

Corpall is a not-for-profit support group and charity run by parents, families and carers of children and adults who have ACC or Aicardi Syndrome.

This website has been set up to provide support and information for parents and those affected by this condition.



Hello everyone

Included in this issue are more wonderful stories from our ACC families as well as information for our forthcoming AGM. I hope as many of you as possible are able to attend. It's a fantastic day and well worth attending if you can make it.

There is also new information regarding the Data Protection law changes and how it affects our Charity. Please make sure you read this section as this will be a legal requirement that Corpall will need to abide by. At the AGM we will be voting in our new committee for the next year. We really need to get new trustees on board so if you fancy sparing a couple of hours a week for Corpall, please get in touch! We can explain more details of what is involved.

Fundraising is something we really need to push this year, so if you have any ideas, please let us know.

Hope to see you all at the AGM.

Leanne

Corpall
Supporting those with ACC or Aicardi Syndrome



Registered Charity Number 1086019

Email: info@corpall.org.uk

Website: www.corpal.org.uk

Twitter: @officialcorpall

AGM/SPEAKERS/FAMILY DAY 2018

SATURDAY 12TH MAY

Refreshments from 9.15am

Entertainer from 9.45am approx.

Speakers from 10am approx.

Buffet Lunch

Informal time for meeting other families and sharing experiences, plus speak with the various professionals attending.

Day finishes no later than 4pm

Further details of how to book is in this

Newsletter

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- They are not medically trained and therefore advise you to seek medical advice from your Gp or medical professional if you need medical advice.

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Sonia's Story



A Journey of Quality Fluor Story submitted by Sonia Mills, Quality & CPI, Farnborough
As some of my UK friends may have seen,

I was recently shortlisted for an International Quality Award. I was extremely honoured and I wanted to share with you my journey and how with the support of my Fluor colleagues I have overcome adversity, grasped opportunities and grown to be the person I am today. Are you sitting comfortably?

It all starts many years ago... I was born into a very interesting family in Kraków, Poland (it's a beautiful place – you must come for a visit if you are looking for your next long weekend destination). My dad was a music producer in the 1980's and we spent my early years moving around, going to punk rock festivals. I remember, everywhere we rented we always had to have a room for a music studio - so many punk rockers came and went. My two younger sisters and I spent summer holidays helping dad do the graphic designs on the cassette tapes and CDs, and then get them ready for printing and packing. From an early age, it taught us how to use computers and have a creative but methodical mind.

My mum said that I was an early starter when it came to talking and also using long sentences too. Apparently, one time she took me out for a ride in my pram with my monkey soft toy and I said, "Dogs have tails; my monkey has a tail... Sonia has no tail... Why?" I was also reading fluently too. By six years old I was doing really well reading in Polish and my auntie gave me my first English book. I remember sitting in the corner of dad's music room, on the doorstep, reading out loud. Obviously my pronunciation was incorrect, but at least I'd started. Mum and dad quickly noticed my interest in learning the language and they used all they could afford to help me learn it before we started the English classes at school. While other (richer) children had private tutors. I learned through English courses on CD with a microphone and headphones.

By the time I was ready to start secondary school, my English teacher doubted that I would make it through to my first choice - the Adam Mickiewicz 6th Upper Secondary School which specialised in teaching foreign languages and was ranked among the best in Kraków. Needless to say, I proved her wrong and studied Biology, extended History programme, Maths and Chemistry in bilingual English. We had about 10 hours of English a week for three years! I really struggled with Maths, but with the teacher's help I did well enough to be allowed to take the final exams and finish the school... at that time neither I or my parents had no explanation for why I was so good at humanities but not in the sciences. I did find out, but not until 2013/14... a

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long time after leaving school! Afterwards, I tried to figure out what I should do regarding work/further education.

In the meantime, I found a job as a shop assistant in a newly built shopping centre in Kraków. I lasted three months, by which time I decided that I would look to move to the UK. It was a choice between a job in Cumbria, an au pair in Ireland or a nanny in the south of England, in a small village called Rogate outside of a Hampshire market-town of Petersfield.

In January 2006 I ended up in Rogate as a nanny for six months. I could tell that it was not for me, and after that stint I managed to move out into a place with a friend and try to find a normal job. Wherever I applied no one would give me a job, they all said that I don't have work experience in the UK and that my shop assistant job back in Poland doesn't count.

