



Overlap Myositis

Hello! I'm Silke Schlüter.

Bad Salzungen, Germany

Diagnostic Odyssey:

1990: Diagnosed with autoimmune hepatitis & liver cirrhosis at the age of 14.

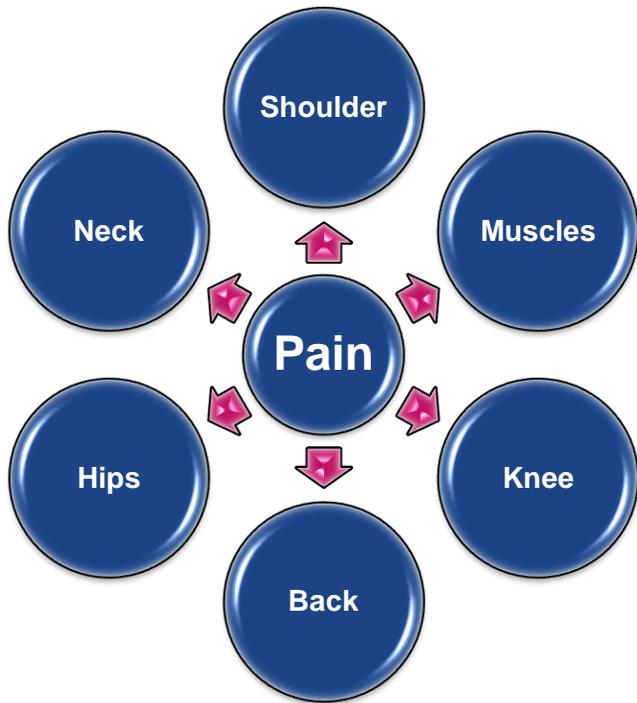
Treatment: glucocorticosteroids, azathioprine

1995: Hip pain and red spots in the face – suspected diagnosis of a rheumatologist = systemic lupus erythematosus (SLE). Another rheumatologist excluded SLE in the next month.

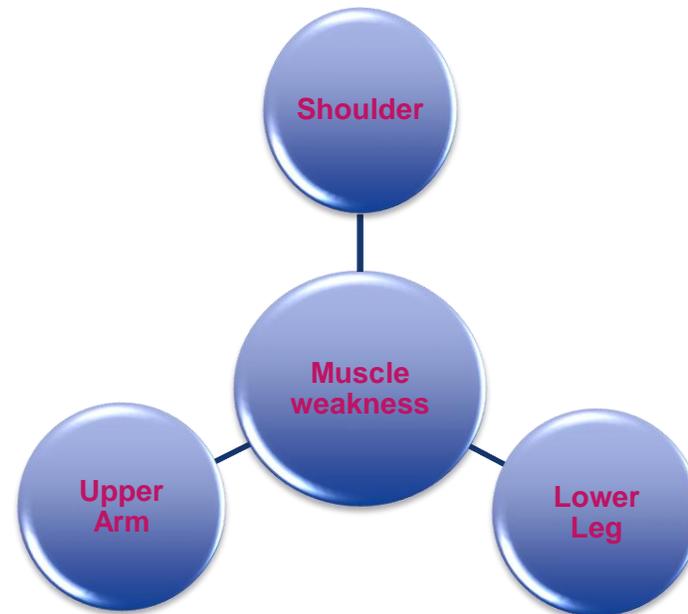
Over the next few years, appointments with various orthopaedists, rheumatologists and neurologists due to increasing symptoms.

Diagnostic Odyssey:

2004:
Pain



2011:
Muscle weakness:



2012:

New suspected diagnosis
after muscle biopsy:

