

Website: www.tvt-messed-up-mesh.org.uk

Serious Concerns with our Surgeons in the UK and the Lax Support from the Governing Bodies NICE and the MHRA

**An urgent review is required on the medical
devices TVT, TVTO, TOT and the use of mesh
graft for hernia repair surgery plus the
Governing Bodies NICE and the MHRA who
regulate these medical devices**

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TVT MUM

TVT Messed up Mesh

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Abbreviations used in this article

TVT – Trans-vaginal Tension Free Tape Medical Device

TVT-O - Tension Free Vaginal Tape Obturator Medical Device

TOT - Trans-Obturator Tape Medical Device

Medical Device – Medical devices using surgical polypropylene synthetic mesh for hernia's, prolapsed, stress incontinence and other bladder and bowel disorders.

MHRA – Medicines and Healthcare products Regulatory Agency

NICE – National Institute for Health and Clinical Excellence

TVT Mum – TVT Messed Up Mesh

Surgeons – Urologists, Gynecologists, Uro-Gynecologists

Introduction

We have serious concerns regarding the surgeons who use the TVT, TVT-O and TOT medical devices and mesh grafts for hernia repairs, stress incontinence, prolapsed, bladder and bowel disorders. The surgical polypropylene synthetic mesh used in the medical devices is the source of the problem and we want this surgery stopped. Many people around the UK are finding it extremely difficult to contact an experienced surgeon to treat mesh related complications and unfortunately many 'inexperienced' surgeons are going ahead with what appears to be 'guess work' surgery and making matters worse for their patients.

The governing bodies MHRA and NICE have shown no interest in pursuing this urgent matter affecting thousands of people who need urgent treatment, we have tried to tell them there are not enough experienced surgeons in the UK to treat us all. We are awaiting a response from them to show their investigations on the 'surgical polypropylene synthetic mesh tape' used in these medical devices as it has caused a serious growing health problem around the UK. They have had meetings behind closed doors with the manufacturers and surgeons however, our request for attendance was declined.

Our TVT Mum support group is here to give help and advice to those who are desperately trying to find an experienced surgeon. Through these peoples experiences we have a clear picture on mesh tape problems and it is disappointing to hear they have to rely on 'inexperienced' surgeons to treat them. There are many people who do not understand our plight plus they do not know what these medical devices are and how we have become 'complex' cases. After years of extensive research we feel the time has come to raise our concerns and to give you an insight on the current situation in the UK.

Concern: Inexperienced Surgeons

My first and main priority concern is unfortunately there are still surgeons who are **inexperienced** in the UK attempting to remove TVT, TVTO and TOT medical devices and they are making promises and admitting they have not done these types of procedures before, these inexperienced surgeons are using laser treatment which is not recognised as a viable treatment plus using laparoscopic surgery to remove mesh. These inexperienced surgeons are making matters worse for their patients.

I have heard some really horrifying stories where mesh removal surgery has gone wrong. These surgeons are giving their patients excuses and hiding the fact they cannot do the surgery and telling their patients to give it time to heal, they are telling people mesh erosion is rare very rare when in fact it is a very common problem.

I have also heard they are treating patients by burying the mesh without taking the eroding mesh out first when in fact as you know this is very dangerous as the mesh is possibly infected, will cause abscesses, constant discharge and pain, nerve damage and could cause internal bleeding and kidney damage.

I am speaking on behalf of all who are suffering so much pain and discomfort from receiving treatment from inexperienced surgeons - *Will the inexperienced surgeons please do the decent thing and not go ahead with surgery, if you are not experienced in mesh related complications please tell your patients you cannot treat them and recommend a surgeon who can do it!*

Stop harming these women more by trying to correct it with what appears to be 'guess work' you may have every good intention but *wouldn't it be better for your patient to get an experienced surgeon to treat the complication rather than going ahead yourself and possibly making matters worse?* This is not good enough, we need experienced surgeons to treat us or at the very best find an experienced surgeon. People are now being referred outside of their NHS catchment area around the UK please find an experienced surgeon and refer your patients to have the proper tests and correct mesh removal procedure.

Stop messing around with our health and lives, please do the decent thing and get trained and become experienced surgeons and stop implanting anymore of these medical devices. I am still hearing from people who have just recently had this surgery and now want help from daily pain and I also hear very often from people they wish they never had this surgery done.

