

OACS NEWS



Organisation for Anti-Convulsant Syndrome Newsletter

Registered Charity No 1116497

September 2014

A lot has happened in a year!

Since our last newsletter a lot has happened within the charity, here's our platform to give you a free friendly view.

OACS is here for anyone that is touched, by any of the Anti-Convulsant Syndromes, our newsletter will be emailed out to anyone that registers an interest, and it will also be posted to anyone that hasn't got the facility to access emails and is a member of OACS.

OACS is a charitable organisation so where possible email is our preferred choice, so that we can continue to provide quality information for free.

This is your newsletter so feel free to contribute with your stories and your ideas.

Please email: - enquiries.oacs@gmail.com

"2014-2015 OACS is committed to coming out in the community, please help us help find you, fill out your free community form, enclosed with this Newsletter!.."

- Jo Cozens, Interim Chairperson

OACS Thanks to our old trustees



OACS Fundraiser of the year

2013 - 2014

Thank you to

Sarah Noel

For Raising £3608,81

In her charity auction.

Some of this money will be used towards a fun day for OACS Members Children, please make sure you have completed a free membership form

Page 1 OACS Second Newsletter

Thanks to our old trustees

Page 2

How OACS has changed my life

Page 3

Meet the new trustees

Our New Logo

Page 4

Meet the new trustees

Our New Logo:

Page 5

OACS Ireland

Page 6

Resent Achievements

APPG Meeting

PRAC Meeting

Page 7

Community Groups

Parent Story

Page 8

Volunteers Needed

Halloween Fundraiser

Page 9

Branwen Needs Help!!

Page 10

Community Group Membership Form

OACS NEWS



Goodbye to Old Friends after 8yrs



Terri McKay

Steve Pollard & Janet Stockley-Pollard

How OACS has changed my life

I first heard of Fetal Anti-Convulsant Syndromes and OACS from an article that I read in the newspaper about years ago. It suddenly felt like, I wasn't alone and the same time as Terri McKay, who has been the voice at the end of the phone for so many, for nearly 8 years.

It was the start of a journey that would change my life in so many ways. I never travelled far because of the panic caused by my Epilepsy but that soon changed, as I needed to attend meetings in Blackpool, Manchester, Sheffield and London to name but a few. I met so many interesting people and made some amazing new friends, who I know are now friends for life. We understand each other as our lives are so similar ...epileptic mums caring for children with special needs. My confidence grew in myself and what I had to say. Who would have known I would have gone on to do TV / Radio interviews, articles for the paper and press conference in front of so many on a subject, that is so close to all our hearts?

I have always been a very quiet person, who likes to avoid conflicts, so I would never have thought would find myself standing up to a drug company and voicing my thoughts in Parliament and the Department of Health. All I can do is hope that it has helped make a difference.

There have been many changes to the OACS board in my 8 years including my husband, Steve Pollard, joining the team 2 years after me. We became regulars at our local radio station and campaigned together both locally and nationally.

I set up Facebook pages in the hope that it would help parents connect and support each other, questions can be asked and hopefully answered, information can be shared and most importantly, you know you are not alone.

Recently, we both made the decision to step down from our positions on the board, as we feel the time has come to hand over the baton, to new people, with fresh ideas to continue taking this amazing charity forward. It has always been my dream to see OACS have local support groups providing the much needed face to face networking and friendships, it's so good to see that now becoming a reality.

I have my family and my OACS family and I feel privileged to belong to both

Janet Stockley-Pollard

OACS NEWS



Meet the New Trustees

Interim Chairperson, Mrs. Jo Cozens.

