



**CYCLICAL VOMITING SYNDROME ASSOCIATION
CVSA – UK**

Newsletter 34:- Spring 2009

Professional Perspectives

Helpline
0151 342 1660
<http://www.cvsa.org.uk>

CVSA AT HOME

Chair: Robin Dover, 77 Wilbury Hills Road, Letchworth, Hertfordshire, SG6 4LD
Tel: 01462 485561 Robin@cvsa.org.uk

Secretary: Jacqueline Baekdal, 16 Woodlands, Grange Park, Northampton, NN4 5FX
Tel: 01604 761131 jackie.baekdal@googlemail.com

Vice Chair/International Liaison: Gill McRonald, 4 Pear Tree Close, Wirral, CH60 1YD
Tel: 0151 342 6620 mcronald@peartree.u-net.com

Treasurer: Alan Brown, 26 Broad Close, Kidlington, Oxfordshire, OX5 1BE
Tel: 01865 375410 alanabrown@tiscali.co.uk

Membership Secretary: Beverley Greenhalgh, 31 West Way, Little Hulton, Manchester, M38 9QN
Tel: 0161 702 6485 b.greenhalgh@sky.com

Committee Member: Amanda Sheehan, 88 Sutton Ave, Seaford, East Sussex, BN25 4LS
Tel 01323 891 810 amanda00666@hotmail.com

Committee Member: Karen Thatcher, 119 Harewood Gardens, Sanderstead, Croydon, Surrey, CR2 9BW
Tel: 0208 651 0938

Committee Member: Steve Cawley, 52 The Looms, Parkgate, Neston, Wirral, CH64 6RF
Tel: 0151 336 8934 stpcawley@aol.com

Committee Member: Lois Peña, 47 Portfield St., Hereford HR1 2SE
Tel: 01432 274440 loisbeeley@hotmail.com

Committee Member: Nicola Kipping, 5 Anthony's Avenue, Lilliput, Poole, Dorset, BH14 8JQ
Tel: 01202 709194 ckipping@tiscali.co.uk

UK & European Medical Advisers.

Prof. Paul Andrews, Professor of Physiology, St George's University Hospital, London
Dr. Ishaq Abu-Arafeh, Consultant Paediatrician, Stirling Royal Infirmary, Scotland
Dr. Sonny Chong, Consultant Paediatrician, Queen Mary's Hospital, Carshalton, Surrey
Dr. Keith Lindley, Consultant Gastroenterologist, Great Ormond St. Hospital, London
Dr. Alberto Ravelli, Brescia University, Italy
Dr. George Russell, Emeritus Professor, University of Aberdeen
Dr. David Symon, Consultant Paediatrician, University Hospital of Hartlepool
Prof. David Thompson, Gastroenterologist, Hope Hospital, Salford

Caroline Alice Cook

13.10.1993 - 16.11.2008

We were very sorry to hear about the sad death of Caroline in November. Caroline, in spite of her special needs and frequent vomiting spells, was a lively teenage girl with a mischievous streak, a strong will and a huge fighting spirit. Unfortunately a series of strokes led to her death in November, when it was confirmed that she was suffering from MELAS – a mitochondrial syndrome.

We extend our sincere sympathy to Sheila and her husband, John, and older sisters, Joanne and Laura. Caroline was a patient of Dr. Chong, our medical adviser. He commented upon how supportive and caring her family had been.

Sheila is a huge asset to our helpline, giving support and advice to families who have children with complex neurological problems as well as CVS.

The family are participants in Dr. Richard Boles's mitochondrial study based in Los Angeles, USA.



Letter from the Chair

After working with CVSA for quite a while now, and being one of the people who receives first contact from potential sufferers seeking help and information, I have heard many uplifting stories and also many shocking ones. I was beginning to think I couldn't be shocked any more at the way patients can be treated - I was wrong. I recently had a contact from a mother who'd printed out information on CVS only to have it ripped literally into small pieces in front of her by a Professor of Medicine no less. Whilst most Doctors would be rightly wary of a patient trying to diagnose themselves this incident shows just how difficult it can be to get sympathetic help. This theme is picked up in this issue in an article by Karen Thomas, about the problems faced during transition from being cared for as a child to being treated as an adult. For some it means starting all over again and facing all the same barriers of comprehension. The Department of Health has a website designed for young people moving to adulthood and the problems they face with medical care. It has a variety of resources, including a DVD, and information you can download. You can find it at www.dh.gov.uk/transitions. It is one small sign that attitudes are changing and that overall quality of life, which includes all aspects of the way you receive treatment, is of great importance to those with long term conditions.

Steve Holding has stepped down from the committee, he and his family have raised considerable sums for CVSA and he plans to continue. Many thanks to Steve and family for their help and support for us over the years. Nicola Kipping has re-joined the committee. She was the previous chair and has considerable experience and knowledge of CVS and brings many skills to the committee - welcome back!

The cause of CVS around the world is being championed by increased international efforts. The North American society, which is the largest, continues its long track record of great work with more research funding, and more publicity. After a major setback in organising a conference the Italian society managed to go ahead with a successful national meeting, hopefully the first of many. The Danes are working on a website and we have a new contact for Germany. Being a CVS sufferer, or caring for someone who is, can often make it seem like you are a very small voice asking for help, but the growth of CVS societies and contacts around the world is genuinely changing that.

We have had some amazing donations this year, some are highlighted later in this issue. A huge thanks to all those involved for your continued efforts.

Robin Dover

Family Day



We had a very successful Family Day on November 15 2008, held as usual in the Education Centre at Birmingham Children's Hospital. Professor Tom Abell (pictured left with Dr. Chong) came all the way from Mississippi to speak to us. Our own medical adviser, Professor David Thompson, gave us the second, contrasting presentation.

We were very pleased to welcome Heinz Göegelein, from Frankfurt, Germany. Heinz is in the process of establishing a German group.

Many people said how much they appreciated the day. Diane Disley wrote: "I hope I'll be able to attend [the Family Day again] next year. I did find the day useful and reassuring; it was good to meet and chat to people who had experience of CVS. Thanks for the day, I was very impressed".

Rosemary Cracknell emailed: "Many thanks to you [Robin] and the other members of the committee for organising the Family Day on Saturday. It was the first time I had attended, but my husband and I found it to be a very worthwhile experience. We were made to feel very welcome and were amazed that the health professionals were prepared to discuss individual cases, even during their lunch break. The speakers were very informative and it is reassuring that research is ongoing.

Having been an adult sufferer for over twenty eight years, it was such a relief to know that there are other people out there who believe you and know exactly what you are experiencing. Please keep up the good work".



Victoria Ray and family

The next Family Day will be Saturday 14th November 2009.

CVS – Autonomic, Enteric and Quality of Life Perspectives

Professor Thomas Abell, University of Mississippi, USA

Professor Abell began his talk by telling us that he originally came from South Dakota in the U.S.A., but he is now based in Jackson, Mississippi, where he is the Director of Digestive Diseases at the University of Mississippi Medical Centre. He also mentioned that he has been able to trace his ancestry to England.