Are the surgeons to blame? Yes in part for not doing their job and finding out if these products are safe. *Did you have proper training? Do you know what to do if anything should go wrong? Do you have both experience in implantation and extraction?* When we hear some surgeons use a video to put these types of medical devices in and hearing the sales representatives from the manufacturing companies are in attendance at surgery without the patients knowledge is one of utter disbelief, but it has happened and is still happening plus the fact the surgeon is believing this is a simple operation, it is not a simple operation as our research shows. I do not think and I know others will feel the same putting a medical device in ‘blindly’ through such a very delicate area with numerous nerve endings is NOT a simple operation. It is known minimally invasive surgery does not imply minimum risk this is the manufacturer’s choice of words and not a medical term.

Boosting CV's? Sorry but I have to say this - *we have come across these surgeons too!* These surgeons have absolutely no experience at all and practising their skills on unsuspecting patients and using us as their experiments. I am sorry to say this but it is a disgrace and I am very surprised it is allowed to go ahead doing this kind of surgical procedure without thinking of the consequences. I think all surgeons need to remember – *you have allowed your head to rule instead of your heart and you have forgotten the Hippocratic Oath.*

This area of concern with ‘inexperienced’ surgeons is ‘not’ regulated as far as we can see around the UK.

Concern: Experienced Surgeons

You the experienced surgeons should be bombarding the MHRA as you have the authority to do it, we can only do our bit here at TVT Mum by trying to give help and support to those who approach us seeking answers where to find treatment and we are trying to direct them to experienced surgeons to get the right treatment which I may add there are not enough experienced surgeons in the UK. *Where are the experienced surgeons around the UK?* Everyone who is seeking help on mesh related complications and our GP's need to know urgently please.

Why did you trust on words and not do your research on these medical devices? We all trusted our consultants had done their research and knew about these products and it is likely most of the patients would believe you had done your own research first too. These supposedly marvellous medical devices which were and still are over-rated and over-marketed with no long term randomized control trails are still on the market and you still do these types of surgeries, stop and think about what you are doing to us and to your own careers.

One day the truth will come out as it always does and we will see more experienced surgeons helping us, the standing 'joke' which I heard in the grapevine - 'surgeons take out more mesh than they put in as they are increasingly having to deal with mesh problems'. The 'boys with toys' phenomenon whereby surgeons enjoy trying new procedures plus the considerable 'marketing' from gynecologists who gain financially in the USA 'fee for service' practice and UK private practice. These are serious quotes.

As one gynaecologist said to me *"this is the tip of the iceberg"* and he is so right at least he admits it and is doing something about it and so are some other medical professionals who have kindly contacted us and showed some truths on what is currently going on around the UK including the whole of Europe and Worldwide.

We need you the surgeons to come clean with us as your patients to speak the truth *it is your duty to protect us from harm isn't it?* Please stop doing these types of surgeries and get the full facts on the products you are using and do not allow these products to come onto the market without proper long term RCT's.

To the experienced expert surgeons who are seriously listening to us and taking time to hear about our situation to achieve success in dealing with mesh related complications we thank you for all your understanding and expertise. I know for a fact you will agree there should be a lot more experts plus more research to be carried out especially on the present inaccurate percentage figures, a review on the guidelines and a review on the RCT's around the UK.

Why do I pursue in my research? At this present time we do our own extensive research as I was told by a Medical Professional and given to me on good authority – as quoted "the medical profession is actually very alert to surgical complications and sadly, investment in research into the area is not regarded as a priority by medical research funding bodies, which seriously hampers our ability to get a true handle on the situation".

Concern: No Medical Tests

I am hearing from people the surgeons who are performing mesh removal surgery are doing so **without** proper medical tests ie: cystoscopy, MRI, Ultrasound and Scans, here is the recommended article from **The British Journal of Radiology, 77 (2004), 261–265 E 2004 The British Institute of Radiology DOI: 10.1259/bjr/63333975**

Pictorial review Prosthetic mesh used for inguinal and ventral hernia repair: normal appearance and complications in ultrasound and CT here is the direct link to this article in PDF Format –

<http://www.tvt-messed-up-mesh.org.uk/pdfs/radiologic-appearance-of-mesh-on-ultrasound-CT-scan.pdf>

I have pointed you to this article as my own surgeon was not even aware of it although he did add the radiologist possibly did have this information. I am also hearing surgeons are just relying on a hand internal inspection with a light to make a decision to go ahead with this serious mesh removal operation. I feel sure many experienced surgeons will agree this is totally wrong and not

acceptable. Any mesh complications must have proper tests to see what the under-lining problem is before attempting any surgery to remove the mesh.

