

# Annex J – Personal testimonies

Many of the individuals and families affected by the three interventions wrote into the Review and shared their personal experiences. The voices of those affected have been central to the Review's thinking and we have included a number of anonymised extracts from these personal testimonies in the report. Whilst we were unable to include details from all the testimonies provided to us, we have nevertheless been able to compile further (anonymised) extracts in order to highlight the difficulties which individuals and their families have experienced.

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## Hormone pregnancy tests

“The effect on our lives have, as you can imagine, been devastating. I would go far as to say we have never had one day's peace of mind since the day he was born. There have been no family holidays, no family birthday's, or Christmases. Nobody invites you to gatherings or get-togethers, and I may say, I don't blame them. No child milestones, no first days at school, no girlfriends, no marriage and no grandchildren. No one to call you Mum and Dad.”

“While in hospital my daughter couldn't suck, so had to be tube-fed until she was discharged. At home we were told to try her solids, or anything she would tolerate. I spent many hours encouraging her to eat, but often she would bring her food back up. At 12 months, she weighed 12lbs! The difference between my Daughter and my other children was so pronounced in every way. She needed help in everything, whereas my other children never struggled, and were always there to give me strength to help their sister.”

“In April 2017, we heard Marie Lyons being interviewed by Jeremy Vine and so many things added up: The time 1967; The 2 tablets; No prescription, and the vastly different abnormalities that a drug Primodos could cause. It was as if we had been hit with a sledge hammer, it was if she was talking about our son's situation. This was followed up with me trying to get my medical notes, only to find most of my notes have either disappeared or had been altered. I have a GP record of me living at an address where I have never lived, it was my husband's address before we were married. The record is of me seeing a GP in that town. I have never seen a GP in that town.”

“I was born with Spina Bifida, with Pulmonary Stenosis, with 2 cervixes instead of 1, and without a back passage. I have no control over my bowel or bladder, I have one kidney and have reduced hearing in my right ear. I unfortunately went through early menopause, so sadly have no children - I'm not sure if my body would have been able to anyway. I want the truth to be exposed and the people responsible to be held accountable. Nobody knows the true detrimental effects of long-term

medical issues and so you do have to think realistically about future years.....what if you're unable to work?!”

“First given Primodos in 1966 - miscarried four days later. Given Primodos in 1968 - miscarried two days later. Given Primodos again in 1969 - once again, miscarried a few days later. After tests, no genetic reason was found for these miscarriages, and was told by the Trust that the next time I thought I may be pregnant, that I should come directly to them. In 1970 I was admitted into hospital for rest and observation after becoming pregnant, and subsequently had a baby girl. Being given Primodos without a prescription - was this part of a trial? There is no mention of Primodos given in my records, although two of three pregnancies were recorded along with the miscarriages.”

“Primodos prescribed or given in 1974. Induced birth in 1975, baby son weighing 5lb 2oz. He was slow at feeding, and I was encouraged to feed more often. He was diagnosed with Epilepsy and had hernia repaired, as a baby. Not making the milestone's as he should. I was told he had a brain damage, with no reason given for this. Also, eye-sight and hearing was not as it should be. Very late in his development - unable to sit on his own, not walking until he was 4/5 years old, and no speech. He died [in his twenties]... The strain of caring for him caused our divorce. We have other children with no health problems – Primodos [was] not given.”

“We have been asked what we feel about this situation and to sum up, we feel that we were used as collateral damage by the pharmaceutical company who were developing the contraceptive drug at the time. Primodos was significantly higher in strength than the oral contraceptive pill prescribed today. We believe regulatory authorities at that time failed to stop the use of Primodos when the dangers had been identified in Canada and other countries.”

“This statement takes about 4 minutes to read - how can that possibly reflect what a devastating effect Primodos has had on our lives for the past 47 years. This is just a very brief summary, the reality is far worse. What I am seeking is:

- an admission of the failure of the duty of care of the drug manufacturer, in allowing the use of Primodos as a pregnancy test without adequate safety testing
- an admission of failure of the duty of care of the UK regulatory affairs organisations in allowing the distribution and use of Primodos as a pregnancy test, long after the safety implications were apparent.”