I have Juvenile Myoclonic Epilepsy & Photosensitive Epilepsy, fully diagnosed at the age of 17, after having my first ever major seizure caused by strobe lights at a nightclub in the 80's. I was told then that I was going to be on Sodium Valproate for the rest of my life. I got married to David in 1997, we had our son Tomas in December 1999, and this is the start of my journey! At the age of 3, I was told Tomas had mild dysmorphic features and bilateral flat feet, I didn't really know what that was, at 5 a statement of educational needs was made for his low IQ, in 2008, he was diagnosed with Asperger's. In February 2013 my father read a newspaper article that turned my world upside down. We read that my Epilepsy medication may have caused all Tom's medical problems, by September 2013 Dr Peter Turnpenny had diagnosed him with Fetal Valproate Neurodevelopmental Effects. I am currently awaiting surgery for Tomas he has a Retraction Pocket Cholesteatoma that is going to be removed in the next few months. What I have experienced with Tomas, what I would like to see happen for all our children, through reaching out through the community groups is educating people that we meet, to our cause, in the hope that they pass on our story.

There are approximately 26 different types of Epilepsy drugs in the UK, the most common drug Sodium Valproate, has effected since its launch 43 years ago up to 45,000 Children where are they now?

Somewhere out there, sleeper people like me, are going about their lives, not knowing about the Epilepsy drug that they took just like you and I, effected their child. Just over a year ago, I didn't know about all of this, it is our duty as citizens of the world, to pass this message on and tell as many people about the effects of Sodium Valproate and other Epilepsy drugs have had on our Children as we can.

Together we can find the missing Children

OACS Membership is FREE, please register today, if you have registered email your latest email address so that we can keep you informed of the latest information regarding the community start up schemes in your area's as it happens

Thank you to everyone all the families that are form OACS, my dream going forward is to meet more of you in 2015!!

Interim Secretary, Deborah Mann

I believe it is our experiences that define who we are, as I look back over my life I can see just how epilepsy has affected my life. I would not change any of these experiences as they have taken me to the computer where I am now writing this, as of today, I have two gorgeous girls that are perfect to me, Rhonwen my eldest aged 20 and Branwen aged 19.

I am really passionate about making a difference. Branwen, the youth representative, keeps posing questions that need answering; these are often deep and far reaching and deserve a real answer. I am one of those people who love to KNOW. I was so pleased when I saw that two mothers have contributed to this newsletter, it is so important that parents have a central role in OACS, the article 'adopting a child with Fetal valproate syndrome' really highlights the importance individual experiences are to understanding the needs of the many.

Fathers Support and IT, Tim Noakes,

I am Tim a father of a child with FACS.

I'm a busy professional and campaigner for FACS awareness. I like helping others.



OACS NEWS



Meet the New Trustees



Youth Representative – Branwen Mann

My name is Branwen Mann, I am 18 yrs. old. I am the youth representative for OACS and FACSaware, I am also a trustee for OACS, which means I sit on the board of OACS giving the children that have FACS a voice that can be heard. My mum took sodium valproate in pregnancy for epilepsy which is why I and my sister have Fetal Valproate Syndrome. I would like to promote the needs of us, the FACS Kids. •I won't forget the adults!!! Adults need feedback. They learn a lot from listening to us FACS Kids. So I am here to talk to parents, should they need our help.