Professor Abell had CVS as a young child, which was never diagnosed by a doctor. When he was about forty-five, the CVS also involved migraine headaches. Thus he himself did not have a correct diagnosis of CVS for about forty years. His mother also recalled, only a few years ago, that she had a brother who would vomit often, making Professor Abell believe that his CVS has hereditary links.

When Professor Abell was at college he was told that his condition was psychosomatic (i.e. 'in his head') and he himself believed for some time that CVS was psychological. His interest in disorders now known as CVS led him on a lengthy path that finally included medical school in his native South Dakota, from where he graduated in 1977. In the 1980s, he realised that the idea that his illness was psychosomatic was incorrect and he changed from studying behavioural medicine to studying Gastroenterology. Dr. Abell now has a particular interest in Gastrointestinal (GI) Motility Disorders within Gastroenterology. His most recent focus has been gastrointestinal electrical stimulation for a variety of GI motility disorders and he highlighted his work in this area during the talk.

Professor Abell said that many CVS sufferers have an abnormal autonomic nervous system. The autonomic nervous system is the part of the nervous system that supplies the internal organs, including the blood vessels, stomach, intestine, liver, kidneys, bladder, salivary and digestive glands. He said that there are many traditional non-invasive ways of measuring if the autonomic nervous system is functioning normally. He and others realised that gastric emptying is related to autonomic nerve function. Professor Abell worked with NASA to try and assist with the biggest health problem astronauts face, that is travel and motion sickness. NASA spent \$20 million on research into autonomic nervous system retraining. Professor Abell reported that this resulted in some improvements in patients with vomiting, including CVS, but was not enough to solve the problem entirely.

Professor Abell presented some statistics that show that CVS sometimes overlaps with other disorders. The research he quoted from showed that 50% of CVS sufferers also have migraine. Some other disorders that CVS overlaps with are fibromyalgia, interstitial cystitis and endometriosis. The medical profession have not come to a conclusion as to why there is some overlap with these conditions and CVS, but this is the subject of intense investigation.

Professor Abell also discussed how the enteric nervous system (ENS) controls the gastrointestinal (GI) tract. The enteric nervous system is considered to be a separate part of the overall nervous system. Along with the autonomic nervous system the ENS contains

more nerves than the central nervous system. The enteric nervous system is embedded in the lining of the gastrointestinal system. The activity of the enteric nerves can be measured with an Electrogastrogram (EGG), similar to an electrocardiogram (ECG) of the heart. This records the electrical signals that travel through the muscles of the stomach controlling the muscles' contractions. It can be, in his experience, a helpful diagnostic tool for people who are suffering nausea and vomiting.

Professor Abell conducted a research study with 120 patients who suffered from nausea and vomiting. It took ten years to complete and it found that 60% of the patients had some form of neuropathy relating to their enteric nervous system. It also demonstrated the frequent occurrence of electrical abnormalities of the stomach in patients with chronic and/or episodic nausea and vomiting. The study should be published in 2009.

Gastroparesis is a condition that Professor Abell says can overlap with CVS. Gastroparesis is also called delayed gastric emptying, but disordered gastric emptying may be a more appropriate term, as some patients empty their stomachs too rapidly. It is a disorder in which the stomach often takes too long to empty its contents, and in many people this will lead to vomiting. He states that CVS and gastroparesis often co-exist and have many symptoms that are similar. The diagnostic tools are also similar, so CVS sufferers will probably undergo the same type of tests. Gastroparesis is primarily an enteric nervous system disorder. Gastroparesis may also have a cyclical pattern and it occurs in both diabetic and non-diabetic patients.

Professor Abell has spent twenty years working on neuro-modulation of the GI tract. This involves stimulating the nervous systems of patients who do not respond to drugs or other treatments. Studies started in the 1980s on animals, but are now common in humans. Professor Abell is conducting several ongoing studies on Gastric Electrical Stimulation (GES) or gastric neuro-modulation, which is a newer term. A gastric neurostimulator is a surgically implanted battery-operated device that releases mild electrical pulses to help control nausea and vomiting associated with gastroparesis. This device is needed when the stomach's natural biological pacemaker does not function correctly.

This process has provided very positive results in many patients. Professor Abell has used it with promising results on patients who had cyclical patterns of vomiting; most of these patients had a temporary endoscopic GES device first, which is not widely available. He also provided this procedure to a few highly selected CVS sufferers, but cautions that the results are very preliminary. Many of the patients he does this procedure on are diabetic, but others have post-surgical disorders or are 'idiopathic' - meaning the cause is unknown. This procedure has been done on approximately 3,000 people worldwide. He believes that there have been at least 100 patients implanted in the UK and 400 in Europe.

The question has been asked, "Is GES a placebo response?" In response to this question Professor Abell was involved in a double blind study to identify if this were the case. During the presentation Professor Abell provided statistics and graphs which showed that

a dramatic improvement for those patients who had the GES turned on, compared to those who had the GES turned off (without the patient's knowledge). In this study a temporary GES device was performed first on all patients. When the GES was turned on the vomiting decreased significantly. The research also showed that two years after being implanted, the patients with the GES turned on had done so much better.

Professor Abell is hoping that in the future this procedure could be done on CVS sufferers and that also in the future the device will be wireless which will alleviate the need for the patient to wear an external device connected to their body. He stated that his life long goal is to stop nausea and vomiting in patients such as CVS sufferers.

During the presentation Professor Abell also discussed mitochondrial diseases which can cause nausea and vomiting. Some of these diseases also have symptoms similar to CVS. Mitochondrial diseases are genetically inherited through the maternal line, and Professor Abell presented evidence that CVS patients have a higher than expected incidence of associated medical problems in the maternal compared to the paternal family history. This observation is consistent with the idea that mitochondrial problems contribute to CVS. The most common mitochondrial disorder is migraine. Some of these disorders respond well to nutritional supplements such as L-Carnitine, CoQ10 and Riboflavin.

Professor Abell uses what he terms 'ZAP' therapy for chronic nausea and vomiting for those patients admitted more than once a month, on average, with severe vomiting. ZAP therapy is IV therapy using Zofran (ondansetron), Additional fluids, and Phenergan (promethazine).

Professor Abell discussed the merits of data sharing. He said that data from the U.S.A. has been shared with Southern and Western Europe for many years although all necessary regulatory and patient confidentiality measures must be followed.

- Data sharing can take the form of:
- Symptom history
 - Physiological data
 - Genetic testing
 - Trials of GES and neuro-modulation
 - Sharing by support groups
 - Sharing by investigators

He believes that CVSA USA is the premier group for support for CVS in the United States and clearly CVSA UK is the premier group in the UK.

Professor Abell kindly said that he was willing to be contacted. Information on how to contact him can be found at: <http://gastro.umc.edu/>.