“As the eldest child, I have been left with all the health problems due to Primodos. I have nearly died three times, and have had [over fifty] operations since birth. I suffer from: congenital hydrocephalus, congenital epilepsy, brain damage and vagus nerve stimulation. I'm left needing regular blood tests, as I'm in constant pain.”

“I took Primodos in 1969, missing two periods. I was 19 and engaged, and went to the doctor and he gave me these two tablets OUT OF HIS DRAWER. My son was born 5 weeks early, weighing 5lbs 8oz. He was soon diagnosed with hydrocephalus, and had an operation for a shunt. Soon after, he had to have an operation for excess fluid in his head. My second son was born [a few years later], very healthy - no tablets taken. I did hear about Primodos when my first son was about 10 years old, but with no internet in those days, it was always at the back of my mind. Then I heard Marie Lyon being interviewed about 3 years ago, and got in touch with the Association. Tablets given by a doctor, taken from his desk drawer - were we on a drugs trial without us knowing?!”

“I was born profoundly deaf and with Cerebral Palsy. I was unable to attend the local primary school so therefore I did not have any school friends local to where I lived. I went to college and university, and I have an Honours Degree .... Gaining employment is difficult as employer's do not want a deaf person working for them, as it is always assumed that they are not able to do anything. During my entire life I have suffered from the effects of Primodos which have caused me to be ignored,

insulted and at times worthless. How would you feel if you had to ask for help for something that everyone else can do for themselves?"

## Sodium valproate

“We... have been fighting for justice for our children for over twenty years.”

“[Our daughter] is looking to her future however she knows that there is a huge risk if she wants children they may be affected by the Sodium Valproate that I have taken, let alone the drugs she is currently being prescribed herself... She herself feels the system is STILL letting young women like her down as the message is not filtering through the system and people are still unaware of the dangers and implications of their medications.”

“We recently looked at some of her medical records and it clearly states she suffers from FACS and spina bifida – [we were] never informed of this.”

“Our son has had to from a very early age grow up fast and do so many things no child should ever have to do. Not just to help around the house with basic chores but to assist keeping all of his siblings safe, flagging down ambulances whilst his eldest sister is having seizures and stopping breathing. This is something that many adults could not deal with let alone a child...”

“I have not been able to be just a mother to our four children but I have had to learn many skills from all of the intervention teams... [and] pass my knowledge onto schools and other Healthcare professionals that do not know about Sodium Valproate Syndrome...”

“I like many mums am looking for help in fighting for my son. It has been emotionally difficult as a mum and the guilt I carry as a parent I will never get over and have to live with, I'd like to see justice done for my son who is now an adult and suffered all his life through school.”

“What I would like is simple: some kind of help for them. Help at the education and health system - possibility to learn in their own way, give them more time, to help them to be able to work/live on the highest level they can. I have to face the truth that my eldest son probably won't be able to live independently, but I know if he can get help now, he can be a useful member of society. I think this is the minimum what they deserve.”

“In 2017 my daughter was finally diagnosed as having Foetal Valproate Syndrome. She was delighted at having a diagnosis. It's hard for her and us she has no real friends as she cannot converse as we do. My big concern is the future as I'm sure every parent is.”

“He will never be able to live unsupported. He needs constant prompts to help him wash, change clothes, eat, cook, hygiene, toilet...”

“We love our boy dearly just the way he is however I feel disappointed and upset that the risks of using Sodium Valproate were not explained or alternatives offered to me prior to becoming pregnant.”

“I went on to have three pregnancies and I was never told the risks that the drug can have on the foetus and even when I asked the doctors if it could affect the foetus or my milk when breast feeding I was told that it is perfectly safe to take - nothing to worry about.”

“I was not aware until September 2017 when I saw the news on the television that the Sodium Valproate causes deformities in foetuses - known as Sodium Valproate syndrome. I was shocked and extremely upset as I relived the difficulties that my children had... I spoke with all of my children about this when I saw the news and

one of my sons said he always used to wonder why he was so different from other children and now this explains it.”

