

ATAXIA

Strategic Plan 2022-2025

VIRTUAL ANNUAL CONFERENCE

Friday 7th & Saturday 8th
October 2022

Sponsored by



Sue Millman
CEO Ataxia
UK



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Mission

We urgently want **treatments and cure**.

We **fund and promote research** with the aim of bringing this about; until this is achieved, we will do all we can to provide **support to people affected by ataxia**, and improve the **quality of treatment and care** they receive, to enable them to have the **highest possible quality of life**.



Plan Objectives



- Consistently **maximise the impact of research activity** leading to treatments and cures
- Enable **greater access to services** aimed at improving **wellbeing & financial circumstances**
- **Improve access to specialist, integrated care** (including mental health care), treatments and drugs for the ataxias
- **Faster, accurate diagnosis**

Research Activities

- Grants for Scientific/Medical Research
- Patient Advocacy
 - Research & drug development consortia (Global and European)
 - Pharmaceuticals
 - UK Policy and Regulation
 - Government Research/Biosciences policies
 - NHS/NICE/MHRA –eg drug approval processes - Omaveloxolone
- Dissemination of ataxia research/information/patient perspectives
 - International Congress for Ataxia Research



Funding Research Activities

- Friends & Supporters gifts/fundraising
- Commissioned by others
 - DRPLA
 - AT Society
 - Euro-ataxia – patient advocacy
 - Pharma
- Partnerships in funding medical research
 - Coeliac UK
 - Other ataxia patient groups e.g. FARA, NAF
- Funded patient advocacy roles in research consortia
- Sponsorship
- Grants from Trusts/Foundation



Peer Support & Volunteering



Local and online
Branches &
Support Groups



Online
Activities &
Information
Sessions



Ambassadors



Friends
Connect



Helpline Information
Advice & Advocacy



Advice & Advocacy



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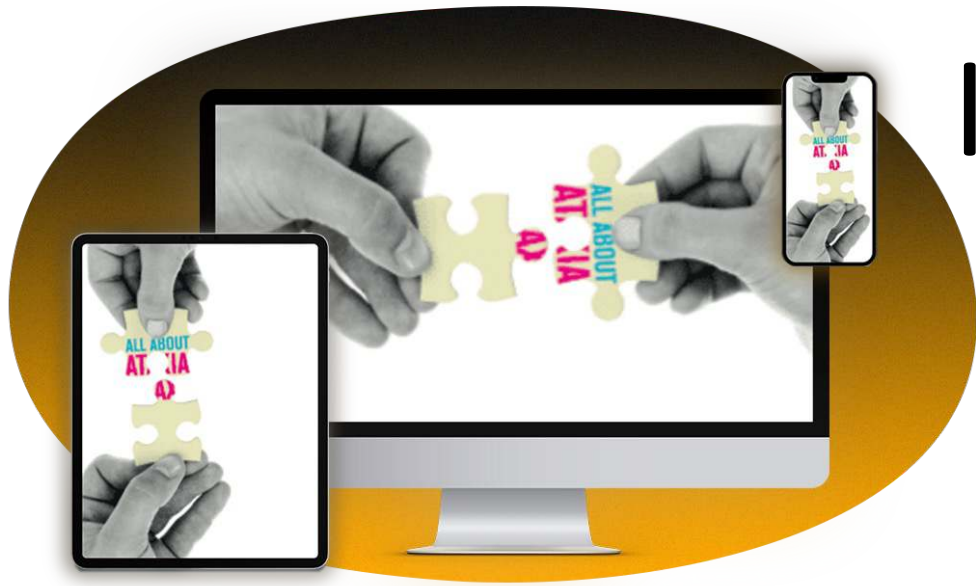
WHAT IS ATAXIA?



Website Information

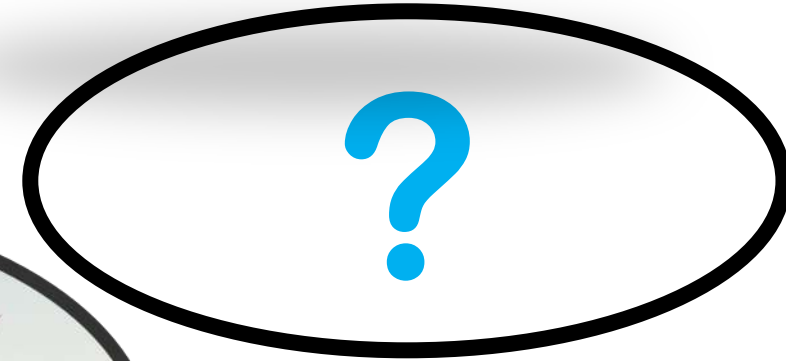
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Information



All About Mobility Aids
(and ataxia)

All About Ataxia **PLUS** +++ ...



