

Newly Diagnosed

“You don’t get told anything, they don’t do anything and nothing changes”

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2023 Annual Ataxia Conference
March 30 - April 1, 2023
Las Vegas, NV

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2023 Annual Ataxia Conference

March 30 – April 1, 2023

Planet Hollywood
Las Vegas, NV

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2023 Annual Ataxia Conference

Newly Diagnosed

What are my diagnosed with ?

Newly diagnosed

- Ataxia is a combination of symptoms due to progressive deterioration of the cerebellum and its connections.

Newly diagnosed

- Symptoms of ataxia include,
- **Motor symptoms,**
- **Vestibular symptoms**
- **cognitive and psychiatric symptoms**

Newly diagnosed

- Motor symptoms;
- **impaired walking, like when one is drunk,**
- **poor balance falls**
- **clumsy, hands, and feet,**
- **slurred speech, stiffness, and**
- **swallowing difficulties**

Newly diagnosed

- vestibular symptoms include
- **dizziness or vertigo,**
- **poor balance,**
- **visual symptoms, such as blurred vision, double vision, or jumping visions**

Newly diagnosed; cerebellar cognitive mood changes include

- emotional dysregulation,
- impulsive behaviors,
- Apathy
- anger, irritability, and
- some of the cognitive symptoms
- frontal executive difficulties with planning, dual tasking and sequencing
- language, and sometimes reasoning are some of the early features

Newly diagnosed

- Other clinical features depends on the type of ataxia include;
- Visual changes
- Presence or absence of neuropathy
- Parkinsonism
- Seizures

Neurodegenerative Ataxias

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graph TD; A[Neurodegenerative Ataxias] --- B[Genetic]; A --- C[Sporadic]
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Genetic

Sporadic

Newly diagnosed

- **Idiopathic/ Sporadic Ataxia's: late onset cerebellar ataxia , Multiple system atrophy- cerebellar type**
- **Genetic Ataxia's :Autosomal dominant , Autosomal recessive, X linked or Mitochondrial.**
- **Symptomatic / secondary ataxia**

Neurodegenerative

Newly diagnosed

ONCE DIAGNOSIS IS GIVEN ; WHAT ARE THE NEXT
STEPS



Newly diagnosed ; Educating self .

- ✓ What does this mean ?
- ✓ Informing yourself , vetting your sources of information.
- ✓ What sources if information have you found helpful regarding your condition
- ✓ Do you received written information from Health professional ? What was it like?
- ✓ Have you found information on the internet – what was it like ?



Information resources

Ataxia Community:

- National Ataxia Foundation (NAF)
- Local Ataxia Support Groups
- Other patients and caregivers

Newly diagnosed :Understanding yourself

- How would you want to best receive care academic v.s local neurologist collaborative care.
- Helping your self
- Give yourself : research or not, resources , support





Newly Diagnosed

Research

- Observational studies; Natural history studies
- Interventional studies
- [Clinicaltrials.gov](https://clinicaltrials.gov)

Support

- ✓ Who helps you
- ✓ Do you have support from friends and family.
- ✓ Are you a member of any support group.
- ✓ Maintaining connections is crucial



Multidisciplinary Approach to treatment is key

- All ataxias are treatable
 - A few cerebellar ataxias have specific drug treatments
 - Knowing cause of ataxia informs treatment
 - Treatment is tailored to individual needs
- Multidisciplinary team approach

CARE TEAM

- Neurologist:
 - MOVEMENT DISORDER or one with great interest in ATAXIA
- Psychiatrist
 - Psychologist
- Cardiologist
- Endocrinologist or Internal Medicine doctor
- Sleep specialist
- Ophthalmologist
- Neurorehabilitation
- Genetic Counselor
- Social Worker
 - Caregiver and family support

