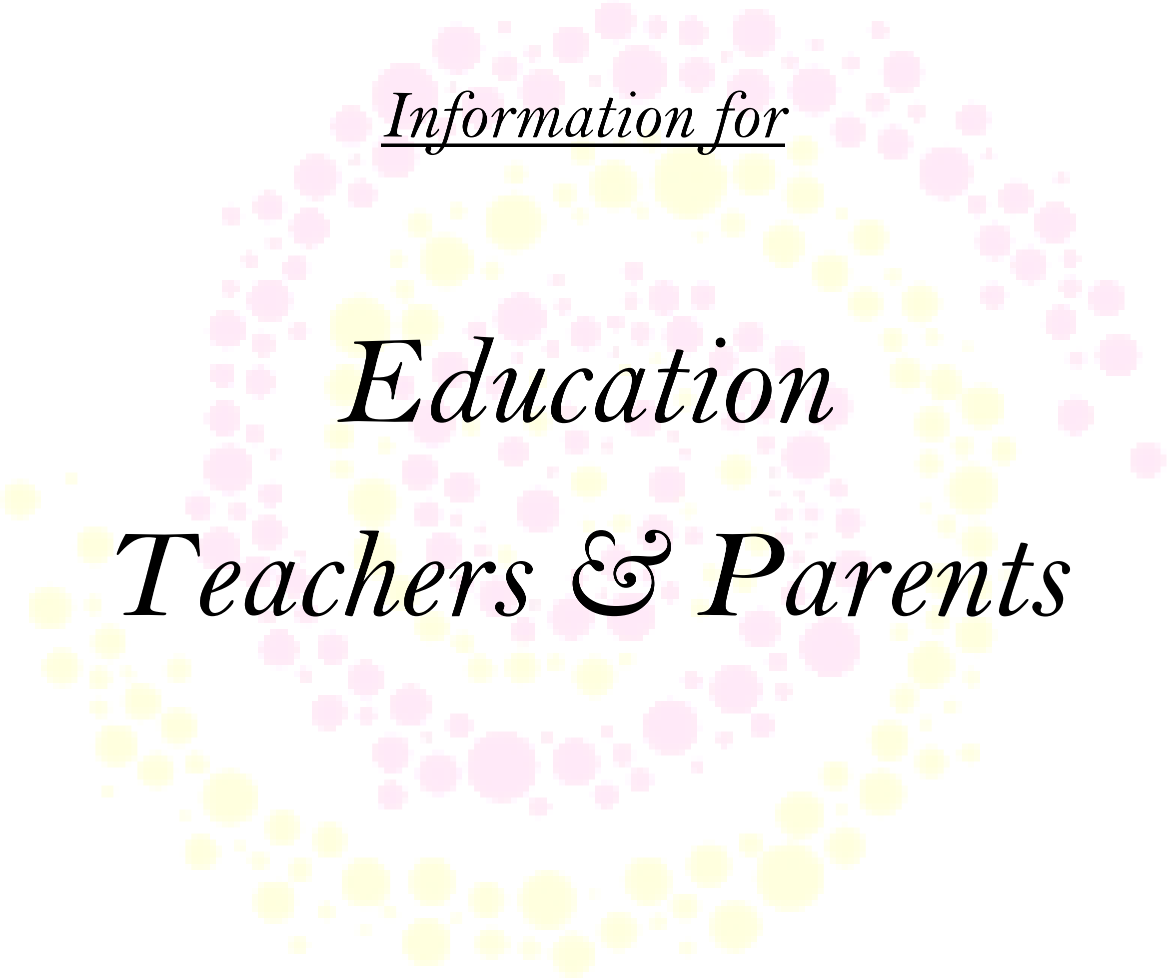
F.A.C.S.A

Fetal Anti-Convulsant Syndrome Association

Fetal Anti-Convulsant Syndrome



Information for

Education
Teachers & Parents

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This includes the specialists from the Anti-Epileptic Drugs in Pregnancy (AEDiP) Maternal & Child Health Advisory Group, who all are recognised for their expertise in the subject of Fetal Anti-Convulsant Syndrome, with many published journal papers in this topic, and with Dr Bromley recognised for her expertise in FACS and Educational issues.

