Marie  Goldman

MP for Chelmsford

Health system issue is potentially a greater scandal than thalidomide

SOMETIMES, as an elected politician, you are contacted by people who tell you such compelling stories that you find yourself unable to get them out of your mind.

In January 2024, when I was a county councillor, I was contacted by a Chelmsford resident who wanted to tell me about her truly terrible experience of doing battle with local services, including schools and Essex County Council, trying to get the support that she needed for her little girl who has special educational needs (SEND).

Her story made me angry, sad, frustrated and defiant all at once. But above all, it motivated me to look into it, to hold those responsible to account, and to fight her corner.

Ultimately, it led to a public meeting at Essex County Council, where the council admitted it was the worst-performing council in the country for issuing education, health and care plans (EHCPs), and then an increase in the council's budget for SEND.

It has by no means fixed the SEND system – that's broken across the country, and we're waiting expectantly for the Government to issue its much-anticipated SEND white paper this autumn – but I hope it has helped at least a little bit.

Recently, another constituent told me her story, this time about a huge, decades-long scandal in the health system.

Chelmsford MP Marie Goldman pressing the Government for a response to the Hughes Report in Parliament on Thursday of last week (September 11)

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She told me that her children had all been born with birth defects, experiencing physical disabilities, learning difficulties and other lifelong conditions.

She then explained to me how she had been prescribed an anti-epilepsy drug called sodium valproate while pregnant, and this, we now know, was the cause of her children's disabilities. She was just one of many, many women across the country whose children were harmed in this way.

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> **Marie Goldman MP**

I'm sure most readers will have heard of the thalidomide scandal, known as “the biggest anthropogenic medical disaster ever”. This was a drug prescribed to pregnant (or soon-to-become-pregnant) women around the world and resulted in more than 10,000 children being born with severe deformities, with thousands more miscarriages.

According to Professor Henrietta Hughes, the Patient Safety Commissioner, when looking at the number of people it has affected, sodium valproate is potentially a significantly greater scandal than thalidomide. And yet virtually nobody knows about it and even fewer are talking about it. That has to change.

In 2020, Baroness Cumberlege published her report into the related issues of sodium valproate, pelvic mesh and the hormone-based pregnancy test, Primodos.

The report, titled First Do No Harm, made several recommendations, including that a compensation scheme be set up for the victims of these scandals. Prof Hughes published a report setting out exactly how that system of redress should be constructed.

That was 18 months ago, but the Government has yet to respond.

In Parliament last week, I pressed for action and a response. The women and children affected by this deserve support.

But I don't want anyone to get the impression that this is just about money – it most definitely isn't.

A key concern for the women is who will look after their children when they are no longer around. And I say women, because it's not uncommon for fathers of children born with birth defects not to stick around.

The excuse is often that they don't recognise in their children any paternal similarities – basically, because their children don't look like them, they don't feel a bond with them and reject them.

It's entirely possible that's a natural, evolutionary response, although I will admit to not feeling much sympathy for that position. But regardless, it means that the caregivers – those left to care for their children alone – are women.

And boy, have those women been fighting for justice. But they're exhausted. After years – in some cases decades – of campaigning, of telling their stories over and over again, they feel that nobody is listening. And despite sodium valproate now being prevented from being prescribed to women under the age of 55, the warning labels on the boxes explaining the severe dangers of this drug being taken by anyone who is pregnant (and there are concerns that it affects breastfeeding mothers and their children as well) are often being covered up by prescription stickers. Another battle that needs to be had with the regulator to get this changed.

Then there is the education of medical professionals to deal with. Campaigners tell me how soul-destroying and exhausting it is having to explain again and again to each new doctor they come across what Foetal Valproate Spectrum Disorder (FSVD) is, what happened, and how the symptoms need to be recognised and treated. In short, the women are tired and running out of energy to keep up the fight.

And that's why I'm determined to have their backs.

What might seem technical and complicated is really quite simple: women and their children have been severely harmed and continuously let down. That has to change.

Just like the issue of special educational needs and disabilities that has filled so many MPs' inboxes over the past year, this is a scandal that will not – and must not – go away. The sooner the Government recognises that and supports the victims, the better it will be for everyone.

So, I've already raised the issue in Parliament, pressing the Government to respond. I've met with victims and their families. I've been raising it with anybody in the media that I speak to. And now I'm telling you. Please tell others.

If you'd like to read more about this issue, Baroness Cumberlege's First Do No Harm report and The Hughes Report: Options for redress for those harmed by valproate and pelvic mesh are both readily available online.

Thanks, as always, for reading.

Marie