

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.



Corpall
Supporting those with ACC or Aicardi Syndrome



Hello everyone!

Wow these last few months have been really busy for the Committee of CORPAL. There are many exciting ideas coming through that we are hoping to develop and grow in the next few months – you will all be informed as and when they arise.

You may be aware, especially if you are a member of our Facebook group, that the Committee members are beginning to organise local meet ups in their respective home areas. As we are in the process of organising a weekend long AGM in the next year or so, we have made the decision to have more local meet ups so as to get access to the committee and work of the charity to as many members as possible. We hope you all get behind every committee member and attend these meetings as it is always nice to reach out to as many members as possible. We can then inform as many of you as we can of how we hope to develop and grow the charity in the future.

Our AGM is still going ahead on Saturday 11 May 2019. It will not be the typical family day that we usually have but all members are free to attend and get to know the committee. Just let Jean our Administrator know if you intend to come. More details will be released shortly. If you would like to join the committee either let myself or Jean know and we can speak in more detail with you and get the

relevant forms filled in.

We hope you find the information in the Newsletter useful.

Leanne

AGM 2019

We have set a date for the AGM on Saturday 11th May 2019 at the Renaissance Hotel, St Pancras London, this will be a smaller event than previous years as we plan to hold ONLY the business part. There will be no speakers or arranged family time to chat. If however you would like to attend, we would be delighted to see you, but please can you let us know no later than 21st of April 2019.

As mentioned above the AGM is still going ahead and we still would like to offer to you the opportunity to join our Trustee/Committee member team who, if elected will be helping Corpall raise awareness and help out where possible to support our members throughout the year. If you are interested and want to know more or would like to have a Nomination form, please email us at info@corpall.org.uk stating Committee/Trust info required in the subject line.

To make up for this smaller event this year, we plan to hold more regional meetings around the UK over the next 18 months, so we can have more informal quality time and be in locations nearer to families who find it too far to travel to London for a day.

We are still hoping to organise a larger Conference in 2020 or 2021. Before we can commit to a date, we need ensure we are using Corpall funds wisely, hence finding the right location, support from our members and speakers for the event. We will update you as soon as we know more. Thank you all to those who have responded with your interest and locations so we can try to look at venues where most members are located.

Regional Meetings in the planning

North West – Saturday 13th April, Family fun afternoon at the Blackpool Tabernacle, Springfield Road, Blackpool. This will be open to the public as well. This event is being run by a family who is affected by ACC.

North East – TBA

Scotland – September, Edinburgh – Scotland (more details soon)

South – June/July (Berkshire)

Midlands – TBA

South West – Exeter – Sunday October 6th. Imperial House, Exeter. (more details will follow)

South East – Surrey – August (Details to Follow)

Wales & West – July/August

If anyone would like to help out at any of the above, please email us at info@corpall.org.uk and we will put you in touch with the main organiser. We can always



do with help setting up and clearing away after All regional meetings. Are informal and aimed at getting families together to meet each other and share experiences. We

plan to provide some kind of refreshments, but any ideas or help with this would be appreciated. We may have to ask for a small donation to help towards the day, but other than that, it's a great day out.

DATES FOR THE DIARY

Friday/Saturday 12/13th April – Lancashire's Lighthouse Radio Station Corpall fundraiser.

Sunday April 28th - Virgin London Marathon – Come along to support our member Leah



May 10th-12th AusDoCC – Connections 2019

Conference – Perth Western Australia
<https://www.ausdocc.org.au/> for more details.

Thurs 16th May & Thurs 4th July – Kidz to Adultz Exhibition
<https://www.kidzexhibitions.co.uk/kidz-south/> (Free tickets available from Website)

Monday 27th May – Vitality London 10k run

Wed/Thurs 13/14th June IRC5 (International Research Consortium for the Corpus Callosum & Cerebral connectivity) Scientific conference. Paris, France. <http://www.irc5.org>

Thursday 4th July - Kidz to Adult Exhibition
<https://www.kidzexhibitions.co.uk/fire-walkers/> (Free tickets available from Website)



Thank you to Mark Carr who has offered to be our representative at the Australia Conference run by AusDoCC in May.

