

## CAMPAIGNING FOR TEST STRIP REIMBURSEMENT: REAL LIFE EXPERIENCES



**Linda Murdoch** has a history of pulmonary emboli and suffers from the blood clotting disorder Factor V Leiden. In addition she has severe asthma, lupus, osteoporosis and problems with her thyroid. As well as being treated long term with warfarin to prevent her blood from clotting, Linda is also needs to take numerous medications, some of which cause her blood INR levels to change daily.

Four years ago Linda, under the supervision of her GP, purchased a CoaguChek point of care monitor, so that she could test her own INR levels at home. Unfortunately for her, not long after this she was informed that her Primary Care Trust (PCT) would not provide funding for the test strips necessary for her to carry out the tests.

With guidance from AntiCoagulation Europe Linda wrote a number of letters to the head of commissioning at her local PCT. She also looked in her local paper for PCT meetings where she could voice her opinion and gain further support for her campaign.

As a result, Linda campaigned successfully and eventually her PCT agreed to fund her test strips. While this news was a big relief, Linda later found out that other patients in her area had been able to receive funding without any such campaign. This revelation highlighted certain inconsistencies, not just between PCTs (often referred to as the postcode lottery) but also within the PCT.

*"It is important to remember that PCTs are just trying to allocate their PCT funds in the best way possible. I would therefore advise a gradual build-up approach to your campaign, keeping in mind that your actions may have an impact on other people also campaigning. If you go through the proper channels and use the help provided by Anticoagulation Europe, obtaining funding is achievable."*

Linda describes her move to self-testing as "Absolutely brilliant, self-testing has given me a new lease of life." Because Linda suffers from numerous conditions resulting in her INR levels changing day to day, with self-testing she feels in control of her treatment and being able to check regularly gives her peace of mind. Previously Linda had her INR monitored at a hospital clinic, which meant she found herself travelling regularly to and from her local hospital, which in her current condition would not always be easy or convenient.

Linda has received continual support, training and advice from nurse practitioners at her local haematology clinic. With this she feels sufficiently confident and comfortable with self-testing.

*"With self-testing I feel I have absolute control of my own life. Testing at home or out and about with the CoaguChek has given me a freedom which I had not thought possible." Linda describes two recent trips she has had to America: "Self-testing has allowed me to travel away from home without the worry of long flights and lack of access to the local hospital. I still have regular contact with my PCT, but this is now flexible and on my own terms. Before self-testing I really thought trips abroad were a thing of the past."*

*"As I am on long term warfarin, if I live another twenty-five years, this represents a significant amount of hospital resources to meet my required needs. In reality, the practicalities of being able to self-monitor my warfarin therapy have considerable benefits. If I am taking other medications that do 'interact', I can check my own INR therapeutic range immediately without relying on hospital resources."*

**"With self-testing I feel I have absolute control of my own life, it has given me a freedom which would not be possible without my self-testing device."**

**"If you go through the proper channels and use the help provided by AntiCoagulation Europe, obtaining funding is achievable."**