Jackie Baekdal

CVS and Adults: Facts, Fancies, Frustrations

(The questions everybody wants to ask but didn't have a chance to)

Professor David G Thompson

We were delighted to welcome back Professor Thompson to this year's Family Day. He gave a very clear and 'to the point' presentation in a question and answer format. We received lots of positive feedback from attendees who all agreed how helpful the presentation had been. It was easy to understand and answered so many of our questions in a 'no nonsense' manner which is just what is needed, after being so frustrated with other doctors who haven't even heard of CVS. What follows is a full transcript of the presentation:

What is CVS?

The easy answer;

- Cyclic (recurrent, well in between)
- Vomiting (vomiting)
- Syndrome (a cluster of features)

The honest answer:

- "If only we knew"

A useful label for a group of symptoms suffered by a number of people which helps us to predict future behaviour and helps doctors know what to do (and what not to do)

So why do people get it?

We don't really know yet, but we are getting some good ideas

So what is the cause?

There are probably several causes which may differ between people

- Male vs. female
- Adult vs. child

Is it migraine?

In some, but not as often as occurs in children. If vomiting is accompanied by headache (even if only occasionally), think migraine

Is it caused by an infection?

Perhaps in a few susceptible people. More likely to be a secondary effect of inflammation-Fever 'flu'-like symptoms suggestive

Is it an Eating Disorder?

NO!

Is it all psychological?

'Being severely sick and having no one believe you would eventually make anybody mental'

Is the cause genetic?

Perhaps in some but also environmental

Why is it related to my periods?

- Usually at onset of menstruation
- Hormonal
- Cytokines (cells of the immune system)

Will I ever get better?

Yes you will but sometimes only slowly over time

This answer was questioned by some of the attendees as misleading. More adults are being diagnosed with CVS and not all adult sufferers choose to continue with their treatment from doctors as they don't believe it helps, but as doctors may not see them, they may assume CVS has resolved.

Can it be cured?

Not at present but it can be suppressed and controlled

Is the adult condition the same as it is in children?

Probably not but the underlying tendency may be the same

Is it getting more common in adults?

We don't really know but more people are recognised (thanks to the use of the term CVS)

Can it be passed onto my children?

Very unlikely

Why can't a proper diagnosis be made?

There is no clear diagnostic marker yet

Why is it not recognised earlier by doctors?

- CVS is still poorly known about in medicine
- Other life threatening illnesses to be considered initially
- But eventually the message gets through

Why am I usually treated as though it's all my own fault?

See all of the above!

What tests do I need to have?

Tests of exclusion depending on who you are

What treatments are there?

- Preventing an attack
- Moderating menstruation
- Migraine prevention medication
- Anti inflammatory tablets
- Avoiding contributing factors
- At the very beginning of an attack
- Anti-vomiting medication
- When symptoms are severe
- What works
- Fluids/nutrition
- Hospital admission?

What about alternative therapy?

Whatever works for you is OK

Should I change my diet?

Only if you are certain you have found a causative factor

So what can be done?

- By the sufferer?
 - Join the CVSA
 - Turn detective!!!
 - Keep a careful record of events
 - Try to find real associations
- By the Medical Profession?
 - Get educated
 - Take the problem seriously
 - Do some research
- By the CVSA?
 - Continue the excellent work
 - Support – Continue education/support of sufferers and relatives
 - Education – Provide medical information for the professionals
 - Research – Consider a study of epidemiology of CVS

The CVSA and Research

- Establishment of patient database cataloguing all individuals....
- Predisposing factors
- Beneficial treatments

The Future?

We all need to work together, to try to identify the cause(s), to develop better treatments, to stay optimistic.

Beverley Greenhalgh

Medical News Update

Consensus Report on CVS Published at Last

We are delighted that the long awaited consensus report on the diagnosis and management of Cyclic Vomiting Syndrome was finally published last September in the Journal of Pediatric Gastroenterology and Nutrition. This is one of the major journals read by paediatricians throughout the world. Hopefully the paper will have a considerable influence on diagnosis and management of children suffering from this long neglected condition.

Li BU, Lefevre F, Chelimsky GG, Boles RG, Nelson SP, Lewis DW, Linder SL, Issenman RM, Rudolph C.

North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. consensus statement on the diagnosis and management of cyclic vomiting syndrome Journal of Pediatric Gastroenterology and Nutrition, Sep 47(3):379-93, 2008

Abstract

Cyclic vomiting syndrome (CVS) is a disorder noted for its unique intensity of vomiting, repeated emergency department visits and hospitalizations, and reduced quality of life. It is often misdiagnosed due to the unappreciated pattern of recurrence and lack of confirmatory testing. Because no accepted approach to management has been established, the task force was charged to develop a report on diagnosis and treatment of CVS based upon a review of the medical literature and expert opinion. The key issues addressed were the diagnostic criteria, the appropriate evaluation, the prophylactic therapy, and the therapy of acute attacks. The recommended diagnostic approach is to avoid “shotgun” testing and instead to use a strategy of targeted testing that varies with the presence of 4 red flags: abdominal signs (e.g., bilious vomiting, tenderness), triggering events (e.g., fasting, high protein meal), abnormal neurological examination (e.g., altered mental status, papilledema), and progressive worsening or a changing pattern of vomiting episodes. Therapeutic recommendations include lifestyle changes, prophylactic therapy (e.g., cyproheptadine in children 5 years or younger and amitriptyline for those older than 5), and acute therapy (e.g., 5-hydroxytryptamine receptor agonists, termed triptans herein, as abortive therapy, and 10% dextrose and ondansetron for those requiring intravenous hydration). This document represents the official recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition for the diagnosis and treatment of CVS in children and adolescents.

Migraines “Mean Less Cancer Risk”

American researchers say those women who suffer regular migraines may have the comfort of knowing they face a much lower risk of breast cancer.

Researchers from the Fred Hutchinson’s Cancer Research Center in Seattle studied a group of 3,412 women and found a 30% lower risk of breast cancer in those who suffered from

disabling headaches. Dr. Christopher Li and his team looked at 1,938 women diagnosed with breast cancer and 1,474 who had no history of the illness. Women were asked whether migraine had ever been diagnosed by a health professional and those who reported suffering migraines attacks were found to be much less likely to develop cancer of the breast. They published their findings in the journal of Cancer Epidemiology, Biomarkers and Prevention.

It is hypothesised that the link between the two conditions concerns hormone levels. Some migraine sufferers find, that when pregnant or on the contraceptive pill, their migraine attacks reduce significantly in both severity and frequency. It is known that very high levels of oestrogen and progesterone fuel two of the most common types of breast cancer. It is conjectured that a high oestrogen state, such as that found when pregnant, could be linked both to a reduction in migraine attacks and to stimulation of breast cancer development.

Dr. (Christopher) Li and his team are the first to link the conditions. Though urging caution in the interpretation of the results, Dr. Li felt they pointed to a possible new interesting line of enquiry.

