

Local Amyloidosis Patient Support Groups

The online National Amyloidosis Centre patient support forum (www.amyloidosis.org.uk/forum) enables patients, family members and carers from all over the country to meet and give each other support, advice and encouragement in cyberspace.



Local support groups in several locations have been arranging regular real life meet ups since 2015. When Covid restrictions were announced, these groups began transitioning to Zoom meetings, which have proved a tremendous success. Some members were nervous at first but for many the online version has been even more effective than the original format, allowing people to join who were unable to attend the face -to -face meetings.

The Scotland group have been meeting by Zoom every few weeks since Covid first struck and have been joined by people from the rest of the UK, Ireland, Denmark, France, the USA and Canada. Some other local groups have now resumed in person get togethers in addition to the ongoing Zoom meetings.

'People's stories are poignant, funny, heart breaking at times; some as patients, some as carers, some bereaved but all of them prepared to share the experience of their journeys to support other people. Within a couple of hours, they became friends and within a few meetings, they became family. Party politics, religion, race, and all the other things that can divide people were left outside the "room". Strange though it sounds, I love every minute of these meetings.' Mark McConway, Scotland group organiser.



The Scottish group at the Black Watch Castle and Museum in Perth

For more details, please contact:

- **Scotland**
Mark - mconway.mark@gmail.com
- **South Wales, Avon Somerset and Wiltshire and Devon and Cornwall**
Lynne - lynnedixon53@gmail.com
- **Surrey**
Pat - pattom@hotmail.co.uk
- **Ireland**
David - mrdauidcommins@gmail.com



Cardiff group meeting,

Please contact Miriam if you're interested in setting up a new group:
miriam.pepys@ucl.ac.uk

Myeloma UK groups – for patients with AL amyloidosis

The charity Myeloma UK welcomes patients with AL amyloidosis at support groups in around 60 locations around the UK – for more information see:

www.myeloma.org.uk