



Code 'V'

Newsletter of the Cyclic Vomiting Syndrome Association—USA/Canada

MAY 2004

VOL. 12, NO. 2

Cyclic Vomiting Syndrome National Digestive Diseases Information Clearinghouse

Cyclic Vomiting Syndrome

- Four Phases
- Triggers
- Symptoms
- Diagnosis
- Treatment
- Complications
- Points to Remember
- CVS and Migraines
- NIDDK

In cyclic vomiting syndrome (CVS), people experience bouts or cycles of severe nausea and vomiting that last for hours or even days and alternate with longer periods of no symptoms. CVS occurs mostly in children, but the disorder can affect adults, too.

CVS has no known cause. Each episode is similar to the previous ones. The episodes tend to start at about the same time of day, last the same length of time, and present the same symptoms at the same level of intensity. Although CVS can begin at any age in children and adults, it usually starts between the ages of 3 and 7. In adults, episodes tend to occur less often than they do in children, but they last longer. Furthermore, the events or situations that trigger episodes in adults cannot always be pinpointed as easily as they can in children.

Episodes can be so severe that a person may have to stay in bed for days, unable to go to school or work. No one knows for sure how many people have CVS, but medical researchers believe that more people may have the disorder than is commonly thought (as many as 1 in 50 children in one study). Because other more common diseases and disorders also cause cycles of vomiting, many people with CVS are initially misdiagnosed until the other disorders can be ruled out. What *is* known is that CVS can be disruptive and frightening not just to people who have it, but to the entire family as well.

The Four Phases of CVS

Prodrome phase signals that an episode of nausea and vomiting is about to begin. This phase, which is often marked by abdominal pain, can last from just a few minutes to several hours. Sometimes taking medicine early in the prodrome phase can stop an episode in progress. However, sometimes there is no warning: A person may simply wake up in the morning and begin vomiting.

Episode phase consists of nausea and vomiting; inability to eat, drink, or take medicines without vomiting; paleness; drowsiness; and exhaustion.

Recovery phase begins when the nausea and vomiting stop. Healthy color, appetite, and energy return.

Symptom-free interval phase is the period between episodes when no symptoms are present.

Triggers

Most people can identify a specific condition or event that triggered an episode. The most common trigger is an infection. Another, often found in children, is emotional stress or excitement, often from a birthday or vacation, for example. Colds, allergies, sinus problems, and the flu can also set off episodes in some people.

Other reported triggers include eating certain foods (such as chocolate or cheese), eating too much, or eating just before going to bed. Hot weather, physical exhaustion, menstruation, and motion sickness can also trigger episodes.

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Caring for CVS Patients

CYCLIC VOMITING SYNDROME (CVS) is an unexplained episodic disorder, characterized by recurrent, prolonged, self-limited attacks of severe nausea, vomiting and prostration with no apparent cause. The episodes can last for hours or days with repeated vomiting occurring at frequent intervals (5-10 times an hour at the peak). Episodes tend to be similar in symptoms and duration and are self-limited. Patients usually experience normal health between episodes.

Occurrence: Onset of CVS can begin in infancy, childhood, or adulthood and can persist for months to decades. In children, it typically persists for several years before resolving during adolescence in exchange for developing migraine headaches. Episodes may recur several times a year or as often as several times a month. There is usually a family history of migraine and a high likelihood that episodes may develop into migraine headaches in later life.

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Editor – Bonnie Van Veldhuizen

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***Opinions expressed by contributors are their own, and not necessarily those of CVSA-USA/Canada. CVSA-USA/Canada does not endorse any specific product, medication, treatment or claim by a contributor and disclaims all liability relating thereto. The content of Code 'V' is in no way intended to replace the knowledge of your physician. We advise working closely with a physician in regard to a patient's health care needs.**

WHAT IS CYCLIC VOMITING SYNDROME?

Cyclic Vomiting Syndrome (CVS) is an uncommon, unexplained disorder that is characterized by recurrent, prolonged episodes of severe nausea, vomiting and prostration with no apparent cause. Vomiting occurs at frequent intervals (5-10 times per hour at the peak) for hours to 10 days (1-4 days most commonly). The episodes tend to be similar to each other in symptoms and duration, and are self-limited. The patient is generally well between episodes.

CYCLIC VOMITING SYNDROME ASSOCIATION-USA/CANADA

"CVSA-USA/Canada will raise awareness, provide education and support to those affected by CVS and advocate for research about nausea and vomiting."

The CVSA-USA/Canada Federal Identification Number is 39-1767509. Donations are tax deductible under the designation of a non-profit organization by the Internal Revenue Service, Section 501(C)(3).

CVSA— Where we've been and what lies ahead by Diane Babbitt and Debra Waites

Where have we been?

2003 was a pivotal year for CVSA. We acknowledged some very crucial issues we needed to face as we continue to grow and serve CVS sufferers worldwide. It was in February of 2003 that we met with non-profit development consultants, and our Board of Directors re-committed ourselves to a refined mission. As part of that renewed commitment we found it necessary to work on our infrastructure in general. Now we've addressed most of the core issues that needed attention and we're ready to swing into 2004 with renewed commitment!

As we move through 2004...

- We are publishing our first brochure directed at health care professionals and will be mailing it out as part of our largest professional education mailing ever.
- We have begun collaborating with a national marketing company that specializes in "cause related marketing" and, with their expert support, plan to take CVS into the mainstream over the next 2 years.
- We added two new and accomplished members to our Board of Directors, Doug Wilson and Pat Murphy, and increased the number of annual board meetings from one annual meeting to 11 scheduled teleconferences and meetings in 2004.
- A variety of fundraisers are taking place around the country, all working together to provide us with the necessary finances to move ahead in our mission.
- Professional support as well as general progress on the work necessary to publish NASPGHAN Guidelines for Diagnosis and Treatment of CVS has exceeded our initial expectations. We currently anticipate publishing the guidelines in 2005.
- Increased project spending for 2004 is paving the way for further development of the many services CVSA offers its members including more public and professional education, our new outreach program, and further development of our online services.
- We completed updating our mission statement and are focused next on a major update of our by-laws.
- CVSA presented information about CVS and our organization to professionals at the AMS Conference on Motility, in Nashville, TN this past January.
- CVSA will attend the Digestive Disease Week (DDW) in May in New Orleans, where we will also be providing professionals with the latest information about CVS and CVSA-USA/Canada.

CVSA, along with CVSA UK, is in the final planning stages of co-sponsoring a professional "get-together" in Paris this July at the 2nd World Congress of Pediatric Gastroenterology, Hepatology and Nutrition. This is an opportunity to allow some of the world experts in CVS to touch base with each other as well as raise professional awareness of CVS on a global platform. We've been diligent and made some difficult decisions over the last year while successfully building a strong team. We overcame some challenges we faced and we have reflected on our past accomplishments while building for our future accomplishments.