IRC5 – The International Research Consortium warmly welcomes all Corpall members to attend the Cortical Connections Conference in Paris. This scientific meeting runs over two days and the program includes many new speakers as the IRC5 engages with more researchers and clinicians studying the mechanisms and genetics of callosal agenesis, including diagnostic and research neuroimaging, and clinical outcomes. The conference is open to the public and includes family oriented sessions on Friday afternoon. Presentations will be 15 minutes, followed by 5 minutes for questions. To learn more about the conference, please visit the IRC5 registration page. [registration page](#).



*International Research Consortium for the
Corpus Callosum and Cerebral Connectivity*

TRAVEL FEATURE



Travelling with child or an adult with special needs or if a person has a hidden disability and travelling on their own can be quite an

experience and not always a pleasant one if there is no help available at major airports.

I have looked into various Airports and Seaports around the UK to see what they have to offer. I am pleased to say that they are taking those with extra needs a lot more seriously over the past few years and have been introducing various systems to help those who need it. Instead of writing a full report on each airport as there is so much information available, I have included the links below for you to check out.

Not all disabilities look like this



Some disabilities look like this



Not all customers with hidden disabilities require assistance through the airport. However, we believe there is an optional opportunity to provide them with a 'discreet sign' which demonstrates to airport staff that they may need additional support or help as they travel through the airport.

This could simply mean:

- Giving them more time to prepare at check-in, security etc.
- Allowing them to remain with their family at all times.
- Giving them a more comprehensive briefing on what to expect as they travel through the airport.
- Reading a departure board or sign.



Recognise, Reassure and Respond



One point I noticed on the larger airports that if you book special assistance for the airport itself, it does not always mean that they will take you to the airline when boarding, this needs to be booked with the airline direct. Please make sure you check this when asking for assistance.

A lanyard system is available for those with hidden disabilities who travel on their own at most airports now, when worn this is generally known to all airport and airline staff. It can hold vital information about where that person should be and what flight etc. so can be helped instantly and discreetly by a member of staff if they are struggling or lost. This is now used at most airports around the UK. Services at smaller airports may differ from the larger airport, but they

still use the same concept where possible. The lanyard (shown on the left) is a discreet way for staff to see that passengers may require additional support or time and will allow them to offer assistance.

Passengers can choose whether to wear the lanyard throughout their time in the airport or just pop it on when they need to – e.g. in queues, at security or anytime they are feeling vulnerable and could use some assistance.

They are entirely optional for the user. The lanyard will ensure that airport staff are aware that a passenger may:

- Need more time to process information or more time to prepare themselves at security
- Need to remain with family at all times
- May react to sensory overload i.e. be surrounded by too much information
- Need staff to use clear verbal language as it may be difficult to understand facial expressions and/or body language
- Need staff to be visual with instructions and use closed questions to assist passengers effectively through the airport
- Benefit from a more comprehensive briefing on what to expect as they travel through the airport

This is such a positive step in making air travel more inclusive for everyone and might be the difference that makes someone take the plunge and book a holiday knowing that there will be someone at the airport who will be aware of their need for support straight away.

The lanyard itself is simple, it doesn't scream disability as you might expect (and which may put some people off using it). It has no specific information on it and there's no sign of the outdated disability logo we all love to hate!

It is simply a visible accessory, recognisable by those working at the airport. If a lanyard isn't suitable then there are also badge/pins and bracelets available instead with the same pattern.

This is a new concept and as with all new things there may be some teething problems but I think this is a really positive step and one that Gatwick and OCS can be very proud of implementing. Who knows, if this is a success perhaps it could be adopted across

the country's other airports, or even other travel networks, where passengers with hidden disabilities need additional support.

The following was written by one of our young adult members –

"I have recently travelled using a hidden disability lanyard.

In summer last year, at the age of 16, I flew alone to Cornwall to stay with relatives for a week. This was the first time I had flown on my own. When I got to the airport, before checking in, I collected a hidden disability lanyard. The staff member didn't have much knowledge about the lanyard so my parents had to briefly explain what it was. After checking in my luggage, we learned that my flight was delayed for 2 hours. We had carefully planned and gone through the flight timings previously. The delay meant that I would be taking off at the time I should be landing in Cornwall. This change really unnerved and upset me. As I was saying goodbye to my parents before heading to security, a staff member must have noticed my lanyard and that I was upset and asked if I was okay. After we explained the situation she accompanied me through security and took really good care of me while I waited for my flight. If it wasn't for the lanyard and her help, I don't think I would have coped with going through the security checks and waiting for my flight after the upset and disruption. Going through security checks at airports has always knocked my confidence at the airport."

