



**CYCLICAL VOMITING SYNDROME ASSOCIATION
CVSA – UK**

Newsletter 38:- Spring 2011

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Dane John Baekdal

August 1992 – November 2010



Dane, loving son of Jackie and Simon Baekdal, had suffered terribly from CVS for many years. He also had ataxia. Sadly, as a result of a number of complications to his illness, he died on November 26th. He was just 18 years old.

Dane was a truly special person with a warm and caring nature. He was full of fun and had a witty, dry sense of humour. He had an entrepreneurial disposition and was frequently entering and winning competitions. He loved technology and was constantly devising ways to get his father to keep abreast of the latest gadgets. He made suggestions at our Family Days, as to ways of utilising the internet to raise money for the Association.

He had a passion for Drama and loved travelling and visiting theme parks - taking pride in clocking up the scariest rides!

He was a brave and determined young man who will be sadly missed.

We offer our heartfelt sympathy to Jackie and Simon.



Letter from the Chair

CVSA is run by a group of volunteers. I said at the Family Day, during the annual meeting, that several members had endured an especially difficult year, for a variety of reasons, including their own health, that of other family members or other personal issues. I didn't, at that time, know just how much more difficult it would become.

Dane Baekdal died shortly after the Family Day.

Dane was a very bright and savvy young man. He had endured a very difficult time with CVS and ataxia. He was lucky to have two great parents, Jacqueline and Simon. I don't have any words adequate for this situation. There can be no more devastating a blow to a family. Our thoughts are very much with them.

The Family Day went well, and for the first time for years all the presenters arrived on time, despite train problems and a broken down car! Prof. Thompson stands down as an adviser this year, and we thank him for all his support. We need to broaden our panel of experts; if anyone has suggestions for medical experts we could approach, please let us know.

As usual we've had some amazing fund raising efforts (see later), and I thank everyone who has helped.

Despite their own problems the committee does the best it can to promote the cause of CVS, raise funds and awareness. We have to ask if anyone can offer us any assistance. New people bring renewed energy, fresh ideas and a new perspective. Alan, our treasurer, has worked with us for quite some time and would like to step back; if anyone has financial skills, please consider helping us. Our membership secretary, Beverley, who has also performed her role for quite some time would also like to resign. The Family Day and newsletter preparation are the major tasks where some effort is needed, but although being involved does take some effort, it doesn't have to be onerous. We'd appreciate anyone volunteering to assist. The work we do really does seem to make a difference. We need to ensure CVSA has a bright future and we need your help to do so.

Robin Dover

The Periodic Syndrome Then and Now

Dr. Sonny K F Chong, Queen Mary's Hospital, Carshalton, Surrey

Dr. Chong first described the history of periodic disorders in children. W.B. Willie and D. Schlesinger first coined the term 'Periodic Syndrome' in a paper published in 1933 in the British Journal of Children's Diseases. They described 80 cases in a detailed study of children with nervous instability and related the syndrome both to migraine and epilepsy. J.J. Kempton further described 'Periodic Syndrome' in 1956 in the British Medical Journal maintaining that any combination of pallor, headache, abdominal pain, vomiting and pyrexia comprised the syndrome.

Sonny then referred back to the first classic description of CVS by Dr. Samuel Jones Gee in 1882 at St. Bartholomew's Hospital.

"These cases seem to be all of the same kind, their characteristics being fits of vomiting which occur after intervals of uncertain length....free from signs of disease. The vomiting continues for a few hours or a few days.... Patients are left exhausted".

Sonny described the Rome III Diagnostic Criteria as:

- 1 At least 3 months, with onset at least 6 months previously of-
- 2 Stereotypical episodes of vomiting regarding onset (acute) and duration of less than one week.
- 3 Three or more discrete episodes in the preceding year.

Sonny stressed that it was important to differentiate between chronic and cyclical vomiting. Chronic vomiting persists regularly with vomiting for a short time every few days. Cyclical vomiting occurs in a more regular pattern with intense vomiting for a few days and then a gap of several weeks.

Sonny and Jessica Bartlett, a medical student, carried out a CVS audit and found that there was a higher proportion of female sufferers to males in a ratio of 1.9:1. The average age of onset was 6.9 years, the mean age of diagnosis 9.0 years and the duration of symptoms 3.7 years.

Factors reported to trigger an episode included; 41% infection, 34% psychological, 26% dietary, 18% exhaustion, 13% menses, 13% atopic and 9% motion. Some reported foods that may trigger an episode include: tomatoes, chocolate, cola, caffeine, artificial sweeteners, soy foodstuffs, dairy products, nuts and eggs, cheese and chocolate.

Over 60% had onset of an episode in the early morning and over 10% in the evenings. Over 65% had a family history of migraine. Sonny explained that in order to make a diagnosis

of CVS, it was important to consider that the episodes were discrete (93% have this), the patient was well in between episodes (64%), the episodes were stereotypical (98%) and the family had a history of migraine (66%).

There are some GI aetiologies that have a similar pattern to CVS and these have to be checked for and ruled out before diagnosing CVS. These are: gastric dysrhythmia, mucosal injury, infections, malrotation, chronic appendicitis, gall bladder and pancreatic disease. Non GI aetiologies that also mirror CVS are: abdominal migraine, epilepsy, neoplasm, metabolic problems, Addison's disease, acute hydronephrosis, kidney stones and psychological problems such as parental anxiety and Munchausen by proxy.

Once diagnosis has been established, a treatment plan needs to be set in place. Prophylactic treatment is needed for patients with episodes more than once a month, but only supportive therapy for those with infrequent attacks. It is important to identify and avoid triggers and parents need support e.g. from the Association.

There are a wide range of treatments for CVS, but no large scale trials have been performed. Treatment remains empirical, and on a patient by patient basis. There is an increasingly extensive body of clinical experience in treating CVS, leading to a developing consensus view of treatment protocols. Some of the strategies used as abortive treatments include antimigraine drugs such as sumatriptan. Antiemetic drugs like ondansetron, lorazepam, stemetil, chlorpromazine are given during episodes and a metabolic cocktail of L-carnitine and co-enzyme Q10 may prevent attacks.

Sonny discussed recent advances in the understanding of the electric rhythms of the stomach, which may lead to a greater understanding and perhaps new targets for therapy.

Conclusions

CVS is an illness of severe episodic vomiting, sudden in onset and associated with continuous nausea and lethargy. The symptoms often start in childhood and can continue to early adulthood, but adult onset is also possible. It is often undiagnosed in the early stages of the condition. It is more commonly seen in girls than in boys in the UK. A family history of migraine is present in a significant number of first degree relatives. Contrary to other studies, Sonny found more than one third of patients were not symptom free between episodes, suggesting a different aetiology.

