

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.

Again, this year any physical activity was very small, due to the (legacy of the Covid19) pandemic. Many events have been provided via on-line platforms.

Although, as we are more of an online charity, we were able to utilise, the advantage of a virtual presence, allowing us to keep interacting with the community.

During this year the theme for all events, was VIRTUAL (either via Zoom or Microsoft teams).

Events (on-line) 144

Meetings Contribute to speaking, at virtual events 9

Radio interview 1

During this year we took part in filming (with BBC Wales) for an article about Ataxia and Health services, shown on S4C Television, Wales

We hosted 2 volunteers during the year (adding to our social media presence)

This was very advantageous during the month of February (Rare disease Day 28th February)

Indeed 1 was very keen and took part in many Wales Gene Park, (Genomics) webinars

We took part in, the annual fundraising event summer called "at home Super Heros" where activities could be done "At home".

We continue to use the sale of (Plain) backpacks, for fundraising

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.

Again we were invited to submit Text to Wales online for a media article (newspaper and online.

We also had an article published in the MediWales newsletter, for the Global Life Science Industry,

Public liability Insurance

Markel London

Bank

Barclays 20-25-19

Financials

Income		Expenditure	
Description	Amount	Description	Amount
In		Out	
Fundraising		Media materials	
Local Giving page	29.54	Just Print	133.99
Local Giving page	97.28	Get Stitched	195.94
Local Giving page	37.99	Get Stitched	245.39
Local Giving page	19.24	Get Stitched	68.87
Local Giving page	2.37	RareRevolution (charity membership)	65
Local Giving page	39.27	SuperHero CharityFriend subscription (24 race places)	
Local Giving page	29.35	Local giving (use of,fundraising platform)	96
Local Giving page	8.87	Ukraine Donation	149.5
Local Giving page	4.78	PSU donation	100
Local Giving page	19.46		
Local Giving page	24.14	Website (123)	
Local Giving page	1.76		
Local Giving page	0.47	TSO Host (web. Hosting)	129.46
Local Giving MLG Grant	500.00	TSO Host (web.security certificate)	49.99
donation via village hall	300.00		
paypal	14.00	Insurance	100.8
paypal	36.00		
paypal	13.00		
paypal	21.00		

amazon	5.00		
amazon	7.55		
Total	1,211.07	>>>> MINUS	1334.94
End			

Ataccsia a Fi / Ataxia and me (CIO 1184030)

Annual Report 2021-2022

Signed


full name
~~Edith~~
ALAN THOMAS

Position
chair

date
9-5-2024

Signed
D. Morgan

full name
DAWN
MORGAN

Position
Secretary

date
9.5.24