Since I received my hidden disability lanyard I have taken it to the airport and I have noticed that staff are a lot more understanding and have kept me calm through situations that may otherwise panic me.

I strongly recommend that anyone who has a 'hidden disability' looks into collecting a lanyard since it has definitely boosted my confidence at the airport."

Written by Annabelle

Some of the major airports that have various travel assistance systems in place.

- Aberdeen Airport:
<https://www.aberdeenairport.com/aberdeen-airport-guide/special-assistance/travelling-with-additional-support-needs/>

- Belfast City Airport:
<http://www.belfastcityairport.com/At-The-Airport/Special-Assistance>
- Birmingham Airport:
<https://www.birminghamairport.co.uk/at-the-airport/terminal-facilities/special-assistance/>
<https://www.birminghamairport.co.uk/media/5121/assisted-travel-information-nov-18.pdf>
- Bournemouth Airport:
<http://www.bournemouthairport.com/special-assistance/>
- Bristol Airport:
<https://www.bristolairport.co.uk/about-us/news-and-media/news-and-media-centre/2017/3/hidden-disabilities-card>
- Cardiff Airport:
<https://www.cardiff-airport.com/special-assistance/>
- Doncaster Sheffield Airport:
<http://flydsa.co.uk/before-you-travel/passenger-information/>
- East Midlands Airport:
<https://www.eastmidlandsairport.com/help/special-assistance/hidden-disabilities/>
- Edinburgh Airport:
<https://www.edinburghairport.com/prepare/special-assistance>
- Exeter Airport:
<https://www.exeter-airport.co.uk/special-assistance/>
- Glasgow Airport:
<https://www.glasgowairport.com/at-the-airport/airport-services/>
- Guernsey Airport:
<https://www.airport.gg/passenger-information/special-assistance>
- Humberside Airport:
<https://www.humbersideairport.com/at-the-airport/special-assistance/>
- Inverness Airport:
<https://www.invernessairport.co.uk/2018/05/18/hidden-disabilities-lanyard-scheme-launched-at-inverness-airport/>

- Leeds Bradford Airport:
<https://www.leedsbradfordairport.co.uk/at-the-airport/special-assistance>
- Liverpool Lennon Airport:
<https://www.liverpoolairport.com/help-advice/special-assistance/>
- London City Airport:
<https://www.londoncityairport.com/request-special-assistance/other-special-assistance>
- London Gatwick Airport:
<https://www.gatwickairport.com/at-the-airport/passenger-services/special-assistance/hidden-disabilities/>
- https://www.gatwickairport.com/globalassets/publicationfiles/passenger/prm/gal_specialassistance.pdf

London Gatwick have a brochure online you can download with many answers to questions you may have. You will find this at the link above.

London Gatwick is the first UK airport to open a sensory room. It is a calming and relaxing environment, designed for passengers with disabilities like autism, dementia or cognitive impairment, who will benefit from a safe and distracting place when in unfamiliar surroundings. The sensory room is free to use, accessible for wheelchairs and availability is on a first come, first served basis to passengers departing from the North Terminal. London Gatwick have opened a new Sensory room for those with fear of flying or need just to calm down or anxious. I have added the link below. Hopefully more airports will follow with this initiative.

- London Heathrow Airport:
https://www.heathrow.com/file_source/Heathrow/Static/PDF/Airport_guide/dementia-passenger-leaflets.pdf
- <https://www.heathrow-airport-guide.co.uk/disabled-facilities.html>

The above link is worth checking for all assistance at Heathrow as they have various tips to follow when flying from this airport.

- London Luton Airport:
<https://www.london-luton.co.uk/special-assistance-landing>

- London Southend Airport:
<https://southendairport.com/flights/special-assistance>
- London Stanstead Airport:
<https://www.stanstedairport.com/help/special-assistance/>
- Manchester Airport:
<http://www.manchesterairport.co.uk/at-the-airport/special-assistance/hidden-disabilities/>
- Newcastle Airport:
<https://www.newcastleairport.com/passenger-assistance/hidden-disabilities/>
- Newquay Airport:
<https://www.cornwallairportnewquay.com/the-airport/passengers-with-reduced-mobility>
- Norwich Airport:
<https://www.norwichairport.co.uk/special-assistance/>
- Southampton Airport:
<https://www.southamptonairport.com/at-the-airport/special-assistance/>

Looking at various Ferry Terminals to Ireland and Europe, I found that the services offered are varied, but I have added a few links below to check out if you are planning a trip. I also get the impression that you need to work quite hard to get the help you need. So if anyone knows different and can recommend a particular system or good ferry company to work with, please share with us and we can add to the next newsletter.