CVS and surviving higher education



I am 21 and I graduated from the University of Sussex this summer with a 2.1 degree in History. I am here today to give you an insight into my experience of coping with CVS during higher education. The reason I wanted to share my story is because it is something I feel I would have benefited from before going away to university myself. I will give you a brief background about my CVS:

- I have suffered from CVS since birth and was diagnosed when I was 7. My cycle was every fortnight where I would vomit every 20 mins for up to 48 hours.
- I missed up to 50% of my primary education, and when I was in school I was always quite secretive about my illness, fearing that people would either make fun of me or think I was lying.
- I was quite a shy child, so it was hard enough to try and make friends, but it was made worse by being accused of being anorexic or bulimic or for “faking it” to get time off school.
- I feel that I have been quite lucky with my CVS as after being referred to GOSH I was put on a cocktail of medications that luckily kept my CVS attacks under control.
- For me, stress is probably the biggest trigger for an attack, so in the academic year, the exam period was always the biggest challenge!
- I managed to finish secondary school with 10 GCSEs and decided I wanted to continue into further education by taking my A-Levels.

Sometimes I think I get carried away wanting to prove to myself that I can do as much as other people without CVS getting in my way, however in reality as soon as I get tired and stressed then I go into a CVS attack. I should point out that I am extremely lucky in that I rarely vomit anymore, my attacks are now focused around dizziness, extreme nausea, sensitivity to light and sound, lethargy, lack of appetite and generally being in the “waking coma” that people describe, just without the vomiting.

During the second year of my A-Levels I somewhat suddenly lost all faith in myself and felt as though I wouldn't be able to achieve the grades I needed to go on to university. I think this was a case of me trying to do too much at once and ignoring the strain it was taking on my body! I was juggling the hefty work load of sixth form, a part time job, applying to university as well as a hectic social life as all my friends and I turned 18! I was put on steroids when I was 7 and taken off them when I was 16, so when it came to my final A-Level exams I was very anxious about being ill. I have a history of being unwell during the exam period, but in the past I was helped through by being on steroids. So it was decided it would be best to put me on a short-term dose of steroids to get me through my final exams. Although I felt much happier knowing that the steroids would keep any

CVS attack at bay, I also slightly resented having to be put on them just so I could succeed. This also made me worry more about how I would cope on my own at university. Luckily I got my A-Level results and was offered a place at my first choice of Sussex Uni, about 120 miles away from home!

Now my first piece of advice to anybody going into higher education is to see what your local council offers to Disabled Students. My head of sixth form got me in contact with my local Disabled Student Support unit. At first I felt a bit silly going because I didn't think that CVS would really be classed as a disability and I felt that we were wasting their time. However my dad and I went to a meeting and they asked some simple questions about the nature of CVS and discussed things I felt would aid me during university. To my astonishment, when the assessment came through they agreed to give me a laptop, a printer, all the software I would need, a Dictaphone, and various other equipment. They were really good at tailoring my package to my needs, e.g they gave me a write out loud programme which meant that if I was in an attack and needed to do some work but was too tired to type, I could just read out loud and the software would type it up for me.

They also got in touch with Sussex Uni and set in place some on-campus help, the library gave me an extended loan period on all books, and offered a collection service where I could ring up and tell them the book I needed, so if I was ill they would go and collect all the books up and I could send a friend with my library card to collect the books on my behalf. I was also given my own private room for all exams, which was to be close to a toilet, which really did help to reduce my anxiety levels, and I was also given 20% extra time to be taken as breaks when needed during the exam. This was very useful as if I started getting stressed in the middle of the exam I could stop and take a break to calm down and relax and take medication so that I didn't go into an attack.

I did find it hard being away from home when I was ill, mainly because I am not very good at spotting when I am working too hard, so I had to learn to restrict myself to avoid illness. When I am in an attack I need to be reminded to try to eat and drink, so the hardest part being at uni was not having my mum there to prompt me to do so. However all my new friends were very understanding and helpful, and I warned them that if I am unwell they may need to check up on me, and they did, often making me some food and bringing me drinks. By the end of the three years, my closest friend and housemate had learnt the "fizzy drink and plain crisps" trick so she only had to look at me and she would pop out to the shop and bring me what I needed to pull myself together!

I think university liberated me into being open and honest about CVS. Everyone at uni seems to come with their own concerns, for example I made friends with a 65 year old mature student who obviously was worried about working amongst 18 year olds. I also made many international friends who were worried about the culture/language etc. and I met many people with their own disabilities varying from a heart condition and asperger's to an amputee and someone paralysed from the waist down. So with such a big mix of people, everyone is very open and understanding.

There were times at uni when I had tried to party as hard as my friends. However, I don't know about anyone else, but binge drinking definitely triggers a nasty hangover-induced CVS attack for me! So there were times when I may or may not have turned up for a lecture hungover, but joking aside, I think a problem for me was that some CVS symptoms are almost identical to a hangover. I would advise anyone going to uni to ensure their tutors know about their CVS, as there were many times in a seminar when I was in the midst of a CVS attack; I was pale, dizzy, nauseous, unable to concentrate etc. Teachers sometimes assumed I was just hungover, which was quite stressful as seminars are assessed and I was worried I would be marked down for appearing to have turned up hungover. The other problem I encountered was the invisible nature of CVS as a disability. I found that my tutors were much more helpful to students with physical disabilities and that I was often overlooked as you can't necessarily *see* the affects of CVS. I found some tutors were more understanding than others, so it really is up to you to talk to them and explain that if you come with those symptoms that you are unwell due to CVS.

Overall my experience of higher education was brilliant, I felt that there was a lot of help out there, and the university really did try its best to cater for my needs. It was hard at first dealing with CVS by myself, but as I am growing up and becoming an adult, I need to be able to deal with it myself. I managed to get through university and was really excited about finishing my final ever exam of university, but the stress and excitement must have got to me as for my final exam I had a CVS attack. This was a massive blow to me as I was worried that I had just ruined all my hard work by being ill. I did sit the exam but I found it hard to think and concentrate and I was really nervous about being sick, but luckily I went to student support and they helped me get a letter from my GP and submitted mitigating evidence for that exam. I knew that I had done very badly in that exam so I spent the summer worrying that it may have affected my final degree result. When results day came, I was so pleased to learn that I had got a 2.1. I felt really proud of myself for being brave and moving so far away from home and coping all by myself for three years!

I would advise anyone worrying about coping away from home to just go for it, because I wanted to have the normal experience of university, and had I stayed living at home and commuted to a local university I think I would have been letting CVS get in the way of a leading a normal life. If I would change anything, I would perhaps have like to have been slightly closer to home, as when I was unwell, the thought of a three hour train journey to get home to see my mum was too much, but equally the fact that I couldn't easily pop home did make me stronger and more independent. You just need to remember that you can still do all the normal things that students do, but you have to pace yourself and know your limits.

As for me, I have once again fled the nest and moved up to Manchester to live with my partner. I am a receptionist at the moment, and am also currently starting to set up my own cupcake business. Once again I am probably trying to take too much on at once, but I don't care, I am determined and won't let a little thing like CVS get in my way!

