

## Video letter, HPV Symposium Tokyo, Nov. 23. 2015

by Charlotte Nielsen, Denmark.

Hello. I'm Sara. I'm 15 years old. I've been injured for almost three years.  
Hello, I'm Sara's mom.

At the age of 12, Sara was in good health, active in music and dancing.  
Short after two vaccinations with the Gardasil HPVvaccine, she got seriously ill.

It's been a battle to gain recognition of the severe side effects.  
Parent activism, social media, TV and newspapers' interest slowly opened up a public discussion with politicians and health authorities.

Patient groups are organizing all over Europe like in Spain, Denmark and recently in Ireland.

Officially over 1800 Danish patient cases of side effects have been reported so far, by September this year.

Sara's case was among hundreds of others classified "serious" by Danish Health Authority.  
But there was no treatment...

Our networking with foreign doctors has led to relevant testing and treatment, which brought some recovery for Sara. Some other Danish families went abroad as well.

Sara was diagnosed POTS by the Syncope Center at Frederiksberg Hospital.  
Apart from guidelines for this condition, there was no further help available in Denmark.

A Swiss medical clinic did help Sara, and her Swiss doctor tells, there's a clear cut connexion between the HPVvaccine and Sara's illnesses. She needed essential substances, just like some Danish and German patients with similar injuries.

Recovering is a long and complicated process. Like other families we have to cover all kinds of costs.

Sara has suffered from over 30 symptoms.

Soon after the first shot she felt unwell for weeks, beginning with high fever and rash of her body.

Two days after her second vaccination with Gardasil she suddenly passed out, followed by near syncope. She was dizzy, had nausea, tingling and burning sensations and strong muscle pains. She was exhausted and could hardly go for a short walk.

A constant head ache developed. All (MRI and CT) scans were normal. The head ache has lasted over two and a half years.

Severe fatigue continued as well.

Her temperature regulation was disturbed by night sweats and chills.

More skin rashes appeared like small red spots on her arms and red stripes of the legs. Wounds in the mouth, tooth pain, ear pain (no infection) and various joint pains appeared. Tingling symptoms from the bladder but no infection.

Abdominal pains, low appetite and weight variations lasted for a period.

Relaxed and calm she could be short of breath or have a rapid heart beating. Sleep disturbances were due to pains.

Over the following months Sara had other severe symptoms like twitching legs, painful muscle cramps and a walking disability. She could only walk about 100 meters, very slowly at pain, with burning feet. Her muscle power decreased, and even a little exertion was exhausting.

She could not lift a glass of water. Her skin and muscles were sensitive to any pressure, even a washcloth on her face would hurt.

She could not stand in a shower or wash her hair.

She could hardly sit on a chair and had most of her meals in a relax chair, where she spent most of her day, listening a little to sound books or music. She couldn't read any longer, she became sensitive to light, and noise around her is still exhausting.

Other major symptoms are low concentration, memory problems and confusion.

She had problems finding the words. Severe learning difficulties and physical symptoms made her unable to go to school for over two years till now.

Her former social life changed into almost social isolation.

Her walking function improved amazingly, and she got more energy over time thank to her Swiss treatment.

Horse riding therapy improved her muscle power and balance.

Pathways of music help her learning. She copes with a few school lessons at home.

Recently Sara began to join a youth choir.

However, we have no prognosis and no guarantees of a full recovery.

This has been like a never ending night mare.

The challenge is how to find treatment for those, who are already injured, and how to prevent future victims.

Thank you very much.