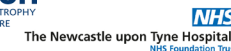




LGMDR9 Standards of Care
SATURDAY 25TH MAY 2024
Respiratory involvement and management in LGMDR9
Dr Robert Muni Lofra



What do we know?

- Disease progression
 - *Breathing difficulties are more common in people living with LGMD R9 than other forms of LGMD*

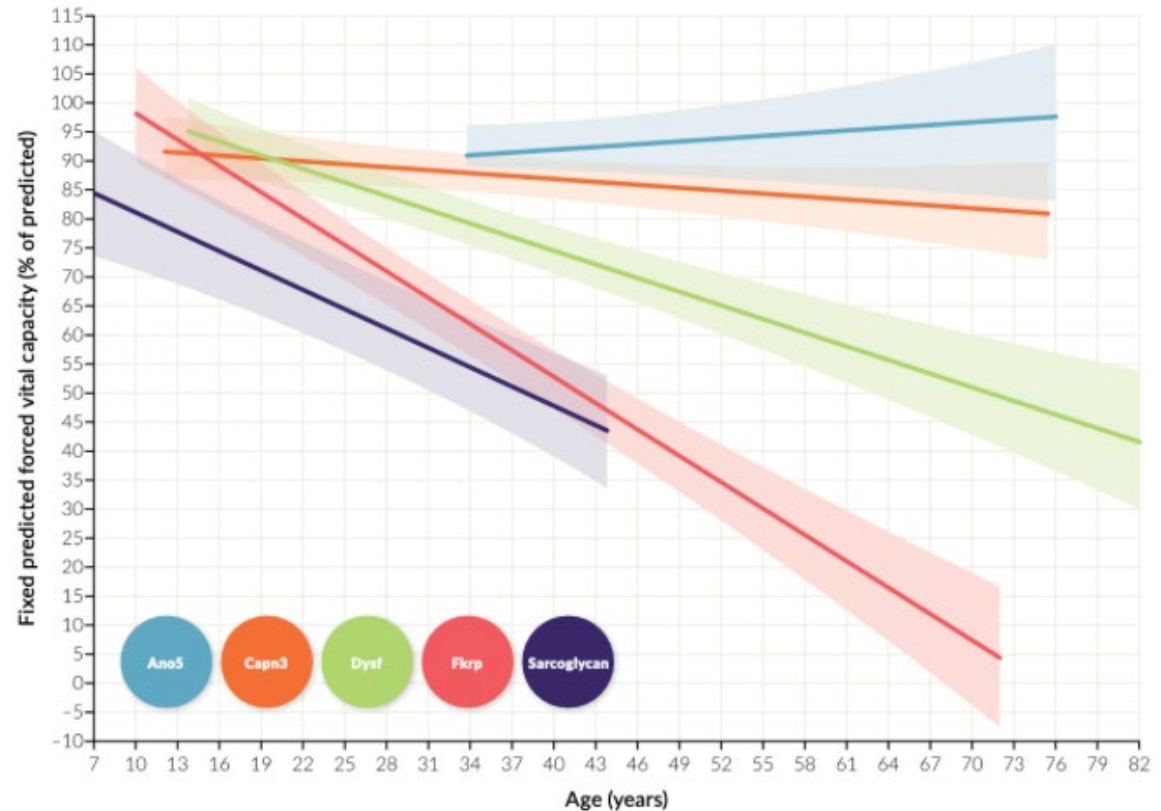
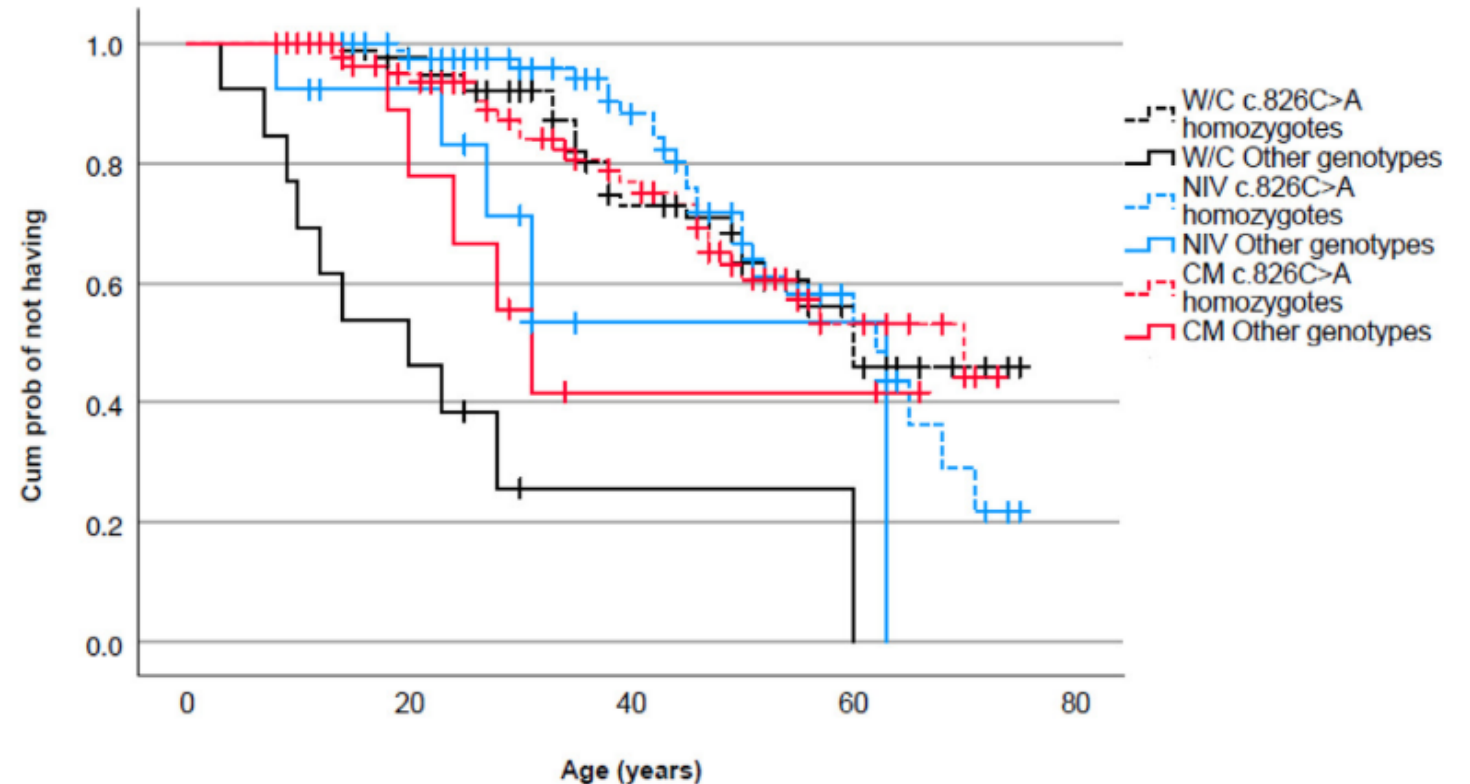