I had friends help me write up my very limited CV and then one Thursday in October 2007 we drove around the Petersfield Industrial Estate knocking on doors asking if anyone had a job. I got lucky when I got to the Aibel UK Ltd office and a lady answered the door. I explained why I was there and she said 'perfect timing, I just submitted my resignation and my manager is looking for a replacement. Go to our other office, round the corner, tell him I sent you and you never know, they might give you a chance'. We didn't waste any time and drove and I asked for Alex. When I met Alex he said he would have to speak to his boss Dave and if they decide anything they would give me a call. That was just after lunch. We got back home, I took my coat off and started making a cup of tea. Suddenly my phone rang. It was Alex asking if I was free straight away to come back and have a look around the office. Dave had decided that as all of them were going to a conference, and there would be no one to answer the door, take calls and e-mails and sort out the post, they could do with me coming in the next day. I started that Friday. I had a two week trial to see how I got on with the job and I had a chance to see if I liked it. After that they gave me the job full-time with a contract. I stayed there from 2007 to 2013 working as an Office Assistant, Admin Co-ordinator and then a Document Controller, until unfortunately the Norwegian headquarters decided to shut the UK operations and we all had to look for other work.

Then in May 2013 I got a job here at Fluor in Farnborough as an entry level Quality Assurance specialist helping Mike Goff on TCO CAR. I was very keen to learn as much as possible and I've been told that the managers quickly realised I wasn't going to be happy being a QA admin support for long. While on TCO FGP WPMP I started helping the Lead Auditors with recording the audits, drafting the reports and chasing Corrective and Preventive actions. My first proper project was Gasco Habshan 5 starting in January 2015 with Phil Thomas, providing part-time support. Later Peter Harvey helped me with other projects.

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Throughout that time I had Phil, Mike and Peter mentoring me and providing guidance. Sadly they are all retired, but now I have Cecilia Suarez-Lledo and Muneeba Carelse, who both encourage and push me to go further and keep improving, even if I think it's out of my reach. While I been in the UK I got married to Rob who I met back at Aibel in Petersfield, and now we have settled in his home town of Portsmouth. He always supports me, even if he has to endure my endless practicing of PowerPoint presentations. He often jokes, keep going Sonia, and then I can retire! Will see how these retirement plans work out in the end!



I had health problems which meant I needed CT and MRI scans and three operations, during the scans it was found that I have a partial Dysgenesis of the corpus callosum, which is a brain malformation at birth but neither my parents nor I let it stop me through education or work. At least it explains my problems with

Maths in school and some other problems, like still struggling learning to drive. I sometimes joke I was born to be driven around and not to drive myself! If anything the condition means that I have to put an extra effort and pay more attention to things than other people need to. But as at school I never got special treatment, I never expect it anywhere not even here at work. My neurologist told me I was lucky, as some children can be very restricted by the condition, so I got off lightly.

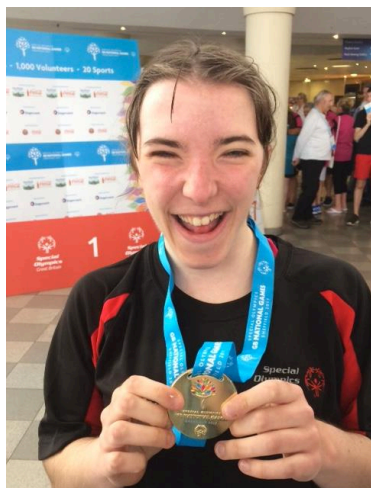
It makes me happy to share my journey with the parents of children with corpus callosum malformations to show them that it does not have to be the end of their children futures. You can see that where I am now has taken blood, sweat and tears and I feel very proud of myself. Living away from my family for 10 years now (even though we do go and visit them) is very difficult, especially when bad things happened. Last year my dear grandma passed away and my sister is suffering mental health problems this year. So the Award nomination comes at a bitter sweet time when I am also struggling with depression myself. However, it has been great having wonderful project teams for the last couple of years on NuGen, Jurassic and now Tilenga.

Without everybody's warm support and understanding I would not be able to do as well as I have done... and my story is not over... I am looking forward to 2018 and hoping it will bring some good things!

