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CVSA at Home

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Medical References

An extensive list of references to journal articles and research on CVS and abdominal migraine can be found on our website at www.cvsa.org.uk/research.html
Welcome to the 20th year of CVSA

We have come a long way, from an informal support group to the establishment of the charity in 1995. We now collaborate with other CVS support groups around the world. We have a wide variety of promotional and informational materials.

It is hard to believe but our website was first set up in 2000. We have helped many people find sympathetic doctors, diagnoses and treatments. We know there are still huge gaps in health provision and awareness for CVS sufferers.

One future aim for the charity is to provide better support for parents/carers struggling with school provision and appropriate care. Some aspects are very technical and an understanding of the law makes this a difficult task. We aim to improve where we can and find better resources to direct sufferers to.

Adult sufferers have long been overlooked and we need more to tell their story and contribute so we can develop better information tailored to their needs.

If you have suggestions for future aims for the charity, this seems like a very appropriate time to share them as we all look forward to the next 20 years.

Mission statement
The Cyclical Vomiting Syndrome Association, CVSA UK, is a registered charity and 100% volunteer association founded by parents and professionals with the following purposes:

• To provide patients, families and professionals with opportunities to offer and receive support and share knowledge about CVS
• To promote and facilitate medical research into CVS
• To increase public and professional awareness of CVS
• To serve as a resource centre for CVS

Join us on Twitter!
Are you on Twitter?
Follow us @CVSAUK for news, research and updates. Let’s work together to help spread the word even further about CVS.

www.cvsa.org.uk
The CVSA invites you to its 20th Anniversary Family Day on:

**Saturday 21st November 2015, 10am - 4pm**
**Birmingham Children’s Hospital**

**Confirmed speakers:**

Dr Thangam Venkatesan  
“Cyclic vomiting syndrome: new insights into an old disorder”

*Thangam is a US-based gastroenterologist specialising in adult CVS and is an adviser to the US/Canada society. She has spoken previously at our meeting and it was a fantastic day. She is a very clear speaker, and empathetic to sufferers.*

Dr Sonny Chong  
‘Cyclic Vomiting Syndrome: yesterday, today and tomorrow.’

*Sonny is a paediatric consultant and is one of our advisers. He is a fantastic supporter of CVS and has helped many of our members. He is a great speaker and brings a wealth of knowledge and experience to us.*

Our Family Days are really friendly, informal events, and a great opportunity to meet other sufferers and their families.

There will be time for individual consultations with the speakers and medical advisers in the afternoon, as well as question and answer sessions. Please do come along and join us.
Another year has flown by as we celebrate 20 years of the CVSA charity. So much has changed in that time. Despite having a child with CVS, neither our doctors or I had heard of CVS or the charity. We finally found a consultant who knew about CVS and having got a name, I set about researching it. I can still recall the relief I felt the first time I spoke to Gill McDonald on the phone - the first person we’d met who understood what it was like to have a child with CVS and how frustrating it was to have taken so long to have reached the diagnosis. We joined, and the rest is history. At that time our newsletter was A4, sometimes typed, and photocopied, we had no website, leaflets and all the other resources we do today.

Despite some huge strides in communication, the fundamentals remain the same. Too many don’t get to hear about CVS in a timely manner and too few get recommended treatments early in diagnosis. We now get referrals from doctors and many contacts have received some information so we have changed things for the better by raising awareness. We have brought people together to share experiences. Our medical advisers have given talks and offered more practical help to our members. The fight goes on.

This year was our first International Awareness Day and many people organised events raising funds and awareness. Thanks to everyone for contributing. Start thinking now what you can do to make next year’s event even bigger and better. Simply writing a letter to your local newspaper would help raise awareness. If you can help just one family get a faster diagnosis or treatment, then you have done a wonderful thing.

I sometimes wonder what the next 20 years will bring. A diagnostic test, and much more successful treatments to prevent attacks? All we do know is that every time we provide information or bring people together, we help others deal with this difficult condition. Thanks for your support.

Robin Dover

Help us spread the word!

The CVSA has a range of leaflets and publicity posters. You can download and print posters from our website (see the Resources section), or email Robin and we’ll send some out to you.
Awareness Day & Donations

Our first International Awareness Day was a success with many events held - start planning for next year now! We report here some of the fundraising and awareness activities that occurred and on other generous donations.
Thanks to everyone for their fantastic efforts.

Medland
“Hello, my daughter’s school have been in contact with myself after your email to them regarding the £100 cheque they sent for donations to CVS. Manor Primary School in Ivybridge were only to happy to support my daughter Alana and other sufferers by having a blue mufti day!

My daughter was diagnosed at the age of three years so we know first hand how this condition affects sufferers. We thank you for this campaign and spreading the word!”

Abi Wilson
This one is special! Abi asked that instead of getting Easter eggs this year, the money was given to CVSA. Thanks, Abi that really is amazing. The rest of the Wilson Family organised a bake sale and raised £33 for us as well.

Dave, Demelza and Elijah Brooks
Thanks for a donation of £373 raised by the family from a CVS collection box and holding a cake sale at Elijah’s school (Market Drayton Infants).

Jackie Coughlan
Jackie managed to get her local MP, John Hemming, to open her “Onsie Walk” and he even tweeted pictures to help promote it.
As if that wasn’t enough, she also organised a sponsored bike ride raising £190 from the customers of the Big Bulls Head.

And even that wasn’t enough! Friends Terry and Catherine Devlin run a B&B; they and their guest raised a further £150 for CVSA.

Donations and proceeds of the Children’s bring and buy sale at the last family day raised £136 for us.

Sasha Kelly did a radio interview about CVS for awareness day, thanks so much!

Robin Dover had articles and letters printed in local newspapers in the area he lives.

Carly Devlin held an awareness event at Curves Fitness in Glasgow, for Awareness Day. Thanks to everyone there for their support.

We also sold quite a few T shirts, wrist bands and trolley coins - but not enough. If you haven’t got yours see our website for details.
Thanks to the Cawley Family for yet another donation raised from sponsorship of the Wirral Coastal Walk. Thanks to them and all who supported them.

Mrs Joanne Onslow recommended us as recipients of a donation of £750 from a group of solicitors. Client funds that can’t for any reason be returned, with permission from the Solicitors Regulation Authority, can be donated to charities. We are very grateful for this generous gift.