For additional information:

<http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/7710674.stm>

Surgery Beneficial in Heartburn

A million pound trial of 800 patients suggests that surgery should be undertaken more routinely for patients with chronic acid reflux.

A team at Aberdeen University, led by Professor Adrian Grant, co-ordinated a trial of laparoscopic fundoplication for patients with chronic reflux at twenty-one hospitals around the UK. It concluded that the operations, in spite of costing around £2,000 each, were cost-effective because patients no longer had to take long-term medication. After the surgery only 14% required medication compared with 90% of those treated by drugs alone.

Acid reflux is a very common problem, with as many as 20% of the population experiencing symptoms at some stage in their lives. At the more severe end of the spectrum some patients have to take daily medication for twenty or thirty years with significant cost implications. At present very few patients receive surgery. Most GPs regard it as too extreme.

Professor Roger Jones, head of General Practice at King's College, London and Chair of the Primary Care Gastroenterology Society said: "For some people, it is a serious problem which could potentially mean a lifetime of tablet taking".

The operation involves wrapping a section of the stomach around the oesophagus to create a new valve. It is now done by keyhole surgery and is proving a lot safer than when it involved opening up the chest cavity. The team are following the patients for five years to monitor long-term benefits or risks.

Professor Grant warned that it, like all operations, has some risks.

Fundoplication and CVS

My understanding is that patients who have had this operation may be left physically unable to vomit. This may have very serious consequences for those with CVS. The intense nausea will remain the same and the patient may have to endure hours or days of violent, unrelieved retching with no physical relief. I know that Dr. David Fleisher warns against this operation except in extreme circumstances. There have been cases where CVS has been wrongly diagnosed as a severe reflux problem and a fundoplication performed which has only complicated the CVS and made the symptoms infinitely more unpleasant.

Caring Parents are More Vulnerable to Pneumonia

Recent research undertaken by Birmingham University School of Exercise and Sports Science has found that those parents providing round-the-clock care to their disabled children have a weaker response to pneumococcal vaccine, which protects against bacterial pneumonia. This gives a good indication of how they would resist and fight pneumonia in real life. It is the first study to examine the effects of round-the-clock care in a relatively young, healthy age group, although similar research has shown the detrimental effects of round-the-clock care on the elderly looking after a spouse.

Sixty parents, whose average age was forty-one, from around the West Midlands took part. Participants gave a blood sample prior to vaccination, then further samples after one and six months. They also filled in questionnaires to assess exposure to stress and the psychological effects of care giving to their children. Those parents who were looking after children with developmental problems showed much poorer antibody response than did parents of children without additional problems.

Stephen Gallagher who led the research commented: "The research shows clearly these parents had a weaker immune response at both one month and six months after vaccination. This is a good indication that their immune systems are not functioning efficiently. We look for a twofold increase in antibody levels as a good measure that the vaccine is providing protection. We found parents delivering care were less likely to produce a clinically effective response to the jab."

After one month 20% of parents providing long-term care had an ineffective immune re

sponse, compared with 4% of the controls. At six months this had risen to 48% while the levels of the control group remained static.

Dr. Anna Phillips said: “These parents are incredibly dedicated to their children, and not in a position to take time off. However knowing the effects that providing round-the-clock care can have on their health may help raise awareness that these parents need help to manage their burden of care. This work suggests that parents should be prioritised as a vulnerable group, potentially making them eligible for annual flu jabs and other vaccinations. We are continuing this work by looking at how sleep patterns affect the rates of infection in these parents – so we can get a better picture of the problem and find ways to make improvements”.

Parental Caregivers of Children with developmental disabilities mount a poor response to pneumococcal vaccination is published by Brian, Behavior and Immunity. The team from Birmingham University are: Mr Stephen Gallagher, Dr Anna Phillips and Professor Doug Carrol from the School of Sport and Exercise Sciences and Dr. Mark Drayson from the School of Medicine.

http://www.newscentre.bham.ac.uk/press/2008/07/Caring_Immunity_Press_Release_20_07_2008.shtml

Comment

I feel this research is relevant to our group, as a significant percentage of our members have children with developmental delay and additional long-term neurological problems, as well as vomiting. Even parents with children who have severe CVS only, can experience a huge amount of additional stress, with numerous broken nights. Some spend a significant number of nights in a chair by a hospital bedside. This can go on for many years. Moreover, there is the extra anxiety of not knowing what is wrong. The unpredictability of everyday life, depending upon whether the child is well or sick, also has an impact. Because the illness is so very frequently misunderstood, attitudes to parents by employers, teachers and health practitioners can also add additional stress.

On the very day I received this report, I heard about two of our parent members who were off sick. I myself was hospitalised with pneumonia (aged 42) at one particularly difficult time during our daughter’s illness. I am quite sure that stress, resulting directly from the ramifications of Fiona’s CVS, played a very significant part in this.

Gill McRonald

Most Recently Published and Submitted Articles November 2008

More extensive list available on the CVSA web page

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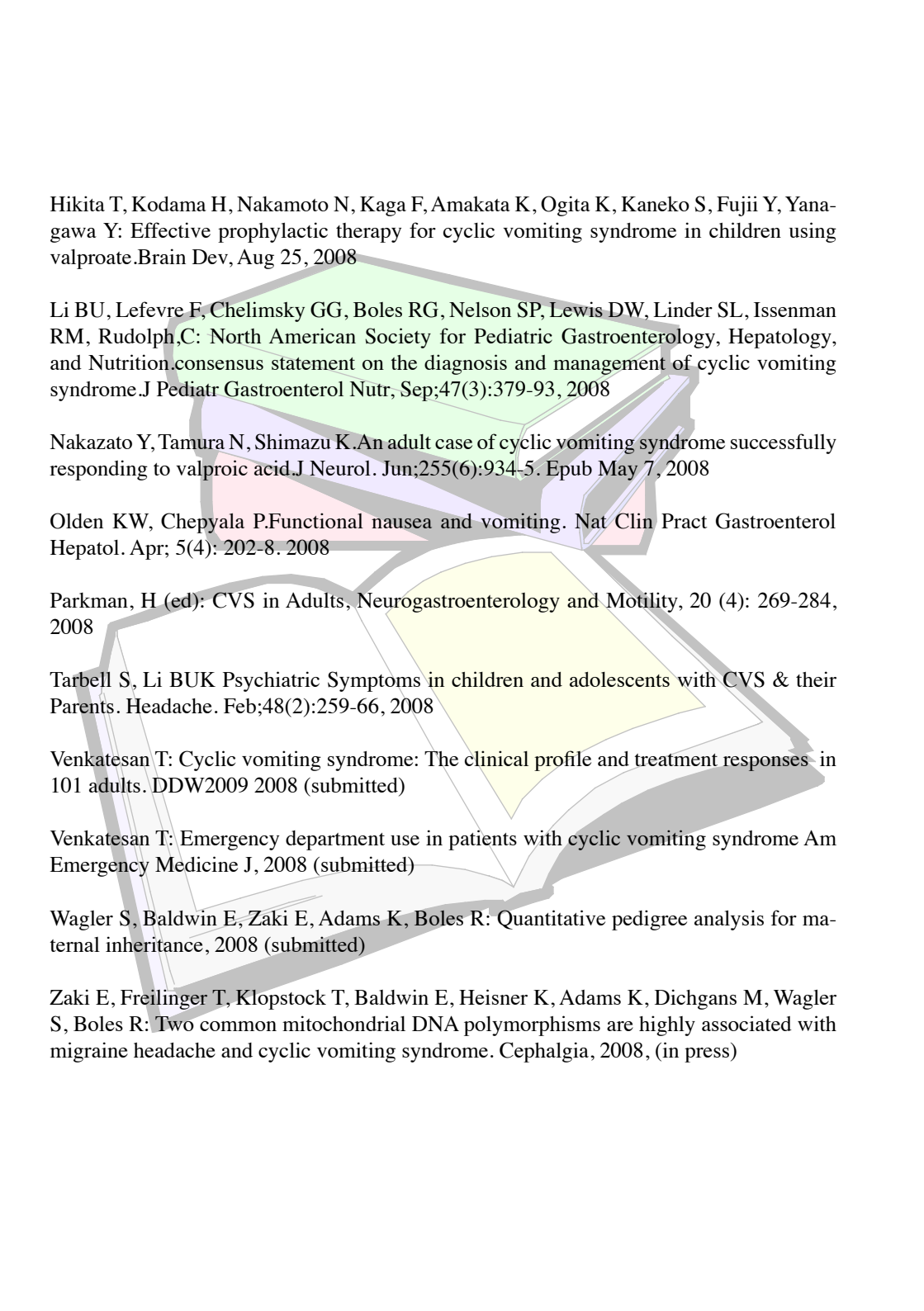
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Media Spotlight