With thanks also to FACSA Ambassador and Educational Specialist Sue Atkins. Sue has spent many years working within Education and with Special Needs children as well has working within TV giving advice and help to parents of SEN children.

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We have tried to write this booklet with visual prompts in mind which teachers or educational professionals would be able to spot if a working with a child affected by an Anti-Convulsant Medication.

It is important to note that anti-convulsant medications these days are not only used or prescribed for Epilepsy but also for Bipolar, Depression, Migraine headaches and as a Pain Relief.

Fetal Anti-Convulsant Syndrome is not only caused by one particular ant-convulsant medication, but an array of drugs, 10 of which may cause the condition to varying degrees.

For many years children have had problems within education due to the effects of Anti-Epilepsy Drugs (AED's) taken by mother during pregnancy.

These medications when used in pregnancy, reported in recent research are known to cause cognitive and neurodevelopmental problems including Autistic Spectrum Disorders.

The latest medical journal paper was released in the Journal of Neurology, Neurosurgery & Psychiatry in January 2013. In this definitive paper Dr Rebecca Bromley et al stated that:

'the increased likelihood of neurodevelopmental disorders should be communicated to women for whom Sodium Valproate VPA is a treatment option.'

It goes onto say:

' Women should be provided with as much information as possible to enable them to make an informed decision'

'Evidence suggests that the neuropathology of Autistic Spectrum Disorder (ASD) develops early in gestation……… Children exposed to Anti-Epilepsy Drugs (AED's) especially Valproic Acid (VPA) should be monitored closely during early childhood to allow for early intervention, diagnosis and support…..'

Currently there are 10 different anti-epilepsy drugs (AED's) on the market which are prescribed regularly. Out of those 10 there are 3 main medications which affect the fetus during pregnancy, these are:

Phenytoin (1938)	Fetal Hydantoin Syndrome
Carbamazepine (1963)	Fetal Carbamazepine Syndrome
Sodium Valproate (1973)	Fetal Valproate Syndrome

<u>Others may be:</u>

Lamotrigine (1991)

Topiramate (1995)

However, of late there has been an addition to that list of another medication which is affecting the fetus similarly but not to the drastic affect as Valproate, although we are now aware that this newer drug is becoming drug of choice amongst specialist. These medications are Lamotrogine and Topiramate.

Any woman taking these medications may find themselves in a catch 22 situation, especially if she is being prescribed the drug for Epilepsy, as in some cases it may well be the only way of controlling her seizures.

It is over the past 5 years that these drugs have also started to be prescribed for other conditions, these are Bipolar/Depression, Migraine headaches, Neuralgia and as a pain relief.

As an organisation FACSA are here to help and support the children affected by an anti-convulsant medication during pregnancy, but also to ensure that professionals involved with their health and educational issues fully understand Fetal Anti-Convulsant Syndrome, irrelevant of which anti-convulsant medication may have caused their problems.

We are aware that the majority of children who have been affected by their mother's medication during pregnancy may not have a diagnosis of a Fetal Anti-Convulsant Syndrome eg: Fetal Valproate Syndrome, Fetal Carbamazepine Syndrome or Fetal Hydantoin Syndrome but may have a diagnosis of an Autistic Spectrum Disorder (ASD)

As on numerous occasions, we find that due to facial features, these children may look similar however their individual educational difficulties are unique to them.

Many FACS children do share certain behavioural characteristics, for example hands to ears due to noise intolerance, not understanding others facial expressions or body language, frustration, impulsitivity and obsession, as well as physical characteristics such as curved toes, prominent finger pads, small fingernails and facial features and so it is important to individualise and work separately with each child's demands.

Research & Information

Through the latest research published in January 2013, it is apparent that an ASD may come secondary to a Fetal Anti-Convulsant Syndrome, however school would have no record of the mother taking this medication unless she offers that information herself.