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Visit <http://www.cvsaonline.org/donateshop&givemall1.htm> and find out how you can "Shop and Give" to CVSA. Giving can't get any easier!

Cyclic Vomiting Syndrome (con't from Page 1)

Symptoms

The main symptoms of CVS are severe vomiting, nausea, and retching (gagging). Episodes usually begin at night or first thing in the morning and may include vomiting or retching as often as six to 12 times an hour during the worst of the episode. Episodes usually last anywhere from 1 to 5 days, though they can last for up to 10 days.

Other symptoms include pallor, exhaustion, and listlessness. Sometimes the nausea and vomiting are so severe that a person appears to be almost unconscious. Sensitivity to light, headache, fever, dizziness, diarrhea, and abdominal pain may also accompany an episode.

In addition, the vomiting may cause drooling and excessive thirst. Drinking water usually leads to more vomiting, though the water can dilute the acid in the vomit, making the episode a little less painful. Continuous vomiting can lead to dehydration, which means that the body has lost excessive water and salts.

Diagnosis

CVS is hard to diagnose because no clear tests--such as a blood test or x ray--exist to identify it. A doctor must diagnose CVS by looking at symptoms and medical history and by excluding more common diseases or disorders that can also cause nausea and vomiting. Also, diagnosis takes time because doctors need to identify a pattern or cycle to the vomiting.

Treatment

CVS cannot be cured. Treatment varies, but people with CVS are generally advised to get plenty of rest; sleep; and take medications that prevent a vomiting episode, stop or alleviate one that has already started, or relieve other symptoms.

Once a vomiting episode begins, treatment is supportive. It helps to stay in bed and sleep in a dark, quiet room. Severe nausea and vomiting may require hospitalization and intravenous fluids to prevent dehydration. Sedatives may help if the nausea continues.

Sometimes, during the prodrome phase, it is possible to stop an episode from happening altogether. For example, people who feel abdominal pain before an episode can ask their doctor about taking ibuprofen (Advil, Motrin) to try to stop it. Other medications that may be helpful are ranitidine (Zantac) or omeprazole (Prilosec), which help calm the stomach by lowering the amount of acid it makes.

During the recovery phase, drinking water and replacing lost electrolytes are very important. Electrolytes are salts that the body needs to function well and stay healthy. Symptoms during the recovery phase can vary: Some people find that their appetites return to normal immediately, while others need to begin by drinking clear liquids and then move slowly to solid food.

People whose episodes are frequent and long-lasting may be treated during the symptom-free intervals in an effort to prevent or ease future episodes. Medications that help people with migraine headaches--propranolol, cyproheptadine, and amitriptyline--are sometimes used during this phase, but they do not work for everyone. Taking the medicine daily for 1 to 2 months may be necessary to see if it helps.

In addition, the symptom-free phase is a good time to eliminate anything known to trigger an episode. For example, if episodes are brought on by stress or excitement, this period is the time to find ways to reduce stress and stay calm. If sinus problems or allergies cause episodes, those conditions should be treated.

Complications

The severe vomiting that defines CVS is a risk factor for several complications:

Dehydration – Vomiting causes the body to lose water quickly.

Electrolyte imbalance – Vomiting also causes the body to lose the important salts it needs to keep working properly.

Peptic esophagitis – The esophagus (the tube that connects the mouth to the stomach) becomes injured from the stomach acid that comes up with the vomit.

Hematemesis – The esophagus becomes irritated and bleeds, so blood mixes with the vomit.

Mallory-Weiss tear – The lower end of the esophagus may tear open or the stomach may bruise from vomiting or retching.

Tooth decay. The acid in the vomit can hurt the teeth by corroding the tooth enamel.

(continued on page 4)

Raise funds for CVSA while you decorate your home!

Have you ever imagined decorating your home with the look of hand painted artwork in a corner, above a doorway, on furniture, or perhaps a one of a kind mural adorning an entire wall? Tatouage high resolution dry rub transfers are indistinguishable from the original paintings by Carolyn Yovan. You may have already purchased Tatouage on Home Shopping Network. Tatouage can be applied to just about any hard surface-- no paint, no glue, no water, no fumes, and no mess. You decide where to apply the Tatouage, cut out the design, remove the protective backing, place the transfer down, rub the design with the applicator stick, and peel the transfer back.



There are many designs to choose from including but not limited to palm trees, roses, vines, beach scenes, picket fences, flowers, ivy, fountains, birdbaths, animals, baby footprints, cherubs, statues and much more. **To participate in the fundraiser, shop at www.tatouagedesigns.com between now and July 31st. Make sure to enter the savings code: CinO'N36 to receive 10% off your order and to ensure the purchase is credited to Cindy so she can donate the proceeds to CVSA.** Items will ship directly to your home within 7-10 days. If you have any questions, please email Cindy O'Neill at cindystatouage@aol.com

Cyclic Vomiting Syndrome (con't from Page 3)

CVS and Migraine

The relationship between migraine and CVS is still unclear, but medical researchers believe that the two are related. First, migraine headaches, which cause severe pain in the head; abdominal migraine, which causes stomach pain; and CVS are all marked by severe symptoms that start quickly and end abruptly, followed by longer periods without pain or other symptoms.

Second, many of the situations that trigger CVS also trigger migraines. Those triggers include stress and excitement.

Third, research has shown that many children with CVS either have a family history of migraine or develop migraines as they grow older.

Because of the similarities between migraine and CVS, doctors treat some people with severe CVS with drugs that are also used for migraine headaches. The drugs are designed to prevent episodes, reduce their frequency, or lessen their severity.

Points to Remember

People with CVS have severe nausea and vomiting that come in cycles.

CVS occurs mostly in children, but adults can have it, too.

CVS has four phases: prodrome, episode, recovery, and symptom-free interval.

Most people can identify a condition or event that triggers an episode of nausea and vomiting. Infections and emotional stress are two common triggers.

The main symptoms of CVS are severe vomiting, nausea, and retching. Other symptoms include pallor and exhaustion.

The only way a doctor can diagnose CVS is by looking at symptoms and medical history to rule out any other possible causes for the nausea and vomiting. Then the doctor must identify a pattern or cycle to the symptoms.

CVS has no cure. Treatment varies by person, but people with CVS generally need to get plenty of rest and sleep. They may also be given drugs that may prevent an episode, stop one in progress, speed up recovery, or relieve symptoms.

Complications include dehydration, loss of electrolytes, peptic esophagitis, hematemesis, Mallory-Weiss tear, and tooth decay.

