

All-Party Parliamentary Group for First Do No Harm

Meeting on redress schemes

Venue and time

10:30am, Wednesday 26th January 2022

Via Zoom virtual conferencing

Parliamentarians attending

- Baroness Cumberlege, Co-Chair
- Emma Hardy MP, Vice-Chair
- Yasmin Qureshi MP, Vice-Chair
- Sarah Green MP
- Dr Julian Lewis MP
- Christian Wakeford MP
- Caroline Nokes MP

Panellists

- Kath Sansom, Sling the Mesh
- Janet Williams, Independent Fetal Anti-Convulsant Trust and FACS Syndrome Association
- Emma Murphy, Independent Fetal Anti-Convulsant Trust and FACS Syndrome Association
- Marie Lyon, Association for Children Damaged by Hormone Pregnancy Tests
- Shaun Lintern, Health Editor, The Sunday Times

Additional guests

- Simon Whale, panel member, IMMDS Review
- Jason Farrell, Home Editor, Sky News

Apologies

- The Rt Hon Jeremy Hunt MP, Co-Chair
- Cat Smith MP, Vice-Chair

Observers: a range of representatives from patient groups and the media.

Introduction

Baroness Cumberlege began by welcoming fellow parliamentarians, patient group campaigners, her fellow panellists, members of the media and other attendees to the meeting.

Baroness Cumberlege then offered attendees background on why the meeting was being held and why establishing independent redress schemes is vital. She referenced the work of the Independent Medicines and Medical Devices Safety Review and its report, *First Do No Harm*, which recommended that separate schemes should be set up for each area examined (hormone pregnancy tests, valproate and pelvic mesh) to meet the cost of providing additional care and support to those who have experienced avoidable harm and are eligible to claim.

Baroness Cumberlege explained how the interventions have caused avoidable harm and that there is a moral and ethical responsibility to provide ex gratia payments to those who have suffered. These payments should be structured within individual schemes for the three interventions, with tailored eligibility criteria. They are not intended to cover the costs of services which are already available, such as NHS care and social security payments, but rather for other needs that could, for example, include travel to medical appointments, respite breaks or emergency payments where a parent has had to stop working to provide care. She noted that the Government, in the almost two years since the report was published, continues to be unwilling to implement the report's proposal on redress schemes. Baroness Cumberlege briefly outlined how she and her parliamentary colleagues are hoping to implement these redress schemes through amendments to the Health and Care Bill.

Panel discussion

Baroness Cumberlege began the panel discussion by inviting **Kath Samson** from the **Sling the Mesh** patient group to introduce herself and her organisation. Kath opened her presentation by sharing her experience of having a mesh implant in 2015, which prompted her to establish a campaign group that now has over 9,300 members. She spoke of the need for financial redress for those suffering avoidable harm as a result of their mesh implant. She referred to the long waiting times for treatment experienced by women, and the negative impact on affected individuals' mental health. Many women's lives have been dramatically changed and there is an urgent need for financial redress for them and their families, she said.

Kath shared the findings of a survey of pelvic mesh implant patients conducted by Sling the Mesh. The survey revealed that:

- 1 in 3 women who received a pelvic mesh implant have been forced to give up work
- 1 in 5 have been required to accept reduced hours of work
- 1 in 4 women need a stick to walk
- 1 in 14 need a mobility scooter
- 1 in 33 have lost their home
- 1 in 6 have lost their primary relationship
- 1 in 4 have considered taking their own life

Kath described how the women experiencing these life changing effects have come from a range of careers. Like many within the Sling the Mesh group she represents, Kath has had to close her photography business as a result of her surgery. Women have had to give up work before retirement age, resulting in diminished pension and national insurance payments. This means many have had to resort to using life savings, re-mortgaging homes or even moving back in with extended family. Costs associated with purchasing mobility scooters and wheelchairs; converting houses to be wheelchair accessible; downsizing to bungalows as they can no longer use stairs; and paying for cleaners and other home help are unexpected and often financially devastating for many patients.

Kath went on to highlight other unexpected medical costs associated with their mesh implants, such as expensive private mesh removal bills, travel to and from doctors' appointments, physiotherapy appointments, and adapted furniture.

She told parliamentarians that every mesh injured person has had to accept a new normal. Kath shared testimony from members of Sling the Mesh, including a hairdresser who could no longer stand for long periods and needed to move into a flat as she can no longer maintain her house and garden. Kath spoke of a NHS nurse who had to leave her job at 38, without a pension or pay-out, due to her post-surgery pain, and of a woman who was forced to take early retirement resulting in a loss of more than 50% of state pension value.

Emma Murphy began the presentation on behalf of the **Independent Fetal Anti-Convulsant Trust** and **FACS Syndrome Association** by reminding the Group that valproate continues to be prescribed with no warnings of potential harm to foetuses. She spoke of the faults within the current Department of Work and Pensions (DWP) system, in which recipients of funds are required to prove their need every 2-3 years. Emma described this experience of regular reassessment as harrowing for many Fetal Valproate Spectrum Disorder (FVSD) sufferers and their families. As FVSD is not recognised by DWP as a distinct disability, the process of proving need can be long and stressful.