Emily Smith & Holmesdale Technology College

On Tuesday 10th February, the Year 13 Sport Studies group presented Holmesdale Technology College’s charity event - Revolution. It was a gymnastics, dance, trampoline and martial arts event that showcased the talent of Holmesdale’s students from every year group in the school. The event was in aid of the Cyclical Vomiting Syndrome Association and we were lucky enough to have one of the charity’s committee members, Amanda Sheehan, in attendance.

The event was a sell-out and the performances did not disappoint. The Year 13 Sport Studies students were tasked with organising and running a sports event. They chose to do this in aid of charity, whilst giving their fellow students a chance to shine in front of family, friends, staff and their peers. School trust partner Smurfit Kappa, The Freemasons Arms, Broadwood Music Productions, Executive Principal Patrick Hannaway and the school governors all donated...
some fantastic prizes for a raffle that was held during the interval to boost the money raised by ticket sales. The event was four months in planning, with the students taking on differing roles from Chairman to marketing, working in small groups or independently, then sharing their ideas and findings with the group in boardroom style meetings. Every decision from who would participate to the snacks that would be sold as refreshments, were made by the sport studies group.

The talent on display was exceptional. Solos, duets, group dances and gymnastic routines containing somersaults and back flips entertained the audience from start to finish. The solos on the night were choreographed by the students, most for their GCSE Dance or GCSE PE assessments. Two of our students not only showcased their exceptional dancing talents, but the pair also choreographed for the groups, including a fantastic cheerleading routine.

Sound and lighting on the night were also all controlled by a student. A Year 10 student deserves individual praise for his knowledge and application of both sound and lighting that really brought the event alive.

As a CVSA representative, Amanda Sheehan drove over 100 miles to attend the event and was pleased to meet Emily Smith. Amanda reported how the CVSA logo was printed on the tickets and how information was highlighted on the illness during the event. Tickets for the night cost adults £3.00 each and £2.00 each per child, while there were about one hundred people in attendance. On behalf of the charity, Amanda thanked everyone at the end of the event and was keen to highlight how immensely impressed she was of the organisation of the night.

Thank you to everyone who took part and attended!!!
Extreme Nausea In Other Conditions

Adapted from a BBC News website article 20 April 2015

It is estimated that 10,000 women every year are affected by extreme nausea and vomiting during their pregnancies, also known as hyperemesis gravidarum (HG), which is much more severe than the morning sickness experienced by one in three pregnant women. One of those with HG is the Duchess of Cambridge. Her pregnancies have helped to raise awareness of the debilitating condition - which can leave women too ill to get out of bed and vomiting 30 times a day - but for 10% of sufferers, the symptoms are simply intolerable.

They feel they have no choice but to terminate their pregnancies.

According to charity Pregnancy Sickness Support, which has produced a report on women's experiences of hyperemesis gravidarum, entitled 'I could not survive another day', too many women don't receive the care and treatment they need to continue their pregnancies. The report surveyed 70 women from the UK who had chosen to end their pregnancy in the last 10 years because of severe sickness.

Case Study

Lily - not her real name - knows how it feels to be seriously ill with HG. Her first pregnancy was "really grim, but I battled through it", she says.

She was bedridden for the first few months, only able to drink a little and was being sick up to 30 times a day. She became dehydrated and starving, eventually losing three stones (19kg) in weight.

"I was really weak and couldn't stand up from dizziness. I couldn't handle food smells, even the smell of my husband made me vomit. I remember forcing down some beans one day, but within seconds they came back up”.

Lily's GP came to visit her now and then and prescribed a drug to stop her being sick - but it didn't stop the extreme nausea. Eventually, after 22 weeks of pregnancy, her HG began to wear off to the extent that she only threw up once a day.

The similarities between patients with CVS and patients with HG are striking. When Lily became pregnant with her second child, she couldn’t even drink water without being sick. As many CVS sufferers will know, the nausea occurs even when tiny sips of water are drank, leading to intravenous fluids drips.

Dr Daghni Rajasingam, consultant obstetrician from St Thomas’ Hospital in London, said HG was well understood and should be taken very seriously. “We can start by giving women tablets to help the sickness, bring them into hospital to receive intravenous fluids and nutrition if necessary and give steroids in very severe cases.”

An increase in public awareness of HG could make GPs and midwives more sympathetic towards patients who have severe pregnancy sickness, she adds.

“We have to ensure when women are pregnant they have a contact to discuss these issues with.”
Quite often when people do not understand something they will dismiss it. As a CVS sufferer, I have seen first hand how people can tut and even laugh when I say I can’t look at a plate of food or I need to get out of the room due to a bad smell. Simple things that many other people do not understand but that can make me feel nauseous mean I have to take actions that others may not take, i.e. use disabled toilets.

I have found myself in work, a big office block with a few hundred people, and needing to throw up. ‘Run to the toilet’, I think, “Easy right”? Not if I am throwing up so loudly that other girls in the toilets think, ‘she must be hungover or pregnant’. This is extremely embarrassing, so I take the safer option and use the disabled toilets, the stand-alone toilet means no one will hear the vomit and the sound of retching. This seemed like the best option until I realised people stared when I walked in and out of the disabled toilets, some people looked irritated that I was using these. Did I need to explain myself? Did I need to tell them I have an illness, it’s just hidden?

This dilemma was set out clearly by another lady Sam Cleasby who suffers from ulcerative colitis. Like CVS, there are no visible signs of disability but Sam found herself having to use the disabled toilets. Sam blogged about her experiences of having to use a disabled toilet, and I found the blog so interesting I thought it should be shared.

Catrina Adams

“Dear lady who loudly tutted at me using the disabled loos,

I know you saw me running in, with my able bodied legs and all. You saw me opening the door with my two working arms. You saw me without a wheelchair. Without any visible sign of disability.

You tutted loudly as I rattled the handle with my hands that work perfectly and my able voice call to my kids that I’d be out in just a minute.

My lack of wheelchair may have suggested to you that I was some lazy cow who didn’t care. Some inconsiderate bitch who was using something I wasn’t entitled too. (I actually carry a card to explain that I’m entitled to and have a disability key if you’d have cared to ask). You may have seen my face blushing as I caught your eye and assumed I was showing guilt at blagging the disabled loos.