NIDDK

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services. Established in 1980, the clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. NDDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

Publications produced by the National Digestive Diseases Information Clearinghouse are carefully reviewed by both NIDDK scientists and outside experts. This e-text is not copyrighted. The clearinghouse encourages readers to duplicate and distribute as many copies as desired. NIH Publication No. 04-4548. February 2004. National Digestive Diseases Information Clearinghouse, 2 Information Way, Bethesda, MD 20892-3570 Email: nddic@info.niddk.nih.gov

2nd Annual Walk to Stop the Cycle submitted by Laura Koch

"You can reach Laura with support and ideas at cvswalk@msn.com, or contact CVSA at 614/837-2586."

We just wanted to let everyone know that after much encouragement we have decided to do a 2nd "Stop the Cycle" of Cyclic Vomiting Syndrome Walk! It will be October 2 at beautiful Sherwood Island State Park, Connecticut. Let's hope it is a little warmer this year!

If you know of anyone interested in becoming a corporate sponsor, please let me know. We will probably do the raffle differently this year so we will be looking for 3-4 donations of larger items that can be awarded as prizes. Tickets will be available prior to and at the event. If you know of anyone willing to donate (i.e., tickets to a show, dinner for 2, new car – I can dream, can't I?), please let me know. Thanks again for your support!

On the Calendar

MAY 15-24 **Digestive Disease Week** – CVSA staff and our information booth will be in the Morial Convention Center, New Orleans for DDW. DDW is the largest international gathering of physicians, researchers and academics in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery. Attendance averages 14,000 people, just over half of whom travel from outside the United States.

JUNE **Professional Outreach** – Our newly designed Professional brochure goes out to over 2000 top-ranked medical professionals throughout the US in an effort to raise awareness of CVS. This is in preparation of the 2005 release of the NASPGHAN guidelines.

JULY 3-7 **CVSA sponsored breakfast, Paris, France** at the 2nd World Conference Pediatric GI - FISPGHAN (Congress of Pediatric Gastroenterology, Hepatology and Nutrition) features B U.K. Li, MD speaking to approximately 50 medical professionals about CVS. This event is co-sponsored by CVSA-UK.

JULY **Stop the Cycle National Fundraiser!** Watch your mailbox for your packet of information on this annual campaign. Commit to do your part in helping CVSA continue to offer the programs and support we are used to!

OCTOBER 2 **2nd Annual CVSA Walk to Stop The Cycle** steps off October 2 in Connecticut. Along with this walk, there will be a Walk to Stop the Cycle held in Michigan the same weekend! Watch for details on how you can be a part of these walks no matter where you live.

CVS continues to gain professional recognition – American Motility Society

CVSA Executive Director Debra Waites, Board of Directors member Doug Wilson, CVSA volunteer Danielle Waites, and I attended the American Motility Society Course on Gastrointestinal Motility in Clinical Practices Patient Workshop where we represented CVSA-USA/Canada and CVS sufferers worldwide. The American Motility Society (AMS) is made up of gastroenterologists from across the United States who care for both adult and pediatric patients. They, along with the University of Kansas, sponsor this bi-annual conference that is intended for a wide cross section of health care providers involved with gastrointestinal conditions. Health care professionals can earn continuing education credits for attending and the conference was attended by over 300 such professionals.

While Debra and Danielle Waites worked at our information booth distributing information about CVS to patients, physicians, nurses and other health care professionals, I gave a short lecture about the services CVSA-USA/Canada offers to our members and CVS sufferers worldwide as well as updating the audience about the our current membership and estimated numbers of sufferers worldwide as well as the impact of CVS on their lives in an effort to raise both professional awareness and support of our cause.

Our presentation was well received and we were delighted at the level of support we received from this group of professionals. The AMS expressed a desire to work with us to raise the awareness within their membership so that they can serve as a professional referral base for CVS sufferers. Since we are in the midst of producing a new brochure about CVS directed at medical professionals, this opportunity comes at an excellent time. I am optimistic that we will be able to distribute this new brochure to the entire membership of the AMS as well as making our entire professional information packet directly available to their members. This is another big step for pediatric care and a monumental step for all adults with CVS.

More than one of the physicians who stopped by our booth to visit mentioned to us that CVS had been discussed several times during the course of the medical professional portions of the course. Health care professionals at this level are offering us more support than ever. The cooperation of medical groups such as the AMS put us in a strong position to pursue our efforts to spread the word about CVS to hometown clinicians and local hospitals. Between this kind of support and the anticipated publication of the NASPGHAN guidelines on diagnosis and treatment of CVS in 2005, all CVS sufferers are going to find it easier to find competent medical attention without traveling miles for it in the very near future.

Diane Babbitt,
President, Board of Directors

Welcome TWO New Board Members!

Please welcome one of our newest CVSA Board of Directors members, Doug Wilson, Sr.!

Doug is a Founding Shareholder, Senior Executive Vice-President and Director of Thomas & King, Inc., a company that owns and operates 88 Applebee's and one Johnny Carino's restaurants. Doug has over thirty years of experience in real estate acquisition and development for hotels, offices, restaurants, shopping centers, condominiums, and various other income producing commercial projects across the country.

He is President of The Wilson Company, which invests in real estate and business ventures. Doug is active in his community raising money for charities. He is a member of First Baptist Church of Greenville, SC, where he serves as a Deacon and Sunday School teacher. Doug is also a member of the Rotary Club and other boards and social clubs.

And also welcome new CVSA Board of Directors member, Patrick Murphy, MBA CHFP!

Pat is Director of Revenue Cycle Management at Thomas Hospital in Fairhope, AL. Pat and wife Amy have 3 children, Zachary age 6, Seth age 3, and Grace age 2. Grace has been battling CVS since three months of age.

Pat and Amy (Amy is a Pediatric Physical Therapist) became involved with CVSA in the hopes of helping other families living with CVS, as well as helping to spread the word to healthcare providers everywhere.

Pat is very interested in working with the Board and assisting in driving the fundraising process to support research. As the parents of a CVS sufferer, their goals are to do everything possible to support her and the other sufferers of CVS.

"This organization is one way to 'get the word out' to the public, especially the physician community to ensure no child or adult suffers without a diagnosis."

Longtime CVSA Medical Advisor Retires

John A. Walker-Smith, Professor of Paediatrics – GI, Royal Free Hospital, Pond Street, London – has announced his retirement from active practice, and his desire to step down from our Medical Advisors list.

From Dr. Walker-Smith, "I have enjoyed being a part of the CVS Association. You have all come a long way and I wish you every success in the future ultimately conquering CVS!"