“[I had a] planned pregnancy where I was told there was unlikely to be any adverse side effects on an unborn baby, risks of having a seizure was far more harmful. 23 week scan showed catastrophic damage to my unborn baby, spina bifida and hydrocephalus, unlikely to go to term and if I did go to term the damage to the baby was likely to be incompatible with life. On advice I chose to terminate my pregnancy, an almost impossible decision and I live with that trauma every day.”

“I was prescribed this as my first medication for epilepsy, brought on by pregnancy, I was half-way through pregnancy, now I find it hard to believe that all these side effects were known, yet I was still prescribed it.”

“My son has been diagnosed with Autism, never had even one friend in his life. He has severe mental health problems, self-harms, attempted suicide... He will need support for the rest of his life.”

“I worry about her future as she would one day like to live away from home... If I had known what I was doing when I was taking the drug, then I would not of brought my children into the world simply because they are so, so unhappy and they will never be o.k.”

“As a mother who continued to take sodium valproate, I cannot help but feel guilty for every difficulty my child faces like somehow it is my fault for being on that medication.”

“I felt so guilty I felt it was my fault for his problems and disability. I kept it to myself till it was on the news and I had to tell him instead of him hearing it from somewhere else. I just feel not to be told what these tablets can do and have done to many families is terrible.”

“I was never given any warnings about the dangers of Sodium Valproate, my son has autism, general learning difficulties, hypotonia, dysplasia, hyper extendable joints, poor eye sight, speech and language disorder, pain in joints, no sense of danger, no life skills, poor co-ordination, gross and fine motor skills disabilities...my son will never be able to leave home and lead a normal life.”

“My daughter will never be independent and will always be reliant on support throughout her life in every aspect. She will always require financial support from the state. She cannot read or write so is not even able to complete forms to claim her benefits that give her the basic requirements of life, food, roof over her head, a bed to sleep in at night and clothes to wear.”

“Feel sad I can't do what everyone else can, sad because I can't work and live my life. Frustrated that I can't do things on my own. Different and sad because I'm different I feel like I'm missing out, no one cares. I have no control, frustrated that people who do not know me don't understand me when I speak.”

“It is important that companies and individuals are held accountable for how the lives of those affected and their families have been affected, this includes compensation as it is a lifelong condition. We also need to prevent it happening to anyone else.”

“[My sons] have no independence they cannot do basic living tasks on their own as they are a risk to themselves and their surroundings mean they will never live independently, can't budget or manage their money, they have no social life or friends. What job prospects will they have, what life do they have? What will happen when we are no longer here?”

“If I'd been told my baby could be damaged by the medication I was taking I would not have taken it. All our hopes and dreams were destroyed by this but we love our

son dearly. We weep for the child who could have been and the man who never was.”

“My husband and myself have devoted our lives to caring for our son to the detriment of other family members and our own personal relationship.”

“A doctor assured me that I was fine to take Epilim through my pregnancy. That however was not the case... [my son] was diagnosed with FVS. Since birth he's had endless counts of hospital stays... he's got ASD, GDD, hyper extensive joints, all the different facial features, problems with his ears the list goes on. He will never be totally self-sufficient.”

“My pregnancy was planned and if I had been fully in possession of the facts alternative medication could have been offered. My son has a daily struggle with all aspects of his life in terms of learning, social interaction, self-help skills. This will ensue for his entire lifespan and it is very sad to think that it could have been very different for him.”

“I feel angry that I wasn't told the truth. How can it be right that I am told to stop drinking tea, coffee, caffeinated drinks, don't eat pate or prawns as it may harm my baby....but here have 2250mg a day of a drug that we know is harmful for your baby, we just won't mention how harmful it is! I can't say I blame individual doctors I have seen, as maybe they didn't know either. But someone did! And they could have told the doctors.”

“...He never made it to his seventh birthday, and had spent his short life in pain. He was my only child, as the fear would always remain that it would happen again. A change in medication could have prevented all of this..”

“My daughter is affected by lifelong disabilities due to Sodium Valproate and lack of medical advice provided by my Consultant prior to pregnancy.”

“As a neurologist had reassured us I continued taking Epilim in pregnancy, we both, as parents felt hugely let down by the medical profession at being grossly misled and thus resulting in our son having foetal valproate syndrome...”