The fact is that I have no bowel. I have a pouch formed from my small intestine which can’t handle volume and so I have to go to the toilet and poo several times a day. My lack of large intestine means that my stool is totally liquid as I have no means of absorbing the fluids in food and so it’s really hard to hold it when I need to go. I sometimes have accidents which means a large toilet that has a sink right by me means I can clean myself up when things go awry.
I hate having to use the disabled loos as I have to deal with people like you staring, nudging, tutting. And whenever I can, I use the ladies toilets. Just so you know, disabled loos usually smell bad and don’t seem to be cleaned as often or as well as the ladies and so I wouldn’t choose this option unless totally necessary.

Whilst I’m at it, I’d like to address the cleaner in the supermarket ladies toilets I used this week. As I ran in, knees together, bursting through the door and running to the cubicle, I’m sorry that the noise of my (lack of) bowels made you burst out laughing. I can actually take the sniggering as since I had a pouch made from my small intestine because my disease ridden colon was removed during surgery, the noise I make when I defecate is hilariously loud. Seriously, I get it. It’s comedic in it’s volume.

But before you ran outside the loos and called to your friend “OH MY GOD! You should hear the noise in there!!! I wouldn’t go in if I was you!!!!” Perhaps you could have noted my daughter who was waiting outside with our trolley because her mum had had to leave her stranded to run to the toilet. Perhaps you could have stopped and heard me sobbing with pain because the acid in my stools has no way to be neutralised because I don’t have a large intestine and so opening my bowels actually burns my skin.

Perhaps you both could have shown a little empathy, a little compassion, a little understanding. Poo is funny. Disability is confusing. I get that. But humanity and care for fellow human beings is a choice. To everyone else reading this, the next time you see someone who doesn’t “look disabled” using a toilet. Or someone bursting through and crashing into the toilets noisily.

Take a moment. Remember that not all people who have the right to use disabled toilets are in a wheelchair. Some of us have a jpouch, a lot of us have an Ostomy bag that needs emptying and changing with the use of space, a sink and a bin. And even more of us just don’t want to shit our pants in public.

Think about the nearly 300,000 people in this country who have inflammatory bowel disease (not to mention the huge number of people with IBS!!!) who need to use the toilet urgently, noisily, smellily...

It’s an embarrassing enough thing to deal with before having to see disapproving looks or hear your laughs and jeering remarks.”

Sam’s blog is a refreshingly frank and open exploration of living with disability, and more critically, other people’s reactions to it.

http://www.sobadass.me/blog/
One day in the summer of 1988, I was skimming through a glossy magazine when I noticed a small insert about an organisation called Contact a Family. It explained how it put people in touch with other families who had a child with a rare diagnosis. Our eldest daughter, Fiona, had been suffering for the last 10 years from episodes of very severe nausea, lethargy and vomiting triggered by common colds, throat and chest infections. I had had very similar episodes with infections as a child and my mother remarked about Fiona’s vomiting that “history was repeating itself.” She remembered how on one occasion I had been sick “day and night for a week - your head hardly left the pillow.” I recall from numerous episodes the severity of the nausea, the retching on an empty stomach, the bitterness of bile. My attacks had variously been diagnosed as “acidosis” or “bilious attacks” and I was also hopelessly carsick.

I remember when Fiona was six and she was vomiting “coffee grounds”. I was concerned and called out the on-duty GP. He said that Fiona had a throat infection and had simultaneously contracted gastroenteritis and was very poorly. I doubted the accuracy of this assessment but felt I could do nothing. Our GP said that our daughter was “a vomiter” and prescribed Maxolon to have readily available. I felt sure Fiona had the same condition that I had had but, since she bounced back from episodes with amazing rapidity, we didn’t press for extensive testing or a specific diagnosis.

However, episodes were becoming longer. In 1986, aged 10, she was admitted to hospital for the first time with profound dehydration and our GP was reprimanded for not having admitted her earlier. He had tried to treat her at home to avoid the trauma of hospital. After negative tests, a senior doctor, upon hearing about her eight-year history of vomiting and my experiences, diagnosed Cyclical Vomiting. He was knowledgeable and compassionate. He suggested she take pizotifen. However, shortly after this he left the hospital for another post.

More episodes and complex metabolic investigations followed. Tests showed liver function abnormalities, but it was stressed she was ill as a result of the vomiting. They could find no medical cause. Fiona was now 11. The consultant decided that the episodes were a reaction to the 11+ (compulsory at that time in our area) and selection exams. He implied the vomiting was manipulative behaviour to avoid school failure and she was nursed accordingly. He insisted she see a psychiatrist. Her class teacher, however, felt she was bright and remarked: “If Fiona fails the 11+, heaven help the rest!” To us she seemed to achieve well effortlessly. Her case was handed to the Department of Psychiatry and the consultant, aware of our opposition to his views, passed her medical care to a paediatric colleague, who took his cue from the psychiatrists. By the summer of 1988, when I rang Contact a Family, she had been admitted to hospital 18 times with a typical duration of 6 days.

In August of that year, I received a long letter from Contact a Family. They had been
in touch with three hospitals that had treated cases of Cyclical Vomiting, but the doctors there didn’t “think it was appropriate to link families up”. The letter said, “It is made all the more distressing because it seems no-one seems to understand very much about this problem…. we have done our very best but have drawn a blank.” They did, however, promise to keep us on their books with the hope of linkage in the future.

