

Parents Guide

to

FACS Syndrome



LOTTERY FUNDED

In association with the Independent Fetal Anti-Convulsant Trust

Anti-Convulsant drugs (AED's) have been prescribed for Epilepsy since 1912, when the first drug, Phenobarbitone was introduced.

There are 3 main medications known to affect the fetus during pregnancy which are Phenytoin (Epanutin) (1938), Carbamazepine (Tegretol) (1963) and Sodium Valproate (Eplim) (1973).

These three medications have been shown in some cases to cause a constellation of symptoms which go together and are labelled a fetal anticonvulsant syndrome (FACS). Research has demonstrated that the chances of a fetus being affected increases as the medication dose gets higher.

There are a number of other anticonvulsant medications (e.g. topiramate (Topamax), lamotrigine (Lamictal), zonisamide (Zonegran), levetiracetam (Keppra) and oxcarbazepine (Trileptal)) which researchers are currently investigating to ensure that they do not present an increased risk of developmental alterations in the fetus .

Exposure in the womb to sodium valproate, carbamazepine or phenytoin are linked to an increased risk of developmental difficulties (physical and in terms of learning ability), however not every child is affected. If a child has a diagnosis of FACS this means that other causes to their difficulties have been ruled out by a Doctor.

Anticonvulsant drugs are typically used to treat seizures, however they are also used to treat certain mental health difficulties, pain and migraine conditions.

The FACS Syndrome Association (FACSA) & the Independent Fetal Anti-Convulsant Trust (IN-FACT) were founded in November 2012 by Janet Williams and Emma Murphy in order to help and support families affected by the condition. Both have experience within the subject of Fetal Anti-Convulsant Syndrome, having children affected and also working for other FACS charities in the past, with Janet Williams working for 17 years on this topic.

FACS can affect a child to varying degrees, ranging from Dysmorphic (unusual) facial features, Cognitive impairments, Spina Bifida, Cleft Lip & Palate etc.... The problems list can be very extensive in some circumstances.

* Fetal Valproate Syndrome:

This syndrome can occur when the fetus is exposed to

Sodium Valproate (Epilim)

Characteristic Facial features

Developmental Delay (late walking & talking)

Gross & Fine Motor control difficulties

Attention Difficulties

Memory problems

Lower IQ

Speech and Language problems

Visual difficulties

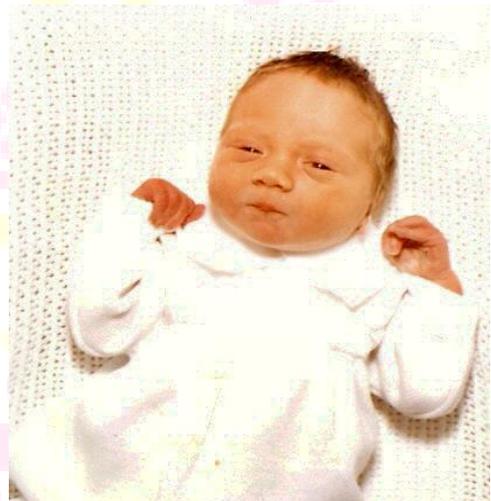
Poor muscle tone (Hypotonia)

Autistic Spectrum Disorders

Inguial Hernia

Hypospadias (only in boys)

Limb & Heart Defects



Spina Bifida (failure of the spina column to close properly)

Cognitive difficulties such as: Attention difficulties, Memory problems, Lower IQ and Speech & Language problems.

Difficulties with Social Skills can also occur within people with this condition.

* Fetal Carbamazepine Syndrome:

Characteristic Facial Features

Nail Abnormalities

Developmental Delay

Lower IQ

Attention & Memory Difficulties

* Fetal Hydantoin (Phenytoin) Syndrome:

Cleft Lip and/or Palate

Small size at birth

Developmental Delay

Lower IQ

Please note: Not all children whose mothers have taken an anti-epilepsy drug (AED) during pregnancy will be affected. You must **never** stop taking your medication without medical advice..!

New & Recent Research

Over the years research attention into the health and development of infants exposed to anti-convulsant medications has increased. Research into the risks associated with anticonvulsant medications takes a lot of time and resources and can only be done if women who take these medications offer to help researchers. Recent research has highlighted that the dose of the medication taken is a key factor in child health. Recently, the risks of the child's cognitive functioning has also been more rigorously investigated and the risks,

particularly for children exposed to sodium valproate (Epilim) have been highlighted.

On Thursday 31st January 2013 a medical journal paper named 'The Prevalence of Neurodevelopmental Disorder in Children Prenatally exposed to Antiepileptic Drugs' was released in the journal of Neurology, Neurosurgery & Psychiatry.

Also the USA paper 'Fetal Anti-Epileptic Drug Exposure and Cognitive Outcomes at 6 years (NEAD Study) a prospective observational study. (Kimford Meador, Gus Baker et al..)