Emily-Rose Dover

The Effects of Conditioning: A Sufferer's Perspective

Dr. Fiona McRonald, Genetic Researcher, Liverpool/Birmingham Universities

Introduction

Fiona began her talk by referring to Emily's presentation. She said that she wished that, when she was an undergraduate in the 90s, as much help had been available to students with chronic health problems. She went on to introduce herself and explain that although, as a geneticist, her day-to-day work was looking at DNA and chromosomes, her interest in CVS had grown out of her personal experience of suffering from severe symptoms since she was three years old.

The evolution of nausea and vomiting and experiences in clinical settings

Fiona explained that there were evolutionary advantages to vomiting. It is a protective response causing rapid expulsion of poisonous food from the body, thus preventing toxins from entering the system. Nausea acts as a strong deterrent to eating that type of food again. She emphasised that "Nausea has to be very unpleasant to work as a deterrent". Rats and mice cannot vomit, so just rely on nausea for protection (conditioned taste aversion). They nibble only a bit of new food to check it is safe. Even though nausea and vomiting have evolved to give protection, they can occur inappropriately in clinical settings, where they can cause problems. Anecdotal evidence in medical literature largely relates to more common conditions.

"Honestly, it's not the throwing up that's the worst. It's the pressing your face against the cold tile floor in the bathroom during a wave of nausea and praying for the world to end."
Internet forum on Hyperemesis Gravidarium

"The severity of vomiting at times made the thought of death seem like a welcome relief."
Young medically qualified patient being treated with combination chemotherapy for sarcoma - quoted in Rang and Dale's 'Pharmacology'

"Only half the problem has been addressed if vomiting is controlled but there is no relief from the nausea." Understanding and Management of Vomiting and Nausea: Jan Hawthorn.

Fiona said she could empathise with all the above quotations. They expressed very well what she had felt during her CVS bouts and emphasised the horror of the nausea.

Conditioning and the Development of Anticipatory Nausea and Vomiting

Most literature about the control of nausea and vomiting comes from the study of the reactions of patients to chemotherapy. Toxic drugs designed to kill cancerous cells cause severe nausea and vomiting as a side effect. Cancer cells divide rapidly and treatments are designed to target fast growing cells. Cells in the gastrointestinal track also divide quickly, so these are attacked by the drugs too, resulting in severe nausea and vomiting. After a number of severe responses to treatment it is widely accepted that patients can develop anticipatory

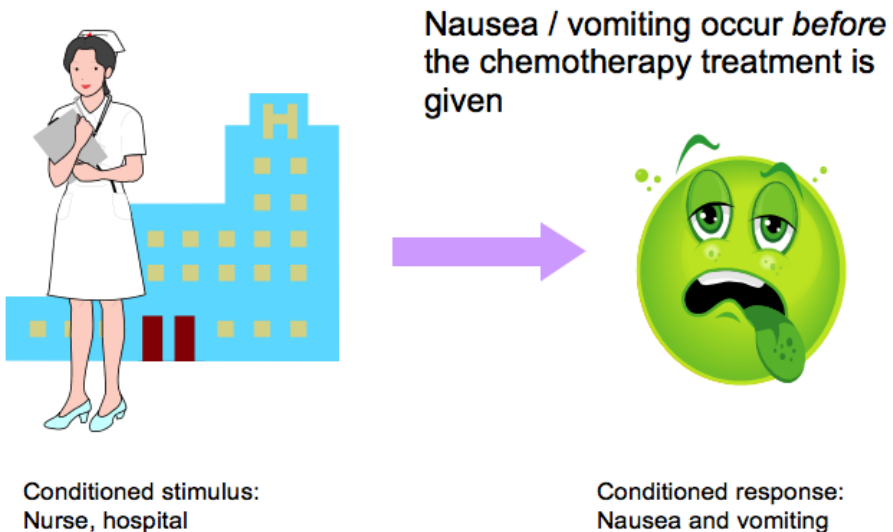
nausea and vomiting even before the drug is administered. This has been attributed to Classical or Pavlovian Conditioning.

Ivan Pavlov (1849–1936) conducted some powerful experiments. He attached a monitor to a dog to record the amount of salivation. The dog salivated naturally (an unconditioned response) when presented with food (an unconditioned stimulus), but not when it heard the ringing of a bell. For the experiment the dog was conditioned. Each time the dog was fed a bell rang simultaneously. The dog salivated as usual – an unconditioned response. This was repeated many times. After conditioning the dog salivated (a conditioned response) each time the bell rang (a conditioned stimulus), even without the presentation of food.

In a similar way, patients receiving chemotherapy drugs, which cause severe nausea and vomiting, may learn to associate their nausea with the administration of the drugs by a nurse in hospital. In time, after repeated visits to hospital for treatment, they may begin to feel nauseated at the very sight of the oncology nurse, even before the drugs are administered. This is called anticipatory nausea and vomiting or ANV for short.

Following several chemotherapy cycles...

Crucially, stimulus generalisation frequently takes place. The patient begins to feel nauseated not only by the sight of the oncology nurse, but at the sight of any nurse in uniform



or even the thought of hospital and treatment. This is distressing for patients and many are reluctant to report it to hospital staff, as they fear it means they have a psychological problem. Moreover it is resistant to treatment with anti-emetic drugs, so is highly problematic.

CVS patients have all the risk factors for anticipatory nausea and vomiting

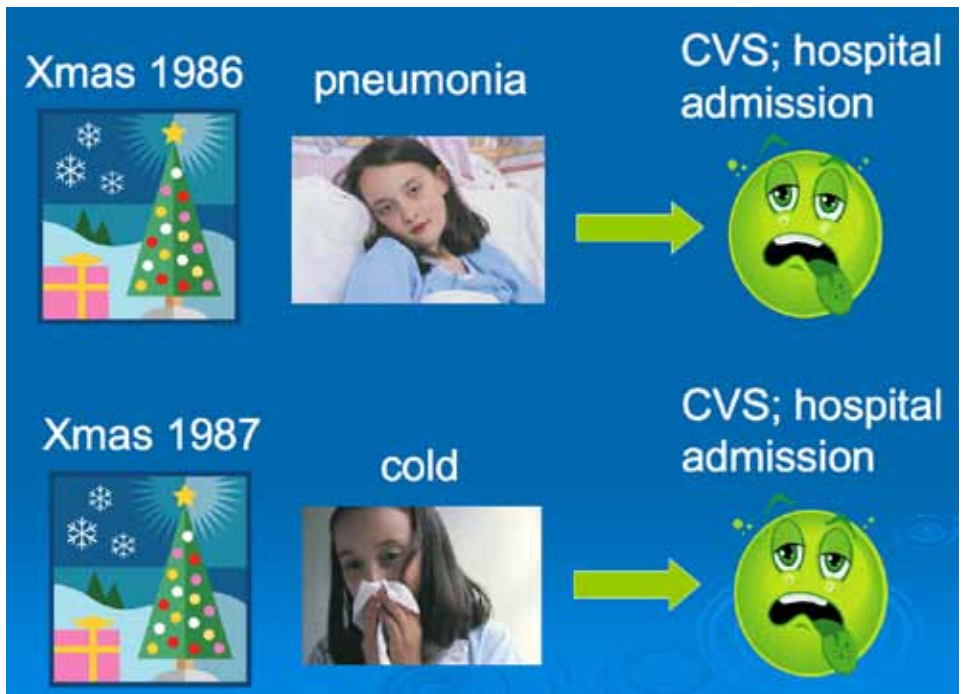
Whether or not patients develop anticipatory nausea and vomiting depends upon certain well-documented risk factors. The likelihood increases with the number of chemotherapy cycles and is dependent upon the severity of the side effects, taking into account the intensity of the nausea and vomiting and the frequency. It also depends on the duration of the nausea. Age is a factor. It is well known particularly to affect younger patients. One study found ANV in 59 % of paediatric cancer patients.