“About 2 years ago I read an article... about the links between Epilim and ASD. It seriously rocked my world and I went into a bad depression due to the guilt. I felt his condition was entirely my fault. I was very angry that I knew nothing about this... I haven't even discussed it with family and friends, not even my husband. I can't discuss it as I feel so ashamed and guilty.”

“[My neurologist] said not to blame myself and that Epilim couldn't be ruled out as a cause... [I watched] this documentary, it filled the gaps, answered the persistent questioning. I saw mothers with their children with facial abnormalities, learning difficulties, all being turned away... It confirmed what my Neurologist had said to me.”

“...her death will haunt me and my family forever. The impact on my life, those close to me, the giving birth but no baby to hold and nurture and watch taking her first steps, just a vacuum.”

“When I was thinking about having children [in the late 1980s/early 1990s] I thought I should see a doctor... I had heard a programme on the radio about the potential dangers of Sodium Valproate. My doctor told me not to worry, that lots of women taking Sodium Valproate had ‘normal’ babies. I felt that I had been dismissed as an hysterical woman...”

“What I was shocked by was the way my GP treated my questions about the potential dangers of the drug... I have always wondered how many other women went through the same thing with their GP but went on to have children anyway.”

“Both of my children struggled with school work particularly reading and writing. In older life both have suffered depression.”

“I had no idea and when I heard I was so shocked, when they described their children it was like they were describing my daughter! I was so upset, shocked, angry, guilty....I just cannot put the feeling into words.”

“[I worry] someone will take advantage of her... she would not know how to see a solicitor over something legal, or pay bills and live alone without support... she doesn't always find the right words to explain or to see something is not right. I worry about support for her once I am no longer here in the future. Though she is doing well, all things considered, I do think of the woman she could have been and the difference she could have had in her life.”

“The guilt, upset and rage over this consumes me every now and then. I just want an apology for what has been done, for justice for her.”

“We still face an everyday struggle just to be heard...”

“It is very hard to see the children struggle with their anxieties and other problems on a day to day basis. [My daughter asked] ‘Why did they give you that drug Mum when you shouldn't have taken it?’”

“I cannot help but feel so pained as to all the things she hasn't or won't achieve.”

“I feel guilty when I read about the effects and think about what I did to my son, even though I know in my rational mind it wasn't my fault. I cry when I think about it too much.”

“Our daughter should not be surviving on good faith. She should be in receipt of a comprehensive, fully assessed care package. We will continue to argue her case and refuse to give in. However, what will happen when we are no longer here to fight her corner? What is already happening with those who do not have someone to fight their corner?”

“He has been diagnosed with Autism and Foetal Valproate Syndrome...[as an adult]. Because this had not been picked up sooner he has struggled all his life trying to make sense of things and not understanding... I think it is so important that this is picked up as early as possible to ensure support is in place at an early age.”

“...the problems associated with foetal Valproate Syndrome seem to increase as they get older.”

“We know he loves us as we do him but we have never been able to experience the joy of a simple hug, kiss or cuddle from him because he cannot cope with contact... We have seen him going through awful pain and discomfort it is heart-breaking to see. We worry about his future health and his inability to lead a normal independent life.”

“I have ongoing problems with my PIP which has affected many of my other benefits. This means I may have to lose my home, which is set up specially to manage my youngest Daughter's needs. Today I feel anxious, depressed and do not know how much longer I can go on as I am.”

“I think it is essential that FVS children have good counselling available when needed to reduce some of the stress that they experienced.”

“...I feel much more can and has to be done, to help and support all these families affected...”

## Pelvic mesh

“I am so angry and feel like the voices of people like me are continually being ignored, we also want justice it's like we are the forgotten ones.”

“...at this point I was becoming extremely depressed and realising that my life wasn't going to be the same again.”

“They refuse to admit any of my problems are due to the mesh.”