Figure 1: Progression of forced vital capacity percentage predicted values during the follow-up

Respiratory Management Guidelines

- Disease progression
 - *Having a specific genotype will result in later respiratory difficulties*



What do we know?

- Disease progression
 - *Difficulties clearing secretions can be part of the consequences of limited breathing capacity*

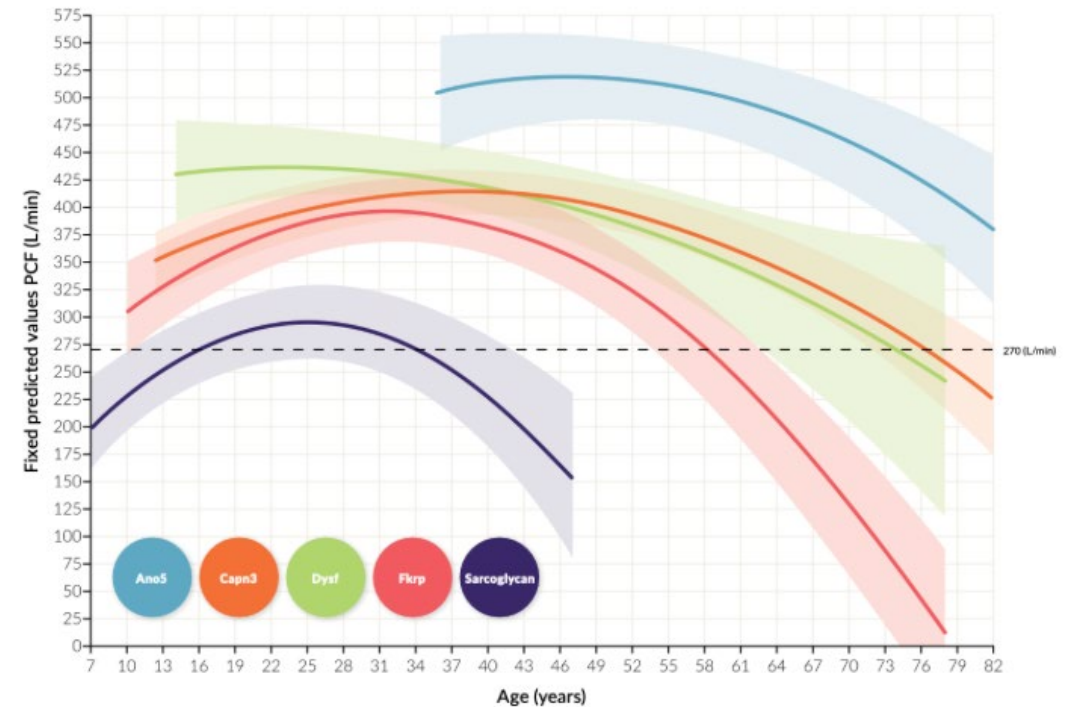


Figure 2: Progression of peak cough flow percentage predicted values during the follow-up

How can we monitor this?

Check your breathing function



- Symptoms:
 - Fatigue, headaches (specially morning), concentration difficulties, school/work performances difficulties, memory changes, shortness of breath, weakness, snoring/gasping/witness apneas, chest infections requiring hospital admission

Frequency

- At least once a year
- Every 6 months if you have any difficulties

What should we do?

- Stay active
 - Aerobic exercise
 - Breathing exercises
- Non-invasive ventilation
- Cough augmentation
 - Secretion management



WITH THANKS

