

# Dermatomyositis

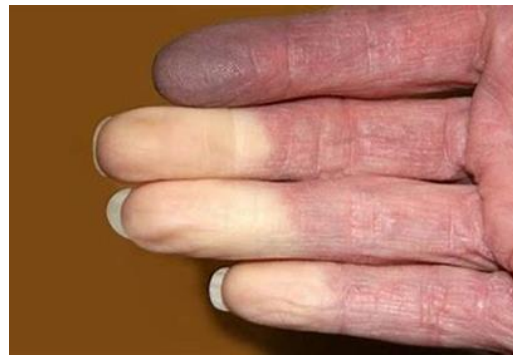
Hello!

I'm Ingrid de Groot

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## ***First symptoms:***



○ ***Heliotrope eyelids, inflammation nailfolds and rash knuckles***

○ ***Severe Raynaud's with ulcerations***

○ ***Sicca symptoms (dry mouth and eyes, later diagnosed as Sjögrens)***

○ ***Muscle weakness upper arms and thighs***

○ ***Fatigue***

○ ***Prolonged recovery time after exercise. muscle pain***



## **Diagnostic journey:**

*GP -> after 1 year (trying creams and AB)*

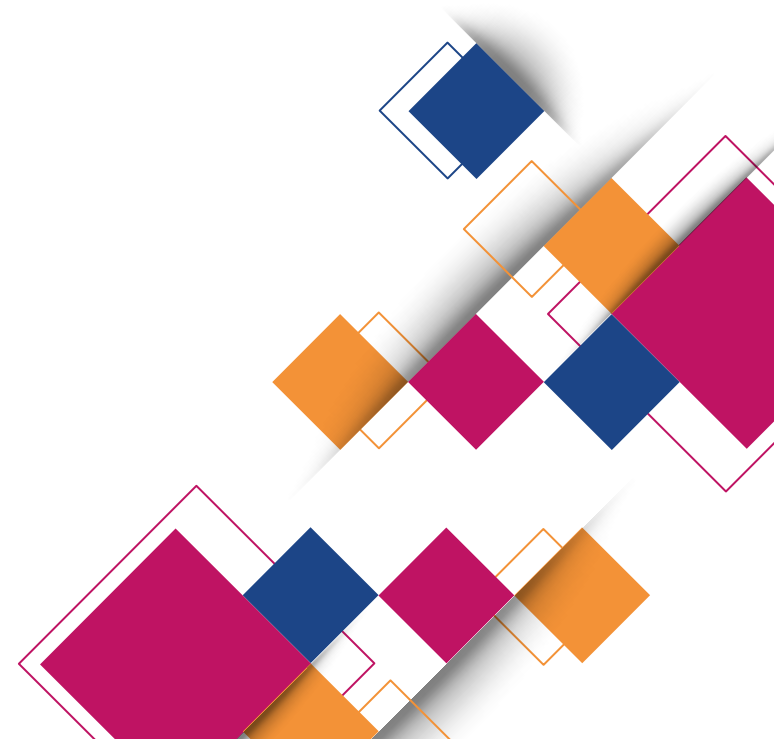
*Dermatologist -> skin biopsy (SLE or DM?) ->*

*Rheumatologist: high levels CK and ANA etc. -> DM*

*Neurologist for 2<sup>nd</sup> opinion: proximal muscle weakness ->DM*

## **Disease course (despite medication)**

- *Foot drop*
- *Muscle weakness in neck*
- *Dysphagia*
- *Diaphragm weakness -> night ventilation!*

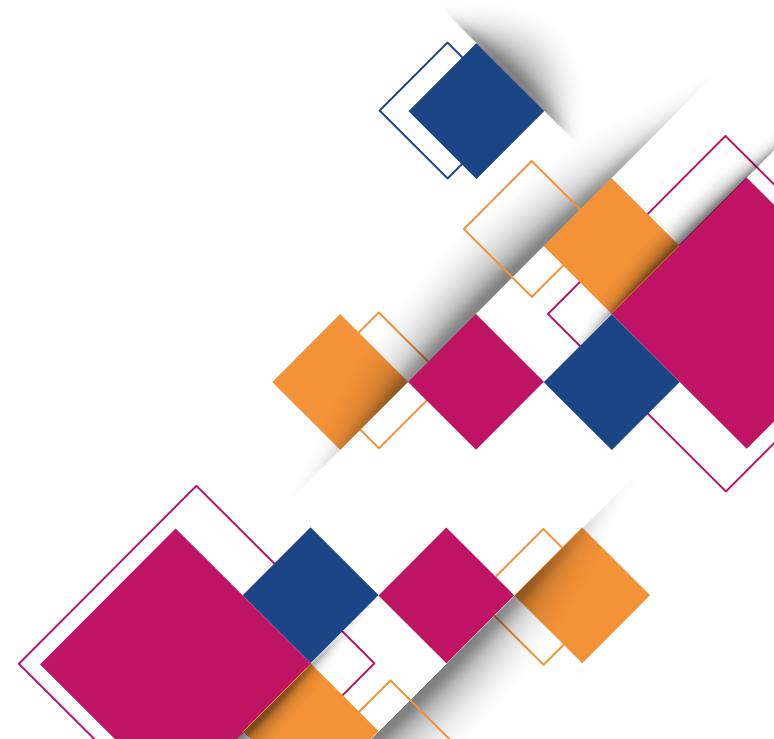


## ***Challenges & most impactful consequences:***

- Impact on private life!*
- Night ventilation (an intimacy nightmare!)*
- Multiple hospital admissions due to severe infections/ suppressed immune system*
- Loss of paid job = social, emotional and financial impact!*

## ***On the bright side:***

- ★ Found new ways to live happy and meaningful life!*
- ★ Learned new skills, met new people, traveled places*
- ★ Patient research partner & patient advocate*



# Dermatomyositis over the years



# Food for thought:

**Shortness of breath in DM?**

***Please consider diaphragm weakness!!***