SEAPORTS

- Dover:
<http://www.poferries.com/en/dover-calais/travelling-with-us/accessibility>
- Harwich:
<http://www.harwich.co.uk/passenger-travel/accessibility>
- Newcastle:
<https://www.newcastleairport.com/passenger-assistance/obtaining-assistance/>

Ferries to Ireland

- [https://www.irishferries.com/uk-en/frequently-asked-questions/top-10-faqs/reduced-mobility-and-special-needs/](https://www.irishferries.com/uk/en/frequently-asked-questions/top-10-faqs/reduced-mobility-and-special-needs/)

- <https://www.stenaline.co.uk/ferry-to-holland/plan-your-trip/passengers-with-special-needs>

Ferry's from Scotland

- <http://www.western-ferries.co.uk/accessibility>

Local ferry service.

CRUISES FROM THE UK

Some various links if you fancy a cruise, where they cater for those with extra needs. Again, if anyone has a personal experience of a cruise with one of these companies, maybe you could share with us, so we can let members know.

- Cruise.com <https://www.cruise.com/cruise-information/special-needs/>

Worth checking the below link if you are considering a cruise, they give a run down on the various cruise lines that are accessible for those with Special Needs and in their opinion the ones they recommend.

- <https://www.cruisecritic.co.uk/articles.cfm?ID=105>

ACCESSIBLE HOLIDAY HOME IN THE UK

A three bedroom bungalow with wheelchair access,



with stunning views over the sea, located just outside Dawlish in Devon. The towns of Dawlish Warren and Dawlish are both accessible by wheelchair. Exeter is

about 20 mins away in the car; a wheelchair friendly taxi is available if required. Details on request when booking. Hoists are also available if required. Please visit www.aplaceforeverybody.co.uk for more details and pictures.

MEET THE TRUSTEES AND TEAM

Who are the committee? How did they become part of CORPAL? For each and every Committee member, we all have a personal interest in this charity of ours and the support it provides for parents and families of children with a Corpus Callosum disorder and Aicardi syndrome. Here is a little bit more to help you learn more about each member:

Leanne Hussey – Chairperson / Trustee

Hi everyone! My name is Leanne Hussey and I am the current Chairperson for CORPAL. I am a single parent to 2 wonderful girls – Natalie, aged 17 and Caitlin aged 16. Caitlin has Agenesis of the Corpus Callosum. I became involved in CORPAL and first reached out to them in 2010 when our difficulties understanding Caitlin's social-communication problems first came to light. Despite having no vision in her right eye and reaching milestones around 6 months to a year later than her peers, Caitlin was all but a typical child and we had no major issues.



When I managed to stumble across CORPAL, I was desperate for whatever help and assistance I could find. The doctors were very dismissive of ACC and how it was affecting my daughter and us as a family. I have heard everything basically describing her from, "She will be nothing but a blob in the corner" to "Many people have ACC and are perfectly fine with it".

The response, support and lending ear I received from CORPAL told me that I certainly was not alone, that this is not a condition that can be pinpointed by how it affects the child and how dismissive the medical profession is toward the difficulties our ACC'ers face on a daily basis. I received so much support, so much information that I wanted to give something back so in 2013 I became a committee member. In 2015 I took over the role as Secretary and then in 2017 stepped up as Chairperson.

This role has been challenging and at times, difficult but I have always felt supported by our fantastic committee and what they also offer the charity. I am looking forward to taking the charity forward in 2019 and am excited for the plans we hope to come to fruition in the near future.

Tom Deevy - Treasurer/Trustee and Helen Deevy – Committee Member/Trustee and wife to Tom

We joined Corpal around 15 years ago and became a committee member a couple of years after that. Our

daughter was diagnosed with complete ACC at birth and although she always reached her developmental milestones and went to mainstream education, we have always appreciated the emotional support and understanding of an extended family through Corpal.

Life with an ACC'er certainly brings challenges but we have learned, and impress upon her, that she will develop at a pace which is right for her and she may need (and have to ask for) some extra help.