Thank you, Dr. Walker-Smith, for your commitment to CVSA – we wish you well in your retirement!



**Thank you,
Dr. Walker-Smith!**

CVSA – USA/Canada Medical Advisors

Thomas L. Abell, MD

University of Mississippi Medical Center, Jackson

John M. Anderson, MD

University of Texas, Dallas

Paul L.R. Andrews, PhD

St. Georges Hospital Medical School, London, UK

Jane P. Balint, MD

Ohio State University, Columbus

Richard G. Boles, MD

University of Southern California, Los Angeles

Athos Bousvaros, MD

Harvard Medical School, Boston

Sonny K.F. Chong, MD

Queen Mary's Hospital for Children, Surrey, UK

Ray E. Clouse, MD

Washington University, St. Louis, MO

Thomas Dunigan, MD

Children's Hospital of Wisconsin, Milwaukee

David R. Fleisher, MD

University of Missouri, Columbia

David Forbes, MBBS

 Princess Margaret Hospital for Children
Perth, Western Australia

Jeremy Gale, PhD

Sandwich, Kent, UK

Paul E Hyman, MD

University of Kansas Medical Center, Kansas City

Robert M. Isсенman, MD

McMaster University, Hamilton, Ontario

Patricio Kenny, MD

Hospital Britanico de Buenos Aires, Argentina

Joseph Levy, MD

Children's Hospital of New York, New York City

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Mayo Medical School, Scottsdale, AZ

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 Columbia University College of Physicians and Surgeons
New York City

Jean Perrault, MD

Montreal Children's Hospital, Montreal, Quebec

Louis J. Ptacek, MD

Howard Hughes Medical Institute, San Francisco

Alberto Ravelli, MD

University of Brescia, Italy

Piero Rinaldo, MD

Mayo Clinic and Medical School, Rochester, MN

Richard C. Rogers, PhD

Louisiana State University, Baton Rouge

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Medical School

Jackie D. Wood, PhD

College of Medicine, Ohio State University, Columbus

CLINICAL, MEDICAL AND TRANSPORTATION AID

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| First Hand Foundation www.firsthandfoundation.org Tel. 816-201-1569 (Pediatric patients only) | The Medicine Program www.TheMedicineProgram.com Tel. -573-996-7300 | Help With Medicine www.helpwithmedicine.org Tel. 573-351-1222 |
| Flights for Life http://members.cox.net/flightsforlife Tel. 480-838-6169 | Hope Air (Canada) www.hopeair.org Tel. 877-346-4673 | More info available at ww.cvsaonline.org |

INFORMATION RESOURCES

| | | |
|---|---|--|
| CVSA-USA/Canada 3585 Cedar Hill Rd. NW Canal Winchester, OH 43110 Tel: 614/837-2586; Fax: 614/837-2586 Email: waitesd@cvsaonline.org www.cvsaonline.org | Australian CVS Association 45 Beatrice Rd., Dalkeith, Perth, W. Australia 6009 Tel: 61 893891287; Fax: 61 893867462 Email: maryt@micromine.com.au www.geocities.com/Heartland/Village/7495 | CVSA UK 77 Wilbury Hills Rd., Letchworth Hertfordshire, SG6 4LD, England Tel:44 1462 485561 email:Robin@cvsa.org.uk http://www.cvsa.org.uk |
| The International CVS Program Department of Gastroenterology Children's Memorial Hospital 2300 Children's Plaza, Chicago, IL 60614 Tel: 773-880-4496 | International Foundation for Functional Gastrointestinal Disorders (IFFGD) PO Box 170864, Milwaukee, WI 53217-8076 Tel: 414/964-1799 Children – http://www.aboutkidsgi.org/ Adults – http://www.iffgd.org/ | Migraine Awareness Group (M.A.G.N.U.M.) 113 South Saint Asaph. Ste. 300 Alexandria, Virginia 22314 Tel: 703/739-9384 Web: www.migraines.org |
| Center for Education Rights University Technology Park 1450 Edgemont Ave. Ste 200 Chester, PA 19013-3920; Tel: 610/499-9280 http://www.specialedlaw.net | The United Mitochondrial Disease Foundation P.O. Box 1151, Monroeville, PA 15146-1151 Tel: 412/793-8077 www.umdf.org | More info available at ww.cvsaonline.org |

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Millions suffer from a condition most doctors have never heard of– Cyclical Vomiting Syndrome: Experts will gather in Paris to discuss

Worldwide, millions of people have suffered from a condition which most doctors have never heard of– Cyclical Vomiting Syndrome (CVS). Studies in the UK and Australia have shown that 2% of school age children suffer from CVS. Due to increasing awareness the number of patients diagnosed with CVS in the US is climbing at a staggering rate. CVS is a condition that generally has its onset in childhood and may last throughout life. Sufferers endure repeated cycles, over days or weeks, during which they suffer violent and repeated vomiting. Many become severely dehydrated and require hospitalization. Sufferers may vomit 5-6 times per hour and an episode may last from one to fourteen days. In the extreme case only sedation can stop the process. Not only is this a terrifying and distressing condition, it is potentially life threatening.

Because vomiting is common in children, CVS can be difficult to recognize. Many suffer in silence, in some cases they are misdiagnosed as having psychiatric illness and are detained against their will, adding to the fear and suffering they already experience. The average time from onset to diagnosis is 2.5 years. Whole families are affected by the disruption this condition brings.

Currently there are neither simple diagnostic tests, nor effective treatments for CVS. Some forms of CVS have similarities to migraine and may represent a variant type, in others the association is less clear.

The Cyclical Vomiting Syndrome Association (CVSA) is a registered charity in the UK and is run by parents and sufferers. The Cyclic Vomiting Syndrome Association– USA/Canada (CVSA-USA/Canada), also a recognized non-profit organization, shares the same mission: promoting awareness, education and research into this condition. There are many health problems fighting for our attention but there are very few which are as hidden, misunderstood and yet so common as CVS.

Through the joint sponsorship of the two groups CVS will be an area of focus during the week long World Congress on Pediatric Gastroenterology, Hepatology & Nutrition (WCPGHN) taking place July 3-7, 2004 in Paris. Pre-eminent leaders in the field of treatment and research of CVS speaking to the professional audience will include:

Professor Paul L.R. Andrews, St. Georges Hospital Medical School, London, UK

B Li MD, Professor of Pediatrics, Northwestern University, Director of Gastroenterology, Division of GI/Hepatology/Nutrition, Children's Memorial Hospital, Chicago, IL, USA,

Dr. Keith J Lindley, BSc PhD MRCP(UK) MRCPCH- Senior Lecturer, Hon Consultant, Institute of Child Health and Great Ormond Street Hospital, London, UK

To receive more information about this conference, please contact:

CVSA (UK)

Chair: Dr. Robin Dover
01 462 680 122
robin@cvsa.org.uk
www.cvsa.org.uk

CVSA-USA/Canada

Executive Director: Debra Waites
614-837-2586
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CVS Satellite Session Scheduled in Paris, France – July 2004 2nd World Congress of Pediatric Gastroenterology, Hepatology and Nutrition Event

We are pleased to announce that CVSA-USA/Canada in cooperation with CVSA-UK will be sponsoring a satellite session about CVS to take place during the 2nd World Congress of Pediatric Gastroenterology, Hepatology and Nutrition in Paris, France, July 3-7, 2004.