ABC News features CVS

“When You Can’t Stop Throwing Up” “Mysterious Condition is Difficult to Treat, Doctors Say”

There has been a major coup in raising awareness of CVS in America. ABC News, a major television company, had a feature about a case of CVS on November 18, 2008.

Natalie Robertson from Chico, California, was interviewed with her mother, about Natalie’s prolonged vomiting episodes. They explained that no amount of vomiting would stop the nausea. At first doctors put the symptoms down to stomach flu or food poisoning. However the symptoms persisted for years. Her mum said, “We knew something was wrong, there was just a lot of guessing”.

At college, when Natalie was eighteen, many put her symptoms down to a heavy night of drinking. Others thought she was bulimic and clearly did not believe her mysterious illness. Her tutors warned that too many absences would risk her failing her course.

Eventually Natalie was diagnosed with CVS. The programme went on to describe some of the salient features of CVS. It described it as a neurological disorder characterised by prolonged attacks of nausea and vomiting, with no apparent cause. It said that episodes usually start with severe abdominal pain or migraine headache, followed by hours or days of vomiting. After the attack, it stressed that sufferers return to normal health with no signs of disease.

One of the very useful features of the interview was to distinguish between CVS and bulimia. It said that, in bulimia, purging follows binge eating and there is often little or no nausea. In CVS, by contrast, sufferers often start and continue to vomit on an empty stomach. Importantly, it stressed that they suffer overwhelming nausea.

Read the online article here:

<http://abcnews.go.com/Health/PainManagement/story?id=6273939&page=1>

At the time of writing there are 50 responses, this quote is from one:

Physicians need to get the word about this condition and treat us like anyone else with what they see is a valid medical condition. The only way to accomplish this is through spreading the word and educating the medical community.

“Pick Me Up”

I Can't Help Being Sick



The September 18 edition of the weekly “Pick Me Up” magazine featured the story of Angela Crooks, aged thirty. You may remember that Angie shared her experiences of pregnancy with us in our Spring 2008 newsletter.

The “Pick Me Up” article described how Angela had suffered episodes of mysterious vomiting for the last sixteen years. She had undergone countless scans and a gastroscopy at her local hospital in Torquay, but the tests had failed to reveal anything. She would have to spend a few days each month in hospital on a drip as a result of dehydration, and would need morphine for the pain. Her weight had dropped down to just six stone. She graphically described how sometimes she would pass out during episodes of vomiting, only to come round to find herself in a pool of

vomit. In spite of everything, she had managed to have three children, Sasha, seven, Liam, six and Aaron, four, but each pregnancy was racked with pain and nausea. Because of her illness she was too ill to look after the children and too unreliable to be employed. Her boyfriend, Colby, had been forced to leave his job when Sasha was born, to stay at home to look after her and the children.

As doctors were unable to help, Angela and her mum, Linda, trawled the internet to try to find answers to her plight. One day her mum rang triumphantly, saying that she thought she had found the answer. “I think you’ve got something called Cyclical Vomiting Syndrome”. Angela went straight on the internet and was stunned. It explained how symptoms include severe nausea, vomiting, abdominal pain, and blacking



out and that episodes could last for days to weeks at a time. Angela said that it was as if someone had written just about her. She talked to Colby about it and printed off everything from the internet to show to her GP.

Her GP agreed and said that low doses of antidepressants could reduce the symptoms. After experimenting with dosages, Angela is now much better and is able to be a mum again to the children. She can take them to the park, arrange parties and play-dates for them. As soon as she feels she has full control of her sickness, Colby plans to go back to work and Angela wants to train as a beauty therapist.

The article concluded with a useful fact file under the headings “What is it, How is CVS Diagnosed and Treatment”. For instance under Treatment it states: “Treatment can include intravenous fluids, anti-nausea medication and anti depressants. For further information visit www.cvsa.org.uk”.

Jade’s Story

We also had an email from April Douglas. She and her daughter, Jade, shared their story with the press. It is due to appear in “More” magazine shortly.

April writes:

“We have sold Jade’s story as below. As it took me nine years to find that she had CVS, we hope this may help sufferers out there find they are not alone and there is help and advice to be gained. I’m not sure how it will read, as they are into finding out embarrassing moments etc and boyfriends, but I really hope this helps. It’s already helping Jade. She will receive £150, which we hope will cover her MOT. She has taken quite a lot of time off work this year losing wages so this is a great help”.



BEVERLEY

Donations

We'd first like to thank Mrs. N. Gandhi for a magnificent donation of £2247.70 raised through Tumble Tots.

Robin saw some information in one of Contact a Family's newsletters about the London Law Trust. They were inviting applications for charity grants. Eager to get money for our cause and thinking there was nothing to lose, he put in an application for £3,000. On December 10 we received a grant of £1,000. Thank you so much, Robin, for your persistence. Thanks also go to Robin for sharing his computer skills. He regularly helps his friends Mike and Valerie Giles. In return they send us donations from time to time. Thank you for a gift of £25 in December.

We also send many thanks to the Rupra family who very generously donated £100.