Every day she amazes us with what she is able to achieve. We are infinitely proud of her. Parents of children with ACC and adults with ACC too, constantly have to explain their condition to friend and family as well as clinicians!

We became committee members to help raise awareness of ACC and offer support to affected families.

Joanne Carty Committee Member /Secretary/Trustee

I have been a member since 2009 and as a committee member since 2017. I have attended many of the Family Get-togethers over the years. My daughter Verity has ACC plus other disabilities including Hydrocephalus, Epilepsy, and Autism. I was lucky enough to have 5 year career break when she was born and I firmly believe this enabled me to be fully engaged with her physical and social development. Despite a very bleak prognosis and extreme encouragement to terminate the pregnancy, Verity is our miracle child. I am always looking forward to meeting other members and raising the profile of Corpal. I work part-time for my local council in their Adult learning department. I am married to Ian and have two children, Verity (13yrs) and Samuel (11yrs)



Richard Dodds-Committee Member/Trustee

We were told that our daughter Jessica was brain damaged when she was young, but never had a great deal of explanation until she started school, and not told what the condition was. While trying to fight for extra educational support at school, we started to

look at what PACC was on the Internet, to try to explain to the school and education authority. At first we found the American Website and then we found the link to Corpal.

We were unsuccessful in our first attempt for educational help, but with the information gained, we appealed the decision and won. Corpal had been so helpful, we decided to attend our first AGM which was held near Heathrow, and we learnt so much, met wonderful families and gained some wonderful friends.

Aspazia Psaradellis – Committee / Fundraising Officer / Trustee



is the fundraising officer for Corpal charity. She is training to be a clinical (radiation) oncologist. Aspazia lives in London with her husband, three-year old daughter, and 16-month old son who has complete ACC. Aspazia has a mission to change how ACC is perceived and interpreted. She has a special interest in school-age children with ACC and how they, their parents and teachers can be helped.

Rachel Watson – Committee Member – Family contact in Scotland

I am a young adult with ACC and the have taken on the role of the Scotland Contact for Corpal. I became involved with Corpal a few years ago when I joined the Facebook group which mum told me about. I reached all my milestones on time although I did go to speech therapy it is not confirmed my speech was affected by the ACC. I was told about the condition when I was 8 years old. At School I had extra help. I had someone scribe for me if the teacher was talking and we had to copy something from the board. I was bullied at High School but I had a group of supportive friends. I passed my exams at school



and two college courses. I find it difficult to talk to new people and start conversations, I don't always know if someone is joking or serious and when I was younger I didn't understand body language or facial expressions. I am a volunteer for a charity shop and also a Heritage Centre. I would like to eventually have a job and was recently put on a waiting list for supported housing.

Keren Wyllie – Aicardi Syndrome contact



Hello, I'm Keren and I live with my husband and two daughters in Stirling. My youngest, Runa, was diagnosed with Aicardi syndrome when she was 17 weeks old in May 2018. I am the Scottish Aicardi syndrome contact for Corpal and I am happy to be contacted by families and individuals looking for support and information.

Jean Dalton – Administration Officer and Family Contact

I have been involved with Corpal for around 22 years now, initially as member then an active member of the committee for over 15 years. My daughter who is now nearly 30 years, was diagnosed with dysgenesis of the CC, epilepsy, hemispherical cysts and a balanced translocation of the 1 and 12 chromosome. After a short break I returned to Corpal a couple of years ago as their administration officer. My main responsibilities are look after the Trustees and charity contacts, look after the database, first point of contact for new members, the Newsletter generally any administration that is required.



Dr Rhonda Booth

I am a Research Psychologist and Senior Teaching Fellow at Great Ormond Street Institute of Child Health, University College London (UCL). I have been involved with Corpal since 2005 when I began working on a research project comparing the social and cognitive abilities of individuals with ACC to those

with autism spectrum conditions and typical development. I was very taken by the level of dedication of the Corpal Committee to help families to understand and support their loved ones affected by ACC. I also learnt about the struggles families often face in getting acknowledgement and support within the education system, despite the hard evidence of a brain difference in their child. I came on board as Corpal's Research Consultant with the aim to help inform families on what we have learnt about ACC, particularly its impact on development and behaviour. I am a member of the International Research Consortium for the Corpus Callosum and Cerebral Connectivity (IRC5) and have attended their scientific meetings. I have presented my research findings at national and international conferences and helped increase awareness of the condition. I would like to develop a research programme within the UK to further understand why individuals with ACC have widely different symptoms and outcomes and how can we best support them.