Polymyositis

Additional treatment:
intravenous
immunoglobulins



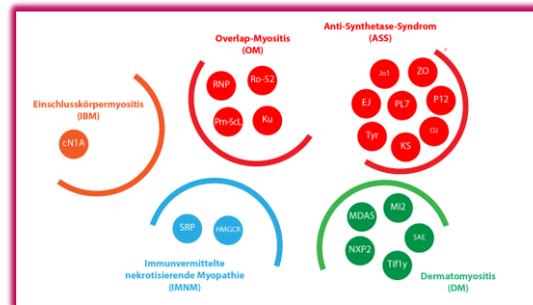
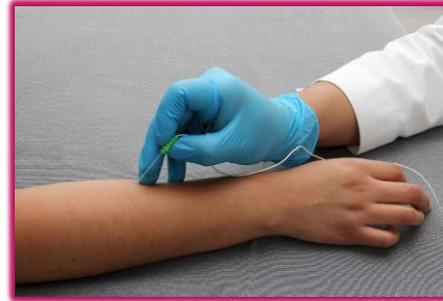
Diagnostic Odyssey:

2015:

More symptoms:

- Additional muscle weakness:
 - Limb girdle, neck, thighs
- Double images
- Swallowing problems
- Shaking and twitching of the muscles
- Slurred speech
- White fingers
- Ptosis left eye

- Change of hospital
 - Additional & repeated tests



Results:

Disorders:

Overlap Myositis:

- Autoimmune hepatitis
- Myositis
- Autoimmune gastritis
- Barrett's Esophagus
- Raynaud's Syndrome
- Polyneuropathy
- Autoimmune thyreopathy
- Mixed connective tissue disease
- Myasthenia Gravis (?)
- Sjogren's syndrome

Tests/Values:

Positive or abnormal:

- Ro 52 & SS-A Antibody
- Acetylcholine Receptor Antibody- AChR
- Potassium Channel Antibody
- TG & TPO Antibody
- Parietal cell & LKM 1 Antibody
- Schirmer Test
- Capillary microscopy
- Nerve conduction velocity measurement (left leg, right arm & left face)
- Repetitive nerve stimulation
- Myosonography
- Esophagus barium swallow exam
- Flexible endoscopic evaluation of the swallowing act

Negative:

- CK-level & CRP
- EMG
- MRI

Not clear:

- Muscle biopsy



Living with myositis:

- Acceptance with a positive attitude - every day is a new day!
- Coping with activities of daily living (meeting friends, doing housework, visits to the therapists, doctors, etc.)
- Coping with the side effects of medication
- Coping with the false expectations of the environment (one often seems "healthy")
- Allocation of resources of energy (e.g. showering OR dishwashing, etc.)
- Follow drug and non-drug therapy instructions
- Use of aids like walker, wheelchair etc.
- Pay attention to mental health
 - Do hobbies and have fun - > if no longer as a motorcyclist, then as a passenger



How can I help other patients with myositis?

Seeing a purpose in my own illness.

- 2014: Start to volunteer in the German Myositis Group in the DGM
- Since 2016: Chair of the German Myositis Group
- Since 2019: Treasurer of the International Myositis Society - iMyoS
- Since 2020: Federal Board member of the German Society for Neuromuscular disorders (DGM)
- Since 2021: Treasurer of the MYOSITIS NETZ e.V.
- Since 2023: ePAG at ERN ReCONNET
- Since 2023: Member of the muscle disease group at ERN-Euro NMD
- Since 2023: 2nd Chair of the German Society for Neuromuscular disorders (DGM)



Activities:

• **Initiating & Implementation:**

Facebook & Instagram Accounts, Myositis podcasts, Explanatory myositis video, Myositis handbook for patients, Webinars Patient days, Symposia, Monthly online meetings, Charity runs

• **Part of:**

Myositis guidelines, Editorials, Surveys, etc.



What I wish healthcare providers note about (overlap) myositis.



Living with Overlap Myositis is → like a rollercoaster ride

- Every day is a challenge. No two days are the same, with many ups and downs.
- Myositis is a rare multi-system-disease → Early diagnosis and interdisciplinary care is crucial!
- Symptoms and overlapping diseases can change every time
- The CK value can be NORMAL despite weakness and pain
- Antibodies, EMG, MRI and other results may be negative
- Antibodies can appear after years
- Listen to your patients carefully and seriously!
- Always think of myositis when making a diagnosis - even if it seems very unlikely:
→ Sometimes the clattering of hooves does not indicate horses, but zebras.



**Thanks
for your attention!**



Do you have any questions?

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