Trying to Connect: 1988-1991
The psychiatrist rapidly ruled out academic problems as Fiona passed her exams and made an excellent start at the selective school of her own choosing. The psychiatrist suggested she see a neurologist, which she did, but he felt unable to help. All the tests were repeated. All were negative. Meanwhile, Fiona was becoming increasingly anxious about her episodes, frightened to go to sleep at night and crying, “Why does it keep happening to me?” It dawned on me that Fiona’s anxiety about being ill was contributing to the frequency of her episodes. I tried to voice my concerns to the professionals, wanting them to address this issue - her dread of symptoms and their consequences. The psychiatrist meanwhile interpreted things differently and felt that I must be the cause of her problems. She made it clear that she thought I was harming her in some way, and despite my tears and protestations, Social Services were brought in. Fiona remained permanently in hospital including weekends, but two episodes began - out of my presence - in three weeks whilst there. The psychiatrist resigned from the case and passed Fiona’s care to a senior colleague. He instigated Family Therapy where the entire family had to be observed and questioned in a special room by groups of psychiatrists, psychologists and a nurse. They apparently had very differing views on the case and could come to no agreement. The senior psychiatrist ruled that Fiona was “an attention seeker”. He said she should be ignored when ill and we should aim to keep her out of hospital. Our middle daughter, aged 11, was very upset by Family Therapy. She felt that because the psychiatrist kept asking her questions, she was to blame for all Fiona’s sickness. She said, “They’ve got it all wrong. We’re just a normal family.” She and other family members felt stigmatised. Fiona, too, (now a teenager) was becoming more and more frightened, confused and distressed and was responding by being irritable, rude to me and bullying her youngest sister, escalating the whole family’s stress levels.

Still no word from Contact a Family (CaF). Our paediatrician made enquiries from the organisation “In touch” who serve a similar purpose. A message came back that there was a family on their books; what’s more, they lived like us in Wirral. Initial optimism, but then it was realised that CaF had simply shared our details with “In Touch”. We were going to be linked with ourselves!

It was now three years since the initial letter from CaF, and in that period alone Fiona had had a further 63 episodes, all but four had resulted in admission to hospital. The episodes, though now shorter in duration, were coming closer and closer together. She was never really picking up and was having morning nausea and lethargy between
bouts. Schoolwork was suffering and her GCSE year was about to begin.

Then on September 4th 1991 through the letterbox fell a handwritten letter from a Wendy Ryall. She explained how her daughter had been treated at Great Ormond Street for vomiting, described her symptoms and ended, “Would you mind very much writing to me and letting me know how your daughter is and how you have coped as up until I was given your address, we have not met anyone else in similar circumstances.” I phoned her and received a letter back saying, “I was so amazed to hear you saying everything about Fiona that was the same as Lucy.” Wendy got back to CaF and with the help of Professor Walker-Smith, who had treated Lucy, she designed flyers and launched “The Cyclical Vomiting Support Group.”

CVSA UK is Born

One of the first things Wendy did was to arrange an entry for the CaF Directory of Specific Conditions and Rare Syndromes in November 1991. Dr. Josephine Hammond, who had published a paper on Cyclical Vomiting in 1974, wrote the entry description. Wendy also set about trying to find other relevant medical papers, but found very few. In retrospect, I think this was one of the big problems for the doctors treating Fiona. They had very little authoritative literature to which to refer. An early initiative was to design a logo: CV Out of the Darkness.

December 1991 saw the publication of our very first newsletter; then in the early months of 1992 came a turning point for Fiona and a seminal step for CVSA. One of the researchers at CaF noticed an insert in a newsletter from the National Organization for Rare Diseases (N.O.R.D) in the USA. It said that a Professor David Fleisher from Colombia University, Missouri was doing research into Cyclic Vomiting Syndrome. Both Wendy and I wrote to him. In April 1992, he replied to me: “Your account of Fiona, her symptoms, and the struggles you’ve been through ring true and are valuable to others trying to cope with Cyclic Vomiting Syndrome...Dread and despair predispose to nausea and uncontrollable vomiting” I felt at last someone understood the illness, believed us and was ready to listen.

Dr. Fleisher put us in touch with Kathleen Adams with whom he was working to set up a support network in the USA. Thanks to the incredibly hard work of Kathleen, the first CVSA meeting took place on April 23rd/24th 1993 at the Children’s Hospital in Milwaukee, Wisconsin. Wendy and I flew out together to attend, whilst Malcolm, my ever-supportive husband, held the fort at home. This meeting saw the creation of CVSA USA. David Fleisher and Dr. B Li met for the first time and forged an important partnership. Dr. Li voiced an idea to organise a scientific symposium on CVS and to invite the world’s leading clinicians and scientists interested in functional vomiting. This fired Wendy’s imagination and before long, with the help of B Li, Prof. Walker-Smith, Kathleen and the sponsorship of Glaxo, she set about organising such a symposium. The very next month, May 1993, the Australian CVS Support Group held
its first meeting at the Princess Margaret Hospital for Sick Children in Perth, organised by Mary Tuder and Dr. David Forbes. Then in September 1993, the first British meeting took place in Chelmsford. CVSA UK was born.

Everyone’s hard work paid off. The first Scientific Symposium on Cyclical Vomiting Syndrome was held on July 29-30 1994 at St. Bartholomew’s Hospital, London. The editor of the Journal of Pediatric Gastroenterology and Nutrition was approached with a view to publishing the proceedings. They agreed to publish in a special supplement, but this would cost many thousands of pounds. It was mainly in order to raise this money that we set about gaining charity status. Exactly twenty years ago, in March 1995, CVSA UK became a Registered Charity.

Dr. Fleisher’s IV medication suggestions reduced Fiona’s nausea and pain. With increased understanding of her illness and the support of others, her dread of episodes and their frequency lessened dramatically and she was successfully able to complete a PhD in cancer genetics and lead a normal life.

Gill McRonald

News from The USA

Kathleen Adams President of CVSA in North America writes:  
In our last newsletter (Spring 2015), we announced another landmark project – the development of guidelines for the diagnosis and treatment of CVS in adults. The project is being sponsored by CVSA in partnership with the American Neurogastroenterology and Motility Society (ANMS). CVSA is the financial sponsor for this project. A very similar project of guidelines for children was developed and then published in 2008.


This pediatric guideline has proven to be an invaluable resource for the global medical community. A guideline for adults will also provide a much-needed resource. The guidelines committee has now been chosen and will begin meeting via conference call in August. They will then meet in person in October at the University of Pittsburgh during the 2nd Biology and Control of Nausea and Vomiting 2015 conference. Two full sessions of the meeting are devoted to presentations about CVS. Full information about the conference can be found at http://www.emesis2015.com

Developing medical guidelines is a rigorous and expensive process, estimated to take two years. CVSA is actively seeking financial donation for this project through our membership and beyond.
Early Days

The very first newsletter

Christmas 1991
Newsletter No: 1.

