COMMUNITY IMPACT REPORT

(Patient Voices on Fahr’s Disease)

Introduction

This report presents insights from a global survey of **165 people living with Fahr’s disease**, exploring their experiences of symptoms, diagnosis, and quality of life. It reflects responses from across North America, South America, Europe, Asia ans Oceania.

Key Findings

- **SLC20A2** is the most reported genetic variation.
- **CT and MRI scans** are the most common diagnostic methods for Fahr’s disease.
- Most patients recorded being diagnosed by a **Neurologist** or referred to one after initial diagnosis elsewhere.

Key Statistics

87% Report Severe Symptoms

41% Movement-related Difficulties

67% Worry about Future of Condition

Most Reported Symptoms

Symptoms chosen were those rated highest (4-5) on a scale of 1-5.

Fatigue 58%

Sleeping Difficulties 50%

Anxiety 50%

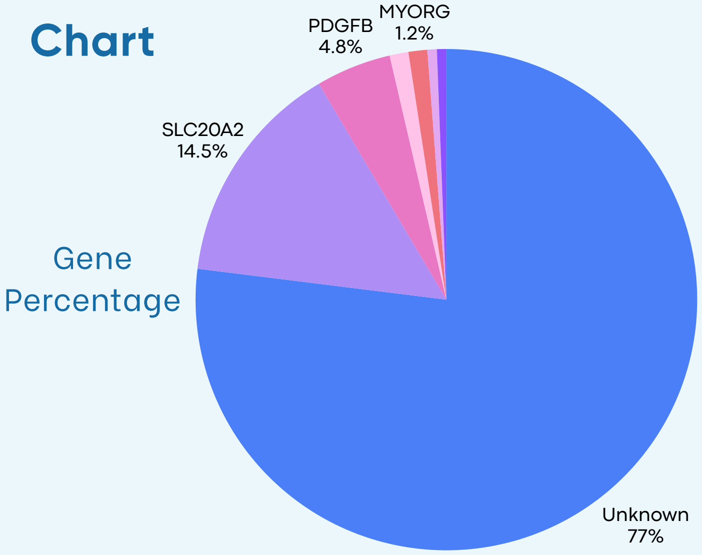
Thinking Difficulties 43%

Survey Insights

Reported Gene

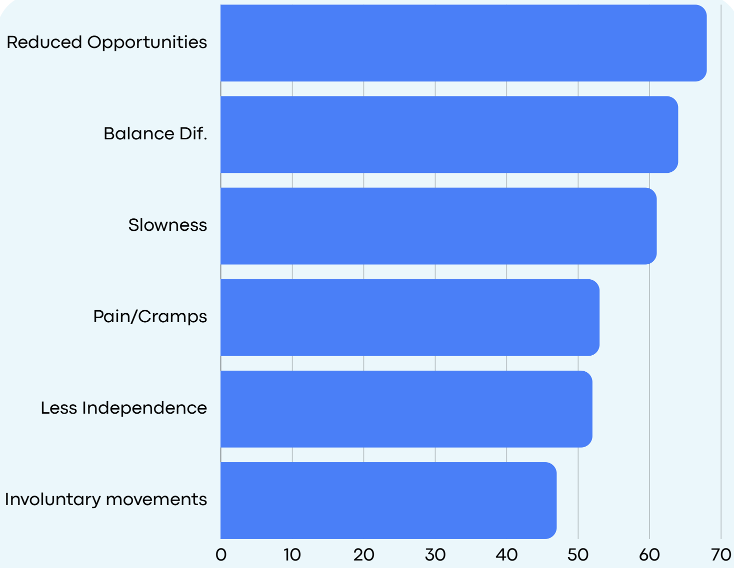
Out of 165 records, **77%** of participants reported **not knowing** what their gene mutation is. This could be due to only **40%** of participants being **genetically tested**, an potentially some tests being inconclusive. Furthermore, **SLC20A2** is the most frequentely reported gene at **14.5%**.