One of our very regular sources of income is the garden party that Karen Thatcher and her family organise each year. It always raises hundreds of pounds for us. Again this year a magnificent sum was raised in spite of several difficulties. Thank you so much.

Karen writes:

"The party was postponed as I was rushed into hospital and, at the same time, Russell had a detached retina, which left poor Zara running the house and looking after Russell. The party finally went ahead on Saturday, 6 September. It was pouring with rain and people had to use umbrellas to get from the house to the first of the gazebos. Food was in the house, which was crammed with people and this made it even more friendly!

If it had gone ahead on the original date, the weather would have been glorious, but we still managed to raise £344.98. It was a tiring day but worth the effort I think, don't you? On top of the £344.98 for the party Zara has saved £35.00 in her copper jar and another £46.02 from the tin in the store, so our total for paying into the CVSA account tomorrow is £426.00".

Beverley Greenhalgh raised £45 by not sending Xmas cards to people at work but getting donations instead.

CELEBRATE

Posters, leaflets and international collaboration.

Last week I had a phone call from Louise Durbidge, one of our members. Her daughter, Charlotte, had had CVS diagnosed in the Paediatric Department of her local hospital in Eastbourne some years previously. Whilst waiting to see the paediatrician, she had seen one of our posters displayed in the children's waiting area. The symptoms seemed exactly like those Charlotte was experiencing. She drew the doctor's attention to this during the consultation. He, too, thought CVS was the most likely explanation. Many thanks go to the mystery member who placed that poster!

Louise was ringing this time to explain that Charlotte was much better and only occasionally had symptoms that needed i/v therapy in hospital. She is now fifteen and hoping to travel with a school party to New York. Her mum was trying to put a plan in place, just in case she were to be taken ill and need hospital care, whilst in America. I was able to contact Judy Babiasz, the administrator of CVSA USA on her behalf, and within a few days, pass on a list of recommended CVS specialists in the city. Hopefully, armed with these names, and a letter explaining treatment from her home consultant, Charlotte can enjoy her trip without worrying about what would happen if she were to become ill.

Please everyone consider placing posters or leaflets in your local clinic or GP's surgery. Go on the website or contact Beverley Greenhalgh (see inside cover) for details. Who knows whom you could help by your action?

Newsletter Printing

No doubt lots of you will have noticed how much clearer and more professional the last newsletter looked, as a result of being printed rather than photocopied. Will Moore very kindly has agreed with his employers Beran Instruments Ltd to print the newsletter for us. Thank you for the financial help of the company and for Will's hard work.

Tragedy Averted - a Disability Living Allowance Appeal Won.

We had some good news about a very sad case. One of our adult members has very severe CVS. As a result of this, he is unable to hold down a regular job and needs attention when he is ill.

He lived alone with his father, who cared for him during bouts. Sadly his father passed away and Peter (not his real name) was left alone, without finance or nursing care. He asked for our help and Amanda Sheehan took a great deal of trouble to support him. Realising he was feeling suicidal, she felt she needed to drop everything and give him time to talk. She tried to build up his trust and give him a sense of hope that things would get better. She also put him in touch with consultants who could help with his treatment and wrote to those consultants on his behalf, emphasising how severe his case was and that there appeared to be a strong hereditary connection.

His claim for Disability Living Allowance was thwart with difficulties. When vomiting, he was too ill to attend assessment meetings – how do you travel on public transport when half comatose and constantly retching? When he was sufficiently well to attend, it was well nigh impossible to persuade the assessor of his difficulties. This was especially true, because the authorities are always on the look out for fraudulent cases that are out to take advantage of the taxpayer.

Beverley Greenhalgh's sister, Samantha, is a Legal Representative. She agreed to fight Peter's corner free of charge and won his appeal for Disability Living Allowance (DLA). Beverley takes up the story:

“It took almost a year and became complicated, but after lots of arguing and a nine page appeal submission, ‘Peter’ has won his DLA appeal. He should get about £4k in back payments and a lot more to live on each week which is great, as he is very deserving.

He had said to Samantha that he was suicidal and thought he couldn't go on anymore and felt nobody cared. He now feels he can turn his life around – he can afford to pay for somebody to care for him each morning.

I know Samantha did most of the hard work, but if it hadn't of been for CVSA UK, he wouldn't have had anybody to help and who knows what might have happened to him.... Because Amanda was there for him and cared enough to listen to and share his story we were able to work as a team and put him in touch with somebody who could help. This is a fantastic ending to what could have become a tragic story.”

We hope this story highlights that other sufferers should know that they may be able to get benefits if CVS is a large part of their life and that, if they decide to pursue a benefits claim, they should not accept the first refusal.

Share Your Story



We regularly try to include stories of individual members. It is helpful for others to realise that they are not alone. It is also useful for professionals to learn of the problems that sufferers encounter and to realise what CVS is like 'on the inside'.

In this issue, we feature the difficulties that many find, when they move from paediatric to adult service providers. We also include a very accurate and vivid portrayal of the hidden reality of CVS.

Thank you so much Karen and Nicola for your articles.

We encourage everyone to 'share their story'. You may remain anonymous if you wish.

Beware of Transition Nightmare

My name is Karen Thomas, my daughter Kelly, who has just turned twenty-one, has been diagnosed with CVS since she was eight years old. She also developed epilepsy when she was twelve. After MRI scans she was found to have cavernomas which are blood vessels which are malformed. Funnily enough though, when she started having seizures, she had a couple of years free of any vomiting attacks until she was around fourteen. Then they returned, but for a number of years, they were less frequent and less severe. In fact, when we left paediatric care at eighteen and went to the adult sector, she had been free from the attacks for two years. They returned again when she was twenty.

We had 'not a bad' relationship with our paediatrician, although I had had quite a few disagreements with him over the years! Kelly had been under his care for ten years and we had trusted him to consider carefully her transition to the adult sector. We expected him to put her with the correct doctors for each condition, considering what she had been through over the past years. It wasn't to be.

I was told she just needed to be with a neurologist for epilepsy and that he would deal with the CVS as well, but that hasn't happened. In fact her first appointment with the adult neurologist at the same hospital was a nightmare. He came out of his room, shook our hands and briefly said he had had a nice long referral letter and that his registrar would deal with us. That was the last we saw of him - not even having the decency to meet up with us for our first appointment. I thought that was rude basically, as if we were too complicated for him.

From there I eventually got referred to a neurology hospital in Tooting SW London to see an epilepsy specialist, who is very nice, but couldn't understand why her CVS was

reoccurring. For some time he thought it might be seizure-related, but then, after bringing a surgeon in on our consultations, coming to the conclusion that this is probably not the case. Apparently the cavernomas aren't in the right position in the brain to cause vomiting. So, after nearly a year of begging for a gastric referral in the same hospital, so the two doctors could work together which I thought was the best thing, I have finally just had our first appointment with a gastroenterologist. Kelly's just waiting to have a series of tests on her bowels and stomach, tests she's never been given before, as I was always told they weren't necessary.