“I have had a constant ‘battle’ to get the help and treatment I so needed with my mesh complications. Gaslighting and a ‘fobbing off culture’, appears to be rife and there is much pro mesh bias out there... There is true sense of distress and shock that I so flippantly agreed to this procedure in addition to Anterior Vaginal Wall Repair, but my belief and trust was total. I believe consent should discuss the full spectrum of possible complications, for example risk of deformation, curling/folding of device, migration, contraction, retraction, infection, injury to organs: urethra,

bladder and bowel, risk of chronic pain, Foreign Body Reaction, dyspareunia, vaginal deformity and scarring, nerve damage etc. The permanency and makeup of the implant made clear, and the complexity and risks explained of removing the device if complications develop... How can the benefits outweigh the risks? I understand that SUI is sometimes debilitating and distressing, but I can assure you these injuries are negatively life changing beyond words.”

“She suggested that it was such an easy fix, that it was almost unthinkable that I would have any other options.”

“I am anxious as to what the future holds for me.”

“We were told of tape, ribbon, mesh being implanted to give us an improved quality of life, we were never told it was plastic, that hardens, twists, breaks and pierces organs and destroys life, just like the fish in the Oceans are being poisoned and killed by plastic, I feel that is how us women are viewed, there are plenty of fish in the sea what’s 15-20 % failure rate, this is a national, indeed international scandal and tragedy and someone needs to take accountability and say stop!”

“I was fitted with a TVT-O... for stress urinary incontinence. I was a super fit, 42 year old Mum of two, who worked out and swam daily, ran my own business, was chair of a local children's charity, who suffered the occasional mild leak when jumping. My surgeon told me that he could fix this issue with a quick and easy twenty minute operation that would see me back at work and the gym within a week... My GP has/had been exceptionally supportive throughout my mesh battle and had been attempting to try and find answers for me. He suggested that I went home and researched TVT-o problems as he'd recently read an article about a "handful" of women who were experiencing some symptoms very similar to mine... So I went back to the consultant to discuss things, Unfortunately he is very pro mesh and when I asked if he thought my issues were linked to my TVT-o he actually screamed at me ‘you need to stop listening to the media and those... women, I fit hundreds of these every year and you're only person I've seen who is complaining and thinking you have problems’...”

“I have attempted suicide, and often think about it as, I feel at times it would be better that way, it’s the only way! Then on the other hand, I need to fight, prevent future generations from suffering such brutality from a barbaric procedure. I couldn’t have this mindset without the Women who I fight alongside.”

“...the blanket of lies about this operation is a crime.”

“The pain I experience has increased over the years, I am incapacitated with the pain, spending most of the day lying on my side which is the most comfortable, although sadly not pain free I was a very active woman until this surgery and consequential pain/symptoms, mother, grandma, cyclist, runner, swimmer. I can now barely read a story to my grandchildren let alone play in any active way I am depressed, at times suicidal and feel a burden to my family. My husband is no longer my lover, he's now my carer, pain prevents any intimacy. I am unable to groom myself, sometimes not brushing my hair all week”

“Mesh injured women are desperate and are therefore extremely vulnerable.”

“I was never offered any alternative conservative treatment and I was certainly never fully informed of the potential risks. Furthermore this device was described to me as 'tape' and not plastic.”

“I do believe that the use of any surgical mesh should never be used again, due to the unnecessary, cruel, life changing result.”

“[I was] told sling quick & easy option whereby hysterectomy was a “major operation with 3 months off work”.”

“The only advice / warning I was given about this procedure was that it ‘may not work’, I was not informed about any possible complications other than anaesthetic related and that was brief. “

“I hope my experience might help or stop someone else having to go through what I have which I am still having to endure!”

“In 2013 I honestly contemplated suicide - actually if I'm honest with myself, I had planned it however I couldn't bring myself to do it because I didn't want to leave my husband or my two beautiful girls.”

“...someone needs to open the floodgates on these corporations and stop them using medical devices that have NOT had human trials.”

“Enough is enough! Please think for one moment, how would you feel if this was your wife or daughter?”

“I've lost years with my family while I sit in the background and just watch.”

“Her life became an endless round of visits to her GP, consultations in hospitals and antibiotic prescriptions.”

“I desperately hope she can get to a point where she's no longer in such pain and can go for a walk again. The mesh has changed her and I, and my entire family, are deeply saddened and changed by it too.”

