

ATAXIA

**Psychological, Social, Behavioural and Ethical
Aspects of a Group of Rare Neurological
Diseases: Ataxias**

ONE PATIENT'S PERSPECTIVE



Seek a Miracle Ataxia Group

Ataxia :

- Ataxia is a lack of muscle coordination which may affect speech, eye movements, the ability to walk and other voluntary movements
- It's a progressive disorder and can be fatal
- Young children, adolescents and adults are affected,
- FRDA often has an early onset, with additional symptoms that need more attention.
- So far no cure has been found.
- Only defense is treating the symptoms
- Research and Education are needed



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Ataxia Causes:

- Inherited – Hereditary – Recessive and Dominant
 - Friedreich's Ataxia
 - Spinocerebellar Ataxia
 - Episodic Ataxia
 - Others
- Non Inherited - Acquired
 - Nutritional deficiency
 - Accidents, injuries
 - Exposure to toxins
 - Stroke
- Sporadic
 - Unknown cause with no family history



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PSYCHOLOGICAL & SOCIAL ISSUES

- Frustration, despair and helplessness
- Hesitation to socialize or mingle with others
- Dependence on others
 - ❖ Physically
 - ❖ Economically
- Due to drunk-like appearance, avoids going away from home.



BEHAVIOURAL ISSUES



The impact of ataxia on patients is reflected in their behavior .

Time bound activities often irritate the ataxian.

Ataxians sufferings are often invisible:

Anxiety

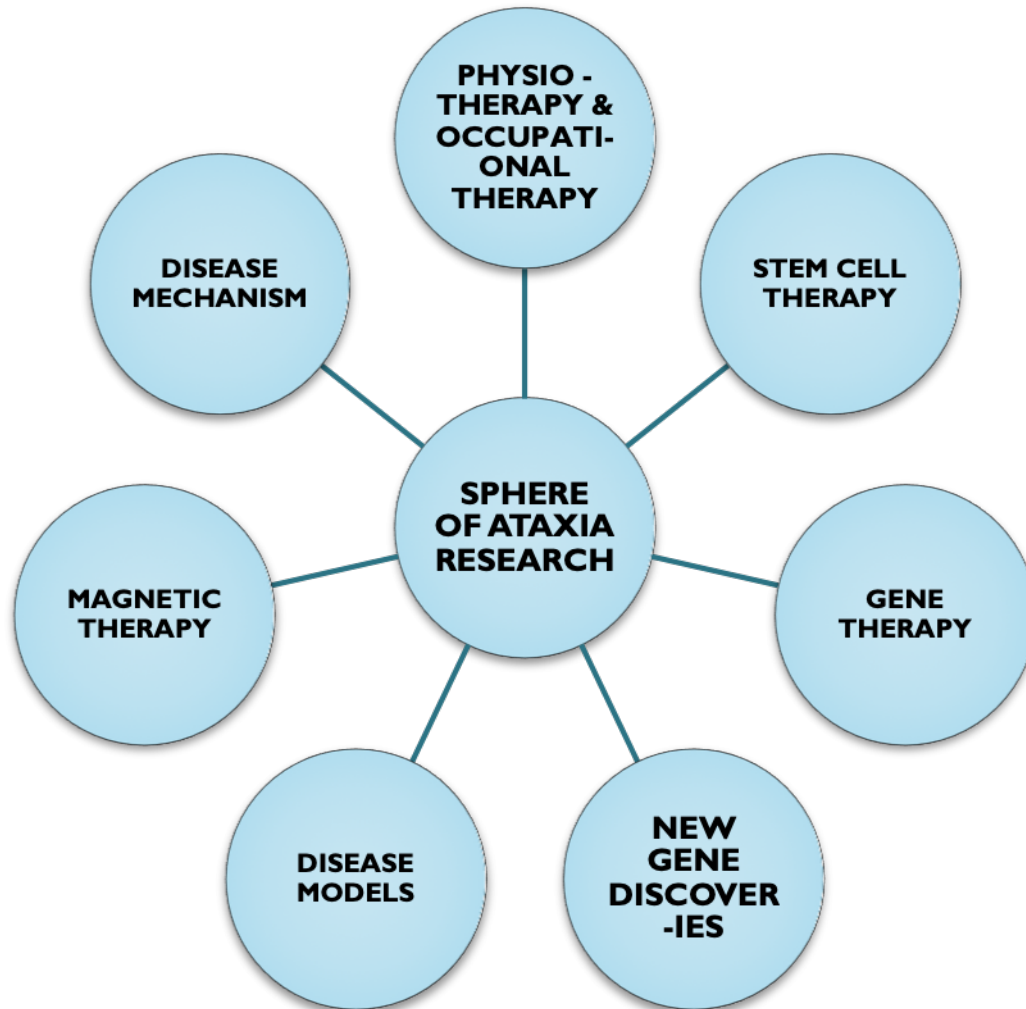
Depression

Muscle cramps/Pains



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Research Outlook



Research Outlook- Some Suggestions

- Ethical barriers on stem cell research, if any, should be relaxed for the benefit of ataxia population.
- Biomedical engineering approach to design devices to overcome imbalance and incoordination. (Balance Vests)
- Study of associated diseases should be made in relation to Ataxia.
- Open compassionate use of newly discovered drugs and make it affordable if the drug helps improve Ataxia condition .

Meet some Ataxians

- Name: Chandu George
 - Age: 38 years
 - FRDA
 - Hyderabad, TS
-
- From right to left
 - Krishna
 - Chandu
 - Vijaya
 - Hyderabad, TS



Things Needed to be Addressed

- Increasing Awareness of Rare Diseases and Ataxia in India
- Preparing a complete database of patients with Rare Diseases and ataxia in India.
- Enacting of Rare Diseases Orphan Drug Act and Help in facilitating clinical trials for ataxians
- Open Compassionate use of new drugs if the drug helps improve Ataxia condition.
- Help us to lead a life of dignity and economic independence
- Increase funding of ataxia research



I would like to thank

Durhene Wong Reider (CORD) Canadian Organisation Rare Disorders & (RDI) Rare Diseases International and Dr. Ramaiah Muthyala (IORD) Indian Organisation Rare Diseases for giving me this opportunity and platform to present.

Also I would like to thank my

Parents & Remembering my Late Sister

for their support and help .

Thank You