This satellite session will provide a platform for our top experts in research, diagnosis and treatment of CVS to present lectures to the professional audience as well as provide time for these experts to interact and exchange information about their current work related to CVS.

This is a major step toward raising world awareness about CVS. We would like to thank you, our members and donors for making this event possible, as well as our extending our deepest gratitude to CVSA-USA/Canada medical advisor Alberto **Ravelli**, MD (Italy) for acting as our liaison with FISPGHAN organizers in the planning of this very important event.

*“This Satellite Session
marks a major step
toward raising world
awareness about CVS.”*

CVSA– Where we've been and what lies ahead (con't from Page 2)

*"We are ready
and able to
'press on' more
than ever!"*

We're excited about the possibilities 2004 and 2005 hold for us.

The anticipated NASPGHAN Diagnosis and Treatment Guidelines slated for 2005 is going to make a great difference in the quality of care CVS patients receive and the lives of all of us. We intend to capitalize on this opportunity to raise awareness and take CVSA-USA/Canada to the next level with major professional and public awareness campaigns over the next 2 years.

What remains to be done this year?

- There aren't as many family meetings planned this year as in the past. Have you considered holding a local meeting?
- Lend your talents to CVSA to further our cause. Call or email us– together we will make a difference!
- And as always– give generously whenever you can. CVSA-USA/Canada receives very little "outside" funding; your donations and memberships are what keep the gears turning!

In 2003 we turned inward to address infrastructure issues; we are now planning in 2004 to once again resume more public activities. In the words of one of our founders, David Fleisher, MD....*we are ready and able to "press on" more than ever!*

Best Regards,

Diane Babbitt – President CVSA-USA/Canada

Debra Waites – CVSA Executive Director

Fundraising Report submitted by Debra Waites

We have held our first ever "**Non-Event Event**"! We mailed out this new fundraiser for us in March, and we have been encouraged by the response it received! We know each time a new idea is introduced, it can take time to catch on. This "**Non-Event Event**" has shown some great potential in becoming a fundraiser we may use again in the future! Watch for an update on our website and in the next newsletter on how much money this "**Non-Event Event**" raised! Thank you to all who participated!

CVSA member **Cindy O'Neill** has found a great way of supporting CVSA! **Tatouage** is a new and beautiful way of decorating your home. Cindy is offering to our CVSA members a way to decorate your home AND give to CVSA at the same time! To participate in the fundraiser, shop at www.tatouagedesigns.com between now and July 31st. Make sure to enter the savings code: CinO'N36 to receive 10% off your order and to ensure the purchase is credited to Cindy so she can donate the proceeds to CVSA. Items will be shipped directly to your home within 7 to 10 days. If you have any questions, please email Cindy O'Neill at cindystatouage@aol.com.

In October 2003, **Kristen Koch** and her family hosted the 1st ever **Walk to "Stop the Cycle" of CVS!** Well, they are BACK in 2004!!! Mark your calendars for the first weekend in October, October 2nd to be exact! Once again **Sherwood Island State Park in Connecticut** will be the location of another great Walk to Stop the Cycle! Last year the Koch family raised over \$11,000 for CVSA! Let's all help them do it again!

And if you can't make it to Connecticut, maybe the **Battle Creek/ Kalamazoo, Michigan** area is better for you?!?! **Diane Babbitt** will host her first **Walk to Stop the Cycle** in conjunction with the walk in Connecticut! Watch your mailboxes and the website for news on how you can be a part of these walks no matter where you live!

There has been discussion of a **Golf Tournament** for CVSA in California! We have the beginnings of a **yard sale** to benefit CVSA in Connecticut, and a possible **benefit concert** in Illinois! There are more **walks** being discussed and hopefully we will get them underway soon! Ideas and commitments are popping up and we are excited about each and every one of them!!!!

CVSA counts on you, our wonderful members, to help us meet the expenses of our programs. Fundraisers, large and small, enable us to continue hosting the educational and support meetings we have in the past, both nationally and internationally. Our Code 'V' newsletter relies on fundraisers to cover the costs of publishing the latest on CVS and delivering it to your mailbox! And fundraisers make possible things such as the NASPGHAN Guidelines.

We need you to make the commitment to host a fundraiser to benefit CVSA!! Contact the Ohio office for more information on how you can be a part of a local fundraiser for CVSA!

Fundraising Ideas!

Raffles! Hold a **Car Wash** in your child's or family member's name! **Garage Sale!** Host a "**Walk-a-thon**" in honor of your child or family member to benefit CVSA! A "**Bike-a-thon**" is another great fund raiser! Why not host a **Golf Outing** for CVSA! With a **Potluck Dinner**, not only can guests bring their favorite covered dish, but a small donation to CVSA can be collected as well! These are just a few examples of how you, your family and friends can **have fun AND help raise funds for CVSA!**

If you need any help planning an event please contact CVSA Ohio Headquarters, we will give you all the help and support you need!

Caring for the CVS patient (con't from Page 1)

Triggers: Many patients are able to identify specific circumstances that seem to induce their episodes, especially positive excitement (birthdays, holidays, vacations) and emotional stress, and infections such as colds, flu and sinusitis. Specific foods, menses, or anesthetics may also play a role.

Diagnosis: Described by Dr. Samuel Gee in 1882, Cyclic Vomiting Syndrome is frequently missed as a diagnosis because it is infrequently seen in clinical practice and because vomiting may be caused by a large number of common disorders such as stomach flu. Moreover, many patients are unable to function during episodes, and so are unable to describe their symptoms, explain their behavior, or express their needs. Diagnosis is made by a careful review of the patient's history with appreciation of the pattern of repeated, similar bouts of intense vomiting, a normal, physical examination and negative laboratory and x-ray studies to rule out other diseases that may cause similar symptoms. Evaluation of a patient with such severe recurrent vomiting may include tests such as abdominal ultrasound, upper GI series, magnetic resonance imaging study of the head, and testing for metabolic diseases (including abnormalities in fatty acid oxidation).