C.V. SUPPORT GROUP

Welcome everybody to the first newsletter for the C.V. Support Group. Most of us will recognize C.V. as standing for Cyclical Vomiting but it also stands for Curriculum Vitae which is quite apt as the translation into English means the Cycle of One's Life and I felt that explained how our children's illness has had to fit into all our lives. A year ago I never thought I would ever be writing to anyone who knew of C.V. let alone starting a support group, it feels as if at long last we are coming out of the darkness. From not knowing anybody and now being able to write to you all is a joy now that we are no longer alone in trying to struggle along and feeling that nobody else can understand.

In November I went to the Contact a Family Annual Conference, details of which are further on. It was a very enjoyable and successful day and having now met most of the names on the information sheets it helps to picture everyone. Which reminds me, is it possible for you to send me a photo of you all. In the New Year I will send you one of Lucy and the rest of us.

An entry for Cyclical Vomiting will be made in the medical directory that C.a.F. produce, this hopefully should be in the springtime. Also by then I hope to have a flyer printed which I am sure will be of use to us all. I have enclosed with this newsletter various articles that I have collected. I am at present making enquiries to see if there has been anything else written since the 1972 Josephine Hammond paper.

If any of you have any contributions which they would like printed in the next newsletter please forward them to me. Maybe one of the children would like to write about their experiences over the years or have any poetry they may have written, in fact if anyone has any chatty personal articles, professional input, research updates or any useful hints that would help please do not hesitate in sending them to me for inclusion.

With many, many thanks to Contact a Family for being in existence and putting us in touch with one another.

Wishing you all a Happy Christmas and a peaceful New Year.

From Wendy Ryall and her family Bob, Sam and Lucy.

Wendy

(The views expressed in this newsletter do not necessarily represent the views of the group.)
Early Days

From a 1995 newsletter when charity status was still pending

I think a lot of us empathize with the following picture!

Information Snippet

Dr Fleisher started to study CVS in 1960 and has been investigating it ever since, hoping to learn the cause or causes and perhaps find a cure or effective treatment. His research has convinced him that Charles Darwin, the British naturalist explorer, was a CVS victim. Though Darwin had been a medical student at Edinburgh University and though he discovered many previously unknown plants and animals and developed the theory of evolution he was unable to diagnose his own recurrent vomiting. Darwin died in 1882 the year that the London physician Dr Samuel Gee became the first doctor to identify the "fitful or recurrent sickness".
Christmas Issue 1995, the first as an official charity

THE MAKING OF A SELF-HELP GROUP

Once there was a person. And one day he developed a problem.

Problem

It was always there.

He felt alone. He couldn’t imagine anyone could have this kind of problem.

Then one day, he met another person who also had a problem...

...and yes, it was the same problem!

They talked and shared and compared and cried and laughed and wondered.

Another person and pretty soon they felt on top of the problem...

And they realized their mutual effort was a good way to help others...

and... too!
Prescription Drugs and Dementia

Researchers in the USA carried out a study comparing the incidence of Alzheimer’s disease and the past use of various prescription drugs. This was reported in the popular press and one example can be found here, on the BBC news website http://www.bbc.co.uk/news/health-30988643.

Two of the classes of drug examined are used in CVS; tricyclic antidepressants and anti-histamines. The studies suggested a higher risk of dementia may result from use of such drugs. However, this is a single study and doesn’t constitute proof of a causal link.

Dr Simon Ridley, head of research at Alzheimer’s Research UK, said the study was interesting but not definitive - there was, he said, no evidence that these drugs cause dementia.

It is a story to watch but not yet be unduly concerned about. This article from NHS Choices discusses the study in detail and critically analyses the results, and, as so often is the case, discusses the over-sensationalising by some arms of the press http://www.nhs.uk/news/2015/01january/pages/media-dementia-scare-about-common-drugs.aspx

Migraine

New Scientist published an article “Not just a headache: How migraine changes your brain” on the 5th March this year. It is a very accessible article and discusses some new studies that suggest brain function may change as a result of repeated migraine attacks. However one researcher cautioned, “Even if there’s a genetic predisposition, it is the disease itself that is driving networks to an altered state.” That means that treatments that reduce the frequency or severity of migraine will probably reverse some of the structural changes too.

Janine John wrote a letter to New Scientist pointing out the close associations between CVS and migraine and how she was misdiagnosed with migraine.

Three Person Embryos

We have discussed this technique in past newsletters, most recently in a detailed way in Issue 39. Parliament approved the bill by a large majority in February this year. The technique would possibly be applicable to all diseases related to mitochondrial DNA dysfunction, including CVS, but is likely to be only applied to conditions that are severely life-limiting or severely disabling. However, it is a significant step forward in treatment of mitochondrial disorders. Further details can be found at http://www.bbc.co.uk/news/health-31594856
Darwin and CVS

We have published a number of stories about Charles Darwin, the famous naturalist and originator of the theory of evolution. Dr John Hayman, a retired Australian pathologist, has written several papers of what has been called “Darwin’s Mystery Illness” and proposing that Darwin has CVS.

This year, Dr Hayman had his PhD thesis accepted by the University of Melbourne. It is titled “Diagnosing Darwin: Charles Darwin’s ‘mystery illness’” and is available here https://minerva-access.unimelb.edu.au/handle/11343/48439.

In it, John describes Darwin’s life and illness and family history. He puts forth reasoned and detailed arguments that Darwin was a CVS sufferer. He points out that his condition was marternally inherited and overlaps with Chronic Fatigue Syndrome, Abdominal Migraine, the Irritable Bowel Syndrome and Fibromyalgia. These conditions are all significantly associated with close relatives of CVS sufferers and are thought to be part of a spectrum of diseases caused by mutations in mitochondrial DNA.

He is hoping to visit the UK soon to continue his research into the family history and health of the Wedgwood family, to whom Darwin was closely related. We hope he may be able to combine this with a visit to our Family Day.

Darwin would probably be the most famous CVS sufferer we know of and although he struggled with the condition, in a time of very limited medical knowledge, it is also a story of someone who excelled in his field despite such adversity.