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JESS'S STORY



Jess learnt to swim whilst in her first year at the excellent special needs secondary school she attended, and was encouraged by them to join the local local disability swim club, as her ability was quickly recognised.

She has been swimming with them now for over 10 years training twice a week and entering competitions on a regular basis.

She was very fortunate to be selected to swim in The Special Olympics in Sheffield to represent the South East last August. There were teams representing all regions of the U.K. together with guest team from Australia. The opening ceremony was held at Sheffield United's football ground just like a mini version of the

real Olympics, with celebrity presenters and performers, with Tony Hadley singing Gold, sung at full volume by all those in the stadium.

Jess had to stay with her team in the Olympic village (Sheffield University halls!) for a whole 5 days without us, which she dealt with very well. The swimming was held at the National Swimming Centre, Ponds Forge. Jess was amazing and won Gold medals in the 50 metre freestyle and 25 metre butterfly smashing her personal bests in both events.

JACK'S STORY



I tend to struggle with my exams because I am under pressure I struggle to understand the questions. I end up missing most of my questions because of it and my memory is terrible so answering the questions it's a struggle. I need constant help I need tutors twice a week and I need my mum with me when I have homework. I only learn things better physically and not mentally. When I am in class at school I can only take in 60% of what I am taught. I am not very social only in afterschool clubs.

HIS MUMS HELP - Jack is doing 10 GCSEs. I tend to get all the work, revision and exams ready for him then I find it easier to go through it with him. It's like I'm studying the GCSEs but it's the only way I know how to help him and actually get the work done. Jack also has help from Private Tutors to back up his support. It's hard work! Night-time is my time and I look forward to it every evening.

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MILLIE

Here's a brief update.

This is Millie, Now a big 10 years old.

Millie goes to our local special needs school, where she is making slow but steady progress.

Her diagnosis's are ;

C-ACC / Cerebral Palsy/ Autism/ Sensory processing disorder/ global developmental delay and visual impairment.....Yes, quite a mixture!!

Millie is a very lively little whirlwind!

Who keeps me on my toes!!!

She can be extremely hard work, with aggressive outbursts and very challenging behaviour!

But on the flip side, she is the most funny and lovable girl, with an infectious personality. Who makes me smile and so proud every day.

Life isn't always easy for her, and I think she is becoming more aware of her disabilities, which bring her lots of frustrationsbut she never gives up trying.

And her amazing determination blows me away!

My Millie.....my little star....my world

AGM/SPEAKERS/FAMILY DAY

Saturday 12th May 2017

Touchbase Centre, Premier Inn, Bath Road, Hounslow, Middx



Once again we are lucky to secure this venue for our Agm and family day.

Dr Lynn K Paul – Dr Paul will be joining us from the NODCC from America and will update us on any new information that has been received and researched along with a talk on ACC in general. We are very honoured to have her attend the meeting. Dr Paul will also be available for informal chats to individuals in the afternoon.

Professor Rajat Gupta – We are delighted to have Prof. Gupta with us, he will speak for a short while with a general overview of ACC and also Epilepsy, so you can be aware of the various seizures that may occur and to reassure you on what needs to be done and the various medications that can help. Prof. Gupta will also be available in the afternoon for individual consultations.

After lunch, we will have some tables where various representatives from organisations that are relevant to members with ACC will be located and

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available to chat with families on a group basis or on an individual basis. **Beverley Searle** from **Rare Chromosomes organisation 'Unique'** <https://www.rarechromo.org/> will be joining us on the day. If you have questions about chromosomes and the genetic side of the condition, this will give a good opportunity to ask those questions.

Mark Davies who will be representing **The Family Hope Center** <https://familyhopecenter.com/> which is an international organization dedicated to working with (and for) parents of children with special needs and neurological difficulties. Using a practical scientific approach, the Team strives to educate and help parents promote functional improvement in their children in the areas of physiological health, physical structure, sensorimotor abilities, behaviour, cognition, and communication.

Please be aware all professionals attending will only be able to advise on general questions, as they will not be allowed to consult you on your own individual situation.

You can find more details of the AGM on our website, where you can download details of the day, complete booking forms and find information about booking at the hotel if you wish to stay. If you have any trouble downloading the forms, please contact us at info@corpall.org.uk and we can send the forms individually.