The fact of the matter is when the mesh becomes a problem it has to be fully investigated considering when I hear some results are showing the mesh tape can wrap around the bowel, the mesh tape can erode through the urethra and the vaginal wall, the mesh can become a mass ball and the mesh can attach to the pelvic bone plus other complications arising, more often than not it has to be removed as soon as possible this is why I am sure any experienced surgeon will agree there has to be the appropriate tests first before any attempt on mesh removal surgery.

Concern: Surgeons Pulling Ranks and Ego

In my opinion and others have said they agree with me that some surgeons ego has got in the way of good medical practise I have to say and again others agree these surgeons ego's have become too big to admit they cannot perform the necessary surgery to correct mesh problems and they are going ahead with what appears to be 'guess work' and could and are making matters worse for their patients. Surely your reputation as a reliable and trustworthy surgeon to ensure your patients get the right treatment comes first *so why ruin it?* Admit you cannot do the surgery or get someone who knows what they are doing.

*Wouldn't it be better to hear your patient praise you up and admire your honesty rather than ruin your good standing? Stop this madness and your way of thinking as your reputation is at stake, keep a good reputation and seek an experienced surgeon who will train you. Stop your ego's getting in the way of good practice and patient safety and stop allowing profits to over-rule your way of thinking, listen to your heart. Do you really want to jeopardize your career? think about what you are doing and listen to these people who want to feel safe in your hands, any decent person would not jeopardize their career for the love of money, rank and self importance, of course you don't want to see yourself as such a person so I say *stop it now and reap the rewards of being the great surgeon you set out to be.**

We have had enough of surgeons implanting these medical devices in us without proper long term randomized controlled trials and also the fact we all trusted you had educated yourself on these medical devices and did not just rely and believe the governing bodies who regulate them, they are the ones who make the decision for these medical devices to come onto the market, they (the MHRA and NICE) have indeed got to give you and us an explanation as to why and how these dreadful medical devices came onto the market in the first place, blame them for bringing such devastation to the fore.

I have it on good authority and shocked to hear there were some surgeons who knew the truth and were fully aware these medical devices are not safe products and in my opinion it seems they literally pulled the wool over some surgeons eyes and blinded everyone to the truth plus the fact it appears profit and money was the important factor in their decision to put these medical devices onto the market rather than having their patient's safety come first, an important question needs to be asked *was it seen as money making?* I have to say it is looking this way considering these surgeons knew these medical devices are unsafe and knew eventually it will give their patients mesh related problems, *maybe the thought of ongoing work was attractive?* Do not under-estimate our intelligence we can see why you decided to do these types of surgeries, you put cost, profit and greed before patient safety and the evidence is clearly pointing in this direction.

Since our Health Secretary Andrew Lansley mentioned Hospitals face financial penalties for readmission I am sure this practise for implanting these medical devices and for mesh removal surgeries does not sound so attractive now considering most of us have to face a future of multiple surgeries to get the mesh out of our bodies, I have now heard the NHS are paying Private Practise hundreds of thousands of pounds to clear the NHS waiting lists and it does involve those patients who are waiting for hernia operations, it does make us wonder *is this another corrupt scenario to hush things over and gain more profits?* Surely people will and can see these unethical practises drastically need to stop and change.

**Concern: Governing Bodies - Medicines and Healthcare products
Regulatory Agency (MHRA) and National Institute for Health and Clinical
Excellence (NICE)**

It is up to you the surgeons to contact these governing bodies and let them explain why they put these products onto the market. We at TVT Mum have done and still are doing our own research and we have found the answers as to why, we need your support and to work with us on this investigation. It is the governing bodies who owe you and us an explanation.

It is you the surgeons who have to deal with the consequences of putting our health right, *why should the governing bodies stand back and watch us all go through debate after debate when they are silent?* They have a duty to protect the public from these manufacturers who send out sales representatives giving the old spill on how fantastic these products are when in fact it is one massive charade of lies and as far as I can see the MHRA and NICE have believed on words without asking questions on safety, non inspection of the manufacturers premises and not reviewing evidence on long term RCT's.

I know why the MHRA and NICE are silent and I also know why they are hiding the facts, it is up to you to get this scenario stopped and get them to tell you the truth why they did it. In my own opinion I feel they owe everyone and that includes you the surgeons, our GP's and also to us the patients a thorough investigation and explanation. We are relying on the Governing Bodies to contact the manufacturers this is their job and they must relay back to us all the answers.