Symptoms: Episodes can begin at any time, but typically start early in the morning and last for 1-5 days. Patients may vomit every five to 10 minutes and can continue for hours or days (with one to five days most common). The most troubling symptoms are invisible, including severe (sometimes intolerable) nausea and intense abdominal pain. Constant pallor, retching and dehydration from loss of fluids and salts also occur. Patients are listless and one mother aptly described the state during an episode as a "conscious coma". Less common symptoms may include esophageal irritation. The degree of abdominal symptoms and unresponsiveness can be frightening to the patient's family, and life threatening for the patient, due to dehydration and electrolyte imbalance.

Behaviors: The severity of the symptoms can give rise to some puzzling behavior:

Hypersalivation and refusal to swallow: Swallowing can cause gagging, retching and an increase in nausea. Patients may drool or spit, or hold their saliva in their mouths (inhibiting speech). They may refuse to swallow water or oral medication.

Compulsive water drinking: Many patients experience intense thirst which compels them to drink, even though taking fluids results in vomiting. Patients may drink in order to dilute the gastric acid and bile and thereby reduce the irritation in the esophagus and mouth during vomiting. Some patients drink large quantities of water to induce vomiting in an attempt to relieve unrelenting nausea.

Unusual postures: Because of severe abdominal or esophageal pain, patients may adopt unusual postures such as a fetal position, and may not move, as any movement intensifies nausea.

Withdrawal: Vomiting episodes are accompanied by extreme listlessness to the point of being unable to walk, talk, or even watch TV. Sufferers tend to sleep whenever they are not vomiting, and describe themselves as being in a state of confusion and exhaustion with no control over their body's reactions.

Needs: Evaluation and Treatment: A patient with known CVS who presents to an emergency room should be assessed and examined for other causes of vomiting, including gastroenteritis, ulcer, appendicitis, gallstones, urinary tract infection, toxic ingestion, and pancreatitis. Patients are often hypertensive, so blood pressure should be documented. Laboratory studies to consider obtaining in the emergency room include complete blood count, serum electrolytes, BUN, creatinine, amylase, lipase, transaminases, bilirubin, and blood glucose. In a patient who has not undergone metabolic testing previously, the physician should consider obtaining plasma pyruvate, lactate, ammonia level, and amino acids, and urine organic acids.

Short-term Treatment: The nausea of CVS episodes is agonizing. IV sugar, anti-vomiting agents, pain medications and sedatives are best given soon after the onset (ideally within an hour). Patients presenting to a hospital should receive intravenous hydration including glucose; for most patients, 5% dextrose 1/2 normal saline (D5 1/2NS) at maintenance is appropriate. Antiemetics administered during an episode may include ondansetron, metoclopramide, or promethazine. Sedation with lorazepam or a similar agent will also aid patient comfort.

During an episode, it is critical to create a dark, quiet environment to promote undisturbed sleep and to minimize waking for vital signs and other procedures as much as possible. Sedation may be necessary. Unfortunately, there is no standardized therapy for these patients. However by trial and error, approaches to prevent, shorten or abort the episodes can be successful. The best treatment often comes from combining multiple approaches.

If compulsive drinking is followed by self-induced vomiting during an episode, do not mistake the behavior for bulimia. The transient lessening of nausea that follows self-induced vomiting motivates some patients to utilize this comfort-seeking behavior. Do not try to stop the behavior as this only increases the patient's distress.

The nausea of CVS episodes is often the most agonizing symptom. The patient is miserable and may be tearful, irritable, rude and demanding; obnoxious behavior should not be taken as a personal affront. It is symptom-behavior in an individual who is suffering misery. Providing relief through a written plan of treatment in the ER or hospital can facilitate overall improvement and lessening of stress.

All patients will begin to talk, drink and take care of themselves when the nausea recedes and they feel well again. Some patients are able to tolerate a regular diet as soon as the nausea lifts; others need to begin with clear liquids. Recovery tends to be prolonged when delayed management of the episode results in severe fluid and electrolyte deficits and marked weight losses.

We're in the planning stage of possibly five more fundraising walks in 2004, with talk of possible walks in New York, Massachusetts, Georgia, New Mexico, and California.

Interested in participating in one of these, or hosting your own?

Let us know— we're here to help!

CVS: Two perspectives on the altered lifestyles it creates

From our CVSA online message board:

A Good Friday indeed

Finally, some answers.

After more than a decade of suffering through this condition, completely believing the only problem was firmly in my own mind, I have come across this site and all of you. Numerous uncaring doctors, countless meaningless tests, endless painful days spent alone, vomiting, retching in the dark silence of my bedroom, all worked to convince me the problem, and solution, were all mine and mine alone. There were no answers. Heck, I was lucky if I could find a doctor to leave behind his predispositions and truly listen, even for a moment.

Finally, some relief.

I knew I didn't suffer from IBS, as every doctor has tried to pigeonhole me. No one I knew with IBS ever went through the agony my life has become. The lost days, and lost pounds, were bad enough, but to feel completely alone and helpless in the face of this monster only served to further disable my mind and body. The future offered the promise of more suffering, but never the promise of any relief.

Finally, some company.

Just the fact I now understand I am not alone in this battle has lightened the burden of guilt. My wife and children have always taken my hand and made sure I would not walk through this hell alone, but never could they relieve my tremendous feelings of inadequacy. Those guilty feelings which constantly reminded me how much harm this was causing those I loved, never could be ignored as long as I believed the problem was all in my mind. How hard it must be for a young boy to see his father so completely weak, so completely helpless, so completely worthless.

Finally, some happiness.

I have not laughed in a long time. I have sat solemnly powerless as my energy, my enthusiasm, my ambition, my lust for life have slowly disintegrated. Little by little I have allowed my spirit to be eaten away, but now it is my time to feast. No more will I be a dietary cripple, afraid of every morsel. No more will I be a social cripple, afraid of every moment away from the safety of my bed. No more will I be a pleasure cripple, afraid of indulging myself in those things which make me feel good.

Finally, I have arrived.

And I'm looking forward to getting to know all of you, myself and this damnable CVS.

Posted Good Friday, 4/9/04, message board member: M.B.

Knife-piercing pains in my stomach,
Nausea,
Retching,
Lethargy.

This is a life worth escaping.

In the tub, as the water showers my body,
I close my eyes and imagine myself
Somewhere else—far away,
Far away from my reality.

I'm floating like a stray leaf down a river
Where the sunlight glistens on the surface
Near trees on the shore,
And where the trees dance to the rhythms of the wind.
A King salmon swims up shore
To lay her eggs in the spawning ground,
A bird sweeps in to catch his prey of salmon,
And a father gives his son his first fishing lesson.