This is a prospective study which has followed children, whose mother took Sodium Valproate (Epilim) , for the first 6 years of their life and has shown that the drug Sodium Valproate does cause Neurodevelopmental/ cognitive impairments to the fetus when taken by mother during pregnancy and a 6 or 10 times increased prevalence of Neurodevelopmental disorders is reported for children with a history of VPA exposure respectively for monotherapy and polytherapy exposure.

Since the drug Sodium Valproate was licenced for use in the UK in 1973, research states that as many as 48,000 children have been exposed to it, and that as many as 20,000 children have been affected by it.

Of course other ant-convulsants can cause Fetal Anti-Convulsant Syndrome, however the extent of the damages caused by Valproate makes it the worst AED to use during pregnancy for the fetus, and it is important for any woman, with the support of her health care professional to be able to make that informed choice before becoming pregnant.

Numerous medical papers have been published in the past giving concerns to Valproate during pregnancy with a definitive paper issued in 1995 stating there was such a condition as Fetal Valproate Syndrome.

We now know that Valproate and other AED's are used for other conditions such as Mental Health conditions like Bipolar, Migraine Headaches, Trigeminal Neuralgia and as a pain relief.

The FACS Syndrome Association (FACSA) – Meet the Team:

The FACS Syndrome Association (FACSA) are working to help and support families with affected children and have a Parental & Educational Officer on board to offer help and advice in situations with school etc...

It is our intention to support families who have children affected by any anti-convulsant medication, not just Valproate, as we understand the implications FACS can have on family life.

Each board member has children affected, all to varying degrees and at different stages in life.

While Janet Williams has 2 sons affected by Valproate at the ages of 22 and 24 yrs old, Emma Murphy and Catherine Cox have children of school age and are still experiencing the usual problems given by education and health issues.



Janet Williams – Secretary & Co-Founder

With both our sons being in their 20's we have already experienced the problems the majority of affected families are going through. Each of our sons has a diagnosis of Fetal Valproate Syndrome but they also have a diagnosis of an Autistic Spectrum Disorder which impacts on their everyday life.

Their experiences have been overwhelming to watch, however with the correct support in place they have the capabilities to reach their goals albeit with the need for a little extra time to get there.

We love both the boys and, as any mother would tell you, wouldn't have them any other way, it is important to remember though that mum and dad are not going to be around forever and so preparing them for their future without you is imperative.



Emma Murphy – Public Relations & Co-Founder

All my 5 children have been affected by the Valproate I took during pregnancy. At no point during any of my pregnancies did any healthcare professional

explain to me the dangers of Valproate in pregnancy even though I did query at the time the development of my children.

Even though it is imperative that you do not stop your medication, you must first and foremost arrange an appointment with your GP to discuss your medication and the fact that you may be pregnant or want to try for a baby.

As a parent you must believe in yourself, a lot of mothers go through the guilt trip which certainly destroys you as a person, but It's important for any mum to remember that you're not to blame yourself especially if you weren't explained of the dangers.



Catherine Cox – Parental & Educational Advisor

I'm mother to Matthew, who has Fetal Valproate Syndrome and Charlotte, who doesn't.

I am experienced in taking to local authority support services and in initiating and successfully navigating the Statementing process from start to finish. I am also proficient in negotiating with healthcare professionals to obtain help and diagnosis for Matthew.

Obtaining what you need for your child is not always an easy or straight forward process, but the confidence you gain and the improvements for your child are worth it. Remember that what has happened is not your fault (even

though you might feel that it is) and that professionals and corporate bodies should have a responsibility to help your child. We want all children affected by FACS to have the help and care that is due to them.

The Independent Fetal Anti-Convulsant Trust (IN-FACT)

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.

Both the Co-Founders have children affected by Fetal Anti-Convulsant Syndrome. Both founder members shared their voluntary careers with this subject working voluntarily for the Organisation for Anti-Convulsant Syndrome. Janet Williams being the Founder of OACS and working for a total of 16 years with this topic, while Emma Murphy being their vice secretary and fundraiser for 3 years.

IN-FACT Objectives:

- 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.
- To support by means of payments to the beneficiaries to help with the cost of care, welfare, treatment and/or education supporting them with their injuries.
- With intentions to pay sums of money to help and support submitted through Government and/or Pharmaceutical Company donations.
- To become actively involved in campaigning for Government redress.

These Beneficiaries must be persons born within the United Kingdom.

For more information please contact:

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Independent Fetal Anti-Convulsant Trust (IN-FACT)

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Please note that both the FACSA and IN-FACT are entwined and work together to ensure that parents receive the best of both worlds while trying to avoid duplication of registering with both parties so your details are shared but will be kept private and confidential.

We, at IN-FACT, hope that each parent/family contacting the FACSA for advice will also feel the long lasting financial benefits which the trust are working so hard to achieve. The only way this is possible is by completing the contact forms you will receive in due course and returning them as soon as possible. The forms will then be entered onto our database with your name so you can be contacted by IN-FACT when the time comes.