



Job Title: Tuberous Sclerosis Complex (TSC) Adviser

Location: Home based

Geographical Region: The areas that may be covered include Wales, the Midlands and the North of England. The person appointed will be home-based, ideally within one of these regions.

Travel requirements: Contact with members is usually via e-mail and telephone but mileage for any travel will be paid. Regular Adviser meetings are held in Birmingham every 6 weeks.

Hours of work: 21 hours per week. Occasional weekends may be required but the majority of the work is carried out between Monday-Friday and hours can be flexible.

Salary: NJC SO2 29-31 £14,598-£15,564 (full time equivalent of £24,331-£25,940) plus mileage

Pension: Stakeholder pension package available (employer contribution 6%) after 6 months in post

Holiday Entitlement: 5 weeks annual leave per year (pro rata) with one extra day off between Xmas and New Year plus 8 bank holidays per year (pro rata)

Notice period: negotiable.

Accountability: The post holder will be accountable to the Tuberous Sclerosis Association (TSA) Board of Trustees through the Chairman and will be line managed by the Head of Development and Support Services.

Job Summary: Provide information, advice and support to families and individuals affected by TSC, on the telephone, by email and through home visits. Work with professionals to ensure that individuals with TSC and their families get the optimum service from health, education or social care

Duties and Responsibilities:

Support and Information

- Provide accurate and sensitive information to people with TSC, their families and carers on day to day issues of living with the condition. This can occur via phone, e-mail or personal visit and letter.

- Provide emotional support as required to individuals and families affected by TSC
- Help individuals and families identify their specific issues and signpost or refer them to the relevant specialist local agencies for appropriate services and support.
- Maintain up-to date information on resources across the region consulting with relevant agencies where appropriate
- Identify and approach suitable individuals and families to link with those requesting mutual support

Advocacy

- Assist individuals, families and carers in accessing and obtaining necessary support and services which will assist them in their daily living. This may include
 - Writing letters of support and referral letters
 - Attending multi-disciplinary meetings
 - Attending specialist appointments
 - Assisting with adjudication, complaints and tribunal procedures
 - Liaising with other professional and service providers

Safeguarding vulnerable adults and children

- Comply with the TSA safeguarding policy

Liaising and Networking

- Connecting with relevant organisations or networks to raise the profile of the TSA and represent the needs of people living with TSC
- Contribute to the development of the TSA by actively forging mutually beneficial relationships with related organisations

Education and Publicity

- Provide training and information on TSC, adapted to the needs of the individual or group
- Contribute to professional study days organised by the TSA
- Participate in the review of TSA publications and leaflets
- Contribute to the TSA annual reports, Scan articles and reports

TSA Member Events

- Organise and manage regional group events
- Contribute and attend National TSA events such as Outlook, Family Weekends and the AGM
- Identify, encourage and support TSA members to attend such events

Knowledge Base

- Maintain an up to date knowledge of TSC including recent significant developments. This may include contact with TSA research staff, TSA Professional Advisers and attendance at training days as required
- Liaise with the TSA Professional Advisers for specific clinical queries and advice
- Maintain a working knowledge of associated services, rights and entitlements and relevant specialist agencies.

Internal/ Organisational

Work with the Head of Development and Support Services, and colleagues to develop the role as follows.

- Participate in meetings, ensuring effective communication across the team
- Keep colleagues aware of trends, developments and issues as appropriate
- Participate in peer support
- Participate in regular supervision and annual appraisals
- Organise and prioritise own workload, making use of supervision
- Maintain and manage accurate database records in line with TSA policy
- Contribute to updating and the formulation of guidance and policy papers for the TSA
- Comply with the organisation's policies and procedures
- Liaise and work with Trustees, Committees, Research staff, Appeals and Publicity staff and Volunteers as appropriate

Person Specification-

Essential requirements	Desirable requirements
Qualifications	
	Health or social care qualification relevant to the issues which arise for those living with a long- term neurological condition
Knowledge	
Knowledge of health and social care sector structure and operation of at least one of the following: education/health services/social care	
Awareness of the psychological, neurological, and social problems which can arise as a result of living with a neurological condition	
	Knowledge of the voluntary sector
Evidence of continuing personal development and learning	
Experience	
Advocating for others either in	

professional or personal life	
Experience of working with (in voluntary or paid capacity or supporting) children or adults with disabilities or chronic health condition	
Skills and Aptitudes	
	Ability to assess and analyze complex problems, making appropriate responses to the benefit of people with TSC
Good communication skills (oral and written) and the ability to communicate with a broad range of people	
Competent IT skills	
Ability to manage a diverse caseload, prioritise needs and manage one's own time accordingly	
Any other requirements	
Ability to work flexibly to meet the needs of the service including occasional evening and weekend work as required	
This position is home based and post holder will need accommodation suitable for this purpose. All necessary equipment will be provided.	
Travel throughout the region and occasionally to other parts of the UK.	
Access to transport in order to fulfil the demands of the job. This will usually mean a driving licence and access to a car (mileage paid) but other ways of meeting the travel requirements of the job will be considered.	
Work in line with data protection with sensitivity and discretion	
CRB advanced disclosure clearance	
Team player	

For informal enquiries about this post please call:

Fiona McGlynn, Head of Development and Support Services on 05602 420809 (Tues-Friday 0800-1400)

For full job description, job specification and an electronic application form, please download a copy directly from our website:

<http://www.tuberous-sclerosis.org/articles/1638>

Alternatively please e-mail Diane Sanson at diane.sanson@tuberous-sclerosis.org or call 0121 445 6970 to request a paper copy.

Completed applications should be returned to Diane at diane.sanson@tuberous-sclerosis.org or posted to:
Diane Sanson, Head of Administration, Tuberous Sclerosis Association,
PO Box 12979 Barnt Green, Birmingham, B45 5AN

We are unable to contact all applicants individually, but thank you in advance for your interest. If you have not heard from us by the 9th April please assume that you have not been short listed. **Interviews** will be held on Friday the 17th April/Saturday the 18th April in London.

Closing date: Sunday 5th April 2009 at 17.00