We of course understand it will take a long time to rectify this ongoing serious health problem and also I have to say it does look like a despicable corrupted gang for a better word is in our midst. *Can you blame me for thinking this?* This is a serious situation affecting thousands in the UK and there are not many acknowledging it in the medical world. I have to stress again it is not hundreds **but** thousands of people so *why are they keeping this so silent and not releasing*

the truth to the public and media? I and many other people have every right to the truth and answers.

Remove these dreadful mesh products off the market and have a full investigation done immediately. Contact the governing bodies MHRA and NICE let them explain why they allowed these medical device products onto the market, it is them who have put your reputations at stake and they have played a part too at destroying our health, *can you blame people for being angry?* Our support group members are facing extremely life changing circumstances not only with our health but we are also facing drastic changes in our quality of life. The MHRA and NICE need to contact the manufacturers and get them to explain why these products are so blatantly over marketed and praised up as safe products when the facts are showing they are very detrimental and dangerous.

The MHRA must know there have been deaths from these medical devices, we already know of 10 deaths showing in the public domain in the UK, there are probably a lot more on their database. *Are surgeons hiding the full truth and not reporting faulty medical devices? Is this the reason they pass on their patients to other surgeons for fear of being sued plus get away with reporting mesh related complications?* It is known if a surgeon passes their patients on for mesh related treatment the surgeon who has implanted the medical device does not have to report it and neither does the referred surgeon. This loophole goes to show how they are trying to hide the true figures and how they can manipulate percentages, the current percentage figures showing are completely wrong, this is why we need a full investigation.

The fact of the matter is we are all extremely disappointed with the MHRA they are incompetent for not protecting the public from these medical devices which has and still is causing our health and quality of life to change for the rest of our lives. This organization is government backed paid by the tax payer and it is the public who has given them jobs it is their duty to get something done and to treat this matter as urgent. Their recent meeting with the surgeons and the manufacturers and everyone involved with these medical devices was held behind closed doors, I requested attendance to represent our support group and

was denied a hearing, I have contacted them to request feedback on several occasions and as of today I have not heard or received anything on the outcome of this meeting. Another question I often get asked by people is *why are they silent?* This is another question we have every right to be answered.

We deserve a hearing and not one person will give it to us including the Governing Body MHRA who should be there to protect the public from these medical devices. **Where is our hearing?** Our hearing at this time is from our website for the time being this is the only way at this present time to report and show you all what is currently going on and to help educate you the medical world and the public. It does appear most surgeons were misled into believing these products are safe, it just goes to show who is educating who on the truth!

Unfortunately there are deaths occurring from these medical devices, there are 10 deaths recorded showing in the public domain and sadly today I have heard another woman has died from a blood clot in her lung shortly after receiving mesh removal, *how many more will there be?* We are speaking up for these people too. Plus there is a current law suit in Liverpool which does involve the use of these medical devices but not solely on this subject.

I really hope these concerns I have raised regarding the governing bodies MHRA and NICE who are supposed to be protecting the public from harm will nudge you into taking action on our behalf, it is you the surgeons who are fit and healthy and not us who are ill and unwell at this time and I have to add through no fault of our own. It is totally unfair women and men have to go out of their way ill and under treatment raising their own concerns and taking whatever action they feel necessary to get the governing bodies to listen and move plus to get them to do something about these dreadful medical devices stopped and off the market.

As we all know when we are ill and still under treatment our way of thinking does get understandably impaired and it does take very brave people to attempt on getting the MHRA and NICE to take notice by demonstrating, petitions and constant correspondence, I really admire their determination and strengths for

trying however, I really feel it is up to the healthy and fit to do this on our behalf especially the surgeons, GP's, family, friends and anyone who feels they could possibly help us in this area of support.

Concern: Mesh Complications and Removal of the Mesh Tape

It is fact and known once the mesh tape is inserted it will eventually erode from day 1 up to 7 years later although it has been known it can erode up to 12 years later according to research.

We understand there is no one in the UK willing to take the whole mesh out once the mesh complication arises. I have heard it is an extremely serious, damaging and a very risky operation, it is bad enough we are having to face partial removal and to accept we have to live for the rest of our lives with multiple surgeries to get the rest of the mesh out, it cannot be removed wholly in one go without huge risk.

