Speech, 11 May 2024, Freiburg: https://www.youtube.com/watch?v=c453oJ5Ebj4

Ladies and gentlemen,

Spring is finally here – how lovely! Except for my son Jonas. For him, everything is dark and dreary, even right now – at this very moment. He is now lying in his nursing bed, as he has been for almost 10 years. He is now 27 years old. Light and noise cause him pain. He is fed artificially, as he cannot swallow. Jonas is fully conscious, but cannot speak and communicates with us by tapping his hands.

Nine years ago, I told our GP that I couldn't manage to care for him round the clock any longer. Back then, he was in terrible pain all over his body and kept me awake many nights. I don't have a 'caregiver's syndrome' either. So we looked for a care home for Jonas. But there aren't any! Not even today! Nowhere takes his extreme sensitivity into account. No one has time for the intensive care he needs. Because it isn't paid for and because carers and doctors have no idea about ME/CFS.

So we're not caring for Jonas by choice – we're forced to. The alternative would be his death. How do I know this? Because I've seen what happens otherwise:

Almost 10 years ago, Jonas was admitted to Freiburg University Hospital – just over there, only 2 km from here!

They tortured him there for a month. Because they suspected he was suffering from depression and wanted to break his resistance. Even though Prof. Scheibenbogen from the Charité personally explained ME/CFS to the doctors. It was all to no avail.

He was in such excruciating pain that he wished for a coma – at least for a day – which was interpreted there as a desire for suicide. He was denied a single room so that Jonas couldn't 'shut himself off'. One treatment after another was administered relentlessly. Always chop, chop, chop.

They almost starved him to death – a tall lad like me – down to 41 kilograms!

When we finally managed to get him out of hospital with a feeding tube, he was more dead than alive, with an antibiotic-resistant infection and five pressure sores. In the end, he could only move his little finger. Our GP said he feared for our son's life. – We eventually managed to get him out of that life-threatening situation.

That was a long time ago. Yet even in recent years, ME/CFS patients have repeatedly faced such horrors. Either they encounter a complete lack of understanding of ME/CFS, or they are treated like flat-Earth theorists at a physics conference. They could present a Nobel Prize for ME/CFS research – many doctors wouldn't even look at it... and still claim that it's all psychological.

But one thing is also clear: without doctors, there will be no solution for ME/CFS patients. Sometimes it is even the very same doctors who champion their other patients in an exemplary manner, yet at the same time treat ME/CFS incorrectly.

With other illnesses, too, it often took a long time for new findings to finally filter through into practice.

So do we just have to wait? Be patient?

No! We won't endure this nightmare for another 10 years.
10 years without a holiday, without a weekend. Just care and work. And one nerve-wracking drama after another involving Jonas.

And I have heart problems, back problems – four years ago I had a slipped disc. Back then, my wife was still able to step in for me. She herself has been suffering from ME/CFS for 20 years. But now she's so unwell that she can barely manage any caregiving tasks. If I were to be unable to work now, Jonas's care would collapse like a house of cards. It's no use to us if things change at some point in the future – it has to happen now!

Who's going to do it? You!

By that I don't just mean you who are standing here in front of me. But also you who are listening on Facebook, Instagram or YouTube. You, our whole society.

If you know people who have influence over the healthcare system – doctors, health insurance staff, politicians, managers – then talk to them about the terrible plight of ME/CFS patients and ask them what they are doing for these patients.

If you yourself are subjected to a glaring injustice: stand up for yourselves and seek help! We must no longer put up with everything!

And here's what each of you can do: offer help in everyday life. Just like my colleagues, relatives, friends, our brilliant GP, and the support groups.

Without this network, we wouldn't have survived the last 10 years.
When we suddenly had to move recently, two colleagues were there to help, from one day to the next.

And over the last two or three years, I've noticed that things are finally starting to change:

Since then, we've received tremendous support from the Social Services Department here in Freiburg, from the job centres, the magistrates' court, the tax office and my health insurance provider. They even amended a doctor's letter for Jonas. The false claims were removed from it. – But these things never happened by themselves. I was always busy for many hours, sometimes for weeks or even months on end. – I can't do any more than that.

But if there is now a little more pressure and awareness – from you, from society – then things will change, everywhere.

Donations are being collected here for the ME/CFS Research Foundation. Why is research so important?

Nine years ago, Jonas felt much better for a whole year – a course of treatment had worked wonders back then. Jonas was like Sleeping Beauty – awakened by a kiss. In a short space of time, he went from the worst state he'd been in for 10 years to the best! He could speak again, eat a little, and was already making travel plans about who he would visit first once he got out of bed. Unfortunately, it never came to that. - But it showed that really, all it takes is for a switch to be flipped somewhere – and everything would get back on track, would work again – he could become completely healthy once more!

Recently, there have finally been small steps of progress with Jonas again. His extreme sensitivity has lessened. He has recently started listening to music again. Just one track a day. He lets us know what he wants to listen to by tapping his hands. Once he wanted a very specific track by Benjamin Francis Leftwich, on a particular album – in a specific playlist on his 10-year-old Spotify account – by the time I'd figured it all out, three hours had passed. And then – finally – 4 minutes of ethereal sounds. It seemed to me as though Jonas was soaking up every single note and comparing it with his 10-year-old memories.

It actually brought tears to my eyes. Because I was so impressed by this incredible willpower and positive outlook on life – despite all those dark years trapped inside his own body!
And this man was accused of being depressed! What utter nonsense!!!
And it was Jonas's willpower that is the reason I'm standing here in front of you today. Not because I enjoy speaking in public. No, Jonas wants us to take action so that something finally happens in research and care. And Jonas is not an isolated case. We live in Denzlingen. Even in the neighbouring towns of Emmendingen and Waldkirch, there are young people just as ill as he is. There are thousands of cases like his in Germany.

And they all want just one thing: to get out of their beds and into life.

Please help make this a reality at last. Not someday. Now!

Thank you.

Common thread

Jonas's condition: on artificial feeding, unable to speak, etc.
We have to care for him at home because there is no support available
What happens if we don't: Jonas's disastrous mistreatment at the University Hospital in 2014
Even today, people with ME/CFS are often not treated any better
And yet: Without doctors, there is no solution for ME/CFS sufferers
Must we simply be patient until something changes, as was the case with other illnesses?
No, we cannot endure this for another 10 years! Something must change now!
Who should bring this about?
You! Not just you here, but listeners, viewers, society as a whole
Stand up for yourselves when you are subjected to blatant injustice
What absolutely everyone can do – help in everyday life
Without our network, we would not have survived the last 10 years
Things are slowly changing: positive experiences with authorities and others
A little more pressure is needed, then things will change everywhere
Research – why we know that ME/CFS can be cured
Outlook and hope for more than just one piece of music a day...