In these circumstances we understand the complex situation for any child with this condition and also that of the teachers and school involved with the child's education.

It is because of this we are currently working with the Medicines and Healthcare Regulatory Agency (MHRA) and the National Institute for Clinical Excellence (NICE) in order to ensure that every person who receives anti-convulsant medications are made fully aware of the possibilities is these medications are taken by a women during pregnancy.

Over the years, from as early as 1968 there have been medical reports in the journals explaining the findings of children affected by anti-convulsant medications. Please see at the back of this booklet for a list of those journal papers if you wish to take a look at the reports yourself.

The most significant over the years has been by Prof Donnia and Dr Clayton-Smith in 1995 'Fetal Valproate Syndrome' when it was confirmed there was such a condition. To date the most significant of all has to be the paper released in January 2013 which was a prospective study completed over 6 yrs and confirmed the connection of Autistic Spectrum Disorders and Fetal Anti-Convulsant Syndrome.

Since 1980, starting with the Dalens report, there have been hundreds of journal papers discussing the findings of anti-convulsant medications taken in pregnancy. It has been confirmed the Valproate (Epilim) is the most toxic to use during pregnancy and causes more significant problems for the child. Unfortunately during the 1980's and 90's this was the drug of choice for Epilepsy and so the figures for children affected by this drug alone may be as high as 20,000 with 40% having neurodevelopmental disorders.

Learning and Development

Whilst the medical journals and the UK Pregnancy Register report on the major malformations, new information now points towards the learning/cognitive and developmental problems the child struggles with.

Since working within Fetal Anti-Convulsant Syndrome organisations over the past 20 years, and coming into contact with over almost 1000 children, we have seen a full range of developmental problems they portray, all of which are to varying degrees.

Published researched demonstrates that those who have been exposed to, in particular, Sodium Valproate (Epilim) during pregnancy are at an increased risk of having difficulties in one or more areas of cognitive functioning with the most common difficulties being:

- Language Difficulties (expressive and comprehension)
- Attention Difficulties
- Working Memory Difficulties
- Memory for Verbal Information (things told)
- Poorer levels of Intellectual Ability (likely due to other cognitive difficulties)
- Difficulty writing for long periods due to joint laxity
- Social Difficulties.

It is important to remember that as with all children, each child with Fetal Valproate Syndrome (FVS) is unique and may not display weakness in all areas of the above.

It is important to remember also that children with a Fetal Anti-Convulsant Syndrome or those with cognitive difficulties due to exposure do not always meet with the criteria for special educational support, which can lead to frustration in the child and for the parents who want to see their child supported in the best way possible.

Physical Problems

Up until around 2005 it seemed that only the major malformations were reported on, for example:

- Spina Bifida
- Heart Malformations
- Kidney Malformations
- Cleft Lip and/or Palate
- Talipies (Club Foot)
- Radial reduction (shortening of the radial bone in the arm)

However, from 2005 things took a shift as new journal reports published information which touched upon educational needs in children affected by anti-convulsants.

Other physical problems affected these children during their school years include also:

- Lax Joints (leading to clumsiness, difficulty in walking long distances and difficulty in writing skills)
- More difficulty with toilet training and bladder control
- Tendency for ear infections which can lead to time off school and needing operations to fit grommets etc..
- Long or short sightedness.

Assessments and Tests

A comprehensive neuropsychological assessment should be carried out by an Educational or Clinical Psychologist to give a full understanding of how a child's brain is functioning.

Sadly, we understand that this is easier said than done due to the Educational Psychologists budgets being incredibly tight and the services offered by the Clinical Psychologists varying from area to area.

It is important to understand that for a parent to receive a referral through their GP or Paediatrician will be extremely difficult and that the waiting lists can be long due to high demand on the services, which in itself will cause more frustration and problems for the child in school reflecting on that child's work and temperament.

The first step would be for the Special Educational Needs Officer (SENCO) at the school to enquire as to whether the school is in a position to fund an Educational Psychologist for a formal neuropsychological assessment.