Many CVS sufferers meet all these criteria - their nausea and vomiting is very severe - at least as bad as in chemotherapy patients receiving cisplatin (the drug causing the worst emetic side effects); episodes may occur frequently over a short space of time, and can last for over a week and CVS mainly affects children and young people.

CVS and ANV – a Personal Perspective

Fiona then turned to her personal experience. She said that she had suffered from CVS since about the age of three. She had had numerous episodes and had, early in 2010, suffered her 101st hospital admission!

Her episodes were always triggered by infection until a dramatic change in 1988. A bout of pneumonia triggered an episode at Christmas 1986, so she missed that Christmas. Again, the following year, 1987, she spent Christmas in hospital when a cold triggered CVS.



On Christmas Eve in 1988 she went to bed free from infection; she said she was determined to have a good Christmas that year. However, in the early hours of the morning, she awoke with nausea and vomiting and was admitted to hospital.

Xmas 1988

24th December
No infections!

"I'm determined to enjoy Christmas this year..."

However...

25th December
CVS; hospital admission

The whole pattern of her episodes changed from that time and the incidence increased massively. In the three-year period 1986 – 1988 she had an average of 7.3 episodes per year. After Christmas 1988, in the three-year period 1989–1991, the number rocketed to 22.3 per annum.

Stimulus generalisation after Christmas 1988

With the realisation that CVS could occur even without an infection, she looked for new patterns to make sense of her experience. Attacks became less predictable, therefore more frightening. New associations became triggers like visits to certain places, day of the week, number of days after discharge from hospital, etc. She said she had a conscious awareness of these patterns, therefore increased fear and anxiety of becoming ill again. Eventually, fear of CVS itself became the conditioned stimulus and attacks occurred merely by worrying about them.

She said that as a young child she thought everyone got sick with infections and did not worry about the cause of her illness. As a teenager, she felt acutely aware that her vomiting was unusual and frightening and no one seemed able to explain it, adding to her distress.

CVS is perhaps most feared when it could cause maximum disruption to life, e.g. before holidays, on birthdays, before family parties or before exams. Due to conditioning CVS may be triggered at these times, therefore strengthening conditioning.

Doctors can make things worse

What the doctor sees

The patient starts in an episode before an exam. What the doctor concludes, “Aha! Easy! This is a no-brainer. The patient is afraid of exams and is using her illness to get out of them. She needs psychiatric help or counselling for exam stress.”

What the patient thinks

“I’ve got an exam tomorrow – it’s an important one. I’m worried that I’ll be sick and miss the exam. I’ll never get any qualifications at this rate. I hate CVS – I’m scared of all that nausea and pain. I’d much rather do the exam! And what’s more, if I’m sick before the exam my doctor will assume I’m doing it on purpose.”

Ways of treating CVS

The psychiatric model

- Ignore nausea
- Make the illness as unpleasant as possible for patient
- Forced feeding, activity, removal of vomit bowls etc
- Blame the patient
- Treat the patient as a collection of symptoms

Results

- Increased fear of illness worsens conditioning
- Patient is stigmatised
- Adverse impact upon patient’s self-esteem and perception of own psychological health that may have long term consequences
- Stress

Helpful Model (Dr. Fleisher)

- Aggressive treatment of nausea, vomiting and pain
- Sedate patient if treatment fails
- Make patient as comfortable as possible in a dark, quiet room with minimum interventions
- Encourage patient to sleep
- Try to identify and avoid triggers
- Treat the patient as a human being

Results

- CVS is less unpleasant
- Patient is empowered
- Patient's fear decreases
- Conditioning lessens

Conditioning is normal: What does this mean in CVS?

Under the right circumstances, nausea and vomiting could be conditioned in anyone – not just in CVS patients (experimentally it has been seen in pigeons!). It is just that CVS patients are at particular risk of developing ANV because their emesis is so severe. Therefore there should be no stigma attached to conditioned vomiting in CVS patients. It is not an indication of psychological problems! Conditioning is not the cause of CVS, but can act as a trigger for some episodes. It cannot explain the persistence of CVS episodes over days.

Conclusions

ANV can occur in CVS as well as in chemotherapy, therefore lessons can be learned from chemotherapy patients. The best treatment of ANV is prevention. If (chemo related) nausea and vomiting are well controlled in the first place, ANV is less likely to occur. Established ANV can be treated by relaxation therapies e.g. counter-conditioning.

Post Script -Morning Nausea

Several adult sufferers at the Family Day said they empathised and agreed with what Fiona was saying during her presentation. Several sufferers were having very frequent attacks and some experienced almost daily nausea, which occurred mainly in the morning. Fiona had similar experiences. After Christmas 1988, for about eight to ten years, she would frequently experience 'morning nausea'. This was never an issue during the first decade of her illness (1978 – 1988). In these early years (ages 3–13 years), an attack would end abruptly and, within an hour or so, she would be up and playing happily. She'd be absolutely fine, with no symptoms at all, until the next infection struck and an episode ensued. Episodes, from the beginning, almost always started during the night - more particularly first thing in the morning.

After Christmas 1988 things changed; she began to develop 'morning nausea' in addition to full-blown episodes. Low blood sugar may have initiated this, but, looking back, Fiona says she feels conditioning played a significant role. Fear (of having an episode that would disrupt her life) was also an exacerbating factor. These attacks of nausea played mayhem with her schooling. Very often, during these years, she was not fit to get up, eat breakfast and catch the school bus with her sisters. Countless lessons were lost, as she often didn't arrive at school until mid-morning or after lunch.

I should be keen to learn if others have similar problems. Please write and let us know.

