

INFACT & FACSA

INFACT & FACSA MAKE AN IMPRESSION!!

Special points of interest:

- The beginning of the INFACT/FACSA Campaign
- The start of the award winning FACSA/INFACT Website
- The advice & support from the Thalidomide Campaign Team.
- Support from TV's Parenting Guide Sue Atkins
- INFACT article issues in the MIDIRS Midwifery Digest.

It's just over 12 months ago since Janet Williams and Emma Murphy made the decision to set the ball in motion and take the bull by the horns.

Of course it was huge decision to make, one which involved the whole of the two families knowing full well that if it was to go ahead it would mean Janet & Emma spending an immense amount of time away from their husbands and children.

So the decision was made with them involved and here we are, 12 months on and having achieved so much..!

2013 began involving MP's, many of which were only too happy to help and support the

campaign, knowing how much this was costing the Government.

Many MP's have supported us on numerous occasions from everything to our Twitter campaign, set up by Emma, retweeting for us and becoming part of the APPG which was so kindly offered to us by the Thalidomiders.

Since last January we have been involved with the BBC programme Inside Out and Panorama, instigated the Westminster Hall Debate, met with the Minister for Care & Support, met with the MHRA and become stakeholders and of NICE too.

Our greatest achievement is



The start of the Campaign in London.

making verbal contact with Sanofi in the space of just 12 months of the campaign beginning..... Watch this space

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Thanks for Thalidomiders Guidance..!

INFACT began in January 2013 with the support of the Thalidomide Campaign Team, and all through the year they met with us on each London visit to help plan the next step.

Most decisions were made solely by Emma and Janet, however their expertise on campaigning has been invaluable and without

it INFACT may not have reached the heights they have.

This vital relationship we hope will continue throughout 2014 as the INFACT campaign becomes more intense.

We owe so much to them for their support and friendship over the past 12 months and look



forward to whatever 2014 has to

Westminster Hall Debate in March 2013



At Parliament for the Westminster Hall Debate in March 2013.

As we began our campaign last January and starting meeting with MP's so many of them advised us to apply for a Westminster Debate on the topic of Fetal Valproate Syndrome.

We approached Scottish MP Anas Sarwar and he kindly offered to make the application in January.

It took a further 3 attempts before we were accepted and the Debate took place on the

26th March and was attended by Anna Soubry MP in place of the Minister for Care & Support Norman Lamb MP.

The Debate itself took 30 minutes and was also attended by a number of other MP's supporting the cause.

Mr Sarwar covered topics such as the numbers of children affected, the seriousness of the condition, the percentages of children also affected by Autism due to Valproate in pregnancy and the work and

media coverage which INFACT had already created including INFACT being the National Campaign Group.

He also asked Anna Soubry to commit to working with INFACT, for new guidelines to be put in place for children affected to be monitored correctly and that the Minister would consider a Public Inquiry into the reason why so many children had been affected.

We are extremely pleased to inform you all that a meeting

Media and Government Awareness is Vital to achieve and succeed..!

Awareness inside and out of Government

Planning to raise awareness began before January 2013, then at the start of the year Emma began making a start on the FACSA/INFACT website, which was brilliantly put together and achieved a Bronze Mumpreneur Award.

Our next important meeting was with Epilepsy Action and the Deputy Executive Simon

Wigglesworth. Here facts and figures were discussed and a figure of 20,000 affected by Valproate alone was suggested.

From this meeting Epilepsy Action kindly offered to feature our work in their magazine the following month.

Following that was the TV awareness on the programme Inside Out. This was our biggest

yet and was crammed with information to bring families forward.

From here we met with the Epilepsy Society who also agreed to work with us. Since then with ongoing circumstances we are thrilled of the fact that now all three of us are working together on particular issues.

Panorama Programme in July



Panorama: The Truth about Pills and Pregnancy.

Following the Inside Out programme in February our next aim was to have the interest of Panorama.

