Contacts

Research



Alison Cooper Head of Research.
Alison is normally in the office Monday - Thursday.

 alison.cooper@tuberous-sclerosis.org
 01256 895 183

Get Involved



Emma Damian-Grint
Head of Fundraising & Communications.
Emma is in the office Monday - Friday.

 emma.damian-grint@tuberous-sclerosis.org
 0114 270 1723



Tanya Darnton Volunteer Manager
Tanya is in the office Monday - Wednesday.

 tanya.darnton@tuberous-sclerosis.org
 0238 0730 823

Fundraising



David Peake Trusts, Foundations & Major Gifts Fundraiser

 david.peake@tuberous-sclerosis.org
 01455 844456



Kathryn Harrison Fundraising Officer
Kathryn is in the office Tuesday - Friday.

 kathryn.harrison@tuberous-sclerosis.org
 0161 681 6015

Communications



Sarah Roberts Communications Officer
Sarah is in the office Monday - Thursday.

 sarah.roberts@tuberous-sclerosis.org
 07870 210308



Sophie Jenkin Information Officer
Sophie is in the office Monday - Wednesday.

 sophie.jenkin@tuberous-sclerosis.org
 020 7922 7731

Get Support

Our TSC Advisers work across the UK. Although all Advisers work part-time, we will answer your query as quickly as we are able.



Lynn Shields covers Scotland.
Lynn is normally in the office Tuesday - Friday.

 PO Box 8728, Airdrie, Scotland ML6 8WP
 lynn.shields@tuberous-sclerosis.org
 01236 608 257



Claire Kirk covers Northern Ireland
Claire is in the office Monday - Wednesday

 claire.kirk@tuberous-sclerosis.org
 07724 591 485



Kendra Rhodehouse covers Midlands, Suffolk and Hereford. Kendra is normally in the office Tuesday - Thursday.

 kendra.rhodehouse@tuberous-sclerosis.org
 01159 384 260



Christine Beal covers Yorkshire, Cumbria, Durham and Northumberland. Christine is normally in the office Monday - Wednesday.

 christine.beal@tuberous-sclerosis.org
 01924 849 937



Maureen Tossi covers South West England plus Oxfordshire, Buckinghamshire, Berkshire, Bedfordshire, Hampshire, Hertfordshire, Isle of Wight, & Essex. Maureen is normally in the office Monday - Thursday.

 maureen.tossi@tuberous-sclerosis.org
 01865 865 089



Jenny Jones covers Wales. Jenny is normally in the office Tuesday-Thursday.

 jenny.jones@tuberous-sclerosis.org
 01239 710 054



Gabby Horeka covers London & the SE. Gabby is in the office Wednesday-Friday.

 gabby.horeka@tuberous-sclerosis.org
 07592 558 970

Please note our address for postal donations or enquires is:

Tuberous Sclerosis Association. CAN Mezzanine, 32-36 Loman Street, Southwark, London, SE1 0EH

VOLUNTEERING OPPORTUNITIES

Ways to get involved

There are plenty of ways for you to get further involved in our work. Here are just a few examples of the opportunities we offer.

Regional Group Organisers

This is an opportunity to set up and manage a local support group for TSC clients, families or carers on a regular basis, which gives face to face support to those affected by or concerned about TSC. This is a pivotal role for the TSA, and will require good networking and excellent organisational skills.

Community Event Leaders Volunteers

If you would enjoy helping to organise and run TSA events or activities then this is the role for you. It will be varied, and you will need to use your motivational and communication skills.

Ambassador

Are you interested in telling "your story" and being a spokesperson for the TSA, or are you interested in media, or campaigning?. If you are interested in raising awareness and learning more about what the TSA does then this could be a great volunteering opportunity for you.

Supporter Volunteer

If you have a few hours to spare, why not offer to support the TSA team, with one-off tasks, local events, and activities, such as cheering-on runners, meeting and greeting at our annual conference, or distributing Christmas cards.

