

Clinical Effects	Key Features
Neonatal Events (seen in newborns)	Hypotonia, apnoea episodes, eating disorders (gluten intolerance), seizures, withdrawal syndrome.
Facial Characteristics	Telecanthus, epicanthus, sub- orbital defects, convergent strabismus, broad or flat nasal bridge, anteverted nostrils, broad or flat nasal tip older children, shallow philtrum or smooth, thin upper lip, micrognathis broad or high forehead, metopic ridging , low set posteriorly rotated ears, Helix sometimes without relief.
Congenital Malformations	Heart defects, genital anomalies, neural tube defects, orificial cleft, Spina bifida, hypoplasia of the fingers or nails, toes or feet, clubfoot varus, limb abnormalities, congenital dislocation of the hip, hernia, craniosynostosis, hypospadias, malformation of the upper airway.
Medical problems during infancy	Myopia, strabismus, otitis media with effusion requiring surgery, joint laxity
Neurodevelopment	Communication disorder and general speech language delay, fine motor delay.
Behaviour	Autism, Asperger's Syndrome, hyperactivity disorder attention deficit,

OACS Ireland

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The Epilim toolkit was produced for patients and prescribers to reinforce the safety message that valproate is not prescribed for girls or women of child-bearing age unless other treatments are not effective or are not tolerated. You will find your Epilim toolkit at OACS Ireland www.oacscharity.org



Karen Walsh Keely Tel: 086 383 6187
Email: oacsireland@gmail.com
Website: www.oacscharity.org

Other links:
Rare Connect Community
<https://www.rareconnect.org/en/community/fetal-anticonvulsant-syndromes>

Foetal Anticonvulsant Syndrome Forum Ireland
<https://facsforumireland.org>



RARE DISEASE DAY St Michaels House

OACS Ireland

Organisation for Anti-Convulsant Syndrome



OACS was created to support those who have been effected by the prenatal effects of Anti-Convulsant medication. OACS is now in Ireland for those families who live with the complex issues caused by FACS

- Raising Awareness .
- Supporting Families
- Developing understanding
- Promoting research

Who are we?

The Organisation for Anti-Convulsant Syndrome (OACS) is a registered UK Charity, which offers help and support to all families affected by the syndrome.

Our main aim is to

Supply as much information as possible covering all aspects of fetal anticonvulsant syndrome (FACS). Our work now extends to Ireland.

All families are warmly welcomed to the group, not only because we understand the problems your child may be suffering, but also because we understand the difficulties you as a parent are facing too, tackling both the medical and educational professions.

Trying to prove to some doctors that your child has a Fetal Anti Convulsant syndrome may be the highest mountain of all. We at O.A.C.S are here to offer advice and support. We can give you as much information as possible on your child's problems and, if required, to point you in the right direction in the form of other support groups, social service benefits and special educational needs services. Fighting without a diagnosis is not easy and so we will do our best to help you through this, to reach a possible diagnosis if your child is affected this is what you want.

O.A.C.S can also signpost or advise families who are fighting for benefits. We know and understand the problems and pressures put on parents when help is so drastically needed but the money is not available to have that help. We want to be able to support and advise parents as to which direction to take and whom it may be best to contact.

Our Aims

- 1) To provide help and support to families with children affected by the syndrome
- 2) To increase the awareness of Fetal Anti-Convulsant Syndrome (F.A.C.S)
- 3) To give information concerning the additional problems caused by the affects of Fetal Anti-Convulsant Syndrome
- 4) To put families in touch with other support groups who are able to help with their specific needs.
- 5) To provide women with more awareness of contraceptives and how they are affected by Anti-Convulsant Medication.
- 6) To help young girls understand their Epilepsy and the issues should they become pregnant.
- 7) To support children with Educational needs and also with Health issues.
- 8) To help families understand social services and benefits available to them.
- 9) Trying to get a diagnosis of FACS may be the biggest challenge of all. We are here to offer advice and support. We aim to give you as much information as possible
- 10) Ensuring that women taking Anti-Convulsant medication are presented with ALL the relevant information, in order to allow them to make informed decisions and to minimise risk to themselves and their children.

Current opinion is that variations in the way AEDs are processed in the body by some pregnant women, and/or their affected children, may increase the chance of damage to the unborn baby. The best information has accumulated on the effects caused by phenytoin (Epanutin), carbamazepine (Tegretol) and sodium valproate (Epilim) and, in general, higher doses cause more damage. Many newer AEDs are now being prescribed and their associated risks continue to be evaluated. Today it is recognised that sodium valproate effects 30 –40% of children, with a risk of 55% of having a second child born with the syndrome.

Prevention is the key issue, where possible Pregnant women should take the lowest dose of AED that prevents seizures, and if possible take only one AED rather than two or more. There may be some protective value if women take folic acid daily around the time of conception and during the early part of pregnancy.

Children diagnosed with FACS should have a full medical investigation, including heart and kidney scans, and hearing and vision assessments.

A neuropsychological assessment will determine if there are learning or behavioural difficulties. Basic genetic tests may be carried out to rule any other non related medical condition.

NEVER STOP TAKING YOUR MEDICATION SEEK ADVICE FROM A SPECIALIST/DOCTOR