“All that I ask is honesty”

“This should not have happened. I was not told of these risks. Would any sane person allow a piece of equipment to be inserted into their body if they were told the risks that it could become infected and possibly kill them? I don't think so. I strongly believe that the TVT mesh should be banned. It is not fit for purpose. It does more harm than good.”

“...so from one little mesh I was minutes from dying, lost my home. It all shouldn't have happened.”

“The life changing effects of having a toxic product fitted are not easy to live with. Over the last 10 years I have been tested for MS, suspected stroke, nerve damage along with numerous other issues. When I go to my GP she is at a loss of how to help. I have been told I need to live with my chronic pain condition and I will not get better. I take a cocktail of medication and this leaves me still in a great deal of pain. To be pain free would mean I would be bed bound as the medication would need to be that strong I would not be able to function.”

“I can't even play with my grandchildren.”

“The operation was described as being an extremely simple procedure, with minimal time off work.”

“I am scared for my future.”

“My Surgeon told me that I was having a simple ‘tape’ fitted that had been trialled in Scandinavia. He also told me that it would last about 10 year.... I put up with this, thinking that it was normal after the operation, whilst all the time my other health problems started and became worse... [*Name of removal surgeon redacted*] said that the mesh had to be scraped from my bones, it had gone into my vulva tissue, my obturator fossa and had gone into my bladder.”

“I was in a very vulnerable position and felt unable to say no.”

“How can anyone say that they have come to terms with living in this sort of pain inflicted by a medical procedure that was to supposedly meant to cure the problem.”

“If I had known of any risks then I most certainly would not have gone ahead with the surgery and my symptoms were not that severe.”

“I now have to find the strength to carry on.”

“Should sick patients have to go through complaint after complaint to get help?”

“I cannot even put into words the pain I am in every day, I never get a full night’s sleep.”

“I worry about what will happen in the future if the mesh isn’t removed fully, the risk of sepsis is more on my mind than ever before, I have been one of the lucky ones when you look at my story, in comparison to others suffering more severe after effects of mesh insertion.”

“My memory and concentration is poor and I have to rely on others to help me, I am losing my independence and control over my life.”

“As time went on, it was clear that I was not recovering as I should. Why was I not informed of the potential consequences? Why was I not given any choices about non mesh repair?”

“...no one was listening to me so just carried on the best I could.”

“Left with ‘little confidence’ in medical profession.”

“There are times when I feel my life is almost over.”

“The problem is that this mesh was used without any research into the ramifications... Devices do not have the same testing regime as drugs. Therefore provided the device is similar to one already marketed and approved that will do. The result is that no one has any information, no one knows how to remove the mesh. Some advocate partial some the whole. Others claim it cannot be successfully removed because it is imbedded in tissue. So far the manufacturers refuse to accept responsibility and the medical profession has been economic with the truth at the point of insertion and at the point of pain 5-10 years later.”

“It truly is the worse thing you could do to someone.”

“I've studied the science it's there in black and white.”

“I feel very depressed life is not worth living for no-one is listening. I will have to live with the pain for the rest of my life.”

“I have been dismissed from my job... lost my marriage, had to sell my house and downsize and it has had a huge detrimental effect on my family. I ... will never be able to work again and am disabled for life. Suicide has crossed my mind many times, but my family keep me going.”

“I did not want to appear a hypochondriac and was too embarrassed to admit just how bad some of my issues were.”

“I feel that I have been lied to, and not taken seriously. I felt completely let down by the way I have been treated and unable to prove what I know is the truth.”

“...my journey to find a surgeon who believed that my current health situation is down to mesh complications has been like traipsing through treacle.”

“I have a copy of the ‘Patient Information’ I was given at the time. It states that overall they would expect 85% of women to say that the TVT has cured them of stress incontinence. A further 10% of patients will be improved but not cured. The operation will not work in 5% of patients. There was no mention of any negative side effects.”

“It's heart breaking, as I was told that the Mesh was the best thing for my prolapse, and that the quality of my life would be much improved in having it done, and NEVER told of any possible complications, and I trusted fully all I was told. Instead it has ruined my life in every way.”

“I am now fighting for removal, as I fear this will, ultimately, kill me, after robbing me of all quality of life. I truly hope you can get mesh banned.”

“Little did I know it would rob me of future health and happiness.”