No experience is needed and you can give as much or as little time as you wish. We will let you know what is happening near you, and you can decide whether to participate or not.

Talent Pool - Volunteers

We currently need to recruit people that have an interest or expertise in the particular areas listed below.



VOLUNTEERING OPPORTUNITIES

Ways to get involved cont...



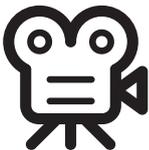
Photographers

Could you help us by being an official photographer at one of our events?



We need creative writers

Could you be the author of an inspirational news piece for our website or magazine?



Video / Film makers

Could you make a short film to explain the work of the TSA, maybe by filming volunteers, events, staff, members?

Resource volunteers

Individuals that could help by researching venues for conferences, or by finding out about organisations, or activities in your local areas that would be of interest to other members?

Click this link to go to our website to download an application form:



<http://www.tuberous-sclerosis.org/volunteers-application.html>

or if you'd like more information on any of these opportunities please contact Tanya.darnton@tuberous-sclerosis.org



VOLUNTEER CHARTER

July 2014 - Version 1

What you can expect from us...

The TSA aims to ensure that volunteers enjoy and derive satisfaction from their involvement.

Accordingly, the TSA will:

- 1 Always treat volunteers with respect and courtesy
- 2 Promote equality of opportunity and inclusiveness
- 3 Be clear about why we need a volunteer, providing role or task descriptions
- 4 Provide the volunteer with an induction to the TSA
- 5 Provide volunteers with guidance, training and support according to their role
- 6 Reimburse reasonable out of pocket expenses whilst a volunteer is engaged in approved work for us in accordance with our policy
- 7 Commit to resolving any problems or complaints
- 8 Cover you under our insurance policies while you are engaged in volunteering for us



VOLUNTEER CHARTER

What we will expect of you...

- 1 To perform your duties to the best of your ability
 - 2 Abide by the TSA's policies
 - 3 Uphold the TSA's values
 - 4 Work collaboratively with staff of the TSA abiding by agreements to undertake or deliver specific tasks or duties
- 5 Never to give statements to anyone from the media on behalf of the TSA unless permission has been granted
 - 6 Maintain strict confidentiality of the TSA
 - 7 Produce receipts for out of pocket expenses
- 8 Agree to any screening such as DBS checks that the association may request as is required
- 9 Declare any potential conflicts of interest in accordance with the TSA policy