All About.....
Please send us your
ideas



All About Wheelchairs
(and ataxia)



All About Travel
(and ataxia)

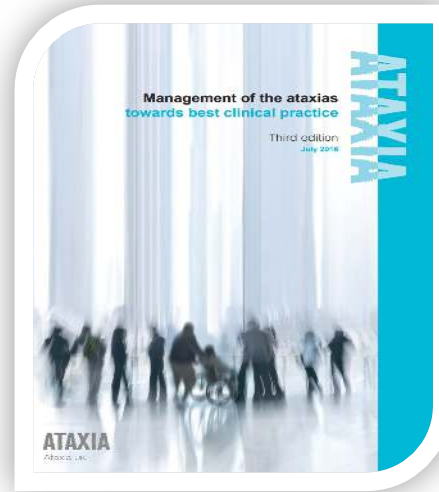
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Treatment and Care



Voice banking



Revise & publish new Medical Guidelines



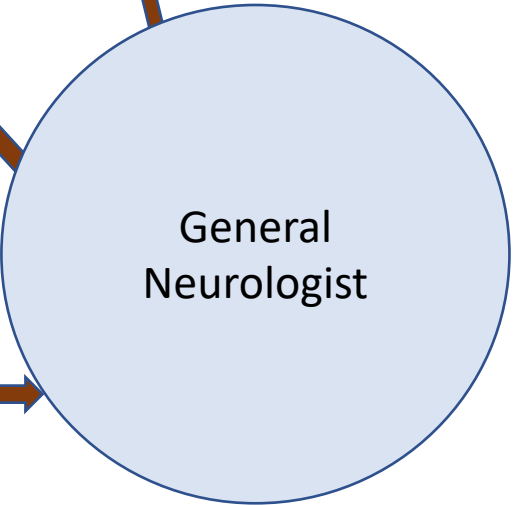
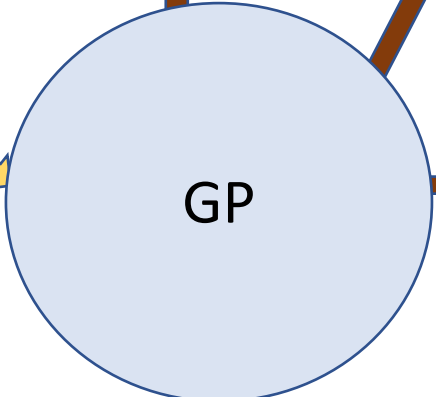
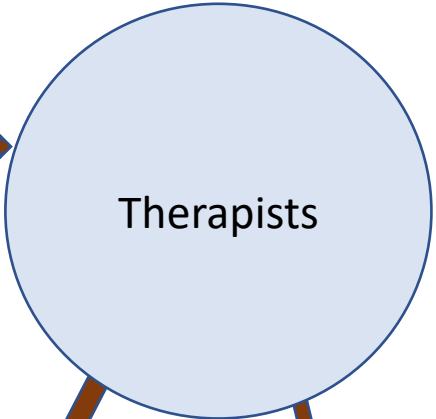
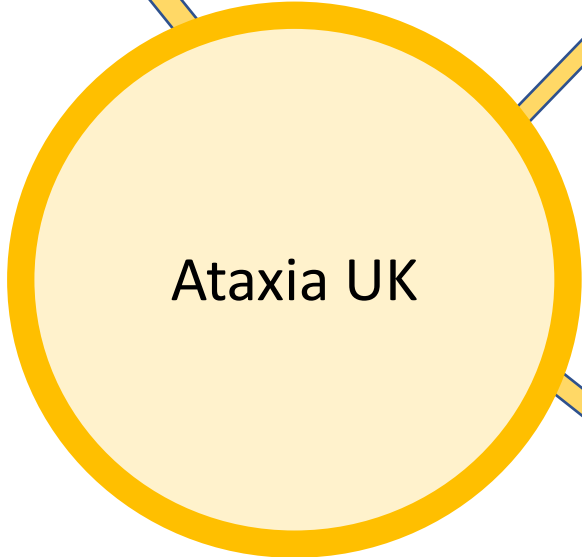
Online therapies



Develop counselling partnerships



Website Internet Search
Word of mouth Press
Social Media



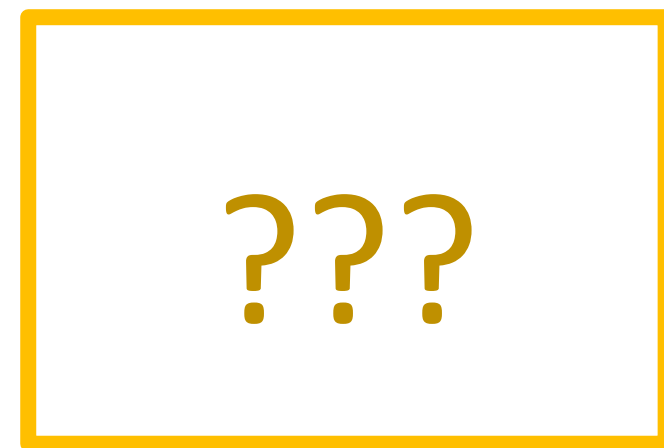
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Treatment & Care