The running water
Sounds like a river to me now.
I can even hear when the water
Hits against those stubborn rocks.

Swish, swish, the water sings to me.
Swish, swish, what a relaxing melody.
Swish, swish, someone please save me.

I wrote this poem about when I take my multitude of baths and how when I take them, I can escape from the pain of the real world.

Dana Simmons, college student, CVS sufferer

CVSA Program in Chicago Welcomes New Staff Member!



Pat Hovany, Pediatric Nurse

Hello CVSA Families,

I'd like to introduce myself to the members of the CVSA as the new nurse at the Cyclic Vomiting Syndrome Program at Children's Memorial Hospital. My name is Pat Hovany and I graduated from Loyola University in Chicago and have worked in a variety of positions. My pediatrics experience includes an adolescent inpatient unit and many years in the emergency department of a community hospital, where I do remember seeing children with an unexplained recurrent vomiting. In recent years, I have worked as nurse in clinic settings and as a care manager in work comp and disability.

Since starting at Children's, I have listened to the parents of affected children tell of their experiences. I try to share this knowledge and Dr. Li's research with the families and their doctors to help deal with this frustrating condition. So often, the recurrent vomiting is attributed to a "flu bug" and ineffective treatment is given to stop it. Hopefully someday through educating providers and the public, CVS will be better recognized and effectively treated. Children will not have to suffer for years before being diagnosed.

If you would like to be evaluated in our program, please contact me at 773-880-4496 or access our CVS Program link through the CVSA website.

International CVS Program Update, Children's Memorial Hospital-Chicago, IL Kelly M. Feehan, Project Coordinator

The Cyclic Vomiting Program continues to actively recruit patients into both the observational and treatment arm of Dr. Li's NIH sponsored grant. A few changes have been made to the observational arm portion of the study and we are going to begin collecting salivary cortisol levels on all study participants. Comparing the salivary cortisol levels with the serum cortisol levels could potentially provide caregivers with a reliable non-invasive technique to obtain cortisol levels from cyclic vomiting patients.

Child psychologist Sally Tarbell is continuing to evaluate the occurrence of depression in cyclic vomiting patients. Sally joined our CVS team late in 2002 and has since then been coming to our CVS clinics every week to see patients.

As part of a new research study at the CVS center investigating the natural history of CVS and possible connections to other medical conditions, questionnaires will go out to Dr. Li's previous patients from Columbus Children's Hospital in Ohio. The questionnaire will cover development of migraine headaches and abdominal pain episodes and occurrences of certain medical conditions in both the patient and the family. Through administration of these questionnaires we hope to gain insight into the progress of CVS patients. Also, the questionnaire will give us information on the association of disorders such as epilepsy, ADHD, and depression, in both the patients and their families.

In Memory of Janet Coleman



Some of you may know her name from the list of outreach volunteers, others of you may have read her posts on the CVSA Message Board. And some of you have had the pleasure of speaking with her on the phone as she offered you support while you tried to cope and understand this monster we all live with. I had the pleasure of getting to know Janet Coleman as a volunteer, as a parent of an adult CVS sufferer, and as a friend. Janet became a volunteer for CVSA in late 2002 when she found us as she searched for answers to her adult sons vomiting. She was eager to help others in any way she could.

Janet touched the lives of others through the emails and phone calls she made for me. Janet was also the volunteer who made all of the "puke dolls" for our 2003 International meeting! Each and every child present received one of Janet's hand made dolls. Janet told me she made each doll "just a little different", so no two would ever be alike, she wanted every child to have one that was as special as they were. I received word from Janet's son that Janet passed away on April 4th, 2004. Janet is a part of our CVSA family, she was always there to offer her support, her concern, and her genuine compassion to anyone who needed it. Please keep her family in your thoughts. She will be greatly missed

— Debra Waites

CVSA and NASPGHAN – Yet Another Successful Partnership Meeting **Establishing Formal Guidelines for the Diagnosis and Treatment of CVS** submitted by Kathleen Adams

Imagine the privilege of spending 2 days with 10 physician scientists discussing aspects of diagnosis and treatment of CVS – discussing and re-discussing, over and over with a fine-toothed comb. It is an awe-producing unfolding of personality, talent, expertise and dedication. The committee members gathered are persistent in their determination to turn out a document that will serve patients, families and physicians in their dealings with CVS. In trying to sort out reasons why these 10 people have come together, there is no evidence of personal gain. There is clear evidence of understanding and compassion. In May and October of 2003 and in late March 2004, this appointed committee from different parts of the country gathered together to work on creating a document that will most likely impact a large number of people who are still dealing in isolation with CVS. The end result will be Guidelines for the Diagnosis and Treatment of CVS – a standard of care. Some of what you read here may be a repeat for the benefit of new readers. As predicted, this current multi-disciplinary scientific project continues to be a rigorous exercise in collaboration and consensus building toward a critical goal for patient and family well-being.

Since the Cyclic Vomiting Syndrome Association (CVSA) is devoted to increasing awareness and accessibility to quality diagnosis and treatment of CVS, the Board of CVSA had agreed to be the financial sponsor of this collaborative effort by professionals that will lead to publication of guidelines for better care of CVS. Behind this sponsorship was the decision by founding and past CVSA board members, Brian and Lisa Jolles, to designate funds from one of their famous fundraisers, a Casino Night, to this critical project. The committee has been able to stay "on budget" so far – pinching pennies by avoiding luxurious meeting places and restaurants but not compromising quality of discussion, research and writing in any way. Dinners have been generously provided by family of committee members in warm homes – a welcome setting at the end of a long day of discourse.

The Goal

The gathering of expertise and experience about this difficult illness continued on in the third of a total of three or four meetings – held March 26-28, 2004 at pediatric GI offices of Dr. B U.K. Li at Children's Memorial Hospital in Chicago. Dr. Li is the Director of the International CVS Program at Children's. Even though the diagnosis of CVS has been emerging out of the cracks in the floorboard of medicine, there is still much to do about the lingering dearth of information about CVS that is available to general pediatricians, school nurses, psychologists and others that are asked to provide care. Having this formal standard of diagnosis and care will go a long way toward ensuring that professionals out in the field are better equipped to care for patients and families who are still struggling.