John contacted us on Darwin Day, celebrated every February 12th, the anniversary date of his birthday. John had been on the Charles Darwin Walk in the Jamison Valley, Blue Mountains National Park, New South Wales, and followed in the famous man’s footsteps.
An anonymous sufferer writes:

I can first remember having this between the ages of five to eleven. Bouts of uncontrollable vomiting and severe abdominal pain. I was always a target for bullies for being the new boy. My parents moved every three years due to work. I remember attending Great Ormond Street Hospital. Loads of tests done (food allergy). Was discharged with no explanation, only told to avoid caffeine, chocolate, cheese and fizzy drinks. Which I did, only for the vomiting to continue.

The next time this started was two years before leaving the RN in 1992 (21). I was being mentally bullied at the time by a senior rating. I complained to my welfare officer at the time, and after a meeting with said senior rate. I was told that he wasn’t bullying me. I was drinking very heavily at the time and realised that I had a problem with it. I ended up self-medicating with cannabis, which led to my discharge. The vomiting continued until 2004 (33).

During this time I had seen councellors and an ex-forces psychiatrist to try and get to the bottom of my vomiting. I was almost diagnosed with PTSD (mental bullying), but the forces didn’t acknowledge PTSD at the time. I had endoscopies (nothing found). During this time, my diagnosis was anxiety with severe vomiting.

This then reared its head again in May 2014. Then in Dec, Jan and Feb this year, after having moved home due to divorce. This came with a doctor change having moved area, who diagnosed CVS.

The vomiting comes with no warning. When it starts, I’m vomiting every 30 minutes, this can last for 12 to 24 hours before easing to every 60 minutes. This can last between 1-2 days before being able to hold water down without vomiting. I have to make sure I can drink water for 24 hours before going onto soup, or I will end up relapsing back into vomiting. Back to every 30 minutes.

During this phase of vomiting I am bedridden in a darkened, quiet room with a bucket by the side of the bed. I am unable to do anything. Dehydrated, feverish, all energy drained away. No sleep, just drifting in and out of consciousness. Other people who have witnessed me in this state think I’m dying. In the past this happened five to seven times a year with no apparent pattern. The periods could be close together or months apart. This would lead to a pattern of avoidance. From avoiding the last food I ate, or avoiding social situations. Living in fear of the next attack.

During my time of wellness from 2004 to 2014 I was lucky to be married, for I could not find anyone who would employ me with such a long history of illness. I ended up a house husband.
Teresa Cabrera, a CVS sufferer from Spain, sent us this translation of an article she had published in Granada for Awareness Day.

It is surprising to discover the different paces followed by science while studying the most varied fields, some fields being developed up to and beyond any thinkable limits, while leaving some others fairly simple fields stunningly behind, outpaced and almost forgotten in the race. Progress resembles a shapeless caricature. In the era of genetic mapping and studies on epigenome, we do not only know our own genetic coding, but also which are the needed modifications in order to get cells to generate different tissues out of the same DNA. Even cells found in pubic hairs secretly contain all the information that actually defines the shape of our nose and the colour of our eyes. While there is a number of researches underway to try to find out the potential future uses and implications of this large scale investigation, scientific research forgets thousands of diseases, simply because they are infrequent, or because they affect countries with very few financial resources or even because it is somehow convenient that they persist, due to some obscure reasons. These are the rare and orphan diseases. One of them is the Cyclic Vomit Syndrome, affecting 2% of infants and children and several adults. World CVS day is on March 5th.

Even though CVS was described back in 1882, its causes are far away from being pinned down nowadays. Some of the varied hypotheses point towards an alteration in the way the stomach and hypothalamus are interconnected. The symptoms are: intense vomit, nausea and abdominal pain episodes, that repeat cyclically. There is not even a medical test that can diagnose CVS, therefore the only way to diagnose it is by discarding any other diseases displaying similar symptoms. It is only thanks to a complex process for accurate diagnosis that thousands of patients will be taught beneficial behaviours and receive the adequate medicines to alleviate the crises, such as sedative drugs or medicines used to treat migraine. Equally alleviating it is to actually be able to meet fellow patients through national and international organisations exclusively dedicated to this disease (i.e. AESVC in Spain).

I once read that the presence of millions of neurons in the stomach had then been proved by science, which could actually scientifically also prove something already known: our stomach often thinks and decides on our behalf. Therefore, it must be certainly possible to support to those who suffer, stomach-to-stomach.

ERIKA MARTÍNEZ, Granada Hoy Newspaper, March 2015
Stephanie Horner

Stephanie had her story published in a number of newspapers and websites, and it went across the world.

Stephanie Horner suffers from Cyclical Vomiting Syndrome (CVS) - a condition that induces severe episodes of sickness that last between three days and four weeks at a time.

This young woman has been left unable to hold down a job and was forced out of university by a rare condition that makes her vomit every 20 minutes.

Stephanie, from Gateshead, suffers from Cyclical Vomiting Syndrome (CVS) - a condition that induces severe episodes of sickness that last between three days and four weeks at a time.

The 23-year-old is hospitalised at least once a month, which means that due to her sickness record she struggles to keep a job and even had to drop out of university after the condition took over her life in 2011. The condition leaves patients with sudden sickness, severe abdominal migraines and nausea. Ms Horner said: “I can be sick every 20 minutes when the condition is at its worst and even in between that I’ll be retching and trying not to cry. It’s really exhausting when I have bad episodes all I can do is get to hospital and keep strong until it passes”.

“It can be a very embarrassing condition because I end up throwing up on myself countless times without any warning from my body.

“I have to plan my life around my illness because I know at any point I could be hospitalised for weeks on end.

“Every morning I lie in the bath and work out whether I can deal with the condition myself or whether I need medical attention at the hospital. If I misjudge it I could die of dehydration.” Ms Horner started experiencing severe sickness and stomach pains in 2011 and at times she was even vomiting blood.

Despite numerous hospital visits, doctors were left baffled by her constant sickness,
“I was in and out of hospital once every couple of months but no one could find out what was wrong with me.

“When I started throwing up blood, I thought I might be dying and was terrified.

“I looked up my symptoms online and after being referred a specialist later confirmed I had Cyclical Vomiting Syndrome.” Since her diagnosis in September 2013, her symptoms have worsened and it affects her five days a week.

