

Ann Conroy Trust

Support • Education • Research



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Registered Charity

Ann Conroy Trust

SUPPORT • EDUCATION • RESEARCH



SUPPORT, EDUCATION & RESEARCH FOR PEOPLE LIVING WITH CHIARI MALFORMATIONS & SYRINGOMYELIA



British
Syringomyelia
Chiari Group

Who are we?

The British Syringomyelia Chiari Group was formed in 2005, by a group of neurosurgeons with particular interest and experience in treating syringomyelia and related disorders. The group was soon joined by a number of neuroscientists, neurologists and veterinary neurologists who also had an interest in this field.

The Group was founded under the auspices of the Ann Conroy Trust, a charity which provides support for patients who live with Chiari malformations or syringomyelia. The Charity also provides educational material about these conditions, for health care professionals and for patients, their family & carers. It also organises educational events for health care professionals in training. The Charity and the Group work together closely in their various endeavours.

The British Syringomyelia-Chiari Group is also affiliated to the Society of British Neurological Surgeons. It has its own constitution, which can be viewed on the Ann Conroy Trust website.

Membership of the Group is open to any health care professional or neuroscientist who has an interest in treating or studying syringomyelia, Chiari or related conditions.

What do we do?

In addition to holding regular meetings (see below), the British Syringomyelia Chiari Group has also initiated a number of important projects, including the organisation of an international symposium, Syringomyelia 2007, held in Rugby. This highly successful event was followed by Syringomyelia 2010, held in Berlin and Syringomyelia 2013, held in Sydney. Both of these follow-on events were organised by international delegates who had attended the Rugby symposium.

Members of the Group subsequently began production of the monograph Syringomyelia, a disorder of CSF circulation, which was published by Springer, in 2014.

Currently, we are looking to develop standards of practice, in the assessment and management of patients presenting with Chiari malformations and/or syringomyelia.

The Group is also committed to establishing a database of syringomyelia and Chiari cases, to form a basis for future clinical research.

Where & when do we meet?

The Group initially met on a yearly basis but now meets twice a year, mainly to discuss individual patients (albeit anonymously), whose conditions present particular difficulties with management or that are otherwise instructive or interesting. Meetings last one day, from 9am to 4pm and are normally held on a Friday. An informal dinner is usually arranged on the Thursday evening beforehand.

Members bringing cases to discuss are asked to copy relevant radiological images on a USB stick, to be projected as a PowerPoint or similar presentation. Although all cases are discussed anonymously, the Group regards it as good practice for members to obtain consent from individual patients beforehand. A representative of the Charity normally sits in on the meetings, as a lay moderator. No time limits are applied to individual case presentations and discussions are wide ranging and productive.

Details of forthcoming meetings are given on the Charity's website.

How do I join?

Simply write to or e-mail the Charity, at the appropriate address given overleaf, providing your title, forename, surname, professional position and where you work. We also require your postal and e-mail addresses, so that we can contact you with details about the Group's activities and meetings.

Once we have confirmed your membership we will send you a copy of the Group's constitution, together with some samples of the educational material that the Charity produces.

To attend one of the Group's meetings you will need to complete one of the attached forms – also available to download from the Charity's website. Please note that consultants practising in the UK & Ireland are asked to pay £50 to the Ann Conroy Trust, as a contribution towards the costs of promoting and running the meetings. Trainees and nurse specialists are also welcome to attend, as guests of Group members and are charged a £15 attendance fee. All those attending the meetings are required to pay for their hotel room, if staying the night before, as well as for the evening meal, if joining the rest of the Group for this event.

British Syringomyelia Chiari Group

Meeting booking form
Please complete, detach and return
to the postal address given overleaf.

Name: _____

Position: _____

Unit: _____

Address: _____

Postcode: _____

E-mail: _____

I wish to attend the meeting to be held

on: _____

at: _____

I wish to pay by:

BACS transfer: 40-52-40; 00011969

Cheque* (enclosed)

* Payable to Ann Conroy Trust

Thursday evening:

I will be attending the evening dinner

Please note, you will need to confirm your intention to join the evening dinner with the hotel, when you make your room reservation