Emma listed the various expenses FVSD sufferers and their families have had to bear: home adaptations, re-mortgages, extensive physiotherapy and occupational therapies, and counselling sessions for anxiety. She highlighted the need for support workers as many sufferers cannot go out alone due to their zoophobia. Many with this fear would run across a busy road to avoid a cat or dog, and they cannot go out to shops or parks without company. In addition, as valproate especially compromises memory, individuals with FVSD must receive speech therapy and other professional support at regular intervals, so progress is not forgotten and lost.

Janet Williams continued by outlining the problems with entering litigation and going to court in order to gain compensation, such that redress is the only option for most victims. She cited the experience of one of her members, who took years to get the required benefits and additional provisions for their FVSD-affected son. As with many people with FVSD, this

person suffers from online and in person abuse due to his disability and has experienced prejudice when applying for jobs.

Marie Lyon, Chair of the **Association for Children Damaged by Hormone Pregnancy Tests**, began by sharing the experience of many newly-pregnant women in the 1960s and 70s who were offered Hormone Pregnancy Tests with no warning of the side-effects and with no offering of an alternative, non-invasive test. She paid tribute to the women who lost children as a result of the tests, and also to the children born with life-changing effects. Her campaign group was formed in 1978 with the purpose of ensuring that manufacturers and regulators were held responsible for these avoidable deaths and injuries. The APPG on HPTs has the support of 131 cross-party MPs who continue to seek justice.

Marie read statements from members of her Association, many of whom spoke of their disappointment at the lack of progress and the Government's reluctance to consider establishing redress schemes. Members are frustrated at the requirement to frequently justify to government departments that they have experienced harm and need redress. For many women, this means having to relive very distressing times of their lives, often causing psychological harm.

In order to access existing support and benefits, Marie spoke of how patients have had to navigate their way through numerous disconnected services to find the appropriate support, putting the onus on the patient. She argued that it should be the Department for Health and Social Care (DHSC) that has the responsibility to actively guide people to the right support.

Marie spoke about the - sometimes prohibitive - costs of medication, treatments and prosthetics for patients. In addition, alterations to cars, properties, and clothing are significant costs families have to cover.

Shaun Lintern, Health Editor at the **Sunday Times**, spoke briefly about his work, which has mainly focused on patient safety. He highlighted that a common theme he has witnessed in his reporting is the dismissive attitude to the pain of patients, and the gaslighting that many patients and their families have experienced.

He talked of the failures of various parts of the healthcare system and how the reported experiences of patients are often not recognised. Shaun spoke of the need to rethink how medications and medical devices are researched and tested. Researchers he has spoken to have expressed concern over the lack of funding for studies into the potential harm of various medical interventions.

He expressed his support for the campaigns and spoke of his intention to get the Sunday Times to report on the issues raised in this meeting.

Q&A and Discussion

Baroness Cumberlege began the Q&A by inviting **Jason Farrell** from **Sky News** to share his thoughts with the Group. Jason asked the parliamentarians present about whether there

are any “champions” in government who can help in the campaign, especially since the Government has publicly been reluctant to accept the recommendation on redress. Baroness Cumberlege answered by highlighting the efforts of MPs to keep this issue on the Government’s agenda by taking part in relevant debates and tabling written questions.

Baroness Cumberlege addressed a question from the audience on the Government’s apparent opposition to redress, and the avenues open to push them towards backing redress schemes and a Redress Agency. Baroness Cumberlege answered by restating that the government remains reluctant to implement a Redress Agency but that the work of campaigners and parliamentarians continues nonetheless.

In response to a question from the audience about an update on the appointment of a Patient Safety Commissioner, Baroness Cumberlege spoke of the successful but difficult struggle to ensure the PSC was enshrined in law in the Medicines and Medical Devices Bill. She updated the Group on the progress of appointing the Commissioner, with the application deadline now extended by a week to ensure more candidates can apply.

When asked why she thinks the government is opposed to a redress schemes, Baroness Cumberlege shared her concern that resistance within HM Treasury appears to be the primary reason for the lack of progress.

Simon Whale, panel member of the IMMDS Review, added to this by highlighting that continued media and parliamentary pressure is the best way to bring about a change in Government policy. He spoke of how the future Patient Safety Commissioner will have significant influence within government and the hope that the work of the Commissioner will increase the likelihood of the recommendations of the *First Do No Harm* Report being implemented, especially on redress.

Emma Hardy MP informed attendees that the Backbench Business Committee had approved an application by Alec Shelbrooke MP, co-Chair of the Surgical Mesh APPG, for a debate on the implementation of First Do No Harm. The debate will take place on Thursday 3rd February at 13:30 in Westminster Hall. The news was welcomed by all in attendance. Emma Hardy said she was keen to support amendments to the Health and Care Bill once it returns to the Commons.

Baroness Cumberlege drew the meeting to a close, thanking all the panellists for their valuable contributions. She reiterated her earlier statement that a recording of the session would be made available on the Group’s website. The Group will consider next steps in light of the information presented by panellists at the meeting.

The meeting closed at 11:45am.