I was a volunteer with the Dutch Lupus Association for a long time where I tried to increase awareness of antiphospholipid syndrome. Unfortunately, illness forced me to give up this voluntary work and I am still looking for a new challenge. There is still a lack of clarity and knowledge about antiphospholipid syndrome although many doctors, professors and patient associations work very hard to change that.

I am 53 years old and my hobby is spending time on my sailing boat, which is where my Stene Prize story began. By participating in this competition, I hope that I can make a positive contribution to increasing awareness of the possibilities offered by voluntary work. I would also like to use the EULAR international platform, by means of this beautiful, powerful and true story, to draw extra attention to antiphospholipid syndrome and the work that is being done on it.
**A steady wind to Pampus**

The difference you can make as a volunteer – in everything you do – became clear to me during a little experience I had on the IJsselmeer*. Now I know sailing on the IJsselmeer sounds spectacular, but I’m a real go-getter by nature – once I’ve set my course and trimmed my sails correctly, I find that boredom quickly sets in.

When I’m done with checking the radio and GPS, I go in search of something else to do. With all the modern technology we have today, I can even check my e-mails out in the middle of the lake. And, on that particular day, I read an e-mail containing a cry of despair.

It came from a woman in the 30th week of her pregnancy. The doctors couldn’t agree on how to help her through the remainder of her pregnancy, except for that a baby was supposed to be born at the end of it. The woman had been diagnosed with the rheumatic condition antiphospholipid syndrome and, back then, all the doctors did was whatever they thought might be a good idea. They really did just do whatever occurred to them… but what did she actually need? The answer was clear: someone with the knowledge and experience to help her bring her baby into the world.

Almost at once, the name of a gynaecologist came to mind. She had recently given a lecture and, by coincidence, I had her private e-mail address. Under a steady wind to Pampus**, I explained the problem and, before I’d sailed two miles, she replied saying that the expectant mother would be welcome to come to the university hospital the next day. The gynaecologist was willing to see her through the pregnancy in person.

It goes without saying that I passed the good news on to the expectant mother, and wrote back later to ask if the pregnancy was going well. After that I forgot all about it in the hustle and bustle of my daily life.

I gained a lot of skills during my career, but I had never known exactly what I wanted to be when I was growing up. When I turned out to have a chronic illness and was declared unfit for work, doors slowly started opening up to me, showing opportunities I had never suspected existed.

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It began with the discovery of the difference between an outlying hospital and an academic treatment centre with trainee doctors and professors. I joined a patient association where I turned out to have a real knack for networking. I was the über-volunteer everywhere I went, even taking a real ‘Uber’ at times.

For honesty’s sake I should add that, as well as reimbursing all my expenses, my voluntary organisation gave me fantastic support in the form of knowledge gained through courses to improve my skills. It was good for our organisation and for my personal development as well.

Back when I was working on the patient association’s website, I was allowed to take courses on “Writing for the web” and “Help Google find your website”. When I found myself behind a microphone on more than one occasion, the course “Present yourself” was waiting in the wings. These are all skills that leave me wondering now why I didn’t learn them at primary school. Ultimately, I was promoted to the top management of the association, and I took the course “Vergadertijger*** or “Meetings for champions”.

As a member of the board, I clearly had obligations beyond selflessly advising and representing our members and their interests. While I was in that role, I had to chair a meeting about antiphospholipid syndrome. As a patient with the same syndrome, I had, of course, planned to attend the meeting about my condition. But now I found my own name up in lights on our website.

Shortly before I walked into the hall, I was approached by a young woman with a baby in a sling. She wanted to thank me for putting her in touch with her gynaecologist on a lovely afternoon last spring in the middle of the lake.

I have bumped into the woman regularly since then. I’ve forgotten the baby’s name now – and even the woman’s name – but it still reminds me of how important my work as a volunteer is, how big some little things can be and how a little effort sometimes goes a long way.

This has added value to my life in the sense of being able to believe – as a human being – in a meaningful existence with a chronic disease. Not just for myself, but for others as well. Sometimes people ask me where I get the strength to keep working so hard as a volunteer with all my health problems and difficulties. And then I love to tell them once again about that day I was sailing towards the Markermeer*.

(Continues on the next page)
(continuation from page 2. Essay “A steady wind to Pampus” by Sander Otter)

* IJsselmeer and Markermeer are two Dutch lakes near Amsterdam. The small island of Pampus is located between the two lakes.

** Pampus is a small artificial island in the waters near Amsterdam. It features in the Dutch saying “voor Pampus liggen”, which means being incapable of any form of activity because of fatigue/illness, or because you have had too much to drink/eat, or simply because you are a bit lazy.

*** Vergadertijger means being very good at chairing a meeting – a tiger, in fact.