Update on Quality of Life Study



Paula Allen

*Head of Department, Interprofessional Studies,
Faculty of Education University of Winchester*

Paula Allen and Dr. Rachel Locke, from the University of Winchester, have undertaken a research study into quality of life issues for children and young adults with Cyclical Vomiting Syndrome (CVS). This project involved interviews with young people and their families focussing on the effects of the condition on quality of life. A detailed analysis of the data is currently taking place and initial findings suggest CVS is still a little known about condition and awareness needs to be raised about this distressing illness for sufferers and their families. The findings will be used to inform staff at the University of Winchester involved with delivering professional programmes for practitioners working with children and younger people.

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Professor David Thompson

We congratulate David Thompson on becoming Dean of Graduate Studies at the University of Manchester. Unfortunately, as a result of his changed and increased workload, he is no longer able to see CVS patients or to be a medical adviser to the Association.

We should like to thank David for all he has done over the last decade. He has seen many adult patients with CVS and helped them enormously. He has also written two articles for the newsletter and has presented twice at our Family Days.



Recently Published and Submitted Articles November 2010

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Erturk O, Uluduz D, Karaali-Savrun F: Efficacy of nebivolol and amitriptyline in the prophylaxis of cyclic vomiting syndrome: a case report. *Neurologist* Sep; 16 (5):313-4, 2010

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Kowalczyk M, Parkman H, Ward L: Adult cyclic vomiting syndrome successfully treated with intranasal sumatriptan. *J Gen Intern Med*, Jan; 25(1):88-91, 2010

Nass J, Winstead N: 53-year-old woman with recurrent vomiting & migraine headache. *Clin Gastroenter Hepatology*, 8:245-7, 2010.

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Medical News in Brief

The Dangers of Amitriptyline

Recent research by a team from University College, London, published in the European Heart Journal has indicated that people taking tricyclics, such as amitriptyline, are 35% more likely to develop cardiac problems, such as heart disease and strokes. They also have a higher risk of needing bypass surgery and other heart operations than those taking different antidepressants or none at all. These drugs, in spite of being developed to treat depression, are sometimes also prescribed for CVS and migraine.

The researchers tracked almost 15,000 people for an average of eight years. Dr. Mark Hamer, one of the research team said, “Our study is the first to contain a representative sample of the whole community. The majority of the previous work in this area has focused on clinical cardiac patients, so studies in healthy participants are very important”. Amy Thompson from the British Heart Foundation said, “Antidepressants are beneficial for many people and so it would be unwise for anyone taking them to stop based on the results of this study alone.” Dr. Hamer also stressed that people should not stop taking them without speaking to their GP.

Migraine Gene Identified



A study by an international group including scientists from the Medical Research Council's Genomic Unit at the University of Oxford have identified a gene known as KCNK18 or TRESK on the long arm of chromosome 10; the gene codes for a potassium channel. Errors in this gene cause migraine with aura in some patients. The team studied the DNA of a very large extended family where many members suffered from migraine. Their results were reported in the prestigious journal Nature Medicine.

It was found that if the gene does not work properly, environmental factors can more easily trigger pain centres in the brain and cause severe headaches. The gene is normally active in areas of the brain that are known to be involved in migraine. Dr. Zameel Cader, one of the Oxford researchers involved in the study, said, “What we've found is that migraines seem to depend on how excitable our nerves are in specific parts of the brain. Finding the key player which controls this excitability will give us a real opportunity to find a new way to fight migraines and improve the quality of life for those suffering.” The team found that the defective gene was underactive, so the aim is to find a drug that will activate the gene.

Professor Goadsby from the Migraine Trust said, “The identification of a mutation in a gene for the potassium channel in a family with migraine with aura provides both a further important part of the puzzle in understanding the biology of migraine, and a novel direction to consider new therapies in this very disabling condition.”

Carina's Trek for Funds

Carina, Karen Thatcher's elder daughter, has raised funds for us by doing a sponsored trek of the Great Wall of China. Here she writes about her experience.



Ok, I love Chinese tea and Chinese food so where better to go for the real thing; no, not the local Chinese takeaway, but China. Oh and why not trek the Great Wall as well? So here's my account of my adventure into the east that will hopefully have you picking up the phone and ordering a number six and prawn crackers to go!

On the 14th October, after two gruelling flights and numerous movies, I landed in Beijing to be told that, even though I had already been awake for 18 hours as local time dictated, it was too early for bed, so we were shipped off to the Forbidden City for a little sightseeing and a local restaurant for my first of many encounters with chopsticks.

On day two, as the alarm clock rang out at 6am, as it would do for the next week, excitement finally kicked in when we got our first glimpse of the wall. It is truly jaw dropping and, as I

would find out three days later, knee crunching! But when you take your first steps on the wall, you feel like a child again and I haven't smiled and laughed so much in a long time. When you're walking with a 30-strong group, the days go by fast and before you know it, you've trekked 50 miles of the Great Wall and made some fabulous friends.

I'm not going to pretend the trek is easy, as it's not. There were days when you wanted to cry when the alarm went off, then walking on parts of the wall that are so broken you wonder if it could ever have been a wall and images of broken ankles flash before your eyes. I think my biggest challenge on the trek was tiredness with trekking for six to seven hours a day and sleeping in a new place every night. Not knowing what to expect when you arrived was the hardest - would there be hot water in the shower? Is it rice again? Is there an actual toilet? However it is all part of the challenge and what brought the group closer together and made it a more memorable experience; it makes you appreciate all you have back here at home - though if I see noodles again, it will be too soon!

Carina Howell

Media Spotlight

Full House

Di Disley, our committee member responsible for adult sufferers, has been interviewed about her CVS attacks for the magazine “Full House”. Di explained that the interviewer, Dawn, asked all the usual questions i.e. about the history and how long she had suffered with CVS. Dawn asked how it had changed over the years, how she managed episodes, what affect it had on her family and her daily living etc. They discussed hospital admissions and how difficult it could be, particularly as many doctors hadn’t even heard of it. They talked about medication and the pros and cons of various drugs. Dawn did call her back to read out the article. Di said that, while most of the facts were right, she felt that in making it into an article ‘something had been lost’. The article appeared in The February 3rd edition.



Widespread Publicity

On November 10th we had some welcome publicity which hopefully raised the profile of CVS.

Sharon Wilson, a 47 year-old mother of two from Doncaster, told her story to the press. Sharon explained how she could be sick for more than a hundred times a day with episodes of CVS that left her exhausted. It took ten years before she got a diagnosis. Mrs Wilson said, “Once it starts it’s like clockwork – I am sick almost exactly every ten minutes until my body cannot cope anymore and I fall asleep. When my husband surprised me with a mini-break to Paris, I was sick 144 times in 24 hours”. When they went on holiday to renew their wedding vows for their silver wedding, she spent much of the time with her head down the toilet. She explained how the attacks often happened when she had something nice to look forward to. “When I was at my worst, I was having attacks that lasted between one and three days about every four weeks. If I can avoid a hospital trip, I consider myself lucky”. At one point she was signed off by her GP for a year and got to the point where she thought she would become housebound.