A few members stay the night before and if you are coming on your own and want to meet up with others that night, let us know and we can try and put you in touch with others staying.

Parking on the day is normally free, what you need to do when you arrive, come to the reception of the Touchbase Centre and give you registration details to the receptionist.

TRUSTEE/COMMITTEE MEMBERS REQUIRED

Yes we are looking for new Trustees this year, would you be interested? Please contact us at info@corpall.org.uk for more information if you would like to know more what is entailed. In brief we are looking for proactive persons who have a minimum of a few hours a week to spare. No official qualifications needed but a proactive and enthusiasm to help Corpal support members, bring along ideas and attend 4 meetings a year, normally held in the comfort of your own home by Teleconference. If interested, we would love to hear from you.

Nominations forms available to download from the website or request a form from info@corpall.org.uk

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This next story was given to us by Ned's parents at the Northern meeting in January.

This was written by Ned aged 9 about his older brother Finn who has C-ACC

My brother is a shape shifter

My brother is a shape shifter but I'm the only one who has noticed. In fact, to the outside world he looks like any other 11-year old boy. He's got scruffy blonde hair, dark brown eyes and is 1.48m tall. He's skinnier than most but maybe that's because he's always on the go and shape shifting must use up an awful lot of energy.

Over the last 3 years, since I was six, I have been building up a detailed picture of some of his shifts and so far have been able to identify five distinct characters, all of which seem to be linked to his mood and personality.

When my brother has lost or can't find something, he slowly turns into an angry pirate, furious that he's lost his treasure. As he starts to shift, the first thing I notice is his voice getting deeper and croakier. He grows bigger and bulkier, taking up half the room. His right hand disappears and is replaced by a dagger-sharp hook, clawing at the furniture. Unless the missing item is found quickly the gnarly seadog spits out swear words and abuse at all those nearby. But once the item is discovered, the pirate disappears like a wave clearing the sandy beach.

At night, just before he falls asleep my brother turns into a magical story teller enrapturing a crowd around a campfire with voices and animations for every character. I drift off to sleep with these tales creating my dreams, warm and cosy under the duvet.

At school, Prince Charming appears. He is dashing handsome and knows just what to say. The teachers all adore him and go sappy over his beautiful manners as he saves the damsels in distress. My brother is addicted to screens. Tablets, phones, computers and his favourite, TV. If these are removed from him, as quick as a flash he is gone and an out of control wrecking ball smashes through the room, its horn blasting and engine roaring. When he turns back to his normal self, my brother doesn't know what has happened and wonders who has made all the mess.

I like it best when he shifts into the giggle. The giggle looks like a satsuma. It's an orange face on legs with a big nose, enormous eyelashes and sparkly white teeth. Even its feet are funny. He makes everybody laugh. Once I saw him bring an entire theatre to its knees with his crazy dancing and custard pie tricks. It was one of the best days ever.

It's not always easy living with a shape shifter because you never quite know what's going to happen or who might turn up. I think with practise other people might learn to spot a shape shifter. I'm sure my brother isn't the only one. Next time your brother or sister is having a meltdown or has you laughing your head off maybe they're shape shifting too.

Stories and photos have mainly been pasted into this letter from information sent to Corpal, therefore you can be aware they have come straight from the families and not by Interviews and re written. We are very grateful to those families who have contributed. Thank you.

AICARDI SYNDROME

We are hoping to organise a Family Get Together for Aicardi Families in September/October time. More details to follow. If you are interested, please can you email info@corpall.org.uk with your name, email and area. This would help us decide on the size of venue we would need and arrange the event in an area where it will be convenient for as many as possible. Thank you.

FUNDRAISING

There are many ways to fundraising, however we have received a donation from Christine Morris in memory for her husband Jon whose daughter has ACC. This is what Christine has sent.

