

Petition 0204/2019 Speech Evelien van den Brink

President Montserrat, Members of the Committee on Petitions, thank you very much for your invitation. I'm honored to be here.

I would also like to thank Francis Martin for his brilliant help and support - #MEAction, Ben and Espe in particular - my parents - and the Red Cross.

I'm very grateful to everyone who supported the petition and helped to make this a success.

The fact that I'm here is a miracle in itself. For years I was unable to speak or get out of bed. Despite the severe limitations that I still have today, I'm very glad to be alive. I survived. Not all patients are this lucky. We have lost some wonderful members of our community to this disease.

The disease is sometimes called 'invisible'. That is true to some extent. Chronic diseases can be quite invisible to outsiders. But with ME this is only up to a certain level; at that point it becomes very visible. The disease has been described as a living death.

(PHOTO 1) This is Whitney Dafoe, the son of Janet Dafoe and Ronald Davis, Professor of Biochemistry and Genetics at Stanford University, a renowned scientist who was involved in the Human Genome Project. (PHOTO 2) He has been working tirelessly to cure his son's disease.

(PHOTO 3) This is Alison Hunter. She was a vibrant girl, full of life. She was only 14 years old when she died of complications of ME.

(PHOTO 4) This is Mark Vink. He was a doctor who ran marathons. (PHOTO 5) Now walking to the bathroom is harder than any marathon he ever ran.

(PHOTO 6) This is me at one of the worst moments. I've been sick for more than 20 years. (PHOTO 7) This is me as a child. I cherish the memory of my healthy life. Once I rode an unsaddled horse.

In this grade of severity ME is only invisible if people purposefully look away. And this is what has happened. Patients have suffered in silence.

The fact that the cause of the disease isn't understood and there is no diagnostic test has created a terrible stigma. Almost all of us have at least once heard the empty phrase; 'it must be all in your head'. ME patients have been treated shamefully because of misconceptions and the terribly inadequate funding that hampered scientific progress.

Cancer was once thought to be caused by 'the suppression of bad thoughts', MS was called 'hysterical paralysis' and AIDS was believed to be caused by 'the stress of being gay'. Thankfully times have changed. This change was made possible by science - not silence.

And that's why I'm here today. To ask you to fund biomedical research on ME. We need to be able to diagnose this disease as soon as possible and make sure patients get access to biomedical treatments.

Scientists have made a lot of progress in the past few years thanks to private funding and public funding that was made available in the United States by the NIH. The major US universities have special research groups. There are clear findings and a clear path forward.

I am convinced that we as Europeans can do much more to solve this neglected disease. We have brilliant scientists, eager to get to work, but they need funding. This will take a long term commitment with structural equitable funding and a comprehensive strategy.

This is not just an ethical and humanitarian question, it will also have a positive economic impact if patients can recover their health and they - and their caregivers - can go back to work.

I have faith in Europe and our common values of equality, justice, and fair chances. I'm absolutely sure that we can make a substantial contribution to solving ME if we put our minds to it. On behalf of all patients I'm asking you; please don't look away. We are here and today we have made ourselves visible. Please help us to get back to our lives. With hope and determination we can solve this together.

Thank you very much!

:-:-:-:-:

Photo 1:

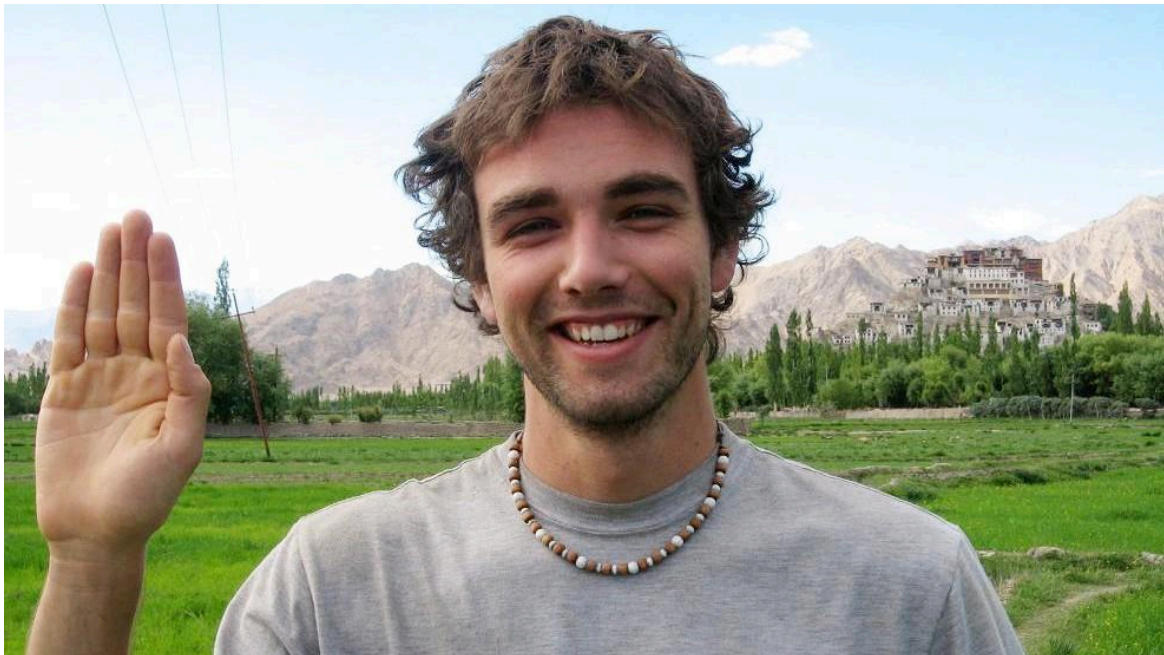


Photo 2:



