



DES Justice UK (DJUK)

The logo features the original style pill bottle that the drug was administered from. It is in the muted shade of the brown colours of the medicinal bottles from that period.

The backdrop is Westminster. This is significant as this drug was created by a state sponsored scientist through publicly funded research. The origin of this drug and its toxic legacy is deeply entwined with government policy.

This scandal began in Westminster, and we believe that is where it should end. The government is culpable, the public paid for the formula of this drug – but the government prioritised profitability over safety concerns. Never appointing anyone to monitor its safety, usage and ultimate Harm.

The yellow behind the image is a deliberate sign of this group coming out of the dark and into the light. This group is empowered to seek justice and accountability. They are a shining beacon of positivity. One of their primary aims is to spread the word of this injustice far and wide.

The use of the shortened version of the drug 'DES' is because this is how the drug is universally referred, in the US, Europe and Australia. The full name of the drug, Diethylstilbestrol, is also included in the logo.

'DESperately seeking answers' is the email sign off from one of our campaigners and struck a chord with all those affected.

The use of 'UK' is included as we want to demonstrate how shamefully behind the rest of the world the UK is, both in recognising this injustice, but also by its lack of medical research, treatment and screening.

DES Justice UK

Diethylstilbestrol, universally known as DES, was a drug, a synthetic hormone, that was marketed as a wonder drug to prevent miscarriage and create "bigger, healthier" babies. It was given to an estimated 300,000 women in the UK from the 1940's through to the early 1980's. It was also prescribed to stop the production of breast milk.

This drug was created by a government scientist using publicly funded research. As a result, it was never patented, leading to its manufacture by 100's of pharmaceutical companies. Despite very real, peer reviewed research into its harm, it continued to be prescribed without any control or regulatory oversight. This led to one of the most devastating pharmaceutical failures in UK history.

For the mothers **who took this drug whilst pregnant**, at their most vulnerable, and at the hands of those they trusted – the effects include increased risk of breast cancer, for some, deadly, and a lifelong unabated guilt for the poison they unwittingly released to the following generations.

Intergenerational harm is very real. **For those exposed in utero**, they suffer reproductive abnormalities, traumatic births, a loss of fertility, and their risk of developing a rare vaginal cancer is tenfold. For those who know they were exposed, they lead a life of uncertainty and misery - multiple, invasive procedures while the threat of cancer lives at



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DES Daughters Sons Support Group



@desjusticeuk



DES Justice UK



DESJustice@broudiejacksoncanter.co.uk



0330 822 7554



desjusticeuk.com



their door. Chronic pain, constant surveillance. Their life on hold, dreams stolen, robbed of a life that most take for granted.

Bodies altered before they have even begun. The DES legacy is hidden, internal, intimate. What can be visibly seen becomes a scandal, what is hidden is allowed to grow in silence.

For those who do not yet know, a lifetime of waiting, let down by a healthcare system grossly behind the rest of the world – no screening, no knowledge, no answers. Let down by a government that failed to inform and failed to protect.

We are a campaign group brought together and empowered by our lived experience. For some of us, we spent years thinking we were alone. Suffering in silence. Our lives ruined. We are strong. We will not back down. We will make sure that others do not suffer in the silence and information void that we have.

Awareness

Within the health care profession, the ignorance of this drug is scandalous. Most GP's have never heard of it, most gynaecologists don't know about it. Many of us have been gaslit into thinking our symptoms were not real.

There is nowhere to turn to find information. We demand change, the NHS that has let us down so badly needs to put this right, we need to be able to access information and those at the start of this journey need somewhere to turn to for answers, maybe the answers we have never had.

We want an information and training campaign to ensure all healthcare professionals are aware of DES, what it is, what to look out for, and how to refer.

Accountability

There is no legal recourse for us. The drug was never patented, meaning that mass production makes it very hard to consider product liability. Poor record keeping and a lack of regulatory scrutiny makes any other claim impossible. This began in the hands of the UK Government, and that is where it will end. A government that prioritised pharmaceutical profitability over regulation, information and harm.

This government knew what the risks were and did nothing to stop it, even faced with early scientific evidence of the danger. The Medicines and Healthcare Regulatory Agency has admitted that they falsely claimed the drug was withdrawn in 1973. The current Health Secretary has admitted the State failed to take regulatory action.

The government is accountable. We want answers. We deserve to know what they knew, when, and why they failed to act. A human tragedy that lies squarely at their door.

We believe the only way to achieve **truth** and **justice** is via a Statutory Public Inquiry and we will be asking the Home Secretary to consider this.

We want to be compensated. For stolen lives, for the theft of joy that a pregnancy normally brings, for the trauma of invasive procedures performed on sufferers, some when they were still children. For the physical pain, for the



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scarring, for the enduring guilt, the fear and uncertainty, and the loneliness. And for some, for a psychological and emotional grief that cannot even be encapsulated by words.

Screening

Currently there is no screening to see if you have been impacted by DES. This is in stark contrast to other parts of the world. We want targeted advance screening. It needs to be lifelong, we know there is an elevated risk with age.

We want research into long term and generational effects of DES, monitoring for cancers and a tracing system so that those who may not even know they are at risk, can be informed.



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