Our New



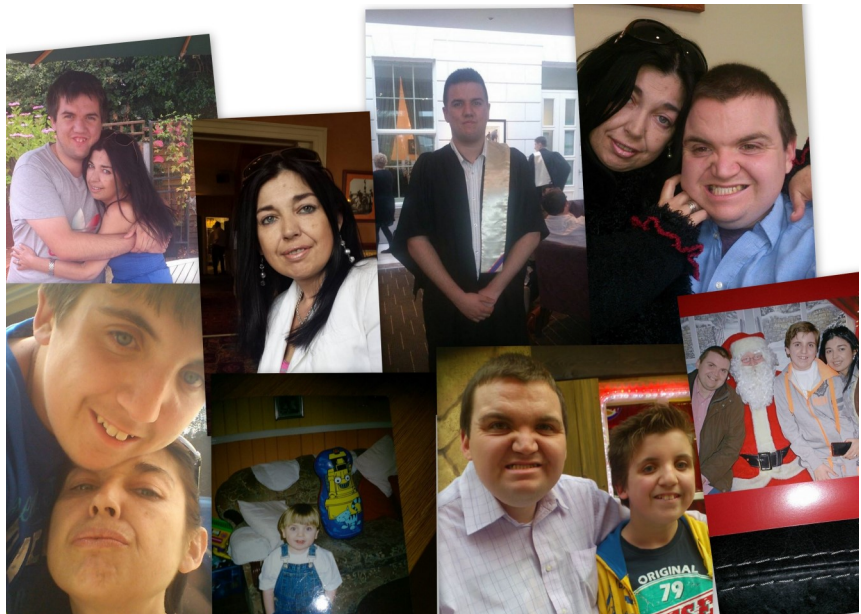
Logo

OACS has a new logo for a new era. We now intend to be proactive as an organisation, with a new approach. The OACS team includes not only the trustees but those parents that also make time to volunteer, fundraise and support others. It is really great to see so many coming together with one goal; 'to make lives that bit easier for their children'. We want to hear your voice, explore your ideas to make that difference for those that we love. The OACS tree represents what has been achieved and our potential.

OACS NEWS



OACS European News Karen Walsh Keely, Big Irish Success



OACS Liaison Officer for Ireland, Karen Walsh Keely

“The Lost Children of Sodium Valproate”

My name is Karen Walsh Keely, my children were affected by Sodium Valproate, I needed answer's not just for me but for all the lost Children of Sodium Valproate; its estimated since the launch of the drug 43 years ago in the UK & Ireland, that in the 15 years, 20,000 Children have been effected by a drug prescribed to their Mum's for their Epilepsy, more recent estimates say that is more like 40,000 since its launch! To date in Southern Ireland only 20 have been officially been diagnosed.

I have being kept busy over in Ireland, with various meetings, that will really push OACS forward in 2015 to New and Exciting places, I have met some very interesting people, who have pledged their help and support for OACS. The organisations that OACS have now forged strong relationships with, who fully appreciate and understand through looking at my life, what each and every one of you are going through and the hurt that we all feel.

Along the way I would have not got to where I am in Ireland today, without the help of Joan, Jeff, Avril, Mike and Philip's personal assistance and the following organisations now supporting OACS Ireland and the UK :- DFI , Disability Federation of Ireland, Epilepsy Ireland, Cystic Fibrosis Association of Ireland, MRCG , Medical Research Charities Group, and GRDO

OACS would like to thank everyone that has helped Karen along her journey in Ireland



OACS NEWS



APPG of Thalidomide and other harmful drugs prescribed during pregnancy

18 June APPG

Alec Shelbrooke MP, Chair of the APPG Thalidomide and other harmful drugs prescribed during pregnancy, has added Sodium Valproate birth defects to the APPG. This meeting plans to formulate a workable strategy to raise awareness of FACS. Emma Friedman developed a strong working relationship with Alec Shelbrook, the meeting was attended by Emma Friedman of FACSaware and Deborah Mann and Branwen Mann. Jo Cozens was also in attendance with Karen Keely observing for OACS Ireland North and South, Tim Noakes was there for the Dads and parents: Amanda and Helen Connolly and FACS person: Sophie Holmes also attended. From this meeting the government will be funding a booklet for use within the NHS and sanoffi and the epilepsy society have said that they will update their pregnancy and

27th June PRAC

The Pharmacovigilance Risk Assessment Committee (PRAC) is the committee that is responsible for assessing all aspects of the risk management of medicines for human use. The main responsibility of the PRAC is to prepare recommendations on any questions relating to pharmacovigilance activities related to a medicine for human use and on risk-management systems, including the monitoring of the effectiveness of those risk-management systems. The review of valproate medicines has been requested by the UK's Medicines and Healthcare Products Regulatory Agency (MHRA) following the publication of new studies suggesting that in some children problems in development, which can include autism, may be long-lasting. The MHRA also noted that there was a need to update the product information of these medicines to bring them in line with current evidence. The European Medicines Agency are now reviewing the available data on the benefits and risks of valproate and related substances and will issue an opinion on the use of these medicines in pregnant women. All those attending have been asked not to share what happened, but we do truly believe that the outcome will be very positive.