Sometimes she is able to medicate herself at home but other times she has to go to hospital to avoid suffering from severe dehydration. Her recurring illness means she struggles to keep a job. Due to the condition not being recognised in the UK there is no disability benefit allowance. Ms Horner, who used to study sociology at the University of Sunderland, hopes to finish her studies some day and from there help others to understand her condition. She said: “Since having CVS I’ve lost five jobs and was withdrawn from university because of absence related to being sick all of the time.

“It’s really frustrating because I can’t do anything I can’t plan a holiday or make plans with friends as I never know if I’m going to be well enough. I really want to get a job and have a normal life again but because of this condition I can’t”.

“Every time I get a job I know it will only be a matter of time before they fire me because I’m hospitalised so much due to my illness.” During less severe episodes she suffers from nausea, disorientation and spends most of her time on a sofa. She manages her condition by taking six drugs a day. She said: “When I wake up I get into a scalding hot bath to help soothe my pain as that’s all that helps to relieve me. ‘I’ll spend up to five hours in there trying to rid the cramping and squeezing feeling in my tummy and the shooting pains up my side. I have waves of nausea and wooziness as I try to stop myself from being sick.

“Then I’ll take Morphine or Tramadol and my other medications and try to relax until I can go to sleep.

“This is a really debilitating condition and I wouldn’t even wish it upon my worst enemy.”
Vicky Horrocks Tells Her Story

I first got in touch and discovered you guys a number of years ago after being ill and undiagnosed for 10 years. You spoke to me, gave me your time and advice and most importantly - hope.

I wanted to return the favour and try and give hope to other sufferers/families through my story.

I am now 25 years old and have suffered with CVS since I was 11, undiagnosed for 10 years. I went through the usual rigmarole of missing school, christenings, weddings, birthdays, giving up jobs, missing deadlines - you name it. Any kind of stress (good and bad), the wrong kind of food, tiredness, period, any combination of the above and other things could set me off. A typical episode for me consisted of 48-72 hours of vomiting every 10 minutes, spreading to half an hour towards the end. CVS for me got worse as I got older and went through phases. Occasionally I would only get ill once a month and other times it would be every weekend.

I missed loads of school, threw up on the way to school, in school, had to be sent home from school. I struggled to eat much when out with friends, I was ridiculously skinny and always behind on work. People (including my mom at one point) thought I had an eating disorder as I often couldn’t eat much food (my body was really weak so IBS was stronger than it is now). I would often get so depressed at the hopelessness of the situation that I would cry and wonder why me?

I went to doctors and specialists appointments a ridiculous amount of times, undergoing any procedures you can think of - barium meals, ultrasound, CT scans, hundreds of blood tests, etc. All of which amounted to nothing. Absolutely nothing.

Despite this, I powered through with the strong and rocksteady support of my mom, I achieved amazing GCSE results and pretty good A Levels and took myself off to university in Leeds to live an independent student life like any other 18year old would want to. Throughout my time at uni, the CVS episodes got worse - not helped by the fact I was chronically smoking cannabis, often to deal with the nausea/depression. I refused to let CVS beat me though and still lived my life to the fullest, just with more downtime than the majority of people.

Whilst attempting to complete my undergraduate dissertation the episodes became more regular and I was throwing up for two days being better for one, attempting to look at my dissertation and then falling ill again. It was awful.

This was when my family decided to go private. I was lucky. My first consultation with the specialist, he diagnosed IBS and potentially CVS and put me in for tests.
Blood tests came back with an overactive thyroid which I think was due to my body being knocked off balance (although obviously I’m not a doctor). Once I was diagnosed this was when treatment started, but more importantly this was when I discovered this thing that was wrong with me was a real thing. It wasn’t in my head and I wasn’t the only one! I discovered CVSA and I discovered hope - as corny as that sounds!

Once I was diagnosed, I was referred back to the NHS (and have not used private since then). Luckily, out of the few specialists in the UK, there was one near to where I lived. The first time I saw him, he told me smoking cannabis was making me ill. I was completely in denial - I’ve been ill since I was 11 and I definitely wasn’t smoking then! They put me on a course of amitriptyline which my GP then steadily increased to a maximum of 75mg, which worked considerably and then reduced me back down. I am now on 25mg a night.

I was still getting ill, however. By this point I had completed an MA and moved to Manchester. Luckily again there was a specialist here. The first time I saw him he prescribed odenasteron for when I have an episode and they worked!!!! It was a miracle - I still felt nauseous but the episode didn’t last nearly as long and I didn’t come out of it feeling anywhere near as exhausted and dehydrated. I was able to sleep!! And for me, sleep meant an improvement :)

It wasn’t until my big brother said something about a connection between smoking and sickness and I started a full-time job that I gave up cannabis and the improvement is immense. I very rarely get sick anymore, let alone an episode. I am still on a low dose of amitriptyline and occasionally take the odenasetron but this is extremely rare. I have tried a couple of times to come off the amitryptyline but I don’t think my body is quite ready for that, however I’m sure it will be in time.

More importantly, I finally feel normal. I am a normal weight and have to exercise to keep myself slim! I go for a check-up once every six months which will reduce to 12 months after my next one this month. Even my thyroid is fixed and IBS no longer seems to affect me anywhere near as much!

I wanted to share this because there is hope out there; different things work for different people - don’t give up. Find the specialist. Find the anti-sickness drug that works for you. Keep the hope.

Vicky :) A healthy CVSA fighter.
Geoff Pepper

This story was from a very early newsletter. Geoff was a committee member, and newsletter editor.

As you may be aware I had to have an operation on my back this year. This involved being on the operating table for about eight and a half hours, so therefore a high dose of general anaesthetic was required.

Well, when I woke up in the Intensive Care Unit feeling a little queasy I pondered whether I was going to get off lightly. Later on I woke up again and was asked if I felt like eating something. Much to my amazement I felt quite hungry and chose fish fingers and chips (no baked beans though) of which I managed to eat a small portion. Wow! I felt fine, no nausea!

The next day I was moved to another ward, where the food is reheated in some sort of steam unit. Probably as a result of the anaesthetic my sense of smell, which is already keen, seemed heightened. Instant nausea. I could not believe that food, could smell so strong and disgusting. Even visitors commented on how strong the smells were and how strange it was to cook or reheat food on the ward.