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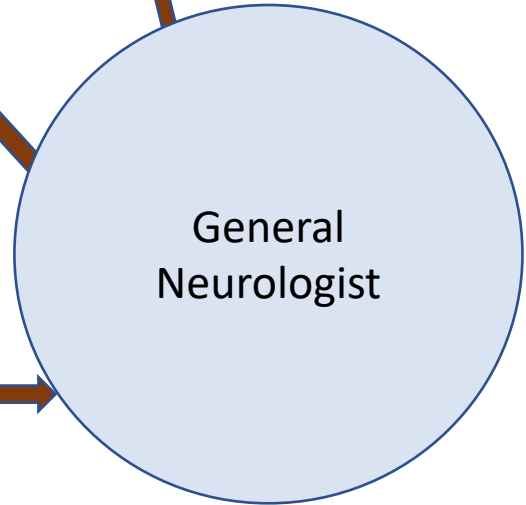
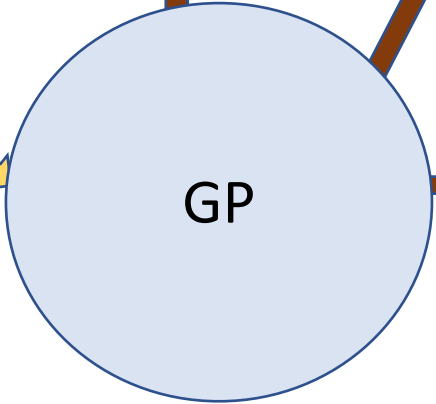
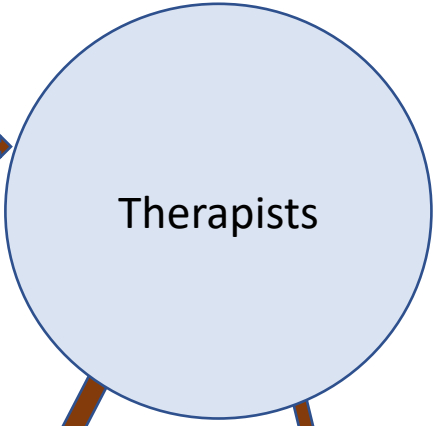
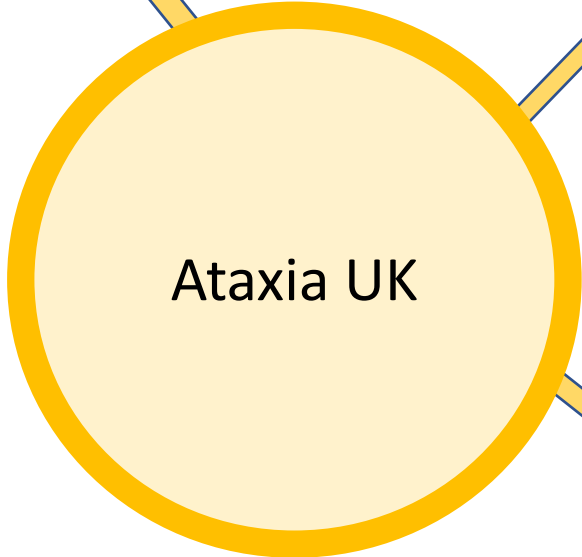


OUR SPECIALIST
ATAXIA CENTRES

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Website Internet Search
Word of mouth Press
Social Media



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Treatment & Care: Influencing Policy

- Covid 19 – early access to vaccines
- Ataxia treatment pathway - NNAG
- UK Rare Diseases Framework
 - Virtual appointment protocols
 - Quality Standards
 - Genetic Testing



Income £1,575K	2021-22	(£1.905k 2020-21)
Donations £858K 2021-22 (£1,278k 2020-21)	Legacies £258K 2021-22 (£188k 2020-21)	Lottery £89K
	Fundraising £240K 2021-22 (£226k 2020-21)	Childlife £80K
	Other £50K	

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Expenditure £1,341K 2021-22 (£3,006k 2020-22)		
Research Activities £501K	Care Services £331K	Raising Funds £340K
	Raising Awareness £105K	Governance £64K

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Reserves levels at year end

	2022 (£K)	2021 (£K)
General funds	570	590
Designated funds	154	8
Total unrestricted funds	724	598
Restricted research funds	(951)	(1,065)
Restricted services funds	99	105
Total restricted funds	(852)	(960)
Total funds held	(128)	(362)

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