

ePAG Co-chair



Lise MURPHY

[Swedish Marfanorganisation](#)

The Swedish Marfanorganisation has been on the go for 22 years and we still find many challenges for Marfan patients. What our members appreciate is our summer camps, our quarterly magazine with updates on the medical field and news from within the community as well as the opportunity to getting in touch with others in the same situation. We try to facilitate that through facebook, calling new members and through personal meetings at our summer camps and annual meeting.

We have a big board to ensure that we have time to work with the various projects we are involved in. A major focus has been life style issues particularly to keep fit and being as healthy as we can possibly be. We had a yearlong project around that with many workshops and opportunities to meet and to learn. A book was the result of that: "*Må bra med Marfan*" available in Swedish as a pdf or paper back. On the webpage we also have the brochure with facts, "*Marfan*" recently updated, all in Swedish so ok for the Scandinavian countries.

<http://marfanforeningen.se/index.html>

We are happy to be in HTAD in Vascern. We are very much aware, however, that our syndrome originates from the connective tissue. This is a fact that constantly has to be born in mind since we have many symptoms from various parts of our bodies, not only from our aorta.

Nationally we have patient representatives in the networks around the six university hospitals in Sweden. Networking is good for us!

[More information at: http://marfanforeningen.se/index.html](http://marfanforeningen.se/index.html)