



# *Invest in ME Research*

# NEWSLETTER



## January 2018 Newsletter

Welcome to a special January 2018 newsletter from Invest in ME Research.

### **Farewell to a Friend**

### **Anne Örtegren**



"Nobody can say that I didn't put up enough of a fight."

"Sadly, for all the work done, we still don't have adequately sized specialized biomedical care for ME/CFS patients here in Stockholm, Sweden – or hardly anywhere on the planet.

"We still don't have in-patient hospital units adapted to the needs of the severely ill ME/CFS patients.

"Funding levels for biomedical ME/CFS research remain ridiculously low in all countries and the erroneous psychosocial model which has caused me and others so much harm is still making headway.

"And sadly, for me personally things have gone from bad to worse to unbearable.

"I am now mostly bedbound and constantly tortured by ME/CFS symptoms.

"I also suffer greatly from a number of additional medical problems, the most severe being a systematic hyper-reactivity in the form of burning skin combined with an immunological/allergic reaction.

"This is triggered by so many things that it has become impossible to create an adapted environment.

"Some of you have followed my struggle to find clothes and bed linen I can tolerate.

"Lately, I am simply running out. I no longer have clothes I can wear without my skin "burning up" and my body going into an allergic state. This means I no longer see a way out from this solitary ME/CFS prison and its constant torture.

"I can no longer even do damage control, and my body is at the end of its rope. Therefore, I have gone through a long and thorough process involving several medical assessments to be able to choose a peaceful way out: I have received a preliminary green light for accompanied suicide through a clinic in Switzerland.

"When you read this I am at rest, free from suffering at last. I have written this post to explain why I had to take this drastic step.

"Many ME/CFS patients have found it necessary to make the same decision, and I want to speak up for us, as I think my reasons may be similar to those of many others with the same sad destiny.

"These reasons can be summed up in three headers: unbearable suffering; no realistic way out of the suffering; and the lack of a safety net, meaning potential colossal increase in suffering when the next setback or medical incident occurs."

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These are the words of Anne Örtegren - a dear friend of the charity - a kind, caring, dedicated, resilient spirit that is an irreplaceable loss to the ME community.

Anne passed away on 6th January 2018, aged 44.

A waste of a life that should have been allowed to achieve so much.  
Yet still a life that has affected so many.

<http://www.investinme.org/Anne%C3%96rtegren.shtml>