



# Martina

MPA patient

Primary disease presentation:  
Kidneys

## Day-to-day living

- Lives in Germany and is a single mother with two young children (3 and 9 years old)
- Is a kindergarten teacher, but had to quit her job due to infection risks and now works part-time as a physiotherapy studio receptionist
- Social media activities include her Instagram ANCA vasculitis blog: @martina\_vaskulitisblog

## Disease history

**First symptoms:** Flu like symptoms, headaches and tiredness diagnosed as a viral infection. Went back to the GP several times but was repeatedly told it was a viral infection. One day it got so bad she had to go to hospital

**Family history:** Her brother died a year before she was hospitalised. The doctor told the family it was related to organ failure. Due to her brother, she had the courage to speak up and seek better support

**Delay to diagnosis:** Several years from first symptoms to ending up in A&E. Fortunately, a rheumatologist was present in the hospital and diagnosed MPA. Tests showed her kidney function was very poor. Nephrologists took good care of her and prevented her from needing dialysis

**First treatment:** Double dose of rituximab + high dose of glucocorticoids (steroids). Rituximab did not appear to be effective at first, so cyclophosphamide was administered between doses. After 12 weeks of rituximab, efficacy occurred. The high-dose steroids also led to weight gain and water retention

**Maintenance therapy:** Rituximab keeps her in remission currently. After each dose she needs to sleep for 2 days, feels nauseous and experiences mood swings. Her work life was also affected as she was recommended to stop working as a kindergarten teacher

**Help:** Web/social media interactions with other ANCA vasculitis patients help her cope with the situation. Although she has fewer friends since being diagnosed, those who remain are reliable and often look after her and get her away from her everyday life

**Today:** Glad about the alternative job offer she received – being able to work part-time and having a boss and colleagues that understand her situation and support her

## In her own words

### Symptoms:

"I was sent back home from the doctors many times and told 'This is a flu – be patient it will be better'."

### Initial side effects of treatment:

"I had to stop my initial treatment because it affected my kidneys negatively. I put on loads of weight and swelled up from the high-dose steroids."

### Long-term effects of ANCA vasculitis:

"I can no longer work in my profession as a kindergarten teacher. I had to look for a job where I was less exposed to infection and could work part-time."

### Personal advice:

"If you feel sick and it is not getting better, don't let them send you home. Ensure they check you over properly."

### Patient support groups:

"There are local patient support groups available. I like to use social media such as Instagram and Facebook. I connect with the patient support group Selbsthilfe Vaskulitis e.V. via Facebook. The connection with others helps me to cope with my disease better."

### Personal goal:

"I am a young mother – I want to take care of my boys and see them grow up."

“If you feel sick and it is not getting better, don't let them send you home.”

ANCA, anti-neutrophil cytoplasmic antibody;  
MPA, microscopic polyangiitis

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