

Local Amyloidosis Patient Support Groups

The online National Amyloidosis Centre patient support forum (www.amyloidosis.org.uk/forum) has been up and running since the beginning of 2015. It has enabled patients, family members and carers from all over the country to meet and give each other support, advice and encouragement in cyberspace.

Some patients who attend the National Amyloidosis Centre have set up small local support groups so they can meet up in real life as well. The meetings are very informal – just a chance for patients, families and carers to meet over a coffee, to get to know each other and to chat.

The Scotland group have been meeting every two or three months since April 2015, and now includes 13 families from all around Scotland. The meetings are deliberately held in a different venue every time, in order to even out the travel burden a bit for people coming from different parts of Scotland. It's also been important that the places the group meets up in are cheery and interesting in themselves.



Scotland amyloidosis support group meeting held at Loch Lomond



London amyloidosis support group meeting addressed by Dr Wechalekar at the NAC

The London group have been meeting since December 2015, and have held most meetings at the Garden Gate Pub near the NAC, and one meeting at the NAC itself, with Dr Wechalekar as a guest speaker.

A new group for patients around the South Wales region held their first meeting in March 2017 and hope to continue to grow as word gets out in the area.

George Turner, who started the Scotland support group: *"The support comes from the building of trusted friendships with people who have experienced a similar journey – as a patient or carer, or someone who has lost a loved one to amyloidosis."*

To hear more, please contact:

- **Scotland**
George – geordie_turner@hotmail.com
- **Wales**
Lynne – lynnedixon53@gmail.com
- **London**
David – davidgoldstone@btinternet.com
- **Surrey**
Pat – pattom@hotmail.co.uk

There has been interest in setting up new groups in the following places: Midlands, Leeds, Colchester, Manchester. Please contact Miriam for more information: miriam.pepys@ucl.ac.uk.

Myeloma UK groups – for patients with AL amyloidosis

The charity Myeloma UK also welcomes patients with AL amyloidosis at its support groups, which meet in around 60 locations around the UK. For more information see the Myeloma UK website: www.myeloma.org.uk.