I mustn't forget to mention the nightmare when you have to go to A & E and wait for hours to get cannulated and have medication administered. After having 'direct access' to the paediatric wards it's hard to take, especially when it only takes ten to fifteen minutes to set-up. Then a twenty-one year old is put on wards with elderly, confused noisy patients - there seems to be no consideration to age. Of course you come up against doctors and nurses who have never heard of the condition, I have even been confronted with 'is this one you've made up yourself?' Unbelievable! You just have to stand your ground with them all.

"I have even been confronted with 'is this one you've made up yourself?'"

I won't go on anymore, but I just have to say a huge thank you to Dr. Chong who has been such a support to me after so many frantic phone calls. I met him some years ago when Kelly was in her mid teens and wanted to be transferred over to his care, but of course that was blocked and she was refused the referral. I only wished I had kicked up a fuss about that at the time. He very kindly rang the new doctor, we have just seen, to go through things with him, which was very helpful. His dedication and caring to our families I think is amazing. Also Karen Thatcher has been very helpful and supportive. It's so good to be able to speak to other people that appreciate what you're going through.

To sum our experience up, I would say, I feel very let down by our paediatrician after ten years of seeing him almost every month knowing what care Kelly needed. I actually trusted him to refer us to the right person, but that certainly didn't happen.

I have read lots of other people's stories in the newsletters, which are very interesting, if anyone would like to get in touch with me I would be happy to chat, my number is 0208 549 0759.

Karen Thomas

What CVS is *really* like

Besides the nausea, migraine-like-headache and familiar gurgling feeling in the bottom of my stomach, I mostly felt disappointed when I woke up this morning. I knew exactly what was happening, as it had happened exactly the same way so many times before. I had gone seven months to the day without being sick, which, in sixteen years, is a new record for me. I had begun to live a life entirely untainted by the thought that I might be, or furthermore would be, sick on a regular basis. In sixteen years, I had previously never been able to take health for granted. During these last seven months of health, all of those years spent with my head in a sick bucket, or with a canula attached to my arm in a hospital bed, seemed a world apart, as though they had happened to somebody else. However, this morning, curled up in one corner of my bed, covers pulled over my face to block out the light which seemed to taunt and distress me further, semi-consciously tapping my left foot in order to distract myself from the intense nausea, I was reminded of the illness that not so long ago, had dictated my whole life. Creeping upon me like a thief in the night, I would wake up in the early hours of the morning feeling intensely sick, no matter how well I had felt the day before. There would be no warning, no way of knowing whether or not I would be able to so much as get out of bed the next day.

It's difficult for me to decide which was worse; the intense feeling of nausea which rendered me to be unable to think of anything else - it took over my whole brain leaving little room for any other thoughts or feelings, stopped me from sleeping, stopped me from being able to so much as lift my head up off the pillow or to even listen to or watch the TV - or, on the other hand, the actual vomiting. Once I have been sick more than once, I am usually sick again and again and again. Unlike most people, emptying my stomach doesn't get rid of the feeling for the need to be sick, and for twenty-four hours, and sometimes much longer than this, I would throw up anywhere between once an hour to once every five minutes.

Being sick so frequently, with an empty stomach also had its consequences. The stomach acid eroding away at my oesophagus and the pain this caused, and the taste of blood and acid in my mouth is something that I will not try to describe. My teeth have now lost most of the protective enamel on the backs of them, due to being sick so much and the acid damage. Spending days in bed being sick often caused me to pull muscles in my stomach and also (I apologise if this is too graphic) affected the workings of my bowel, and as a result I came to have Irritable Bowel Syndrome as well as the CVS.

During the worst years of my illness I spent nearly as much time being sick as I did well. It was not uncommon for me to spend one week at school, and the next in hospital, and the cycle would repeat itself. Some teachers found this very difficult to understand, that my illness was as predictable as was the fortnightly school timetable, and I'm sure that certain teachers that I rarely saw, thought it was some strange ploy to get out of their subject.

When I was thirteen years old, seven years after this strange illness became such a prominent part of my life, I was diagnosed with CVS. After seven years of being told things like, “it’s just a virus”, “there’s nothing physically wrong”, or “it’s all in your head” by some doctors, it was a relief to meet a doctor who had heard of other patients who had experienced the same symptoms I had. That it was a real illness and some doctors took it very seriously.

I consider myself extremely fortunate that today, I have only been sick a couple of times. After a couple of hours of lying in bed trying to ignore the feelings of nausea I was eventually able to fall asleep, and when I awoke several hours later the nausea had subsided enough for me to be able to get out of bed, sit up, and look at a computer screen. I still have a bit of a headache and my stomach is restless, for want of a better word, but I know I’m going to be ok. I know I don’t have to look forward to a night of no sleep, a bucket by the bed, and throwing up every five to fifteen minutes throughout the night, and severe dehydration the next morning. A year ago, this was something I could expect on a monthly basis and two years ago on a weekly, or even twice weekly basis. It would seem that, although this illness has not gone completely - today was further evidence to me that I will probably still get occasional days of illness and that I should never take my health for granted – I am “growing out” of this condition. My episodes are less regular, and although they can still be as intense (though today’s definitely was not), they are much shorter, typically only lasting a couple of days rather than over a week. I feel like my condition is manageable and these days I barely have to even think about it, which is something that, during my teenage years I had little hope of believing would be possible.

I would like to add that the biggest comfort to me during the years I was quite ill, were my friends, my family and my faith in God. The people closest to me have always tried to be understanding and saw me as a person, rather than just somebody who was ill all of the time. My parents took my symptoms seriously and sought second opinion after second opinion until we were finally taken seriously, for which I am eternally grateful. My friends stuck up for me when other children, and even teachers at school misunderstood my situation and treated me with some unkindness due to their fear of the unknown. They became experts at recognising when I was about to have an attack and sought help for me. Some of them even saw me to the toilet and held my hair back for me while I was being sick, or helped to clean me up when I made a mess of myself. If you have ever been sick in a public place, or, more specifically, in a secondary school full of teenagers who can be very critical, you will have an idea of what this meant to me. One friend even wrote to me regularly when I was off school most of one year, so that I wouldn’t feel left out and could keep up to date with what was going on.

I hope this brief description of my experiences will be of some use to others who have, or are suffering with CVS, and also to people who have no experience or little understanding of what CVS is and how it may affect a person’s life.

Nicola Willis

International Initiatives and News from Abroad

USA

In 2008, CVSA-USA proudly accomplished:

1. Support for genetic research and the connection between CVS and mitochondrial disease. Several research projects are underway.

2. The completion of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition consensus statement on the diagnosis and management of Cyclic Vomiting Syndrome. This is an international guideline published in the Journal of Pediatric Gastroenterology and Nutrition. These guidelines will serve well to standardize our children's care and offer guidance to physicians caring for adult CVS patients as well.

3. The 5th International Family and Adult Conference, and plans for a major scientific symposium on CVS.

4. Collaboration with three CVS Centers for patient treatment, education and support. Nearly 2000 outreach calls/emails for support and information about CVS, and assistance to local CVS support groups.