After partial removal we again face urine leakage and plus I have heard there is damage to the bladder and bowel we again now have to face wearing incontinence pads daily with no further treatment as our tissue has become so badly scared. Mesh tape is a foreign body fighting to get out of us, it is fact once the surgeon starts messing around doing the partial removals the other bits of the mesh tape left will move and no one can answer where it migrates too, even after partial extraction there is still a risk of further mesh erosion weeks, months or years later. I have heard it can adhere to the organs, pelvic bone plus it causes nerve damage hence our daily pain and discomfort.

I am hearing GP's are referring their patients outside of their NHS catchment area to find an experienced surgeon thankfully these GP's are listening and they have their patients well being at heart, I really admire them and I know many patients who have an understanding GP has full respect for them. We thank you all for your understanding.

There are people around the country who desperately want treatment from experienced surgeons please can you let me know if there are anymore surgeons in the UK who can do this type of surgical procedure to correct mesh related complications so I can pass the details on to those who approach us for help.

Please understand we want all the surgeons to contact each other and to get trained in mesh related complications especially for mesh removal we need your help urgently. This is a serious ongoing daily health problem in the UK we have every right to show our concerns and show we care for those who are suffering from daily pain. We will try and stop others having these medical devices containing polypropylene synthetic mesh which is the source of the problem.

Everyone says to me *why are they still putting these medical devices in us?* Now I want you the surgeons to answer this question because *how can I answer it?* It's not up to me to answer that question it is up to you the surgeons and the governing bodies to answer it so I implore you to give me your answer as I would love to know 'why' then I can relay your answer back to all those people who keep asking me. In fact why don't you ask the MHRA and NICE they are the ones who should be really answering this question for they are the ones who allowed these medical devices onto the market in the first place.

Our 'long term health' is a concern too, not one surgeon can tell us what our health is going to be like for the future we are all literally living on the edge on a daily basis and has ruled our lives to the extent we cannot even plan for anything this is totally unjust and wrong.

Concern: Lack of Services - Suggestions to improve services

1. We want money diverted by productivity savings to be used to set up multi-disciplinary teams at regional centres to deal with complex problems and especially the patients who have been damaged by procedures with limited benefit such as mesh surgery
2. We need more experienced surgeons urgently around the UK
3. We need a telephone advice and support help-line
4. We want to see medical professionals come forward to give medical advice when things go wrong, practical help and support
5. We need professional pain management counselors
6. We need a factual informed consent form on the product and to show all mesh related complications. We do not want this handed to us just before surgery please give full information at the pre-assessment so we have time to make our own decision
7. Post operative care is lax, educate the nurses
8. We want our consultants to explain the whole surgical procedure and possible full complications from the mesh tape and not to just give the normal complications associated with any surgery

There are other valued services to add but for now I think this will be a good start to achieve positive action and at best to start noticing we need these services.

Concern: Our Mesh Tape Nightmare a Reality

It is unbelievable to realize that one piece of mesh you have put in our bodies has caused such devastation not only to our health but it has also affected our quality of life, we have people who have lost their homes, careers, marriages, family and friends. This is not just about putting our health right and about you the surgeon, it is also about the governing bodies NICE and the MHRA who are keeping silent and trying to hide the true facts, it is also about showing us you care.

I have been hearing you the surgeons saying to your patients do not trust the internet for advice, now you tell us - *where do you suppose we go for help if we did not have this website and I have to add run by people who work voluntary whilst ill, where is the help out there for us apart from this website?* If you have the answer we would love to hear it. We have approached government backed organizations such as the Bladder and Bowel Foundation but no help absolutely no help at all and this goes for other government backed organizations *so what are we supposed to do sit at home and hope?* Not good enough! Please all you

surgeons who say do not look on the internet *stop it!* We are here and we will give the support to all the people who approach us. Stop hindering our work and help us!

There are more and more people approaching TVT Mum website every week seeking help do not judge us we are not stupid we are intelligent people who did have fantastic careers and a great life at one time until you destroyed it, this is not our fault most of us have ended up depressed, lonely, facing difficult times to the extent of losing our homes, family, friends, careers plus making us financially insecure this is through no fault of our own but through you the surgeons your ignorance, greed and also the un-educated at the MHRA and NICE for allowing such a despicable product onto the market they too did this to us.

Our lives have been changed drastically to the extent our femininity and self esteem has been destroyed possibly for the rest of our lives.