The story was picked up by a wide variety of papers including The Daily Mail, the daily Express, The Sun and Metro. The story prompted a series of online comments. One father from London commented that his 20 year old daughter was in hospital with CVS at that time, being fed by tube. He commented that the article had helped publicise a “relatively unknown but horrible” illness. Almost inevitably the press got some key facts wrong, such as that the illness is very rare and they suggested it was caused by excitement. Robin has put some useful corrections on our website.

Thanks for all your Help

Demelza Burn, from Migraine Action, told us that they had credited CVSA in the October edition of their newsletter.

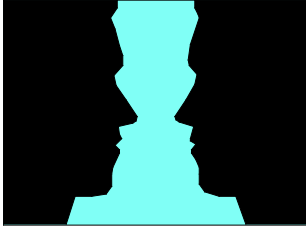
Many thanks go to Paul and Margaret Mellor, who collected more than £85 over the year for CVSA. They attached a note saying, "Hope it helps and thanks for all the help I have received over the years".

In order to spread awareness and raise funds for CVSA, Julie Wright, Hannah's Mum, organised a Strawberry Tea Party with stalls and a raffle on July 18th and hopes to arrange another one later this year.



Julie wrote to tell us that they had been through some horrendous times over the years. Hannah seemed to get an attack almost every month, and it was difficult to get the doctors to see that this was not 'run of the mill' vomiting. At worst she was bringing up blood and stomach lining and looked like skin and bone. It took five to six days of constant vomiting, often at five to ten minute intervals before Julie could get the doctors to do something for Hannah. It was a worrying time. Now they have a protocol with their local hospital. The ward staff know Hannah and as soon as she is in they put the plan into action.

Nicola Kipping held a Christmas Craft party in early December and managed to raise £100. Unfortunately the snow came down so numbers attending were very limited.



Share Your Story

Do write and tell us your story. It often helps new members to know that others are going through the same thing. If you prefer to remain anonymous that is fine – just let us know. Below are two very different stories showing the range of severity that can occur with CVS. They also illustrate the age range that may be affected. While the first story concerns someone in their late thirties, the second is about a nine year-old.

CVS at Christmas

Daniel started being ill about three days before Christmas. I thought with the new medication I would be able to cope. However the vomiting continued. On Christmas Eve Daniel was adamant that he didn't want to see a doctor, particularly because it would be an 'out of hours' doctor. From past experience he knew full well that they would have 'no idea'. He tried to hang on. On Christmas Day he was still being very sick and bringing up blood, but still begging not to go to hospital.

At six o'clock I decided to call the 'out of hours', where I was told I would have to wait for a doctor. OK - I did understand that it was Christmas, so I tried to keep my son as comfortable as possible. Six hours later there was still no doctor or any phone call to say why not. Suddenly I heard my son screaming. He was on the floor and there was blood and sick in the bowl. At this point I rang for an ambulance; they came quite quickly. My son was thrashing about with pain and my husband was in such a state of shock he had difficulty in holding him. By this time it was 12.30, six and a half hours since my first call for help.

My son and I went in the ambulance and the ambulance man tried, but failed, to get a line into him to give him pain relief. We were left in a cold corridor - my son being sick all over the trolley and floor. He was so cold they couldn't find a vein to get morphine into him. We were left for three and a quarter hours in the freezing corridor, open at times to the elements, before they finally succeeded.

Eventually, he was taken into the Emergency Room. I asked them to test his potassium levels. I knew that low potassium could be dangerous and the last time he was admitted his potassium level was only 1.8. He was still vomiting blood everywhere. I asked for some ranitidine, but they didn't think they had any. At 4.30 in the morning some was at last found and administered.

A doctor from theatre came to see my son to assess whether he needed surgery. She said, "You've only got a bruise in the muscle". I was very shocked by the off-hand way she examined my son – she wasn't interested in the blood and the pain. She sauntered off to the desk with a colleague talking. I was so shocked by her manner that I went up to her and asked her name. She muttered her name and walked away. I told her I didn't like the way she had treated my son and that he had CVS. She just walked away and went on chatting.

It was now 6.45 in the morning. They took Daniel for an X-ray and said they couldn't see anything wrong. By now the drip site had tissue and there was blood going back up the tube, so they had to re-site the line. Eventually he was taken to a proper ward and had 'a morphine shunt' fitted and he became more comfortable. However he had an allergic reaction and had to be given antihistamine.

While on the way back from ringing my husband, I overheard a consultant and the rude junior doctor from the Emergency Department discussing my son. They got his details up on the screen and I saw that it mentioned CVS and having been seen by Professor Thompson in Manchester. They only glanced at the screen briefly, before going to see my son. I asked if I could talk to the consultant privately without the junior doctor being present, but the junior doctor still 'hovered' only a few steps away.

*"I can't believe that in this day and age
CVS patients have to be treated
like this in hospital."*

I started to tell the consultant that my son's condition was CVS. He said, "I don't know anything about that rare condition". I said it wasn't rare. I complained that it had taken six hours for a doctor to come in the first place. I had had to ring for an ambulance as my son was screaming in pain and vomiting blood. He had then been left in a freezing cold corridor for over three hours while they tried to find a vein. I went on to complain about the rudeness of the junior doctor, who was still there with his team.

I explained how my son had had a seizure with an episode. He asked when, and I told him it was on April 4th 2007. A smile came over the consultant's face and he indicated that he thought that was totally irrelevant, as it was so long ago. That made me mad. I said I wouldn't waste any more of his time. I discharged my son, took him home and rang someone I knew well from the CVSA Helpline; contacting my GP the next morning. The GP has been excellent giving us all the drugs at home. He has arranged for him to be nursed at home with access to district nurses 24 hours a day.

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I can't believe that in this day and age CVS patients have to be treated like this in hospital. If it wasn't for a CVSA helper being there on the end of the phone, I think I would have taken an overdose myself. However, I have to take care of my son and fight this thing; even though I feel so traumatised and emotionally shocked that I can hardly do anything. I never want my son to go to that hospital again.

Brenda Phelps

Our Experiences so far: Ewan aged Nine

We got as far as ‘there is a strong possibility that it is cyclical vomiting’ for our son, Ewan in 2010. I guess that’s as good a diagnosis as we might expect for a condition which is clearly little understood by many medical professionals.

To be fair, Ewan’s CVS episodes are comparatively short-lived compared with some; they have not lasted beyond 24 hours and typically last around 18 hours. Nonetheless, episodes are, as is typical with CVS, acute and very distressing. First there’s the paleness and unwillingness to talk which is quickly followed by the vomiting which occurs up to six or seven times an hour. Withdrawal, dribbling and sheer misery continue until Ewan asks for a drink – then we know the attack is probably over.

