ATAXIA: TEAM-BASED CARE
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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
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)**

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

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

OMIM # 229300
CASE 3

Multiple system atrophy-cerebellar type (MSA-C)
- Movement Specialist
- Urologist
- BP specialist (Cardiologist)
- Nutritionist
- Pulmonologist
- Sleep specialist
- Social Worker

Medications
- Neurorehabilitation: Motor training
- Need Evidence Based Guidelines

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

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

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

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

CARE TEAM MEMBERS

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

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

Team Members
- Genetic Counselors
- Internist
- Movement Disorders
- Neurorehabilitation
- Nurses
- Clinical Social Worker
TEAM MEMBERS

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

TEAM MEMBERS

Community:
- Patient Support Groups
- Philanthropists
- National Organizations
- NAF

TEAM BASED MODELS

UTSW MSA
HD
PD
ALS
Epilepsy

COE

MSA (MSA-C AND MSA-P)

- Poor Balance
- Slow Mobility
- Slurred Speech
- Light-headedness
- Bladder problems
- Stiffness
- Constipation
- Swallowing problems
- Sleep disturbance

UT SOUTHWESTERN MSA COE

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!!