

ATAXIA:TEAM-BASED CARE

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PRESENTER DISCLOSURES

- No relationships to disclose or list relevant to this presentation

OBJECTIVES

- Discuss Ataxia Cases illustrating need for multidisciplinary or team-based care
- Challenges in multidisciplinary ataxia care
- Need for multidisciplinary care for ataxias
- Models of multidisciplinary care

CASE 1

- 24 year old woman
- Concerns: progressive walking and balance problems
- Started in adolescence
- No family history of ataxia
- Initial genetic tests were normal
- Whole Exome Sequencing showed a mutation for **Ataxia Telangiectasia (AT)**

AT

- Predisposition to cancer
- Immune defects
- Infections
- Neuropathy
- Weakness

OMIM # 208900

AT

- Movement specialist
- Hematologist Oncologist
- Gynecologist
- Neurorehabilitation
- Genetic Counselor
- Family Counseling

CASE 2

- 25 year old man
- Mild gait and balance problems
- Started in early 20s
- No family history of ataxia
- Thorough investigation for ataxia was normal
- Genetic testing showed **Friedreich Ataxia (FA)**

FA

- Cardiomyopathy
- Visual impairment
- Endocrine problems
- Musculoskeletal problems
- Neuropathy
- Weakness

OMIM # 229300

FA

- Movement specialist
- Cardiologist
- Endocrinologist or Internal Medicine doctor
- Ophthalmologist
- Neurorehabilitation
- Genetic Counselor
- Family Counseling

CASE 3

- 55 year old woman
- Concerns: progressive walking and balance problems
- Started in early 50s
- No family history of ataxia
- Genetic tests were normal
- All other tests were completely normal

CASE 3

Over the next 4 years

- Progressive slurred speech, balance problems, falls
- Urinary frequency, urgency and recently incontinence
- Light headedness
- Slowness of Movements
- Acting out of dreams
- Completely dependent on husband for most tasks

CASE 3

Multiple system atrophy-cerebellar type (MSA-C)

- Movement Specialist
- Urologist
- BP specialist (Cardiologist)
- Nutritionist
- Pulmonologist
- Sleep specialist
- Social Worker

Cerebellum (2014) 13:248-268
DOI 10.1007/s12311-013-0531-6

REVIEW

Consensus Paper: Management of Degenerative Cerebellar Disorders

W. Ilg · A. J. Bastian · S. Boesch · R. G. Burciu · P. Celnik · J. Claassen · K. Feil · R. Kalla · I. Miyai · W. Nachbauer · L. Schöls · M. Strupp · M. Synofzik · J. Teufel · D. Timmann

- Medications
- Neurorehabilitation: **Motor training**
 - Need Evidence Based Guidelines

JOURNAL OF PALLIATIVE MEDICINE
Volume 13, Number 6, 2010
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2009.0318

Original Articles

Caregivers of People with Neurodegenerative Diseases: Profile and Unmet Needs from a Population-Based Survey in South Australia

Samar Aoun, M.P.H., B.Sc., Ph.D.¹ Ruth McCorry, B.Nurs, Ph.D.¹ Amy Abernethy, M.D.² and David C. Currow, B.Med, M.P.H.³

- Greater unmet emotional, spiritual, and bereavement needs in caregivers of patients with neurological diseases compared to other diseases

Original Article

SAGE Open Medicine

Trouble with ataxia: A longitudinal qualitative study of the diagnosis and medical management of a group of rare, progressive neurological conditions

Gavin Daker-White¹, John Ealing², Julie Greenfield³, Helen Kingston⁴, Caroline Sanders¹ and Katherine Payne⁵

- Extensive, Expensive, Exhausting Diagnostic process
- Uncertainty in 'idiopathic' ataxia is emotionally taxing
- Financial Constraints

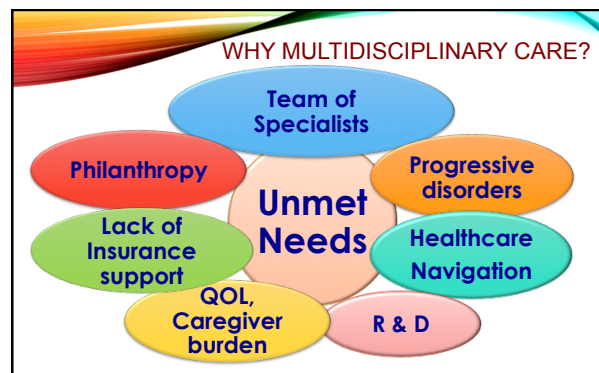
**Management of the ataxias
towards best clinical practice**

Third edition
July 2016

ATAXIA
Ataxia uk

ATAXIA

- Knowledge of new treatments
- Customize treatment
- Coordinate care
- Participate in Research



CARE TEAM MEMBERS

Movement Disorders

- Diagnose ataxia
- Medical treatment
- Orchestrate care
- Spearhead Research
- Educate trainees, community docs

CARE TEAM MEMBERS

Internist

- General medical health
 - Blood pressure
 - Diabetes
 - Cholesterol
 - Timely testing (lab work, colonoscopy, etc.)
- Common Infections
 - UTI, Flus
- Immunizations

CARE TEAM MEMBERS

Neurorehabilitation

- PMR Specialist
- ST, Speech language specialists
- PT
- OT
 - Motor training for gait and balance
 - Equipment needs
 - Fall Precautions
 - Home Modification

TEAM MEMBERS

Genetic Counselors

- Preauthorization
- Ordering tests
- Pre-test counseling
- Post-test counseling
- Education (of patient, family, team)

TEAM MEMBERS

Nurses

- Coordinate care
- Navigate hospital system
- Patient Advocacy
- Education (of patient, family, team)
- Make things happen!