Please we ask you to remember this was not a natural occurrence with our health issues it is **not** like a normal 'disease' which developed in a 'natural way' these man-made products the surgeons have implanted in us has caused our ill health to the extent the mesh material has caused other health issues to arise which I may add is currently having extensive research as many people did not have these other health conditions before surgery such as diabetes, myasthenia gravis, fibromyalgia, excessive tiredness and other auto immune diseases.

This is not only affecting our health but also affecting our quality of life and all from one piece of mesh, I repeat '**ONE PIECE OF MESH**' absolutely unbelievable and disgusting.

The following points and questions are situations we face on a daily basis. It has all come about from having this surgical procedure TVT, TVT-O and TOT and then after surgery we get complications from the mesh tape causing damage to the extent it affects our health and life for years possibly for the rest of our lives. We did not 'ask' to be in this situation this is not our 'fault':-

- With so many health issues - Who will employ us now?
- Some have lost their homes - Can you bring our houses back?
- People have lost their careers - Could you cope with losing your career?
- Financial ruin, paying private practice - Could you cope being forced into financial ruin?
- No short or long term care – Where is the correct care?
- Mesh tape erodes and is like chewing gum, once embedded in our tissues it can only be taken out a bit at time - Would you like a future of multiple surgeries?
- Our energy has been zapped – How can we give our partners and children the love and attention they deserve?
- Our marriages have been strained – How would you like your marriage destroyed?
- Painful intimacy for both partners – How would you like this loving part of a relationship to be non-existent?
- Our once stable lifestyle has been changed forever - Would you like to face a complete upheaval and change of lifestyle?
- Housebound through constant ill health - Would you like to be stuck in four walls every-day?
- Social life disrupted - Would you like your social life stopped?
- Misinformed on common mesh related problems - How would you like to be told 'you are rare' and then find out you are 'not' rare?
- We did not ask for daily incontinence pads - How would you like to be forced into the situation of wearing daily incontinence pads?
- Broken sleep - How would you like sleepless nights with stress urgency, constant itching, swelling and pain?
- Daily pain - How would you like daily pain and not being able to sit and walk or even lie in bed comfortable?
- Too weak to walk - How would like it not being able to walk very far?
- We did not ask for daily medications - How would you like it if you ended up taking numerous medications every-day after having this surgery?

- We did not ask to be low in mood and lack of self esteem - How would you like it to have your personality changed through depression and medications?
- No understanding at Hospitals - How do you think we feel when we face A&E and no one knows what we are talking about? The majority of the time people do not even know what we are on about or what these medical devices are.
- Our family and friends do not understand - How would you like to lose your friends and family through lack of understanding? How can we ever describe to them what has happened?
- Every week people are approaching us for help and advice – Where is the professional help and support? Where is our help-line?
- Desperate people - How would you like to try and console desperate people?
- End it all? Unfortunately this is common and often heard, but and I say a ‘big but’ most of us have immediate families and this is what keeps us going we force ourselves to live and cope the best we can. Do you face this?
- Did we know about other health issues arising from the mesh tape? No we did not! Besides mesh tape problems there are many people who have additional health issues since this surgery - Would you like to have your health destroyed by one piece of mesh tape?

The list goes on and on, considering the above points it is difficult to comprehend the depths people will stoop to try and disrupt our daily lives unfortunately they are around. To those people who try and attack our good work and also try to bring disruption please think on - *don't you think we have enough to cope with having ill health and our lives so messed up from these medical devices and I have to add forced on us?* take a good look at the list above as this is just a few of the situations we are facing on a daily basis and it's through no fault of our own but through the greedy practices of the pharmaceutical companies, the un-educated on these medical devices, ego's getting in the way of good surgical practice and also through ignorance from our governing bodies.

The people who have been affected by these medical devices deserve to have their voices heard, we want answers and we definitely deserve a hearing.

Why has no one heard of this before? I know why, because it is so hushed up within the medical world, they are all pulling ranks plus the Governing Bodies who are supposed to be protecting us are so embarrassed and will do everything not to reveal the truth, they stop the media having access to the truth plus the fact who can really tell their story on such a taboo subject and who would want to share their story revealing details on their 'bits below'?

Surprisingly people are coming forward after seeing they are not alone they are in so much pain they have had no choice but to seek help as they are so often fobbed off from their surgeons! These are the ones who been brave enough to step forward and seek the help and support they deserve it is extremely difficult for anyone to talk about this subject - *is it any wonder not many people know about this?* I hope after reading this article it will give a clearer insight to everyone this is a very serious situation happening all around the UK and Worldwide.

