Valproate Victims

Newsletter August 2019

Cumberlege, Conferences, Compensation, Community, Controversy

IMMDS Review

(Independent Medicines and Medical Devices Safety Review)

Submitting personal testimonies

As you know Valproate Victims submitted oral evidence to the Review. Unfortunately this has not yet been published.

In the meantime if an individual wishes to submit their personal testimony there may still be an opportunity. Here's a link to the current videos, there are very few from Valproate victims/survivors.

IMMDS Review Evidence Hearings

Please contact the Review Team independently or contact me if you prefer.

Reviewteam@kcl.ac.uk

Next Steps

The Review Team has asked us back to attend a meeting with all the other valproate groups and we are pleased to say most of the groups have all agreed to attend together.

The groups attending are

OACS Charity Organisation (Jo Cozens, Carol Lapidge and Karen Keely)
Facsaware (Emma Friedman)
INFACT (Janet Williams)
Valproate Victims (Susan Cole, Josie Tapper and Trish Greenhalgh)

We don't know which representatives will be attending yet. We will be discussing to reach a consensus on

a) the history of valproate and

b) any missed opportunities within that timeline

This work will remain confidential until it's complete but the Review Team are still taking evidence from families should anything spring to mind that you'd like to share.

Compensation and Redress

You may have received an email with the Family Futures Survey. We've been fortunate to have been given further assistance from solicitors to draft an outline a Trust should compensation be offered to victims. The survey was helpful to get a picture of what families want their future to look like, what assistance they want for children, who should care for them and manage their finances. The results of the survey were used in the final document, which will remain confidential for now. It is an outline only. Should compensation be offered, it would take the best part if a year to establish exactly how it would run.

This has now been submitted to the Review Team. You may fill out the survey as the information may be useful in future.

Family Futures Survey

Legal Action

If your child was born after 2004 you may be eligible for compensation under a medical negligence claim. Please do find a local solicitor to get advice. We have used Leigh Day for many cases but the choice of solicitors is yours.

Please be aware that US Law firms are currently settling in the UK and are hoovering up cases. They may approach you and although it's fine to sign up with them please be cautious as they may be giving people false hopes.

CONFERENCES AND ENGAGEMENT EVENTS

MHRA Medicines Health Regulatory Agency (UK Gov) Patient Engagement consultation

On the day we were at Oxford it was announced that this MHRA consultation is taking place. The valproate groups set a precedent in patient engagement over the years as part of the Valproate Stakeholders Network.

We will be submitting our thoughts on how this process is working and where MHRA are doing well with patient engagement.

MHRA Consultation on Patient

Engagement

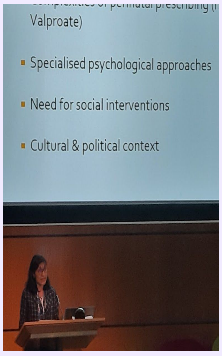
Oxford Nuffield Centre for Evidence Based Medicine

As mentioned in the last newsletter I was given the opportunity to speak at the CEBM at their three day conference at University of Oxford. I spoke on a panel alongside Kath Sansom of the Mesh Campaign and Marie Lyon of the Primodos campaign and the event was hosted by Carl Heneghan. Carl produced a cumulative meta-analysis of the history of valproate research which is a key document for legal purposes. This was a great privilege and I hope I did well. There was so much more that could have been said.

We met many interesting people and as a result have several projects to take forward.

Josie attended with me, it was a long hot day and she was a great support. I was also supported by some of the mesh campaigners in the run up in preparation for the talk.

Womens Rights in Healthcare



Some Stark Statistics and Moving Messages

I attended conference run by Leigh Day, who often take on human rights cases. I was lucky to meet Nadine Montgomery, whose legal battle against Lanarkshire HealthTrust altered the statute books to ensure that women consent must be fully informed. Her child has cerebral palsy following a bad decision made by her midwife, without fully agreeing the process with her first. I believe that if Nadine's case had been won 20 years ago womens healthcare would be in a very different place now.

Westminster Health Forum

Attended this forum for businesses, government officials and policy people in Mayfair. Much concern about medicines and devices post Brexit. There is concern about how future regulation will work

SUPPORT

Care and Diagnostic Pathway

Over New year I was asked to input into a document written by a team of academics and patient representatives.

This is a significant document for our families and now it's published it would be great if you as families could take a look at this and respond with your thoughts in case you think anything's been missed.

Once again I've done this in a survey format (it makes filing easier) so please do submit your thoughts to us as soon as possible. This is a significant piece of work and will affect the future care of our families.

Care and Diagnostic Pathway for Fetal Valproate Spectrum Disorder

Research Participants

Some members have been concerned about studies they've been part of. **If you've been part of a study and have not been happy with** the way it went or are unsure about what you were involved in we would like to hear your views and experiences and can point you in the right direction.

OACS Charity Trustees have asked me to organise their volunteers. I'm pleased to do this as it makes things less complicated for families who will have just one main Charity to engage with and we will also avoid covering same ground.

I have many years of training and experience in charity work. We will be working in regional teams and if you'd like to join up please contact me on valproatevictims@gmail.com

OACS Board has been extremely stretched. Please give an indication of the type of work you wish to do, our Facsjustice/ValproateVictims group has always collaborated with OACS and continue to do so.**FINALLY**

Please note that if you have concerns or need further information to help you and your family OACS has a helpline on their website, www.oacscharity.org

and the IMMDS Review Team also have supporters. If you'd like to speak to the Review Team please email them with your details on reviewteam@kcl.ac.uk.

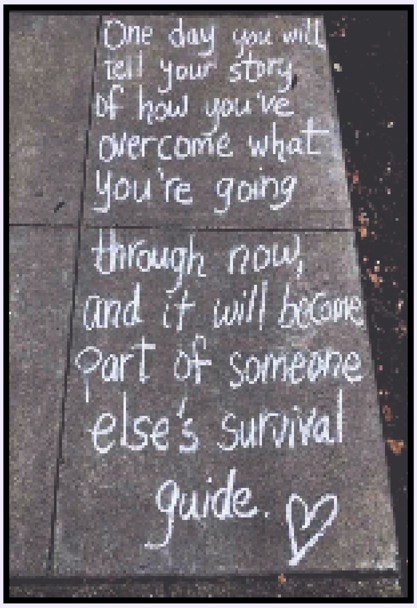
It can be extremely difficult running a household as a person with epilepsy and where children have disabilities. Asking for help is sometimes hard. A problem shared on one of the closed Facebook groups (OACS Charity or Valproate Victims) may also be of help so please do try.

These are difficult times when our friends and family will see us through. Please do join the Facebook groups to support each other.

[Private Facebook Group]()

[Valproate Victims]()

[Private Facebook OACS]()


One day you will tell your story of how you've overcome what you're going through now, and it will become part of someone else's survival guide. ♡