It’s in the last 18 months that we have learned about CVS. It’s been a very steep learning curve, but we do feel much more empowered and better able to deal with the problem than we did in the summer of 2009. We now do what we have learned, through information gathering, trial and error, to deal with attacks. Crucially, Ewan knows the best thing for him is to go to his dimly lit bedroom and try to get as much sleep as possible. It has without doubt taken considerable effort and much angst to get to the understanding we are at now.

Looking back now, it is obvious that Ewan had a propensity to vomit from an early age. Certainly we had some very traumatic car journeys where vomiting occurred repeatedly and seemed quite difficult to control with the usual car sickness tablets. This period of travel sickness lasted from around 18 months to about five years old. There was one particularly memorable journey to a camp site in Wales one Bank Holiday weekend when Ewan repeatedly vomited for the four hour journey. We arrived at the camp site to find that there was no way we were going to get our family-sized tent up in the particularly strong winds – a worrying ripping sound made us stop and repack the tent into the car. Being a Bank Holiday, all B & Bs were fully booked, leaving no option but to return home. I can’t tell you how dispiriting the whole affair was! Poor Ewan was just exhausted and I remember wanting just to go to bed so that the day would end.

I also have recollections that Ewan was sick more than other children at nursery and early school. I put the vomiting down to viral infections picked up from other children and concluded that that was the way Ewan’s body dealt with infection – there was probably some truth in this. I can’t quite recall how the early episodes of vomiting panned out. We just dealt with it at the time. I know the school secretary reminded me of the ‘48 hour rule’ every time Ewan was sick so that, even though Ewan often recovered quickly, we still had to keep Ewan off an extra day to comply with this rule.

As Ewan has gone through the years of junior school, a pattern developed where attacks occurred almost exclusively on Mondays. Looking back, with hindsight, I think we may

have inadvertently reinforced the Monday pattern. I recall having discussions with my Mother-in-law (often our carer for Ewan as both my husband and I work) who commented how often Ewan was sick on Mondays. We (my husband and I) were then watching out for this pattern and went through a period where we got quite anxious on Monday mornings. We would get up and ready, pretending, and failing, to be relaxed and normal, whilst watching for 'signs' in Ewan. Normally Ewan would go to school without any signs of a problem but we would get the call at work. I got to the point where someone would hand me the phone telling me 'it's the school secretary' and I would just say 'not again' without the secretary having to utter anything. Automatically everyone I spoke to associated the Monday pattern with not liking something at school, but this did not fit with everything we saw and heard from Ewan and his teachers. All through Ewan's school years he has very much enjoyed school and has some very good friends. He seemed to, and still does, enthuse about much that he does at school! We did briefly consider that sausages which were on the school menu on Mondays were the cause, but once Ewan was on sandwiches, this theory was quickly shown to be incorrect. I started to keep a diary to record vomiting episodes – nine out of ten episodes occurred on Mondays. This was about two and a half years ago.

Having battled on for years and, as things seemed to be getting worse, I finally consulted our GP. Initially, we were asked to try milk of magnesia and we went through possible psychological causes. Our GP suggested the Child and Adolescent Mental Health Services (CAMHS) and we waited to be referred. The process to get referred to CAMHS was long and tortuous. An initial wait of around six months eventually resulted in an initial assessment. There were then another few months before we finally got to see a Child Psychologist for a number of sessions. By this time, we had discovered CVS.

"The light bulb moment for us was finding the CVS website."

The light bulb moment for us was finding the CVS website. I read the symptoms and got very excited as I felt that what I was reading exactly described Ewan's episodes. This was around October 2009. We found out about the Family Day and booked our places. I absorbed and printed off much information about CVS and went back to our GP armed with articles. I certainly didn't want to burn any bridges and having waited so long to see a Child Psychologist, thought we should continue. However, having learnt more about CVS, I knew it was important to rule out other potential causes of vomiting, so our GP agreed to refer Ewan to a Consultant at the Birmingham Children's Hospital. We attended the appointment at the Children's Hospital armed with our CVS literature. The Consultant agreed that CVS could be a cause and also acknowledged some familial history of migraine (my husband and his mother). Over the following weeks, blood tests and a MRI scan ruled out other causes of vomiting. In the meantime, sessions with a sympathetic and understanding Child Psychologist did make some small steps to understanding how episodes develop and to help Ewan feel less anxious about them. The Child Psychologist had not heard of CVS until she met us; she did, however, make considerable efforts to read up on the syndrome.

We did get a very nice story from her about an elephant with a wobbly trunk who happily ended up worrying less about his odd trunk!

Where are we at now? Well, we do our very best to manage things and they aren't bad at the moment.

- Sleep is key. Ewan does and always has liked getting up early and no amount of persuasion or going to bed later changes this. So, Ewan goes to bed between 8 and 8.30pm whether it's a weekday or weekend.
- We spent time minimising the trigger that had developed, i.e. Mondays. No, we didn't somehow skip Mondays (though I did consider pretending to Ewan that, on a Monday, it was in fact Tuesday or finding a completely new name for a day – then I remembered he's not stupid!). We started taking Ewan out on Mondays at morning break, bringing him home for a snooze and some lunch, then returning him if all was well. I now just bring Ewan home for lunch only (fortunately I have an understanding manager and work flexibly on Mondays).
- We learned to listen to Ewan. Initially, I did what I thought was best in dealing with the Monday problem by instigating different regimes to deal with it. Over time, we have learned to listen more to what Ewan thinks will work and this seems to have been more successful.
- We have also started using Migralve on Mondays (the pink tablets that are designed to prevent nausea and vomiting). This was suggested by our Consultant. I grind up tablets and Ewan takes them in a milkshake drink on a Monday morning. There has been an element of headache which Ewan has complained of in more recent months.
- We have spent time with Ewan's school to ensure they are aware of CVS, the symptoms and now tell them to phone us as soon as Ewan stops talking and goes pale so that we can get him to bed as soon as possible.

"We do our very best to manage things and they aren't bad at the moment."

Since the start of our current regime, over the last three months, Ewan has had just one episode, on a Thursday. This occurred at the end of term, just before Christmas, when there had been a lot going on at school and at home, so tiredness was a factor. The episode started around lunchtime, but we managed to get Ewan to sleep around 6pm and a good 11-12 hour sleep saw Ewan fine again the next morning.

Certainly our understanding has been crucial and I am sure we would be in a much worse position now if I hadn't stumbled across the CVS website. I'm definitely not counting my chickens, but I do think with continued vigilance, experience and learning, we stand a reasonable chance of dealing with things. Ewan is doing very well at school and most of the time is a normal boy who loves animals, chocolate and annoying his brother!

News from Abroad



Australia:

We send a very warm welcome to Kylie Ramstadius, who has taken over from Mary Tuder as the co-ordinator of the Australian Support Group. We were very sorry to hear about Mary's resignation in December. Mary was the founder member of the Australian group and has worked hard to keep contact with sufferers all over the vast continent of Australia. We send her our grateful thanks for all she has done.