There are literally thousands of people out there who do not even know we exist to help them, *why?* some people cannot afford the internet, some people have no or little PC skills, their GP's do not know we exist, surgeons who are trying to deter patients from reading our website, surgeons saying we are rare complex cases, surgeons telling people do not look on the internet (funny most authorities rely on the internet isn't it? and telling others not to use it), people who are in care homes with no access to help, no information is given to anyone post operatively for help, nothing in the media, no information or help anywhere publically except from TVT Mum website and our own support group, although there are other ongoing websites, forums, blogs and now video's around the internet, we all support each other and of course our word does get out by having excellent webmaster skills!!!!

This is a nightmare for us when things go wrong with this surgery our lives have radically changed. We do not wish or want anyone to go through what we are experiencing, this is why we will do everything we can to try and stop this surgical procedure using these types of medical devices.

There are plenty of other alternative treatments that should be offered to people. Unfortunately our consultants did not mention these to us or offered these other treatments. You do not have to accept your consultant's advice to use medical devices that has surgical polypropylene synthetic mesh in them which is the source of the problem. **Do 'not' allow anyone to put this dreadful man-made petroleum based mesh tape material in you.**

Conclusion

All we can do is live in hope that one day this scenario on these medical devices and how it has affected our lives will encourage everyone to give us the correct help and support and it will be noticed by all concerned especially our Surgeons, our Prime Minister, our Health Minister, our GP's, NICE, the MHRA and all the government backed organizations within the UK and stop these manufacturers from using 'you' for their own greed and means. It is up to you all to get this investigated and question the manufacturers for allowing these products to come onto the market without no long term RCT's which has destroyed our health and quality of life plus it is having a huge impact and strain on our NHS.

We live in hope and will remain until we can have a hearing and be involved in these investigations as I feel and I speak for everyone at TVT Mum support group this cannot go un-noticed for much longer we deserve help, support and answers. We will continue with our campaign for the need to have experienced medical professionals to come forward and to give us the help and right treatment we so rightly deserve.

I hope this article raises some eyebrows and pinches your gut and heart. *Can you not hear our voices and see our pain?* Do something about it and stop this growing serious health problem causing life changing circumstances to thousands who are currently in despair. Those who 'can' change it or can make a difference we need you to come forward and contact us.

A well respected medical expert surgeon said in one of his articles and is referring to these TVT, TVTO and TOT medical devices *"If you are female, ask yourself whether or not you would want this procedure performed on yourself. If you are male, ask yourself whether or not you would want this procedure performed on your wife, sister, or mother."*

So there you have it, this is my own personal opinion, thoughts and views. I hope I have touched the hearts of many people to come forward and to be brave enough to help us at our support group to help raise these serious concerns urgently in a dignified and honourable way.

This article does 'not scratch the surface' to how serious this situation is and the full picture on the truth to what is going on. I hope with all my heart there will be people out there who will see this article and decide to join us in our campaign to push and make the governing bodies listen and do something about this serious growing health problem, to stop the use of these medical devices and to have a full investigation.

My last thought to round this article up - We are all tiny little microbe specks in our vast Universe, do not be afraid to seek and speak the truth as the Truth will always prevail. All untruths come out eventually in an unexpected way, trust me I know this will definitely happen and that great day is drawing near.

Thank you for your time to read the article as it really does mean a lot to me and I know it will mean a lot to all the people who currently have ill health from their own mesh tape surgery experiences and to those who are recovering from surgery at this time.

Keep strong and brave everyone.

By Lorraine Evans
Owner and Researcher

Website: <http://www.tvt-messed-up-mesh.org.uk/>

Facebook: <http://www.facebook.com/tvtmum>

Twitter: <http://twitter.com/TVTmum>

Do you want to comment? We welcome all comments and we will add them to this webpage
<http://www.tvt-messed-up-mesh.org.uk/serious-concerns.html>

Contact us: <https://secure.hosts.co.uk/~tvt-messed-up-mesh.org.uk/contact-tvt.html>

References

Recommended Surgeons for people experiencing mesh related complications from the TVT, TVTO and TOT Medical Devices

Website: <http://www.tvt-messed-up-mesh.org.uk/mesh-complications-recommended-surgeons.html>