This set the scene for the next five days. Every time I smelled food or attempted to eat anything at the insistence of the staff and family, I was sick. The anaesthetic was obviously still in my system but was having a delayed reaction. I am sure that having to lie on my back all this time did not help either, as this cannot be good for your digestion. I was given antiemetics by injection, orally and worst of all suppositories. CVS suffers will have of course gone through the indignity of this many times. Nothing seemed to work and events such as being taken to the X-ray Department in the bed would spark off a new round of vomiting.

After several days of this I started to feel weak, lethargic and somewhat strange, not really knowing what was going on around me (nothing unusual there then). Linda was becoming concerned as when she visited, every day, I would drift in and out of sleep and could not remember what had been said to me by the staff and also what I had been saying. Linda tried to encourage me to eat, first of all with jelly but I could not even keep a spoonful of this down. I must admit that I was also becoming worried, in my lucid moments, at how bad I was feeling. The constant nausea, lack of deep sleep and maybe the drugs (I was on strong painkillers) were making me feel anxious.

The nights seemed really long and I would lie on the bed and imagine some really strange things. For a couple of nights I was convinced I was in a futuristic hospital with beds arranged around a circular ward. It was like something out of a Star Trek film. On a couple of occasions I had quite bad involuntary movements of my hands, arms and legs. The first time was bad enough, being like an attack of the fidgets, but the second time was much worse and my movements were quite violent. It was not until a few months later whilst looking at Alison's leaflet on ondansetron, which I had been given for the nausea, that I read that this can be a side effect, although unusual.

Anyway getting back to what I was trying to say. The repeated vomiting, lethargy, general weakness and anxiety were something I would not choose to go through again. Words cannot adequately express the way I was feeling physically and emotionally and I can now see how hard it is for sufferers to talk about their condition. Having said that I am also aware that this is not the only reason they are reluctant to talk about it. There is of course the fact of not wanting to accept that they have the condition, therefore not allowing it to become part of them. Whilst it is not a part of you, it can at some point be got rid of. (True or false?)

Even now I cannot fully understand what sufferers go through, not just when they are having an episode, but also during the "normal" times. I can tell you though that what I went through has given me some sort of understanding and that knowledge is not nice.
Emily–Rose Dover

Emily’s first article on CVS in 2000. After attending our first CVS meeting, Emily became more confident about talking about her CVS.

In Your Own Words

Your chance to share your story

Emily’s Story: Emily is 10 and has suffered with CVS all her life and like many people doesn't want to be defined by her disease, and for a long time didn't want to talk about it with anyone outside the family. She now knows that it can help to find out that you are not alone, and has put down in her own words how she feels about CVS.

Me and My CVS and How People React: When I feel sick I can’t stand light or noise or people around me. I hate taking 5 medicines a day I am so fed up. I visit the hospital about every 3 months. It’s different for everyone with CVS, no-one is the same some are in hospital on drips for weeks. I am luckier than others but I hate having CVS. The most amount of times I have been sick in one night is 34 times I was being sick 4 times an hour. When I would have an episode I would wake up at about 4 O’clock in the morning run in to the bathroom and start being sick. I would stop at about 8 or 9 O’clock a.m. I don’t usually feel like eating much. I also get the worst tummy aches in the world and really bad headaches. Not many people have heard of CVS when I told my friends one of them said “Is it contagious?” and others say “Is it something you eat?” they just don’t understand. Some people think that they are fed up when they have antibiotics but if they took 5 or more medicines a day then they really would get fed up. I am often off school but I try to go if I can because last year I missed 30% of the school year.

What it Feel’s Like During an Episode: I know when I'm going to have an episode but I can't explain how. Before I wake up I have these weird dreams, I can't explain it, then I wake up and have a fit and throw my head in between my legs, it's pretty scary because it's like I'm not in control of my body, but I am and I just don't know what to do. I often end up asleep in the living room or the bath room and I just can't get comfy in my bed and I cant go to sleep because it scares me when I have the dream and I know that before I'm sick I have the dream, and I know I won't be asleep for long. I seem to spend so long in the toilet room that I get bored of it!

Is it Just Me: I sometimes wonder what it is like for other people with CVS. Do they feel the same as me? None of the teachers understand, one time I said I felt sick, she said “Are you sure its not 'cos you have forgot your P.E. kit?’ I don’t want to feel sick all the time, I can’t help it, but they don’t know what its like. My mum and dad have sent a letter into school every year explaining about CVS and the medicines I have to take, so they should know.

Mum & Dads Note: Until she wrote this we didn’t know about the teacher story, like all CVS sufferers, she doesn’t make a fuss about it, she just tries to have a normal life. Other people’s ignorance doesn’t help. Talking about it can help, it brings issues out into the open, and may highlight areas we can try to change.
Other CVS news in brief

Contact Wanted

We have a family, looking for someone to speak with their son, who has CVS and is 11 years old. If you’d like us to pass your details to the family please email Robin.

CQC “From the Pond Into the Sea”

The Care Quality Commission (CQC) has published its findings about transition from care as a child to adulthood. This is an issue that is relevant to a lot of CVS sufferers.

“The findings from our recent review show that young people with complex health needs do not always receive the necessary care and support when they move on to adult care services.”

The report can be downloaded free from the CQC website.

Text donations from Just Giving

We have a text donation service! Simply text CVSA10 £XX where X is an amount (£2, £5 or £10) to 70070, to support our work.

And don’t forget to join us for the 20th anniversary CVSA Family Day on Saturday 21st November 2015 in Birmingham. We look forward to seeing you there!
### Informal CVS Groups and Contact Families

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<tr>
<th>Country</th>
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<th>Email Address</th>
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### Groups with a Medical Co-ordinator

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</tbody>
</table>
Data Protection Act 1984

The personal data you have submitted to CVSA is stored on a computer to facilitate the efficient working of the Association and ease the administrative workload on the voluntary and unpaid office bearers. The practical end product of this computerisation is the production of labels we use on the bi-annual newsletter and relevant information sent out. However, under the Act we are required to ask each member whether they object to their personal information being stored in this way. If you do object you should write to the Association and your personal data will be kept as a separate manual record.

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