TEAM MEMBERS

Clinical Social Worker

- Needs assessment
- Navigate Insurance system
- Patient and family Counseling
- Hospice, Palliative care, Nursing home, Home health, Advanced directives, Caregiver burnout

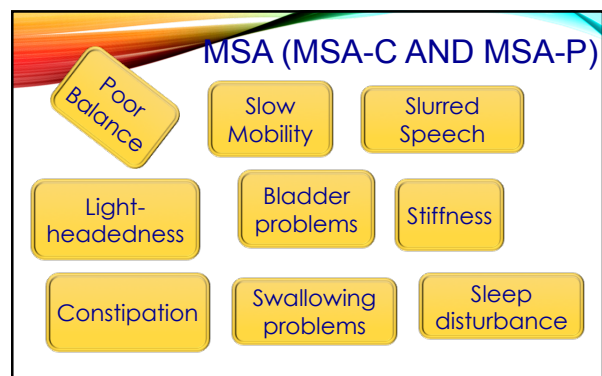
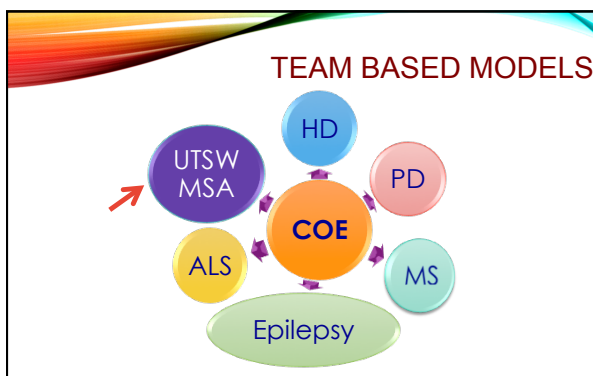
TEAM MEMBERS

- Cardiologist
- GI
- Pulmonary and Sleep
- Urologist
- Fertilization Specialist
- Clinical Psychologist
- Psychiatrist

TEAM MEMBERS

Community:

- Patient Support Groups
- Philanthropists
- National Organizations
- NAF



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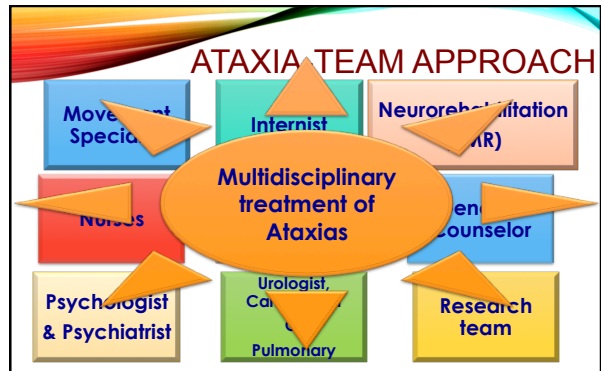
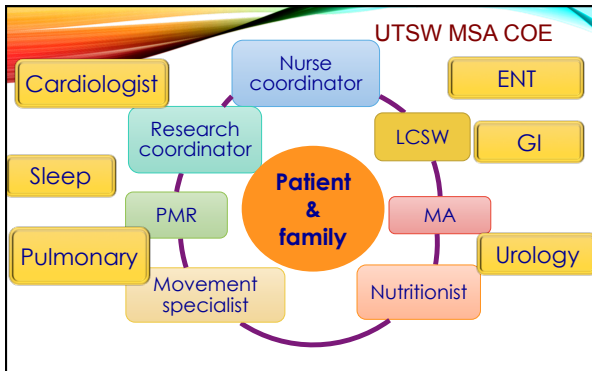
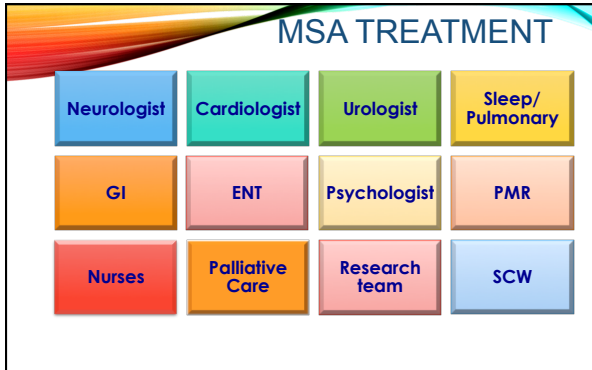
Mission:

Improve the QOL of patients and caregivers affected by MSA through multidisciplinary care

UT SOUTHWESTERN MSA COE

Objectives:

Excellent Clinical care
Research
Education



SUMMARY

- Ataxias are **complex, multiorgan** disorders
- Ataxia treatment requires a specialized **team-based** approach
- **National organizations & philanthropic efforts** can assist in formation of multidisciplinary ataxia clinics
- Team-based clinics can **accelerate ataxia research and education**

Thank you!!