The British Journal of Radiology, 77 (2004), 261–265 E 2004 The British Institute of Radiology DOI: 10.1259/bjr/63333975

PDF Article: <http://www.tvt-messed-up-mesh.org.uk/pdfs/radiologic-appearance-of-mesh-on-ultrasound-CT-scan.pdf>

This article dated for the year 2006 is in the public domain there has been 10 deaths after this year date it is unknown to the public how many more have died. Please read this PDF from the BMJ page 16

PDF Format Website: [**BMJ \(British Medical Journal\) - harms-with-medical-devices-2007**](#)

Hospitals to face financial penalties for readmissions By Michelle Roberts

Website: <http://www.bbc.co.uk/news/10262344>

To see our current list of mesh tape related complications please click on the link below. The list has been compiled by expert medical professional articles and from people who have come forward and shared their experiences with these medical devices...

Website: <http://www.tvt-messed-up-mesh.org.uk/important-issues.html>

Stories from people around the world

Website: <http://www.tvt-messed-up-mesh.org.uk/stories.html>

The Committee on the Public Health Effectiveness of the FDA 510(k) Clearance Process will hold a public workshop on June 14-15, 2010 in Washington, DC. The purpose of the workshop is for the committee to gather information related to the statement of task.

Website:

<http://www.tvworldwide.com/events/iom/100614/default.cfm?id=12479&type=flv&test=0&live=0>

Website: <http://www.tvt-messed-up-mesh.org.uk/institute-of-medicine.html>

Truth in Medicine USA – Founder Lana Keeton

Thousands more lives are put at risk every day because of Synthetic Surgical Mesh. Industry, the FDA, the CDRH and the health system in general are NOT addressing the problem.

Website: <http://truthinmedicine.us.com/>

Article Title: Vaginal Mesh for incontinence and/or prolapse: caution required. "Even if the rates of these devastating complications are fairly low, they are life-changing for the patient, sometimes irreversible and often sources of litigation"

PDF Format Website: <http://www.tvt-messed-up-mesh.org.uk/pdfs/Dr-Zimmern.pdf>

Article title: Vaginal mesh grafts and the Food and Drug Administration

Author: Ostergard, Donald R.

Publication Date: 2010

Website Open Source: <http://www.escholarship.org/uc/item/3j89k81j>

PDF Format Website:

http://www.tvt-messed-up-mesh.org.uk/november_research/vaginal_mesh_grafts_2010.pdf

Take note those advocating the use of mesh in hernia repairs.

Richard G Fiddian-Green, FRCS, FACS.

Website: <http://www.bmj.com/content/338/bmj.b2321/reply>

Research and Expert articles <http://www.tvt-messed-up-mesh.org.uk/research.html>

FDA Public Health Notification: Serious Complications Associated with Transvaginal Placement of Surgical Mesh in Repair of Pelvic Organ Prolapse and Stress Urinary Incontinence Issued: October 2008

Website:

<http://www.fda.gov/MedicalDevices/Safety/AlertsandNotices/PublicHealthNotifications/ucm061976.htm>

Surgical Mesh - FDA has received reports of complications associated with the mesh. The complications include adverse reactions to the mesh, adhesions (when the loops of the intestines adhere to each other or the mesh), and injuries to nearby organs, nerves or blood vessels. Other complications of hernia repair can occur with or without the mesh, including infection, chronic pain and hernia recurrence. The most frequent complications included erosion through the vagina, infection, pain, urinary problems and recurrence of the prolapse and/or incontinence.

In some cases, erosion of the mesh and scarring of the vagina led to discomfort and pain, including pain during sexual intercourse. Some patients needed additional surgery to remove the mesh that had eroded into the vagina. Other complications included injuries to nearby organs such as the bowel and bladder, or blood vessels.

Website:

<http://www.fda.gov/MedicalDevices/Safety/AlertsandNotices/ucm142636.htm#popsui>

Disclaimer:

TVT Mum is a support group and it receives no Government funding. The website is difficult for me to finance and to keep it active and running. I am not a professional medical adviser, doctor or a practitioner. I do not give medical advice to anyone but I do try to direct people who approach me for medical advice to the right expert medical professionals.

All my work has been achieved through years of dedication to rigorous research, listening to other people who are experiencing similar health issues, using viable and true expert medical articles, help from expert medical professionals and other expert researchers and also from having first hand personal experience with TVT mesh tape.

All my work producing the website and articles is an open resource and it is there to give help, advice and support to the best of my knowledge.