Chart

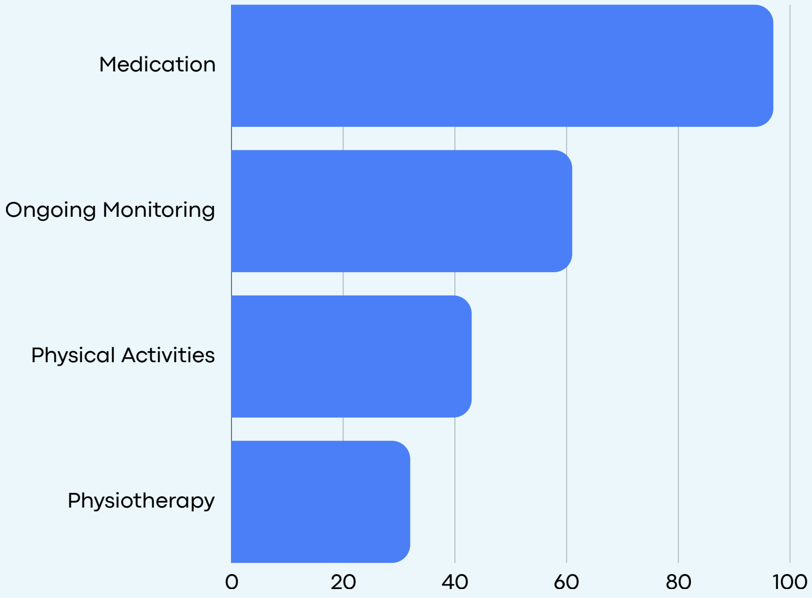


Symptoms

From the survey, **41.1%** of participants reported having **Reduced Opportunities** due to Fahr's. This could be due to motor difficulty symptoms such as **39%** having **Balance Difficulties** and **37%** experiencing **Slowness**. This also leads to patients feeling lonely due to increasing limitations in daily activities.



Managing Condition

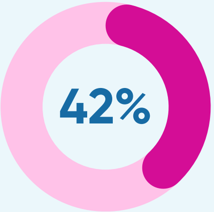


Medication is the most commonly reported management method **(58.8%)**, with far fewer patients using other approaches such as **Monitoring (37.0%)** and **Physical Activities (26.1%)**. Most other **supportive therapies** are used by **under 20%** of respondents, and few patients reported not using management strategies. This suggests that management of the condition is **largely medication-based**, with limited use of supportive or rehabilitative approaches

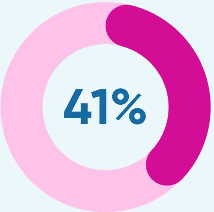
Support

Fahr Beyond

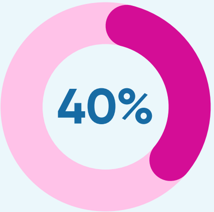
Top Suggestions



Patient Helpline



Patient Experience Videos



Research Conference

Main Concerns by You

“To give a diagnosis as soon as possible. It was 14 months before I was finally diagnosed.“

“Nobody seems to know about it.“

“The impact on daily life beside the symptoms in themselves. The emotional toll and the social aspects“

“Age, because I’m young I’ve been told it’s an older person thing, 60s plus“

“That just trying out meds sometimes makes me feel worst and doesn’t help .it adds more symptoms and limitations to my already going struggles and symptoms“

Further Suggestions		Current Available Support
Need for accessible information and education on Fahr’s disease.	→	Information leaflefts are available on the Fahr Beyond website.
Need for support for both patients and their carers.	→	Support group available at Fahr Beyond Facebook community group.
Acess to medical professionals and resources.	→	We connect with clinics globally, get in touch to find yours.

Thank You!

Thank you to all survey participants and supporters of the charity, your contributions are greatly appreciated and make a meaningful impact.