VOLUNTEER INFORMATION

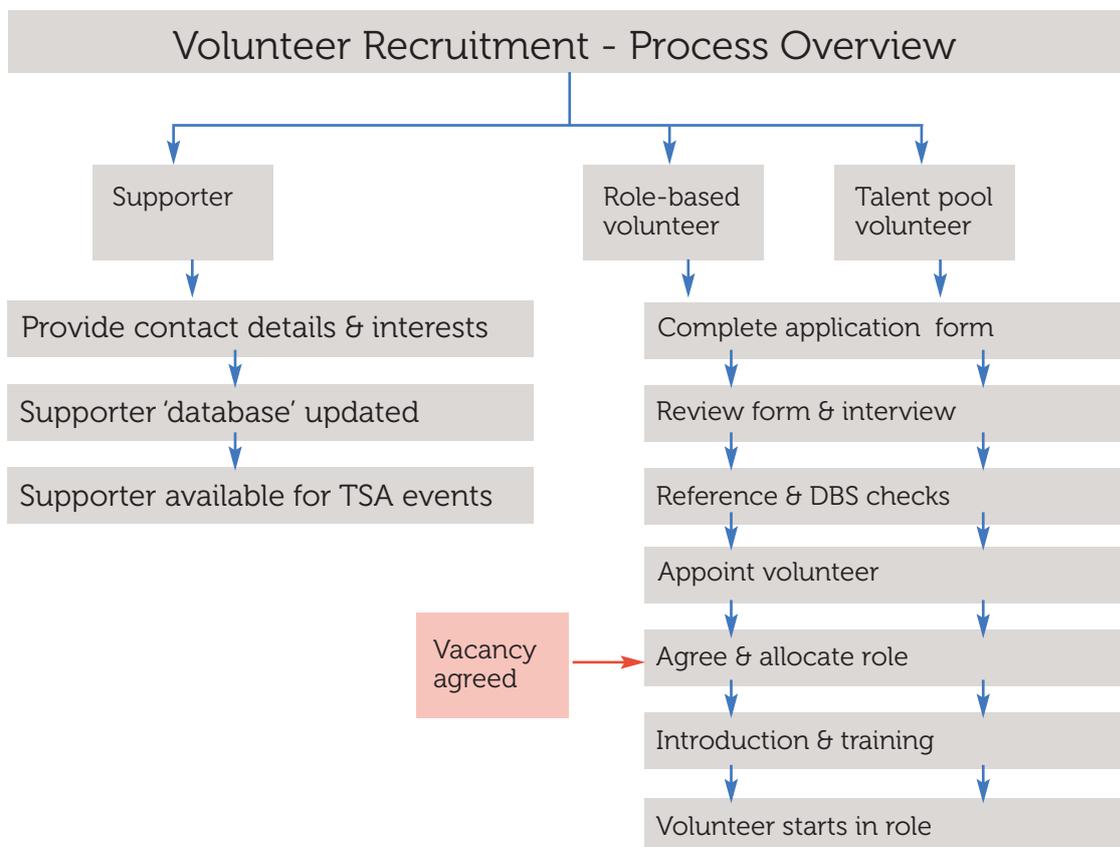
Volunteer Policy

The TSA's volunteer policy sets out our approach and commitment to volunteering and you should have received a copy as part of your welcome pack.

Recruitment

Every new volunteer will go through a recruitment process, and will be asked to complete an application form and, if needed for the role, to supply 2 references and complete DBS.

When all the paperwork is completed the Volunteer will receive a welcome pack.



VOLUNTEER INFORMATION CONT...

Volunteer role description

Each task we ask you to undertake will be agreed with you and will be defined through your volunteer role description. This outlines who will support you, what activities you will normally be engaged in and the training involved for the role.

Volunteer induction

The induction is designed to ensure that you know what is expected of you and to ensure that you are safe and effective. Our aim is to ensure that your volunteer experience is positive, productive and rewarding, and will be completed within 3 months of your starting your role.

Training

Training which is appropriate to your volunteering role is offered free of charge. Please speak to the volunteer manager for more information. Some training is essential and is a requirement for continued volunteering.

Ambassadors

All volunteers are ambassadors for TSA so please use every opportunity to promote the work of the TSA

Attendance

Volunteers are vital to our operation, and without your commitment certain activities may not take place. Please bear this in mind when planning your diary so that you can fulfil the commitment you have made.

Annual reviews

Every year you will be contacted by the volunteer manager to complete an annual review, this will be your opportunity to discuss your role or anything else to do with your volunteering.

Leaving

When you decide to stop volunteering with the TSA we hope that you will complete our exit questionnaire so that we can obtain feedback on your experience of volunteering with us.



THE ESSENTIALS

Policies & Procedures

As a volunteer, you'll need to be aware of the following policies and procedures at TSA.

Please take a few minutes to have a good read through and familiarise yourself with them.

Expenses

The TSA will reimburse volunteers for any reasonable out-of-pocket expenses. We'll only reimburse the amount that you have spent as a result of your volunteering. Tickets and receipts must be provided in order to reclaim this money. It remains the decision of the volunteer as to whether they want to claim expenses or not. The volunteer manager can help you fill out your claim form.

Motor insurance

The TSA does not provide motor insurance cover. If you hold business class motor insurance you will be automatically covered for your work on behalf of The TSA, but if your insurance is limited to social and domestic use then you will have to discuss your work as a TSA volunteer with your insurance company to ensure that you are fully covered.