I am immensely grateful of the time families give to research and believe there is a lot we can from each other – thank you and I look forward to meeting you at future Corpal meetings!

FUNDRAISING

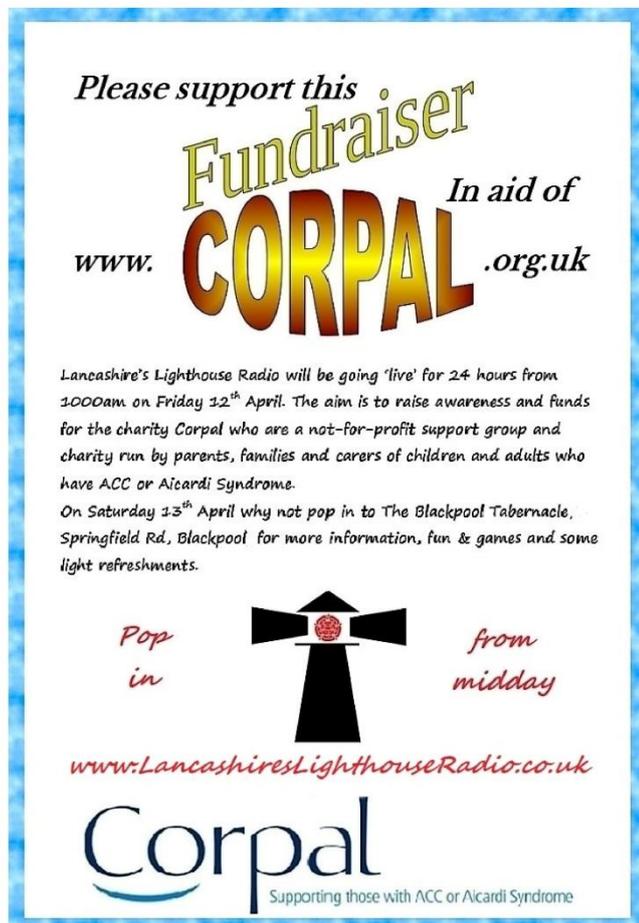


A very big Thank You to Lisa, Minnie (ACC), Lee and Autumn (pictured above) for running in the 5K run at Crystal Palace Park in January who between

them raised over a whopping £4,000 for Corpal. We would also like to thank those who supported them by their kind donations.

Lancashire's Lighthouse Radio Corpal Fundraiser event on Saturday 12/13th April at:

The Blackpool Tabernacle, Springfield Road, Blackpool



Katy and Sean Thompson, members and have a son with ACC will be working hard alongside this Radio Station which will be going live for 24hrs from 10am on Friday 12th April to raise awareness and talk about the condition during their programmes scheduled for that time. If you or your child affected by ACC would like to send a recording of a poem or speak about their condition, they are very interested in hearing from you. Please send a recording to info@lancshireslighthouseaudio.co.uk This will be played over the air during their 24 hour Marathon. You can be anonymous, but if you can give them a contact number on the email to call you just in case they need to ask any questions before the event.

Their main aim is to raise awareness and funds for Corpal who support those parents, carers and

children who are affected by a disorder of the Corpus Callosum or Aicardi Syndrome. We hope to arrange a professional to attend to answer questions and a committee member to also be present.

Why not join them for some fun and games, from 12pm – 4pm at the Blackpool Tabernacle, Springfield Road, Blackpool. FY1 1QL. this is open to families affected by ACC and the general public. A great way to raise awareness and meet new friends.

If you are unable to make this day and would like to contribute, please visit....

<https://www.justgiving.com/fundraising/katy-thompson19llr?fbclid=IwAR0FsN7f6o24CDk-BJMC60RfeoE5odtnA57CAzLmGZ8Z0800Q6eG1enGEb8>

Virgin London Marathon – Sunday 28th April 2019

Leah Ozdemli (member) will be running in the London Marathon this year for Corpal on the 28th April. Her Just Giving page can be visited at:

<https://www.justgiving.com/fundraising/leah-ozdemli>

Leah is working very hard towards this event please visit her Just Giving page to find out why. If anyone would like to join Leah and her family, supporters and some of the Corpal Team, please let us know so we can arrange a meet up. The more supporters the more fun and the easier it will be for Leah.