It has come to a sorry state of affairs within the system if a school cannot afford this service for any child without the ability to cope in the school environment, however it must be made clear to the parents that their option would be through their local Child Development Centre or the Child and Adolescent Mental Health Service (CAMHS) which should be a possibility through their GP or Paediatrician. It must be borne in mind though, that with the country's cut backs many local areas no longer have these services to hand.

Any Neuropsychological assessment should include an assessment of language (expressive and receptive), attentional capacity, rate of learning and of general memory functioning as well as intellectual functioning.

Some children with Fetal Anti-Convulsant Syndrome may have an intellectual ability within the low average range but may have language and attentional deficits which are much more severe. The abilities of children change over time and an assessment completed three years or more ago may not be a reliable reflection of the child's abilities to date.

It is important for any child affected by a Fetal Anti-Convulsant Syndrome to be offered information on a repetitive basis.

The majority of children with FACS will have memory problems, especially short term memory which will not allow them to hold onto information.

Many parents have found in the past a home and school diary/book has been extremely helpful where teachers and parents can continuously communicate concerning the day at school or explanations of homework or problems relating to the school day.

Due to these two problems any child with FACS may find the school day very frustrating, due to not understanding the work or explanation given, or the behaviour of her/his peers and their lack of ability to communicate with them.

Many of these child, without a diagnosis for whatever reason, due to the problems mentioned above are, more often than not, looked on as 'problem children' , however these are 'children with problems' which must not be ignored or allowed to progress without investigation.

For any education professional dealing with the younger age group it may also be of interest to know that the majority of children affected by an anti-convulsant medication during pregnancy may have a number of facial features to look for.

These would be:

- High Forehead
- Broad Nasal Bridge
- Wide spaced eyes
- Epicanthic Folds (skin between eyebrow and eyelid)
- Upturned nose
- No or shallow philtrim (dip between nose and top lip)
- Thin upper lip
- Downturned upper lip
- Low set ears
- Prominent Fingerpads
- Extremely small finger nails or non-existent
- Closely packed teeth
- Curved/bent toes

For the Parents

Special Education Needs and Schools

In July, 2014, the Department for Education and the Department for Health jointly published a new Code of Practice for Special Educational Needs and Disability.

It will be used from 1 September, 2014 and covers children and young people from the ages of 0 to 25 years and is designed to ensure that the developmental and healthcare needs of children are met jointly by all appropriate professional agencies.

Children with FACS often have Special Educational Needs (SEN) and it can be upsetting for parents to find out, that as well as any medical conditions, their child's ability to learn may also have been affected. Additionally, a child's medical conditions can also make learning more difficult, eg, if a child has poor muscle tone, their ability to concentrate can be affected if they become tired from sitting up all day.

We understand how learning that your child has SEN can be deeply upsetting, but to know that it is possible for the parent to play an equal part in the SEN choices that are made for their child. The SEN code of practice should enable a child to access the help to enable them to achieve their potential.

What does that mean?

SENCO: Special Educational Needs Co-ordinator (*every school is required to have a teacher who is responsible for ensuring the needs of SEN children are met)*

Strategy/Intervention: A programme of activities, resources and support to help your child learn effectively (*these should be reviewed every term at least, but preferably every half term*).

IEP: Individual Education Plan (*this is a form that sets out what strategies the school are going to use to help your child and what they want the result to be. You should be asked to sign it, so you should have some say about what areas of your child's learning should be focussed on*).

EHCP: *Education and Healthcare Plan (this is a document written by the Local Authority that details the needs of children with the most complex special needs. It also gives details of how that child will be helped and how it will be funded. Not all children need one to have their needs met by a school*).