I chose Corpal as my Jon's daughter was diagnosed with full ACC 27 years ago. Back then nothing was known much about it and they told Jon and Tessie's Mum she'd be dead by the age of 1,3,5 years old etc. in those days she was used as a guinea pig really, as they did not know much about it, she is blind, and deaf with severe fits and with other disabilities but in a family of 5 other brother and sisters she was on the floor rough and tumbling as often as she could. She is 27 now and although I lost Jon 3 years ago, I chose Corpal to receive the funeral donations as a way to make sure that Tessie is remembered as part of the funeral arrangements and in Jons memory our fishing friends hold an annual memorial to raise funds for you. You do an amazing job and if this small contribution pays for a couple of cups of tea and some nibbles for of the families you support to get together and find respite with others going through the same emotions and endless hospital visits we would be very happy. Back when Tessie was diagnosed there was no support and no parent should ever feel as alone like Jon and Tessie's Mum did when they were finally told Tessie has. Obviously things move on medically but the human emotions still take a battering and if Corpal support can ease that just a little bit then at least people know they are never alone. So please accept £170 from Me and Hermy's Match league in memory of Jon Graton and to keep awareness of Tessie.

FANCY SUPPORTING CORPAL??

Please contact us at Corpall@hotmail.co.uk to inform us of forthcoming events/fundraising opportunities. We are always happy to support your events with various promotional items and leaflets. Why not hold a Coffee Morning or mini Get Together for your area? We can also help by contacting other members who may like to attend.

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With **Just giving** getting sponsorship for an event hasn't been easier. By organising your own fundraising activity, you can make a contribution, however big or small, to supporting those with ACC and raising awareness. We appreciate all donations and value all support. Visit corpal@justgiving.com

RESEARCH – Dr Rhonda Booth (Institute of Child Health) would welcome members to contact her if they would be interested in research projects and especially those who would like to share their experiences when they or their children were first diagnosed with ACC. You can contact her at Rhonda.booth@ucl.ac.uk

DATES FOR THE DIARY

SATURDAY 12TH MAY 2018

CORPAL AGM

VENUE – Touchbase Centre, Premier Inn, Bath Road, Hounslow. TW6

Our Annual event where we have speakers and take care of the business side of the Charity. Plus a day for everyone to catch up and meet new members.

28th June 2018

CORTICAL CONNECTIONS SYMPOSIUM

Westin South Coast Plaza (Details below)

JUNE 29TH – JULY 1ST 2018

NODCC – National Organisation of Disorders of the Corpus Callosum

DCC ANNUAL CONFERENCE

Orange County California

Check their website for more details www.nodcc.org

SEPTEMBER/OCTOBER 2018

Proposed **AICARDI FAMILY DAY**

Lynn Paul has sent the following information as a brief description, just in case you will be interested in attending.

CORTICAL CONNECTIONS SYMPOSIUM

June 28, 8:30am - 5:30pm, Westin South Coast Plaza

A special event hosted by the International Consortium for the Corpus Callosum and Cerebral Connectivity (IRC5) in collaboration with the National Organization for Disorders of the Corpus Callosum (NODCC).

The Cortical Connections Symposium is a scientific meeting for physicians and clinical professionals who treat individuals with developmental malformations of cortical connectivity (specifically the corpus callosum) and researchers studying

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these conditions. Individuals with corpus callosum disorders and their family members are also welcome to attend. (Please note that the presentations will be quite technical, as the program was designed for physicians, clinical professionals and trainees in these fields. Several of the symposium speakers will provide less-technical presentations at the DCC Conference.)

The program consists of a series of brief presentations arranged in general progression from cellular and molecular studies, to neural diagnostics in humans, and finally to higher-level cognitive and behavioural issues related to malformation of cortical connectivity. Speakers include scientists and clinicians from around the world; leading experts from the fields of developmental neuroscience, laboratory genetics, clinical genetics, paediatric neurology, neuroimaging and neuropsychology.

Registration for this event is required and is separate from DCC Conference registration. [Register now!](https://www.eventbrite.com/e/cortical-connections-symposium-2018-tickets-42957762825) (<https://www.eventbrite.com/e/cortical-connections-symposium-2018-tickets-42957762825>).

For more information visit the meeting page at [IRC5.org](http://irc5.org/cortical_connections/) (http://irc5.org/cortical_connections/).

Useful Information

Contact a Family is now known as '**Contact**'
Free Help line 0808 808 3555 <https://contact.org.uk/>

Contact is a brilliant resource for everyone who needs to find out more about support, groups and resources. Their main office is in London, but have branches all over the UK, but you can normally find out what you need by just a phone call.