After contacting the BBC and Panorama office we received a visit from Shelley Jofre to discuss the topic of FACS and how Panorama could help.

Shelley was surprised with the amount of information concerning Valproate which

had been ignored over the years.

It wasn't easy to convince her we had the proof for the programme, however the following months were to be extremely busy.

The programme went out on the 1st July and shocked the nation knowing that there had been another Thalidomide taken

place.

The response was terrific and the stories so upsetting especially when a mum realized she had found the support she needed.

The programme opened the doors to so many other avenues including that of a meeting with the MHRA which took place in August.

MHRA Meeting in August

This meeting followed the Panorama programme in July after numerous toing and froing with emails with June Raine the Director of Pharmacovigilance.

Eventually we were able to convince Dr Raine to meet with us and our medical advisor Dr Peter Turnpenny.

The meeting was set for the 16th August where so many objectives were achieved for both sides.

The meeting went on for 2 &

half hours during which time we agreed on the figure of 20,000 being affected by Valproate after understanding both teams were using the same journal papers to make their calculations, we also agreed on the survey which INFACT had began the week before and that the MHRA were, at a later date to play a part in that.

Dr Turnpenny's involvement was invaluable as he explained the research over the years and

the medical aspects of the condition and how he and his colleagues could also play a part.

The Yellow card system was a big issue for INFACT as we felt that it didn't allow women to report the details of the Fetal Anti-Convulsant Syndrome. After deep discussion about this they agreed to revisit the scheme and also put out an update to make GPs aware of the dangers.

This update was issued in November and since then we have



INFACT with Dr June Raine and Colleagues

Meeting with the Minister for Care & Support.

This meeting was originally spoke of and agreed upon at the Westminster Hall Debate back in March and originally planned to take place in September.

Eventually the meeting took place at the Dept of Health on Whitehall on the 29th October with Mr Lamb and civil servants.

We were given the opportunity

to explain to Mr Lamb the problems which comes with Valproate syndrome including the number affected and the meetings which INFACT had attending over the past months with the MHRA etc.. To agree the figure of 20,000.

Our main aim of this meeting was to ask for a Public Inquiry to find why so many children had been affected and why it

had been allowed to continue.

Mr Lamb seemed surprised to find how many children had been affected since 1973 and the damage which had been caused by this drug even with its effectiveness for Epilepsy and other conditions.

Although this meeting was to get our points across to the Minister it is our every



For the Future...

The next 12 months will be crucial in ensuring children with Fetal Anti-Convulsant Syndrome, especially Fetal Valproate Syndrome as it is the most potent of all AED's according to research, do receive financial support from the drug companies who are responsible for the drug causing

their problems.

INFACT originally made contact with Sanofi back in March and this continued until they received our Agenda in October when we were informed that any meeting would have to be postponed temporarily realising our consequential demands on the

company allowing the issues to be discussed at board and legal level.

As we now await a response from their headquarters in France, it may well be necessary to put on added pressure, and so we are looking for parents/carers and volunteers to help us succeed in





Advised and Supported By:

The Thalidomide Campaign Team

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Medical Support by

*The Anti Epileptic Drugs in Pregnancy (AEDiP)
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*If you would like more information about the
Independent Fetal Anti-Convulsant Trusts work or for
parental advice from the Fetal Anti-Convulsant
Syndrome Association please get in touch.*

**Supporting Inspirational,
Independent people..!**

Independent Fetal Anti-Convulsant Trust &
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The Work of INFACT & FACSA

- IN-FACT has been set up for the purpose of giving relief and assistance to all persons whose disabilities were caused by the fact of their mother taking an Anti-Convulsant drug during pregnancy to treat her condition.
- The Trusts work entails providing long term support for those affected by Anti-Convulsant medications during pregnancy, and working with a wide range of professionals and organisations in raising awareness of Fetal Anti-Convulsant Syndrome (FACS) within Government and Health Agencies.