What your child's school should do:

If your school defines your child as having SEN, they should:

- *Tell you and explain how it will be monitored*
- Explain whether their needs will be met by the school, or whether they will be seeking advice from outside professionals
- *Explain whether the resources and support your child needs will be funded by the school or whether they will be asking for additional funding*
- Consult you regarding the support and strategies they use
- *Invite you to termly reviews to discuss your child's progress*
- Ask for your permission before they talk to outside professionals
- *Answer your questions and treat you as an equal.*

If your child's school is not doing this, contact us and ask for advice

Useful links:

SEND Code of Conduct July 2014:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/342440/SEND_Code_of_Practice_approved_by_Parliament_29.07.14.pdf

Special Needs Jungle Website:
www.specialneedsjungle.com

Useful Questions to Ask in Meetings:

- Can I explain my child's condition to you?
- Are there any questions you would like to ask about my child's condition?
- Who is the Special Education Needs Co-ordinator (SENCo) at the school? Who is the named governor for SEN?
- How will this strategy/resource help my child make progress in every lesson?
- How will you know if this strategy is helping my child to progress?
- When will you be reviewing this strategy?
- Will my child be included in all the activities the other children are able to enjoy? (they should be!)
- If so how do you propose to support my child in them?
- Has the staff undertaken training to help them support my child?
- My child's condition may change over time. Are you confident that you can continue to support their needs?
- Do you need any other information regarding Fetal Anti Convulsant Syndrome? (You can provide our contact details to schools)

Did you know...?

- School governing bodies hold responsibility for ensuring a child's healthcare needs are met in school and can be held to account for not providing them.
- Every governing body has a named governor responsible for SEN and complaints regarding SEN can be investigated by them if you wish.
- All schools have to make provision to allow children with SEN to participate in activities regardless of whether it will cost more money, eg: residential, school plays.

The Fetal Anti-Convulsant Syndrome Association (FACSA) hope that this book has and will continue to be of help to you and your colleagues and parents. Giving information and support to those members of staff, teachers and Education specialists who are looking for a comprehensive guide to Fetal Anti-Convulsant Syndromes and the problems created by anti-convulsant medications when taken during pregnancy.

The facts and figures have been based on research undertaken over the years and the experience of parents whose children have been exposed and affected by an anti-epilepsy drug in pregnancy.

In August 2013 it was confirmed by the Medicines and Healthcare products Regulatory Agency (MHRA) that the figure of approximately 20,000 affected by Valproate alone, calculated by FACSA and its incorporated trust the Independent Fetal Anti-Convulsant Trust (INFACT) was correct.

Since then INFACT/FACSA have become stakeholders at the MHRA and the National Institute for Clinical Excellence (NICE), where they continue to have an impact on the way in which Fetal Anti-Convulsant Syndrome is accepted within the Health & Education professions.

Time line: Key publications which altered the way we think about anticonvulsant exposure.

1963 – Lawrence, A. Anti-epileptic drugs and the foetus. British Medical Journal 1973; 16; p267. Possibly the first report of problems in a child where an antiepileptic drug is considered the cause.

1970 - Meadow, R. Congenital abnormalities and anticonvulsant drugs. Proceedings of the Royal Society of Medicine 1970; 63: p12-13. The first group study into the incidence of major malformations.

1973 – Fedrick, J. Epilepsy and Pregnancy: a report from the Oxford record linkage study. British Medical Journal 1973; 2:p442-448. The first population based study.

1974 – Hill, R et al. Infants Exposed In Utero to Antiepileptic Drugs: A Prospective Study. The first prospective study to investigate this issue.

1974- Barr, M., et al. Digital hypoplasia and anticonvulsants during gestation: a teratogenic syndrome. The Journal of Pediatrics 1974; 84(2):p254-256. The authors suggest that a syndrome may be associated with prenatal exposure to phenytoin, phenobarbital and primidone exposure.

1975- Hanson, J.W. & Smith, D.W. The fetal hydantoin syndrome. The Journal of Pediatrics 1978; 307: p285-290. Termed the constellation of features noted in some children following exposure to phenytoin, phenobarbital and primidone as *Fetal Hydantion Syndrome*.

1976- Hanson, J.W., et al. Risks to the offspring of women treated with hydantoin anticonvulsants, with emphasis of the fetal hydantion syndrome. The Journal of Pediatrics 1976; 89(4): p662-668. The first paper to raise that a child's intellectual abilities may be lower in children with fetal hydantion syndrome.

