

Ataxia aware

England & Wales · Charity number 1184030

Details

Other names ATACSIA A FI / ATAXIA AND ME

Status Registered

Legal form CIO

Registered 2019-06-21

Register [View on the Charity Commission register](#)

Contact

Address Tybach
Cefnbrafle
Llanboidy
SA34 0SA

Phone 01994448397

Email info@ataxiaandme.org

Website www.ataxia-and-me.org

Activities

Objects: TO RELIEVE THE NEEDS OF SUFFERERS OF ATAXIA OR OTHER NEUROLOGICAL DISORDERS, THEIR FAMILIES AND CARERS FOR THE PUBLIC BENEFIT BY PROVIDING PATIENT LED SUPPORT AND BY RAISING AWARENESS OF SUCH CONDITIONS.

Activities: A patients focused charity Raising Awareness of Ataxia. Sharing Ataxia, associated rare disease, movement and health information to Empower the patient, family member, carer of this Life limiting rare disease. Collaborating within these communities to advance and amplify the Patients voice within the health arena. Participating in fundraising events to allow this task

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Education/training, Disability
- **Who:** People With Disabilities, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees	
2025-03-30		£348	£561	-	-
2024-03-30		£284	£1,591	-	-
2023-03-30		£1,211	£1,335	-	-
2022-03-30		£2,603	£1,595	-	-
2021-03-30		£2,161	£1,144	-	-

Trustees

Name	Role	Appointed
Alan John Thomas	Chair	2019-06-15
Dawn Morgan		2019-06-15
Stephen Karl Treharne		2019-06-15

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Accounts

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
	DAWN MORGAN	SECRETARY	16.1.26

Signed	full name	Position	date
	ALAN THOMAS	CHAIR	16.1.26

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Although, most 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 most events, was VIRTUAL (either via Zoom or Microsoft teams).

Events (on-line) 128

Meetings (F2F) 18 (Virtual) 4

Contribute to speaking, at virtual events 2

Supply text for media articles 2

Display/stand at 2 events

We hosted 2 volunteers during the year (adding to our social media presence), 1 volunteer relocated to Spain, but continued to contribute to our social media, by translating posts into Spanish and Catalan languages.

Interactions with local merchandise suppliers (for team Ataxia) 6

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 book published, " Ruffling Feathers", from which she reads excerpts, from, at many Spoken Word, events. This continues to raise awareness of Ataxia, Neurology, and a positive outlook.

A highlight of the year was to be invited to the opening of the Genomic Centre in Cardiff

Which was officiated by the Health minister, and made the TV news, as a HUGE advancement in the Genetic/Rare disease arena.

Public liability Insurance

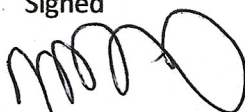
Markel London

Bank

Barclays 20-25-19

Financials

Income		Expenditure	
Description	Amount	Description	Amount
In		Out	
Fundraising		Media materials	
Local Giving page	48.64	Just Print	150
Local Giving page	17.92	Get Stitched	200
Local Giving page	33.93	Get Stitched	165.4
Local Giving page	43.74	Get Stitched	168.99
Local Giving page	9.61	RareRevolution (charity membership)	65
Local Giving page	50.00		
Local Giving page	9.61	Local giving (use of,fundraising platform)	180
Local Giving page	19.42		
		Website (123)	117.54
		TSO Host (web. Hosting)	129.46
		Cheque to AT 23 balance	301.81
GAYL	15.03	postage to Volunteer	12.15
GAYL	15.39		
		Insurance	100.8
amazon	5.00		
amazon	15.96		
Total	284.25	>>>> MINUS	1591.15
End	1306.9		

Signed	full name	Position	date
	ALAD THOMAS	CHAIR.	16.1.25

Signed	full name	Position	date
D. Morgan	DAWN MORGAN	SECRETARY	16.1.25

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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			

Atascia a Fi / Ataxia and me (CIO 1184030)


Annual Report 2021-2022

Signed


full name
~~Edith~~
 ALAN THOMAS

Position
 chair

date
 9-5-2024

Signed


full name
 DAWN
 MORGAN

Position
 Secretary

date
 9.5.24

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This year any physical activity was very small, due to the (Covid19) pandemic. (most events “pivoted” to 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 254

Meetings 22

Contribute to speaking, at virtual events 2

Webchats 5

Virtual interview (volunteers 6)

We continue to use for fundraising the sale of (Plain) backpacks, which Atascia a Fi / Ataxia and me

We took part in 2 Fundraising events (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, and, conveying the patients perspective, including many creative writing and videos, poems, podcasts and speaking as patient advocates to many organisations.

We submitted Text to Wales online for a media article (newspaper and online) which was published around the end of the year.(for a second time). We also had an article published in the MediWales newsletter, for the Global Life Science Industry, and our trustee and his wife featured in the Rare Revolution digital Magazine for Ataxia Awareness day with article and video.

Public liability Insurance

Markel London

Bank

Barclays 20-25-19

In	Out	
Fundraising	Media materials	
Local Giving page	Just Print	70
	Get Stitched	213.41
96.55	RareRevolution (charity membership)	65
19.64	SuperHero CharityFriend subscription (24 race places)	540
19.64	Local giving (use of,fundraising platform)	96
29.42		
19.64		
19.64		
187.10		
117.96		
9.70		
176.28		
68.98		
19.64		
19.64		
99.04		
29.54	Insurance	100.8
68.54		
19.64	Local giving (use of,fundraising platform)	96
6.91		
126.02		

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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.

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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

Atascia a Fi / Ataxia and me (CIO 1184030)

Annual Report 2020-2021

Signed


full name
A. THOMAS

Position
CHAIRMAN

date
27-1-2022

Signed


full name
Stephen Karl Tschhe Truske

Position

date
27-1-2022