



**FALA**

Friedreich Ataxia  
Lebanese Association

**FRIEDREICH  
ATAXIA  
LEBANESE  
ASSOCIATION**

# 01 ESTABLISHMENT OF FALA

**FALA - Friedreich Ataxia Lebanese Association -** (17068 /2018), is the first non-governmental organization in Lebanon and the region supporting people afflicted with Friedreich Ataxia (FA).





# WHAT IS FRIEDREICH ATAXIA (FA)?

FA is a recessive genetic neurodegenerative disease associated with neurological and cardiac symptoms, that leads to impaired muscle coordination and functional mobility.

## **SYMPTOMS**

- 1- Loss of balance, control and coordination (ataxia) in the arms and legs
- 2- Vision & hearing impairment and speech disorder
- 3- Gradual nervous system damage and muscle weakness
- 4- Heart conditions: Cardiomyopathy and Arrhythmia
- 5- Aggressive scoliosis
- 6- Diabetes mellitus (10-20% of cases)

## **FACTS**

- 1- The symptoms are not present in all individuals living with FA and their progression degree varies from one person to another
- 2- FA affects 15-20,000 people worldwide
- 3- The mental capabilities of people with FA remain completely intact
- 4- Most people with FA lose the ability to walk unassisted, 6-8 years after diagnosis
- 5- Everyone has the FXN gene. Those with FA have a mutation which silences the FXN gene reducing the protein frataxin which is essential to energy production

# 03 TREATMENTS & CURE

THERE IS NO  
CURE AVAILABLE  
FOR THE  
DISEASE YET,  
**HOWEVER**

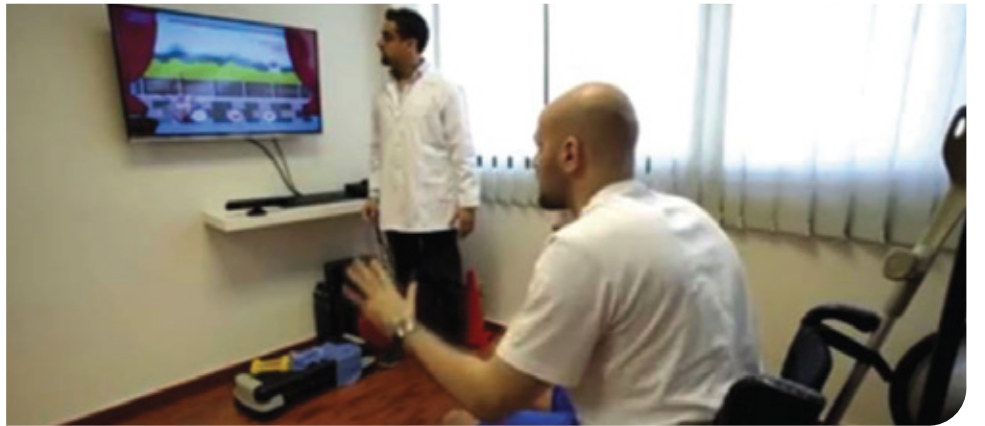
THERE ARE WAYS TO:

- 1- Slow down its progression
- 2- Manage its effects on mobility and function
- 3- Lead a better quality of life
- 4- Cope with FA

**THERE IS A RANGE OF TREATMENTS THAT MAY  
HELP CONTROL THE SYMPTOMS OF FA:**

- Physical therapy
- Functional training
- Hydrotherapy
- Speech therapy
- Psychotherapy

These therapies help FA patients manage their daily life and support their functional independence.







# 04 FA IN LEBANON

## FACTS



243

Only 243 Lebanese living with FA are registered at the Ministry of Social Affairs



!!!

No official record of the total exact number of FA cases in Lebanon exists

## OBSTACLES FACING FA PATIENTS AND THEIR CAREGIVERS:

- 1- Lack of awareness
- 2- Limited education (in underserved communities)
- 3- Absence of medical research and associations  
(The first to research and write about FA in Lebanon and the importance of physical reeducation is Kamal Al Kassir, doctor in physical therapy and FALA co-founder-  
“Prise en charge physiotherapique de l’ataxie de friedreich”)
- 4-Lack of informative communication tools
- 5- Absence of infrastructural facilities in public places
- 6- Poor inclusion in educational institutions and workplace

# 05 FALA'S GOALS



- 1- Provide support, orientation and awareness for FA patients and their caregivers
- 2-Guide FA patients and link them with medical doctors and therapists
- 3-Work with concerned parties including governmental authorities, educational institutions and companies to encourage FA patients inclusion
- 4-Deliver ergo-therapeutic services to FA patients and equip their houses to facilitate their mobility
- 5-Offer psychosocial support services for patients and their caregivers

# REFERENCES



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A photograph of a man in a wheelchair, smiling and looking back over his shoulder. The image is overlaid with a semi-transparent blue and purple gradient. The text "FEEL ALIVE" is written in large, white, sans-serif capital letters across the center of the image.

FEEL ALIVE

**IT'S TIME FOR FALA!**

You can be part of our support system too!

Visit our website [www.falassociation.org](http://www.falassociation.org)