

Welcome to the second newsletter of the AntiCoagulation Self-Monitoring Alliance (ACSMA) which was formed in September 2012 and comprises four of the UK's leading charities and patient groups – AntiCoagulation Europe; the Children's Heart Federation; the Atrial Fibrillation Association; the Mechanical Heart Valve Support Group. The healthcare company Roche is also part of the alliance.

ACSMA'S WORK IN 2013 SO FAR:

ACSMA has had a busy start to 2013 with a number of key events taking place:

Parliamentary Reception Access to self-monitoring: a call to action.

On 6th February, Virendra Sharma MP, member of the Health Select Committee and a keen supporter of our campaign, hosted a parliamentary reception in the Strangers' Dining Room on ACSMA's behalf.

Over 60 people attended the reception, including parliamentarians, patients and clinicians, which called for the Government to consider making self-monitoring devices available on NHS prescription to people on long-term warfarin in the UK.

Andrew Gwynne MP, Shadow Minister



for Health, said "the NHS should be looking at the merits of the technology based on the patients' need not ability to pay as this was the founding principal of the NHS."

Stephen Johnson, the Department of Health (DH) Deputy Director of Long-Term Conditions, also spoke at the reception. He leads the DH's 3millionlives project, which builds

Our Objective

We are campaigning for greater choice for patients on warfarin about how their condition should be managed. Our goal is to empower patients and we believe where possible they should have

the choice about whether to self-test or self-manage their treatment. We believe that this change would enable improved health outcomes and save time and money for both patients and the NHS.



services for people with long term conditions, supporting with technology where needed. The collaboration intends to increase co-operation between industry, government and other stakeholders to help support the widespread adoption of telehealth and telecare. He agreed self-monitoring had a role to play in improving care for patients with long term conditions.

Robert Cleaton, a Graphic Designer, has to take long-term warfarin and talked about how self-monitoring has improved his life and minimised the impact on his work. He also demonstrated his innovative OATbook mobile phone application, which assists people who self-monitor in recording their results and medication levels.

The reception also heard from Rachel and Katherine Perkins, a mother and daughter. Rachel and Katherine spoke about how self-monitoring had given Katherine independence and freedom from time consuming clinic appointments, which was particularly welcome during her exams.

All of the speakers voiced their support for patients having full understanding and control of their condition.

Those attending included David Amess MP, Lord Colwyn, Baroness Gardner, Baroness Masham, Grahame Morris MP, Paul Blomfield MP and Sir Bob Russell MP.



Andrew Cawayne MP



Virendra Sharma MP

Katherine and Rachel Perkins

Virendra Sharma MP kindly tabled Early Day Motion (EDM) 1047 immediately after the parliamentary reception. An EDM is a motion submitted to Parliament. Although it is not expected the motion will be debated they are a means of MPs publicising their views and often gain media and public interest.

The wording of the EDM is given below:

“That this House welcomes the Anti-Coagulation Self-Monitoring Alliance campaign to give greater choice and control to the estimated 1.25 million patients in the UK who take long-term warfarin; notes that only two per cent of these patients currently self-monitor their blood clotting time, despite evidence that self-monitoring is effective in improving health outcomes, convenient and saves money for the NHS; further welcomes the Government’s efforts to mainstream assistive technology across the NHS; notes that innovative self-monitoring technologies support the important concepts of patient choice, empowerment, self-management and shared decision-making in the NHS; and calls on the Government to consider making self-monitoring devices available on NHS prescription to long-term warfarin patients in the UK.”

So far 51 MPs from across all the political parties have indicated their support by signing the EDM



NICE is evaluating the CoaguChek XS in its Diagnostics Assessment Programme



The National Institute for Health and Care Excellence (NICE) has announced that it will undertake a review of the clinical and cost effectiveness of CoaguChek XS and issue guidance about its use to the NHS. At the moment, we don't have any further information on the timings, but we will keep you updated as the timescale becomes available.

The information is available at the NICE website here: www.guidance.nice.org.uk/DT/16

Taking Our Message to the Policy Makers:



Geoff King

ACSMA are continuing to undertake meetings with key policy makers and parliamentarians to explain what self-monitoring is, and how it can help patients regain their independence and freedom while saving the NHS considerable amounts of money.

Over the next few weeks we have meetings scheduled with:

- NHS England
- Professor Huon Gray, National Clinical Director for Cardiovascular Disease

Our first campaign newsletter was sent to 85 parliamentarians and 72 medical professionals informing them of ACSMA's campaigning work to date and the benefits an increase in access to self-monitoring technology could bring to patients' lives and NHS budgets. We now have over 400 individual and organisations on our mailing list!

How can you get involved?

If you want to pledge your support for our campaign, would like to tell us your story about living on long-term warfarin and the benefits of self-monitoring, or would just like to keep up to

ACSMA at Little Hearts Matter

On 2nd March, ACSMA members attended the Little Hearts Matters annual AGM and open day. Little Hearts Matter offers support and information, and raises awareness of those affected when a child has only half a heart, due to conditions such as Complex Pulmonary Atresia, Tricuspid Atresia, Hypoplastic Left Heart Syndrome (HLHS) or Double Inlet or Outlet Ventricle (Univentricular Heart).

Depending on their individual conditions, children need different doses of warfarin to keep their blood levels stable and dose changes can impact on how warfarin can accumulate in the body. It's important that the child undergoes regular blood tests until the levels of the drug are stable. ACSMA and Little Hearts Matter are working together to make sure children - as well as adults - on long term warfarin are offered the option to discuss self-monitoring and have it provided on NHS prescription if they are suitable and choose to do it.



ACSMA Online

We are delighted to announce that we now have a website dedicated to our campaign. If you visit www.acsma.org.uk you can keep up to date with everything we are doing, pledge your support, share your story and let us know if you or your organisation want to be involved.

date with what we are doing please visit www.acsma.org.uk, email us at info@acsma.org.uk or follow on Twitter: [@ACSMA_UK](https://twitter.com/ACSMA_UK)