Mary wrote:

Hello to everyone connected to the CVS family. I need to inform you that the Australian CVS Association is changing hands after many, many years. We need new blood and a younger co-ordinator.

Kylie Ramstadius has offered to take up the baton. She lives in New South Wales with her husband and three children. Her middle child, Reece, is the CVS boy. Kylie has a degree in Social Welfare and Community Services.

I have found my years as the Australian CVS person to be very rewarding and I have "met" so many anxious families all around the country. From the first beginnings of Tim's sickness in 1987, at age six, when we were struggling to understand what was happening, to contacting a couple of other families in Perth with Dr. David Forbes' help and our little meetings.

[Following this there was] the extraordinary discovery of the simultaneous nascence of groups in USA and UK - synchronicity at its best. Through the exchange of information with Kathleen and Wendy we heard of Ondansetron and things changed dramatically for Tim and many others. I was fortunate to meet Kathleen and Wendy at Wendy's home in England in 1994, at about the time of the First International Symposium on CVS in London, at which David Forbes presented.

The increased use of computers changed my job too - from hand written letters and photocopied newsletters, to the mass communication and dissemination of material we now enjoy. There was a huge increase in medical interest in CVS thanks to the support groups' agitation and there is now a wealth of literature to be read - we started off with Samuel Gee's first description and about three other papers that were available.

There is still much to learn about this distressing and frustrating condition, but with our medical researchers and other interested parties such as John Hayman and his treatise on Charles Darwin, and of course the continuing work at "grass roots" of all you great representatives, a lot of anguish is being overcome.

Tim, now aged 29, is well, and coping with any occasional episode himself. He is working, playing a bit of rugby and travelling for work and pleasure. He lived for four years in Japan and one in Beijing - and I only had two urgent CVS related phone calls from him!! As near to “cured” as possible.

Please stay in touch with me!! I still want to be a part of the CVS family and to hear of successes and events around the world.

Italy/USA

In September Kathleen Adams, President and founder member of CVSA-USA, visited a meeting in Italy of the Italian CVS Association- Sicvo Associazione Italiana Sindrome del Vomico Ciclico. She writes:



Imagine the scene...a lovely September evening in the foothills of the Tuscany region of Italy, just a few miles north of Florence; a group of about 25 people representing three generations gathered for an evening of enjoying each other and welcoming a foreigner. Even if you try to imagine in your mind's eye what an Italian potluck table looks like, it would not be close to the reality of the spread!

It was my distinct honour to be a guest of “SICVO” - the founders, the Board of Directors and the families of our fellow CVS association in Calenzano, Italy - very near Florence. In spite of the language barrier - I speak about five words in Italian including

“Ciao” (chow) - the conversations were full of common experience, determination and passion for our global mission.

In 2006, President Denys Figliuolo and his wife, Francesca Bartolini, founded the association on behalf of their dear daughter, Sofia, who was eight years old at the time. The couple were aided by our mutual international medical advisor, Dr. Alberto Ravelli, a pediatric gastroenterologist at the University of Brescia. He is an active clinician and researcher particularly interested in CVS. Sofia had been suffering from CVS from a young age. The family's story is all too familiar. Meeting Sofia brought on more emotion than I expected as she is still in the midst of the years of CVS episodes. My daughter, Mollie - now 32 - no longer has episodes but the memory of her younger years surfaced quickly as I watched and listened to graceful Sofia talk about her illness. Sofia's five year old sister, Chiara, also brought a picture of the love and spunk in this family with her enormous Italian smile, giggles and innocent delight.

In the few days that followed my arrival, I was able to meet with several professional advisors to SICVO - several physicians, a psychologist, an epidemiologist and a nurse. One of the physicians is an emergency room doctor who agrees that the problem of finding good ER care exists in Italy as well. I was also able to tour remarkable historic Florence with natives Denys and Francesca, including the 467 steps to the top of the Duomo. We also meandered through the outlying hills of Tuscany, stopping for a “simple lunch” (not so) in an out-of-the-way outdoor picnic café. Denys and I spent some time sharing heartfelt thoughts of the ups and downs of our presidential duties while wading in a Tuscan lake. Both Denys and Francesca were able to communicate the deep emotion and passion of their work. Without a doubt, we are driven by the common thread of doing all we can to alleviate the suffering of our children and so many others plagued by CVS.

It is important for our members to know that there is a global network of people bound together by a common mission. We now have six official associations - Australia, Denmark, Italy, Spain, UK, and USA/Canada. We also have professional and/or medical contact people in approximately 20 other countries as well. With the aid of the internet we are able to network globally. So take heart, there is a circle of people moving forward with dogged determination on behalf of so many to continue to solve the mysterious puzzle of CVS.

Italy:

Denys Figliuolo, President of SICVO, wrote to tell us that they have appointed some regional medical coordinators to help sufferers in different parts of the country. These are:

- Ravelli MD (North Italy Centre for CVS),
- Romano MD (South Italy Centre for CVS),
- Lombardi MD (Central Italy Centre for CVS),
- Buccioni MD (CVS Task Force)



Denys has also recently set up an Italian Facebook group offering support and shared experiences

USA:



CVSA Welcomes Chandra Wilson as Spokesperson

There has been some very welcome national publicity for CVS in the USA. The actress, Chandra Wilson, best known for her role as Dr. Miranda Bailey in Grey's Anatomy - for which she earned four Emmy nominations for best supporting actress in Drama - spoke for about five minutes on a national chat show about her 17 year old daughter, Sarina, who suffers from CVS. As a result of this broadcast, Chandra Wilson has agreed to be spokesperson for CVSA USA. Since the coverage the Milwaukee CVS office has been inundated with enquiries.

eNews Update:

Chandra Wilson, was interviewed about her daughter and CVS on "The Doctors" for US TV Feb 23rd 2011, <http://tinyurl.com/5wdmrrer> There are three linked videos, keep watching!

Belgium:

Karen Panhuszen wrote:

Sammy had a great period, nine months without being sick! We almost forgot what CVS was like. Then at the end of August, while in France on holiday, Sammy got motion sick in the car while driving through the mountains. We had to come back earlier from our vacation and Sammy was again in the hospital.

"Now every morning we are worried again, will he be well today or not?"

Since August he has already been in the hospital four times. It was a slap in the face for all of us. Now every morning we are worried again, will he be well today or not? It is very hard to manage! His life and ours is again put on hold. You know the feeling.

I read Fiona's speech (from the Family Day) everything is so recognizable! It is wonderful to know that even with this illness she got a PhD!

For the moment Sammy is feeling nauseated, as almost every morning! He often gets up, does not feel well, then he goes to lie down on the sofa for an hour. When he is lucky, he gets better and goes to school. Luckily in school they know him and his illness. Last year and the year before it was also in November that he was feeling at his worst!

CVSA - ABROAD

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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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