1980- Dalens, B. Teratogenicity of valproic acid. The Journal of Pediatrics 1980; 97(2):p332-333. The first report of an infant with major congenital malformations thought to be linked to exposure to sodium valproate.

1982 –Rovet, E. & Guibaud, P. Maternal valproic acid and congenital neural tube defects. The Lancet 1982; 2(8304): p937. – Demonstrates the potential association between prenatal exposure to VPA and spina bifida.

1988 –Ardinger, H., et al Verification of the Fetal Anticonvulsant Syndrome. American Journal of Medical Genetics 1988; 29:p171-185– the first group case series of children exposed prenatally to sodium valproate and highlights potential characteristics of the syndrome.

1996 – King, P.B., et al. Spina bifida and cleft lip among newborns of Norwegian Women. American Journal of Public Health 1996; 86(10):p1454-1457. Demonstrated that changes in anticonvulsant use across the country lead to an alteration in the type of birth defects seen in the children.

1997 – Samren, E.B., et al. Maternal use of antiepileptic drugs and the risk of major congenital malformations: a joint European prospective study of human teratogenesis associated with maternal epilepsy. Epilepsia 1997; 38(9): p981-990. This collaboration of a number of different research groups highlights the importance of the dose of the drug.

2000- Moore, S., et al. A clinical study of 57 children with fetal anticonvulsant syndromes. Journal of Medical Genetics 2000;37:p489-497. The first study into a group of children diagnosed with fetal anticonvulsant syndromes.

2001 –Adab, N., et al. The longer term outcome of children born to mothers with epilepsy. Journal of Neurology, Neurosurgery and Psychiatry 2004; 75:p1575-1583. The first study to include a large group of children exposed to sodium valproate and to find that they require increased levels of educational support.

2004- Gaily, E., et al. Normal intelligence in children with prenatal exposure to carbamazepine. Neurology 2004; 62:p28-32. This large and well designed study found that the IQ of children exposed to carbamazepine was not significantly different from a group of unexposed children.

2006-Hunt, S., et al. Levetiracetam in pregnancy: preliminary experience from the UK Epilepsy and Pregnancy Register. Neurology 2006; 67: p1876-1879. The first investigation into prenatal exposure to levetiracetam (Keppra) and birth defects.

2008 –Hunt, S., et al. Topiramate in pregnancy: preliminary experience from the UK Epilepsy and Pregnancy Register. Neurology 2008; 71: p272-276. The first paper to investigate prenatal exposure to topiramate.

2008 – Bromley, R., et al. Autism spectrum disorders following in utero exposure to antiepileptic drugs. Neurology 2008; 71: p1923-1924. The first prospective study to demonstrate an increased prevalence of autistic spectrum disorders in children exposed to sodium valproate.

2009- Meador, M., et al. Cognitive function at 3 years of age after fetal exposure to antiepileptic drugs. The New England Journal of Medicine 2009; 360(16): p1597-1605. The largest prospective study into sodium valproate and lamotrigine demonstrating that the first is associated with reduced IQ.

2011 –Shallcross, R., et al. Child development following in utero exposure: levetiracetam vs sodium valproate. Neurology 76; p383-389. The first study to investigate the rate of developmental delay in a group of children exposed to levetiracetam.

2011- Tomson, T., et al. Dose-dependent risk of malformations with antiepileptic drugs: an analysis of data from the EURAP epilepsy and pregnancy registry. Lancet Neurology 2011; 10: p609-617. The largest study to date which shows level of risk by dose of antiepileptic drug.

2013 – Bromley. R., et al. The Prevalence of Neurodevelopmental Disorders in Children Prenatally Exposed to Antiepileptic Drugs. J Neuol, Neurosurg, Psychiatry 2013; **0:** 1-7. The first study of its kind which stated that Women prescribed Sodium Valproate should receive communication concerning the possibility of the drug causing Neurodevelopmental problems for the child when taken during pregnancy.