Photo 3:



Photo 4:



Photo 5:



Photo 6:

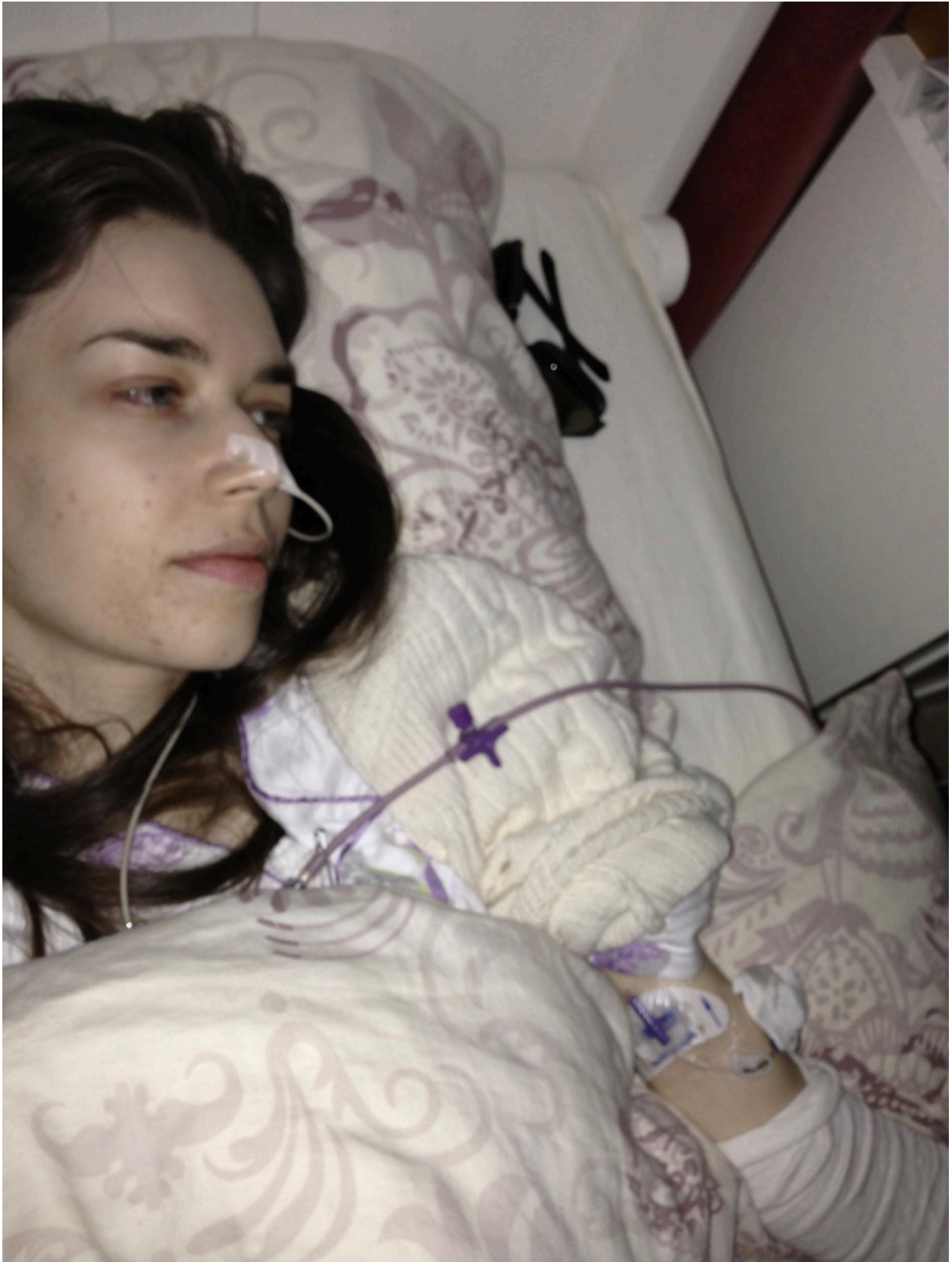


Photo 7:



:~::~:

I would like to thank everyone for their contributions and support. I'm very grateful that you have listened and that it has become clear that the need for change is enormous. This is so important to so many people. I hope this meeting and this historical moment will get a positive follow-up, so that change will really take place. Let us turn this hope into deeds, into concrete action that will improve the lives of many.

Thank you very much! I'm very appreciative.

:~::~:

The recording of the meeting can be found here;

<https://www.europarl.europa.eu/ep-live/nl/committees/video?event=20191003-0900-COMMITTEE-PETI>

The part about the ME petition starts at 1:12:50 and ends at 1:32:33.

Click the speech balloon bottom right in the video to select the language that you want to hear.