The next stage in this process will be the Co-ordination group for Mutual recognition and Decentralised procedures – human (CMDh), will examine questions relating to marketing authorisation of a medicinal product. It will be after this that the EMA will make their final decision.

Attending for OACS are Deborah Mann; OACS secretary, Branwen Mann; trustee and youth representative. In the photograph: Emma Friedmann; FACSaware and Marine Martin; APESAC, France.

Recent Achievements

24th September 2013

The MHRA contacted Emma Friedmann to confirm they will be seeking advice from experts on the use of Sodium Valproate with the view to issue further regulation if required.

10 October,

The EMA (European Medicines Agency) review began.

29 October Norman Lamb Meeting

The meeting with Norman Lamb on the 3rd was cancelled, but reset for 29th of October 2013. As you will probably remember working with Emma Friedman; Anas Sarwar MP made it his undertaking to take the findings of the Westminster Hall debate to Norman Lamb MP; Minister of Care and Support. In October OACs attending a meeting with FACSaware, Ian McLachlan a campaigner from Scotland travelled from Glasgow. InFact and Facsa were also represented, with the intention of putting across the experiences of our children and our fears for their future. Susan Cole and Deborah Mann, on behalf of OACS and Emma Friedman, and Branwen Mann from FACSaware attended. We were shocked to find that the governmental awareness stemmed from the epilepsy and pregnancy register in 2013. Emma Friedman and Deborah Mann explained the concerns of FACSaware and OACS.



OACS, FACSaware & APESAC

at PRAC



OACS NEWS



Groups

Dream Come True Inspired by

Janet Stockley Pollard

Community Groups Here at Last!!!

Janet Stockley Pollard had a vision in her mind of community groups, around the country bringing real support to each other. We are now going to make her dream come true, and bring OACS to you. In this newsletter you will see the community group's registration form, if you want to join or found a community group near you fill it out and get it back to us so that we can put you in touch with others.



Parents Corner, written by families and friends affected by FACS

Adopting of a child with Fetal Valproate Syndrome



As adopted parents of children diagnosed with Fetal Valproate Syndrome (FVS), or any of the other anti convulsant syndromes; we would like to express all concerns and worries for our children. We feel detached in some respects as we have children with this condition, but as parents we do not have the same complex issues with our health, it is because of this that we do not receive the same level of support that others might. It is often forgotten that our problems are not lesser they are different. We are in a minority as some professionals have an attitude towards us of, "you chose to parent a children with Fetal valproate syndrome" so therefore do not have the same needs as a birth parent with a child with the syndrome.

Although my children came with a diagnosis of FVS we were given very little information, and lack the natural process of information and experience that comes with giving birth to a child with special needs. Even today we still have very limited information from professionals. We realise this is not uncommon; however the attitude towards us as a minority group is dismissive.

With families of adopted children, there is a massive emphasis on confidentiality, and protecting the child's and adoptive family's identity due to complex history and safety of the child and birth family. When there is a special needs child with a rare syndrome, this creates many unexpected complex medical challenges, as there is no contact with the birth parents; this is a problem rarely

understood. It is one that needs to be recognised, understood and addressed in total confidentiality, as this affects the child's wellbeing.

There must be many more families with adopted or fostered children with a Fetal anti-convulsant syndrome, let alone a Fetal valproate syndrome; even if they are not diagnosed; that have a likelihood of FVS, or another anti convulsant syndrome, out there. These may not be so lucky to have obtained a diagnosis due to the lack of contact with the birth parent; so with adoptive families the onus should perhaps be on the mother that took anticonvulsant medication that has a special needs child.