USEFUL LINKS

Children with special educational needs and disabilities (SEND)

Education -

<https://www.gov.uk/children-with-special-educational-needs/special-educational-needs-support>

<https://www.gov.uk/children-with-special-educational-needs>

NODCC – National Organisation for disorders of the Corpus Callosum

www.nodcc.org

info@nodcc.org

Useful Resources

<https://www.sensorytoywarehouse.com/>

Email: info@sensorytoywarehouse.com

<http://www.specialneedstoys.com/uk/>

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This link sends you to further links for Toys.

<https://www.cheapdisabilityaids.co.uk/index.asp>

www.betterlifehealthcare.com/Disability

<https://specialkids.company>

Adaptive clothing for children with special needs.

<https://www.cheapdisabilityaids.co.uk/>

(Sensory ideas and toys)

(If anyone knows of any useful links please share them with us and email corpall_jean@hotmail.com)

Facebook – If you not already a member, find us on Facebook, search for Corpal, it is a closed group, so to be accepted you will be asked to give a brief explanation of why you would like to join.

Twitter – We are now on Twitter

AICARDI SYNDROME

Aicardi Syndrome Foundation

(US based:) <https://aicardisyndrome.foundation.org/aicardi-syndrome/>

Epilepsy Action (UK) <https://www.epilepsy.org.uk/info/syndromes/aicardi-syndrome>

Aicardi support Facebook Group (UK & Ireland)

<https://m.facebook.com/groups/1463862363921368>

If you wish to speak with an Aicardi Syndrome contact, please email John on info@corpall.org.uk (In the subject box, please put Aicardi enquiry.)

Data Protection legislation May 2018

As I am sure most of you are aware that there is a new legislation on Data Protection from 25th May 2018. Over the last few weeks Corpal has been taking advice to make sure that we are compliant. There will be a few changes and updates needed and we are working on them at present. For those we have an email for will be sent a request to re validate your interest in Corpal and ask if you would still like to receive information for us by email. We will only be taking basic information. We do have to stress that if we do not receive a reply from you within a certain time, we will be removing your details from the database. Therefore if you would like to receive updates by email, you will have to re register. We apologise for any inconvenience on this, but we have to be compliant with the Law. Your co-operation in this will be much appreciated and we hope that the majority if not all will reply to our email re Data

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Protection so we can update our Data Base and be fully compliant with the Law.

COMMITTEE/TRUSTEE INFORMATION

LEANNE HUSSEY	CHAIRPERSON	info@corpall.org.uk
VICKY GAUNT	SECRETARY	info@corpall.org.uk
TOM DEEVY	TREASURER	info@corpall.org.uk
HELEN DEEVY	COMMITTEE	
JOANNE CARTY	COMMITTEE	
RICHARD DODDS	COMMITTEE	
JOHN JAMES	COMMITTEE	info@corpall.org.uk (Aicardi Contact)
JEAN DALTON	ADMINISTRATION	corpall_jean@hotmail.com

Address – for all orders, enquiries, cheques etc.
 240 Malden Way, New Malden, Surrey KT3 5QU

PRIVACY POLICY

Any personal details given to us via the website, correspondence or telephone will be entered onto our database. We will use these details to circulate our Newsletter and other useful information. This information is solely for Corpal’s use and will not be given to any third party without prior consent. Your permission will be asked before your details are forwarded to any researchers interested in Agenesis of the Corpus Callosum or Aicardi Syndrome.

The Information We Collect

- Name
- Address
- Email address
- Phone number

Our Commitment To Data Security

To prevent unauthorised access, maintain data accuracy, and ensure the correct use of information, we have put in place appropriate physical, electronic, and managerial procedures to safeguard and secure the information we collect online. Our return email address from the website or message board will be no-reply@corpall.org.uk this will be used to reply to any email that we receive .

How To Contact Us

Should you have other questions or concerns about these privacy policies, please send us an email at info@corpall.org.uk

Disclaimer: Please be aware that all links mentioned in this newsletter are for your information. Corpal is not responsible for any of their sales. If you are speaking with a family contact, please be aware they are not medically trained and can only support you by experiences of their own. You are advised to speak to your GP or medical professional if you have any concerns at all.

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