

## The role of GSD Type Co-ordinators

### Introduction

The work load of the GSD Type Co-ordinators will vary according to the number of GSD Type members, their needs and the level of professional activity such as clinics, treatments, research, etc. These are voluntary roles and it may not be possible, or even relevant, to undertake all the work outlined. However, the responsibilities section can act as an overall guide to the possibilities available to the GSD Type Co-ordinator.

**Appointed by:** The Board of Trustees. Ideally each GSD Type Co-ordinator should concentrate solely on that role and not hold any other officer roles within AGSD-UK.

**Reports to:** The Board of Trustees, and to the Chairman between meetings.

**Liaises with:** The Development Officer and Administrator (once appointed) and other AGSD-UK officers.

### Responsibilities

#### MEMBERS AND THE PUBLIC

- Act as the principal contact within AGSD-UK for enquiries from the public, members, medical professionals and other associations regarding the particular GSD Type.
- Respond to enquiries by email, telephone, post and/or on-line forum as appropriate.
- Monitor GSD Net and any other forum which is regularly used by people affected by the particular GSD Type.
- Assist patients/families to make contact with each other, subject to the constraints of confidentiality.
- Maintain, in liaison with the Administrator, details of the particular GSD Type members/contacts in the AGSD-UK database.
- Encourage, where appropriate, those affected by the particular GSD Type and their relatives to join as Full Members.

#### MEDICAL PROFESSION

- Maintain links with key medical professionals who have a special interest in the particular GSD Type.
- Keep abreast of developments in the field and update members and the Board of Trustees as appropriate.
- Encourage applications for research grants and to facilitate researchers to submit applications to the Board of Trustees under AGSD-UK's policy on research grants.
- Liaise with patients/families wishing to apply for grants and to assist the applicants to submit to the Board of Trustees under the AGSD-UK's policies on patient/family grants.

#### GOVERNANCE

- Submit an annual budget to the Board of Trustees for approval.
- Submit a brief written report of activity to the Board of Trustees for each of their meetings, to attend the Board meeting on the Annual Conference weekend and other such meetings when requested to do so.
- Prepare a report on activity for the AGSD-UK annual report which is presented at the AGM.

#### COMMUNICATIONS

- Organise speakers for the particular GSD Type workshop at the Annual Conference and lead that workshop.
- Prepare and/or source news items and articles on the particular GSD Type for the AGSD-UK Newsletter.
- Maintain and update, in liaison with the webmaster, the particular GSD Type's section of the AGSD-UK website.

#### VOLUNTEERS

- Recruit other members affected by the particular GSD Type to assist with the responsibilities and identify possible successors for the role.
- Encourage and support people wishing to raise funds for the particular GSD Type, in conjunction with the Development Officer and Fund Raising Consultant (once appointed).

### Powers

- Authorise, only in accordance with the annual budget approved by the Board of Trustees, expenditure from general funds and the restricted funds held for the particular GSD Type.
- Authorise, in liaison with the Treasurer, unusual expenditure (if any) additional to the budget up to a maximum of £500 p.a., anything else to be submitted to the Board of Trustees for prior approval.

### Constraints

- Not to provide any medical advice, but only advise patients of generic good practice and inform them of the experience of other patients whilst maintaining confidentiality.
- Comply with all AGSD-UK policies, particularly those regarding child protection, confidentiality and data protection.

### GSD Type Co-ordinator meetings

The Co-ordinator is expected to attend occasional meetings of all the GSD Type Co-ordinators. This provides a forum to exchange ideas and experiences and to learn from each other. These meetings will be no more than twice per year, one of which will be at the Annual Conference.

### Expenses

Expenses such as telephone, postage and travel to meetings which are necessarily incurred in carrying out the responsibilities may be reclaimed from the AGSD-UK. Full details are given in the policy on expenses.