We need strategies and useful advice, not only to help adoptive families but professional working with these children. Adopted children come with many complex and diverse needs regarding behaviours and attachment issues, as well as these issues they also have the additional challenges caused by having special needs. Written by two anonymous member carers for OACS

OACS NEWS



Your Child Needs

You

**Please Volunteer for Anything
you can to lighten the Load**

VOLUNTEERS NEEDED

Any help is a big help, thank you in advance

Fundraisers, Community Support Workers, Grants and Funding Organisers, Admin workers, Child Protection Compliance Experience in education, Experience in Social services, Experience regarding GPs, Website Designer and Phone Support Workers

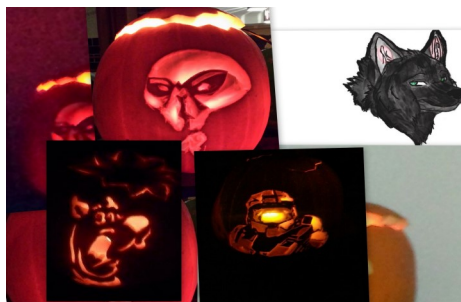
If you can help with any of the above, or think you have a gift, experience or qualified in any other area, that we could use please contact us on the following email address: enquiries.oacs@gmail.com

Halloween Fancy Dress Fundraiser

Ask your School, College or Workplace

To go Fancy Dress for the Day to raise Money for OACS,

email or telephone for your pack



OACS NEWS



FACS Kids are Welcome, Children Youth & Young Adult Page

Branwen Needs Help!!!

I am always surprised by what people think life is like for a FACS kid. There are often things that others do not seem to get about having FACS. I want to do something to change this so if there is there any FACS person; child or adult, which can share their experiences of having a Fetal Anti-Convulsant Syndrome? I don't just want to know about the bad stuff, but the good stuff too. Then forward it to OACS, I want to see what you are thinking and to know what help you are wanting.

- You can write about your experiences
- Dictate what you want to say to a friendly adult
- Make a short video, to share your thoughts
- Record yourself speaking about your ideas, hopes and dreams



Do pictures about anything that you think us adults need to understand.

If you are, or have been, a carer for a FACS person, you too might have some thoughts about what the sort of experiences your children might not even think about. Could you also think about sharing them with me too.

I am hoping to hear from FACS people/children of all ages with a bit of insight from those that care for them.

I am sorry but my mum won't let me use my email address, but if you email me at OACS -

enquiries.oacs@gmail.com I will receive it.

Don't forget you can always contact me on Facebook, in the private OACS page.

Thank you very much in advance to those that give their valuable time to this project!!!

FACS Kids Competition time, Aged 0-5, 5-12, 12-18 & Young Adults



Competition Time

OACS are looking for two pictures, to be used by OACS.

The pictures can be photographs, or painted, coloured or black and white paintings or drawings.

**We are looking for a picture from a member carer, and a picture from a person/child affected by any of the anticonvulsant syndromes
There will be a £10 gift voucher for each of the winners.**

We look forward to seeing your work!!!

Post to: - 23, Morrision Close, South Oxhey, Watford, WD19 6UB



Find us on
Facebook

Organisation for Anti-Convulsant Syndrome (O.A.C.S - Private)

OACS Address :-23, Morrision Close, South Oxhey, Watford, WD19 6UB

Website:- www.oacs-uk.co.uk

Email:- enquiries.oacs@gmail.com

Tel:-0208 386 9271

OACS NEWS



Groups

Sign up and Register now!

For

O.A.C.S. Community Groups

Coming to you soon!

Support for Fetal Anti-Convulsant Syndromes

What will we offer?

**Support, Information, Chance to talk with
like-minded people going through similar issues?**

How to register for free

Complete and return the details below and post or email them back.

Please Return By Email to: - enquiries.oacs@gmail.com

First Name	_____	Surname	_____
Address 1 st	_____	Address 2 nd	_____
Town	_____	Post Code	_____
Contact Tel. No.	_____		
Email	_____		

IMPORTANT IF YOU HAVE AN EMAIL ADDRESS, PLEASE INCLUDE IT AS WE ARE A CHARITY AND ARE TRYING TO BE PAPERLESS TO KEEP COSTS DOWN THANK YOU!

Post to: - 23, Morrison Close, South Oxhey, Watford, WD19 6UB.

Charity Registration Number 1116497