The North American society also ran an online fund raising initiative: *In order for CVSA to continue to raise awareness and provide the education and support to those affected by cyclic vomiting, abdominal migraine and related disorders while advocating for, and funding research, we are asking for you help by supporting the CVSA Holiday Giving Tree. As your contributions are received, our giving tree will come to life on our Giving Tree.*



View Giving Tree at <http://tinyurl.com/cxejpe>

Kuwait

Lara Arcadia wrote to us in some detail from Kuwait. I include a few extracts here.

Sami started the vomiting episodes shortly after we moved to Kuwait in August 2006. They were two to three weeks apart, lasting about a day and a half, with a day to recover. I started to do a lot of research on the computer and found an article in one of the medical journals entitled “L-carnitine in cyclical vomiting syndrome” from Archives of Disease in Childhood 2004. Since I had no help from doctors here except a diagnosis, I decided to give it a try. I started Sami on L-carnitine capsules from Epic regularly in April of 2007, after two really bad episodes in March that were only a week apart. The capsules are 250mg and I separated them into approximately 3rds. I don't know why but that's what I did. He had one episode in mid April, but it was not bad and it was brought on by driving in the mountains in Jordan, so I wasn't too discouraged and kept him on it religiously.

After reducing Sami's intake of L-carnitine, Sami complained of nausea more often and even woke up early in the morning with extreme nausea a couple of times, but never actually vomited. This pattern continued through November then I went back through my notes and found that the combination of L-carnitine and CoQ10 seemed promising. I then started Sami on the reduced amount of L-carnitine combined with 30mg of the chewable CoQ10 and it appeared to work, to my amazement. He stopped complaining of nausea and seemed to calm down a bit. With the combination of CoQ10 and L-Carnitine Sami was incident free all through December and the beginning of January, until I ran out of CoQ10 (someone accidentally threw away two bottles in my kitchen cupboard). Sami immediately started to complain of nausea regularly and even had an episode in mid January. I speculate that the reduced amount of L-carnitine was not enough to prevent episodes, but that the combination of the two was and is enough to control CVS. However, he does complain of nausea quite a bit, but is ok after he eats. I feed him frequently. I shouldn't let more than three hours go by without food. I have seen a change in the symptoms of Sami's CVS from classic vomiting episodes to headaches, nausea and fatigue. I am hoping that the increased intake of L-carnitine will help. As you can see, I need to get Sami to a doctor for various tests. He no longer suffers from the classic horrible vomiting episodes, but the nausea and fatigue are still a problem and, of course, the headaches which have just started.

Additionally, I believe that I suffered from CVS infrequently at times of stress, which I did not develop until I went away to University. It coincided with my cycle and I would not stop vomiting until I went to Clinic or hospital for a shot which just knocked me out. The episodes stopped abruptly after I went on birth control pills. I went off birth control a couple of years later and the episodes returned for the next two or three years (maybe twice a year) until I went back on them.

My maternal aunt, who is in her mid-seventies now, said that she had the same thing that I did (vomiting horribly before her monthly) and that it stopped after she started having children.

Italy



Associazione Italiana Sindrome del Vomito Ciclico

In the last newsletter we reported how a planned scientific symposium on CVS in Italy had been postponed because of funding problems. However, we are now very pleased to say that the new Italian group did manage to arrange a successful inaugural national meeting for doctors and patients. This was held on Saturday, December 6 in Florence.

The proceedings started at 9.30 a.m. with a series of lectures given by doctors. Dr. Ravelli, our shared medical adviser, from Brescia University, gave the first thirty-minute presentation. This was followed by talks by Drs. Roberto Micheli, Anna Magliano and Domenica Taruscio. Silvia Martinazzi also spoke about her clinical experience of CVS. Discussions followed in the afternoon, before the close at 5 p.m. We should like to thank Denys Figliuolo and Dr. Alberto Ravelli for all their hard work in arranging this meeting.

Germany

As I have mentioned, Heinz Göegelein, the new Contact for Germany, attended our Family Day in November. He said he found meeting the advisers and specialists in the field of CVS and our members helpful. He wrote: "Until now, I have made contact with some German physicians who are, or were, involved with children having CVS. I am in contact with a German organisation called "Achse", which takes care of rare diseases. I hope that they will mention CVS on their website". He also plans to approach other German societies and will send them information.

Belgium

Karim Khan, from Antwerp, has a young son, Sammy, who suffers from CVS. He has been in touch with us a few times and has agreed to be the new contact for Belgium. He says he is always ready to help other Belgian families dealing with CVS.

Karim Khan - Karen Panhuyzen
Karel De Preterlei 114
2140 Antwerpen, Belgium
0032.3.235.96.80
karim.khan@telenet.be
karen.panhuyzen@telenet.be

CVSA - ABROAD

USA	Judy Babiasz	cvsa@cvsaonline.org
Canada	Jodie Jonas	jodiejonas@sympatico.ca
Australia	Mary Tuder	maryt@arach.net.au
Italy	Denys Figliuolo	sicvo@libero.it

Informal CVS Groups and Contact Families

Austria	Christiane Koszka	ckoszka@aon.at
Belgium	Karim Khan	karim.khan@telnet.be
Cyprus	Marios Georgiou	mazgeorgiou@yahoo.co.uk
Denmark	Pia Hoelstad	pia@hoelstad.dk
Finland	Jauni and Rauni Jorasmaa	jouni.jorasmaa@kolumbus.fi
Germany	Heinz Göegelein	heinz.goegelein@web.de
Greece	Anna Ioannou	bidoo5@hotmail.com
India	S Srinivasan	
Ireland	Carmel Duffy	carmelwatersduffy@hotmail.com
Japan	Hiroko Shinada	VFD06342@nifty.ne.jp
Mexico	Agustin Terrazas	agustin_terrzas@yahoo.com
New Zealand	Anne and Steven Thomas	steveMthomas@xtra.co.nz
Pakistan	Sohail Asghar	ali_soh@hotmail.com
South Africa	Ruth Naude	ruthn@mweb.co.za
Thailand	Reka Aguilar	rekapeti@phuketinternet.co.th

Groups with a Medical Co-ordinator

Brazil	Dr. Rogério Dantas	rogeriodantas@terra.com.br
Chile	Dr. Ernesto Guiraldes	eguirald@puc.cl
Cuba	Dr. Maria del Pilar Escobar	mescobar@infomed.sld.cu
Hong Kong	Dr. Kaming Cheung	jennykmcheung@hotmail.com
Italy	Dr. Alberto Ravelli	alberto_ravelli@yahoo.com
Oman	Dr. Padmanabhan	padmnabn@omantel.net.om
Peru	Dr. Luis Felix	luafoxp@yahoo.com
Spain	Dr. Ramon Tormo	rtormo@conexis.es
Ukraine	Dr. Yuri Sapa	sapa@privat-online.net

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