May 27th 2019 (Bank Holiday Monday) - Vitality London 10,000 (10k run)

Ryan and Joe Keeley have offered to run in this event to raise awareness and funds for Corpal.

Would you like to join them for the 10K run and do your bit for Corpal? Please contact us at info@corpall.org.uk for more information or if you are interested in taking a place.

AICARDI SYNDROME

We are delighted to introduce Keren Wyllie who has taken on the role as our Aicardi Syndrome contact for the group. Although located in Scotland, Keren is very proactive and keen to be there for



anyone who would like to chat. Here is a small intro from Keren herself.

"Hello, I'm Keren and I live with my husband and two daughters in Stirling. My youngest Runa, was diagnosed with Aicardi Syndrome when she was 17 weeks old in May 2018. Although living in Scotland I am happy to be contacted by families and individuals anywhere in the UK and Ireland looking for support and information.

If you would like to read my blog, please follow this link <https://mystrongru.wordpress.com>

"Aicardi syndrome is a disorder that occurs almost exclusively in females. It is characterized by three main features that occur together in most affected individuals. People with Aicardi syndrome have absent or underdeveloped tissue connecting the left and right halves of the brain (agenesis or endogenesis. of the corpus callosum). They have seizures beginning in infancy (infantile spasms), which tend to progress to recurrent seizures (epilepsy) that can be difficult to treat. Affected individuals also have chorioretinal lacunae, which are defects in the light-sensitive tissue at the back of the eye (retina).

People with Aicardi syndrome often have additional brain abnormalities. Most affected individuals have moderate to severe developmental delay and intellectual disability, although some people with this disorder have milder disability.

In addition to chorioretinal lacunae, people with Aicardi syndrome may have other eye abnormalities. These eye abnormalities may cause blindness in affected individuals.

Some people with Aicardi syndrome have unusual facial features including a short area between the upper lip and the nose (philtrum), a flat nose with an upturned tip and sparse eyebrows. Other features of this condition include hand malformations and spinal and rib abnormalities leading to progressive abnormal curvature of the spine (scoliosis). They often have gastrointestinal problems such as constipation or diarrhoea and difficulty feeding.

The severity of Aicardi syndrome varies. Some people with this disorder have very severe epilepsy and may not survive past childhood. Less severely affected individuals may live into adulthood with milder signs and symptoms."

If you would like to contact Keren, initially please email her via info@corpall.org.uk with Aicardi Syndrome in the subject line.

More information on Aicardi Syndrome can be found at the following link:

<https://ghr.nlm.nih.gov/condition/aicardi-syndrome>

Useful Resources

Aiming Higher is a unique charity established in 2011 for disabled children and their families, set up to improve the children and families lives and offer them much needed support.

<https://www.aiminghighercharity.org.uk>

Contact 'Get in Contact' for helpful information and guides for those looking for support.

www.contact.org.uk

Family Hope Center: Although their main office is in America, they have a UK representative if anyone finds their support helpful www.familyhopecenter.com or email: team@familyhopecenter.com

Family Fund – Provides grants for essential items for families who have special needs.

www.familyfund.org.uk

To check out the benefits you may be eligible for <https://www.gov.uk/dla-disability-living-allowance-benefit>

Privacy Policy

This notice applies to all information collected or submitted by Corpall through our Website, Newsletter or Email.

Any personal details given to us via the website, correspondence or telephone will be entered and stored onto our database. We will use these details to circulate our Newsletter and other useful information. This information is solely for Corpall's use and will not be given to any third party without prior consent. Your consent 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

Please note that transmission of information via the internet is never completely secure. Therefore we cannot be responsible for the security of your data at

that time and the information is transmitted at your own risk. Once we have received your information, we will use procedures and security features to prevent unauthorised access to your information.

Links to other Websites

Our Website may contain links to other websites of interest. However, you should be aware that we do not have control over other websites. We cannot be responsible for the protection and privacy of any information you may provide whilst visiting that website, especially those that are not governed by this statement. Please take caution at always check the privacy policy of the website visited.

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.

Access to Information

The Data Protection Act gives you the right to access information held about you. Your right of access can be exercised in accordance with the Act.

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

NEW HELPLINE!

If you would like to speak with one of the team, please call the number below. Please be aware we are not medically trained, but can offer support and point you in the right direction for further help if required. Please leave your name and phone number and we will get back to you as soon as we can.

HELPLINE - Mob: 07427 429388