You will be asked to show valid Business Class motor insurance cover or will need to sign the relevant section on the Expenses form to confirm that you have agreed your driving on TSA business with your insurers before we can reimburse mileage costs.

Accidents and incidents

All accidents and incidents must be reported to your TSA contact as soon as possible. In an emergency please use 999.



THE ESSENTIALS

Policies & Procedures cont...

Confidentiality

Volunteers must maintain confidentiality during their time with TSA. For this reason, when you complete an application form you are also signing a confidentiality declaration. This means that confidential information about people we support, volunteers, TSA employees and our work is kept private, unless sharing this information is required by law.

DBS (Disclosure, barring system)

The TSA is involved in working with or supporting children, young people and vulnerable adults in a wide variety of ways. If your role involves working with these people you will be required to undergo a DBS check as part of our policy on safeguarding. The Volunteer manager will be able to provide you with more information if it's required for your role.

Complaints, issues and concerns

The TSA is committed to ensuring that grievances are settled in a fair and consistent manner and as quickly as is practicable. If you have a problem relating to your Volunteering or you feel that you have been treated unfairly, you should first discuss the matter with your TSA contact. They are there to support you as a volunteer and it is important that such matters are resolved. The policy and guidance is available to help everyone through the process, which details the steps that can be taken and who should be involved.

Protection of children and vulnerable adults

The TSA should make certain that its volunteers and staff act in a way that ensures protection and safety of all persons it assists. There are a variety of policies and procedures to guide volunteers on these matters, including our safeguarding children and vulnerable adults policies.



THE ESSENTIALS

Policies & Procedures cont...

Health and Safety

The TSA has a responsibility and is committed to ensuring the health, safety and welfare of all volunteers. We aim to ensure that you are aware of and understand the health and safety risks associated with your role and provide you with the appropriate information, instruction, supervision and training required to enable you to work safely whilst volunteering for The TSA.

As a volunteer you must:

- Take reasonable care of yourself and others
- Follow the health and safety policy and procedures of The TSA
 - Co-operate fully with your TSA contact
- Report on any health and safety concerns you may have in good time

Equal Opportunities

The TSA is committed to providing equal opportunities for all Volunteers, regardless of individual differences such as gender, ethnic origin, disability, sexual orientation, race, marital status, gender reassignment, age, social background, religion and beliefs.

Discrimination of any kind will not be tolerated and will be dealt with in line with the TSA Equal Opportunities Policy.

We are committed to applying this policy throughout all areas of Volunteering, recruitment and selection, training and development.



RECOGNITION & REWARD

Keeping in touch

We work hard not to keep volunteers informed about the charity and all that is going on. We do this through:

- A regular newsletter for staff and volunteers (volunteers with email addresses are sent a copy electronically)
- Our website, facebook and Twitter have a wealth of up to date information
- We produce the magazine SCAN on a quarterly basis and we welcome articles from volunteers. The member of staff or person who supports you will let you know when each issue is published or you can download a PDF version it from our website at:



https://issuu.com/uktsa/docs/scan_feb_2016_output_issuu?e=9809007/30000297

Acknowledging your contribution

- A volunteers' focus group. If you are interested in being part of this and improving the experience of volunteering at TSA please contact the volunteer manager.
- An annual volunteer survey. (As a charity we welcome your suggestions on how we can improve volunteering)

Volunteers' Week

This is a national celebration of volunteers and volunteering and is held annually between 1-7 June.

Volunteers awards will also be celebrated at our Annual Conference.





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For any further Information- please contact:

Tanya Darnton - Volunteer Manager

TSA, CAN Mezzanine, 32-36 Loman Street, London, SE1 0EH

tanya.darnton@tuberous-sclerosis.org | mob: 07597180088 | tel: 02380 730 823

www.tuberous-sclerosis.org