

A small charity based in West Wales, established by a few patients, of this rare disease, coming together and sharing, the patients experience, of living with this "Life limiting" health condition.

Focusing on Ataxia and associated rare diseases and movement disorders, Allowing us to cater for a wider patient community, who might feel isolated, with a health condition that is generally un-heard of.

Ataxia –"the most serious condition you`ve never heard of".

Ataxia is a Greek word meaning "lack of Order"

We aim to bring some order, to the lack of order.

Events (on-line) 72+

Meetings (F2F) 4 (Virtual) 5

Contribute to speaking, at virtual events 3

Indeed We had a good presence at the augural Swansea Rare Disease Study Day , speaking with Medical students

Supply text for media articles three times

Display/stand at 3 events

Interview 4 volunteers, leading to hosting 2 volunteers during the year (adding to our social media presence),

Invited to UK`S premier Genomic Science event, The Festival of Genomics and BioData , in London (Plus, being invited back in January the following year,

Our trustee and his wife, continue to make amazing links with other patient advocates, and other organisations, contributing to, and, conveying the patients perspective, including many creative writing and videos, poems, podcasts and speaking as patient advocates to many organisations.

Indeed, Louise, is quite an Ambassador, having had a books published, from which she reads excerpts, from, at many Spoken Word/ open mic. / , (including at a book festival) ,events. Indeed at one event Louise got chatting to a "Rapper" who made up a few lines to add to his performance during the world renown Abergavenny Writing Festival !.

This continues our "Mission" to raise awareness of Ataxia, Neurology, and a positive, patient experience, outlook.

Public liability Insurance

Markel London


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Bank

Atacsia a Fi / Ataxia and me (CIO 1184030)

Annual Report 2024 - 2025

Signed	full name	Position	date
D. Morgan	DAWN MORGAN	SECRETARY	16.1.26

Signed	full name	Position	date
	ALAN THOMAS	CHAIR	16.1.26