Multidisciplinary team

Research team

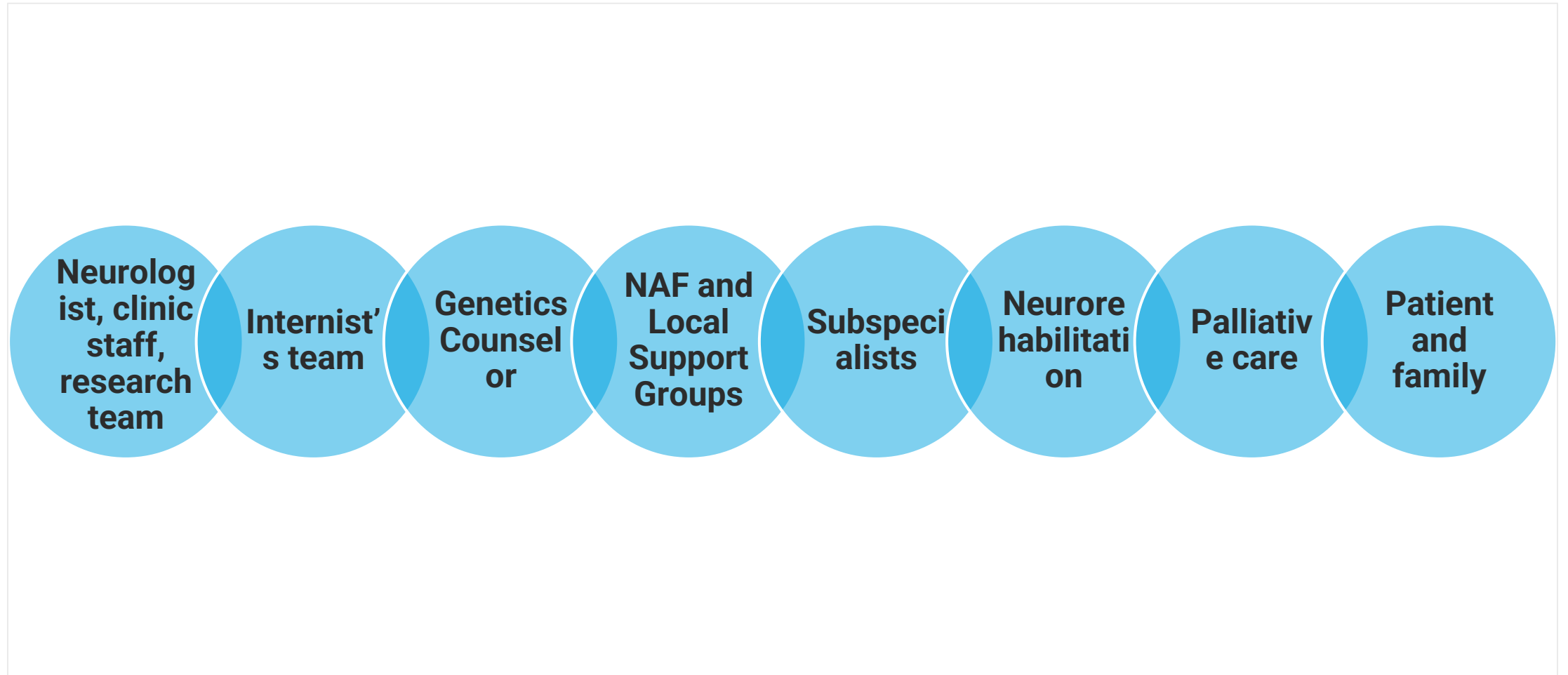
- Patient and family
- Research Coordinators
- NAF
- Research sponsors
 - Biohaven (Phase 3 study of Troriluzole)
 - NIH & NINDS
 - Other Industry sponsors
- <https://clinicaltrials.gov>
 - 102 studies on ataxia nationally and internationally

Multidisciplinary team

Palliative Care team

- Social Workers, Nurse specialists
- Advance care planning
- Patient and family Counseling
- Home health
- Dysphagia treatment
- Hospice care

Multidisciplinary team





Newly Diagnosed –checklist empowering yourself

- ✓ **Seek out the most advanced and specialized care that is available to you**
- ✓ **Join a your support group.**
- ✓ **Educate yourself**
- ✓ **Designate a support team**
- ✓ **Consider a clinical trial**



Newly Diagnosed –References

- I. Box H, Bonney H, Greenfield J. The patient's journey: the progressive ataxias. *BMJ*. 2005 Oct 29;331(7523):1007-9. doi: 10.1136/bmj.331.7523.1007. PMID: 16254302; PMCID: PMC1273458.
- II. Marwaha, S., Knowles, J.W. & Ashley, E.A. A guide for the diagnosis of rare and undiagnosed disease: beyond the exome. *Genome Med* **14**, 23 (2022).
- III. Daker-White G, Kingston H, Payne K, Greenfield J, Ealing J, Sanders C. 'You don't get told anything, they don't do anything and nothing changes'. *Medicine as a resource and constraint in progressive ataxia*. *Health Expect*. 2015 Apr;18(2):177-87. doi: 10.1111/hex.12016. Epub 2012 Oct 24. PMID: 23094806; PMCID: PMC5060777
- IV. Manto, et. al. Cerebellar Ataxias-an update, *Curr Opin Neurol*, 2020
- V. Ramirez-Zamora, et. al. Treatable causes of cerebellar ataxia, *Mvt. disorders*, 2015
- VI. Perlman, S, Update on the Treatment of Ataxia: Medication and Emerging Therapies, *Neurotherapeutics*, 2020
- VII. Gandini, et. al., The neurological update: Therapies for cerebellar ataxias in 2020, *J Neurol*, 2020 A. Zesiewicz, George Wilmot, Sheng-Han Kuo, SusanPerlman, Patricia E. Greenstein, Sarah H. Ying, Tetsuo Ashizawa, S.H. Subramony, Jeremy D. Schmahmann, K.P. Figueroa, HidehiroMizusawa, Ludger Schöls, Jessica D. Shaw, Richard M. Dubinsky, Melissa J. Armstrong, Gary S. Gronseth, Kelly L. Sullivan *Neurology* Mar 2018, 90 (10) 464-471; DOI:10.1212/WNL.0000000000005055



Newly Diagnosed QUESTIONS