

**Patient panel : the voice of the patients during the International  
Symposium Sjogren's Syndrome  
Washington DC  
April 2018**

Three patients, from The Netherlands, UK and USA were invited to speak on the podium during the opening session international symposium. The session was moderated by Steven Taylor, CEO of the Sjögren's Syndrome Foundation in the USA and it was an honor for the patients to be so highly regarded at the start of the congress! And how interesting and informative for the other participants of this symposium - researchers, doctors and other visitors to hear and learn from the patient perspective.

The main topics they talked about are summarized here under:

1. Finding the **right rheumatologist**, someone who knows and understands Sjogren's and doesn't think "it's just dry eyes and mouth" is difficult.
2. The patients have to struggle with the **lack of knowledge** about the management of the disease and with the **lack of treatments**.
3. The burden is very heavy:  
**Economic burden** because most of the absolutely necessary products to compensate the dryness are not reimbursed. Many doctor and dentist visits, as well as dental procedures, are not covered. Sometimes, you have to hire people to help with tasks you cannot do anymore because of fatigue, pain or disability. The income from a job can be missed too, because you cannot work or cannot get the promotion you could get otherwise.

**Burden in terms of time** because it is very time consuming to use, everyday, all the products necessary to relieve dryness, to start moving painful limbs, to fight against fatigue and brain fog and to visit health professionals.

**Emotional and social burden** because fatigue prevents you from doing what you have or would like to do. Fatigue is not understood by friends or family because it is invisible. You're always worrying about managing your personal life and you have difficulties with self-esteem. For a young patient: How do I handle dating? Will I be able to have a healthy child? How will having a child affect my disease? Will I have the energy to take care of a child?

Even severe organ involvement is not visible and thus misunderstood by family and friends.

The risk of developing lymphoma or other cancer is a constant worry.

One thing that Sjogren's patients know is that there are no breaks from the disease. Sjogren's is with them every hour of every day and every week. **There are no vacations**

**from Sjogren's.** To cope, you have to learn how to manage Sjogren's, take control of it and learn your limitations.

4. **The patients now play their part in research, they become partners.** This is good news!