

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.

This year any physical activity was impossible, due to the (Covid19) pandemic.

Although, as we are more of an online charity, we were able to utilise, the advantage of a virtual presence.

(In the closing days, of the previous period, {March 29th 2020} we were able to launch our new website www.ataxia-and-me.org)

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

Events 89

Meetings 96

Webchats 23

Virtual interview (of short term) volunteers 7

During this "Virtual" timescale, a trustee and his wife embarked on sharing their Ataxia story by contributing to a podcast ("Permission to be Human") facilitated by People Speak Up (PSU). This mentions illnesses and the meeting with the local Medical Director of the local health board (to which he shared a photograph via his social media).

During late summer we were able to print and make available some Ataxia aware facemasks.

In addition we were nominated to distribute some (colourful) children's school backpacks to the local NHS (nurses with children) and also a local Food bank charity, to launch their annual toy appeal, and some local school families with school children.

This welcomed a second batch of (Plain) backpacks, which Atacsia a Fi / Ataxia and me could use for raising funds.

Fundraising events 2 (1 summer and 1 winter) (both called "at home Super Heros" where activities could be done "At home").

Again, our trustee and his wife, made amazing links with other patient advocates, Genetic Counselling researcher (for interview) and the Community Health Council (CHC). As well as contributing to YouTube videos, conveying the patients perspective.

We submitted Text to Wales online for a media article (newspaper and online) which was published around the end of the year.

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.

Public liability Insurance

Markel London

Bank

Barclays 20-25-19

Income		Expenditure		
Description	Amount	Description	Amount	
Start				1,090.99
In		Out		
Fundraising		Media materials		
Local Giving page	1.29	mini pop up banner	45	
	38.84	banners	105.69	
st.30	97.34	RareRevolution (charity membership)	60	
	19.48			
	59.08	ARCA conf.	47.74	
st.31	4.73	Printing		
	33.88	Stickers	36	
	56.94			
	112.10	Website (123)	14.39	
st.32	83.29	st.37	52.75	
	19.46		115.06	
	9.66		94.73	
st.33	114.14		45	
	13.70			
	5.69			
st.34	9.74	Insurance	100.8	
	48.27			
	9.61	Local giving (use of,fundraising platform)	96	

st.35	4.70	Masks	264.5
	9.74	Postage	
	43.74	Envelopes	3.55
st.36	24.15		19.82
	29.22		15.2
	19.56		20.5
st.37	9.74		7.6
	9.74		
	39.24		
	49.34		
st.39	24.08		
Donations			
Ergomed/PSR	911.28		
Pembs. Share, Give, Care	200		
PayPal	39.24		
Misc.	10.00		
Total	2,161.01	>>>> MINUS	1144.33
			1,016.68
End			2,107.67

Atacsia a Fi / Ataxia and me (CIO 1184030)

Annual Report 2020-2021

Signed 

full name Position
A. THOMAS CHAIRMAN

date 27-1-2022

Signed 

full name Position
Stephen Karl Tschhe Truske

date 27-1-2022