Progress

A more complete article including project background and process is available in the Fall 2003 CVSA newsletter. The collaborative efforts of CVSA and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) have been a very good coupling along the way. CVSA is the financial sponsor; NASPGHAN is the professional guideline sponsor and appointed the committee. At this meeting, I was again struck by the level of commitment to excellence of thought, research, clarity, consensus building and production. At least 3 hours were spent revising the draft of criteria for CVS drawn up at the first two meetings. As an example, the discussion about the terms 'syndrome', 'pattern' and 'disease' went on "*ad nauseum*" – no pun intended. For consistency of verbiage, Don Lewis, MD, pediatric neurologist of Eastern Virginia Medical School, provided the committee with published criteria for CVS [International Classifications of Headache Disorders, *Cephalgia* 24:8-152, 2004 [suppl]]. In spite of lengthy scrutinizing deliberations, progress is right on schedule and the members left with assignments for writing sections of the document to be submitted to Dr. Li who will then incorporate the sections into a complete document draft. Thoroughness is one of the committee hallmarks.

End Result

The committee is continuing to utilize the approach used by NASPGHAN in the preparation of formal medical guidelines. This process has been used for other pediatric gastrointestinal illnesses such as reflux, constipation, and H pylori. The end result of these meetings will be a publication of a guideline for CVS in the widely circulated and highly respected *Journal of Pediatric Gastroenterology and Nutrition*, on the NASPGHAN website and most likely on the website of the American Academy of Pediatrics.

The Committee

B U.K. Li, MD, Professor of Pediatrics, Director GI, and International CVS Program, Children's Memorial Hospital, Chicago was appointed Chair by the NASPGHAN Executive Committee. Members recruited to serve are **Rick Boles, MD**, Associate Professor Pediatrics University of Southern California, Medical Genetics; **Gisela Chelimsky MD**, Department of Pediatric GI, Case Western Reserve, Cleveland, OH; **Bob Isseman, MD**, Professor of Pediatrics, Chief Peds GI, McMaster University Hamilton, Ontario; **Frank Lefevre, MD**, Associate Professor General Internal Medicine Northwestern University Medical School and Senior Clinical Scientist, BCBSA Technology Evaluation Center, Chicago IL, (familiarity with epidemiology and literature review); **Don Lewis, MD**, Eastern Virginia Medical School, Neurological Developmental Center, Norfolk, VA (experience in writing guideline for pediatric migraine), Steven L. **Linder, MD**, Dallas Pediatric Neurology Associates (pediatric migraine); **Suzanne Nelson, MD**, Department Pediatric GI, Children's Memorial Hospital, Chicago; **Colin Rudolph, MD, PhD**, Professor of Pediatrics, Chief, Peds GI & Nutrition, Medical College Wisconsin, Milwaukee. Logistical support is being provided by **Margaret Stallings**, Executive Director of NASPGHAN, **Jody Nolan**, CVSA member and past member of the CVSA Board, **Lynda Parrott**, current CVSA Board Member and **Kathleen Adams**, CVSA Research Liaison.

(continued on page 14)

CVSA Board of Directors – Call for Nominations

Term beginning January 1, 2005 through December 31, 2007

In accordance with the bylaws of CVSA, elections for seats on the Board of Directors must be held every two years. The Election for the next 2-year term will be held October, 2004. Below you will find the official description of each of the board positions.

CVSA members interested in volunteering their time and expertise to our board, please look over the duties listed below. If you are interested in running for a position on our board during this next election, please contact Glenda Sirota, Nominating Committee Chair (or Ohio Office) no later than June 20. We will provide forms needed to nominate an individual or for self-nomination. Please contact Glenda Sirota at 630-922-0056 or by email gds1640@aol.com.



Board of Director Positions

President – (incumbent running) Presides at all meetings of the association, sees that all orders and resolutions are carried into effect, ensures all items are reported to the membership that are pertinent to the association. President will appoint committee heads as needed.

Vice President –Has authority to perform the duties of the office of the president in the event the president is absent or unable to perform the duties of the office. (Note: The VP will not be expected to immediately perform the duties of the president should the president resign.)

Secretary – The person holding this position will keep minutes of the meetings, see that all notices and documents are provided to other board members on up coming meetings and issues in a timely way, and perform other duties incident to the office or which may be assigned by the president.

Treasurer –The person holding this position, will provide (along with CVSA Executive Director) annual reports on the financial status of the association, as well as be responsible for the state and federal forms that come due.

Members-At-Large –7 seats (6 incumbents running) The person(s) holding the position of Member-At-Large serves on the board for the purpose of representing the general membership in a voting capacity, and brings the views, thoughts and needs of the general membership to the attention of the rest of the board members.

Some general responsibilities of a Board Member include:

- Maintain knowledge of CVSA's mission, services, policies, and programs and commits to its goals and objectives
- Attend all board meetings if at all possible. Historically, there has been one board meeting held in person each year, others by conference calls.
- Participate as a vital part of the board leadership
- Assist in developing long range strategic plan for broadening resource development and continuing to build the health and effectiveness of CVSA
- Assist the board in carrying out its fiduciary responsibilities
- Follow conflict of interest and confidentiality policies
- Participate in all communications, primarily by email
- Communicate and work with President and Executive Director
- Serve on committees and/or task forces and offer to take on special assignments
- Attend all committee meetings and functions, such as special events if at all possible
- Be available for members phone calls, emails, etc., offering support as well as taking member's concerns to the board for discussion
- Make a personal financial contribution to the organization, as much as personal circumstances allow. This can be in the form of direct or indirect donation.
- Keep up-to-date on developments in the organization's field.

CVSA and NASPGHAN (con't from Page 13)

What's Left To Do

The committee has accomplished 10 of the 13 steps in the guideline process summarized in an article written by Richard B. Colletti, MD, Past President, NASPGHAN and Professor of Pediatrics, University of Vermont, Burlington. ["Can a good guideline improve patient care?" *J Ped Gastroent Nutr*, Sept 2002]. The remaining steps involve compiling the sections into a draft document to be sent to peer physicians for review. After further revisions, the manuscript is then sent to the NASPGHAN Executive Council for review – hopefully at the Council's October 2004 meeting. Once approved, the document will be submitted for publication and circulated widely.

The spirit of collaboration and focus has been evident during the three meetings. The sense of commitment to patients and their caregivers is the overriding concern and I am confident that the end result will provide excellent guidelines for many still waiting for accurate diagnosis and treatment based on this new standard of care.

Membership and Renewal Application

Why become a member? Membership in CVSA makes possible future newsletters, physician mailings, and conferences. An annual membership entitles you to receive four newsletters, medical advisory updates, and information on studies and research. Membership also entitles you to a subscription to the CVSA sponsored Message Board. If you are not a member, or membership has expired, complete this form and return it to: CVSA, 3585 Cedar Hill Rd NW, Canal Winchester, OH 43110.

Membership Options

Please check one: (Note: All annual memberships run from January 1– December 31.)

\$35 Individual / Family (one year)

\$60 Individual / Family (two years)

\$65 Physician or PhD Membership (one year)

\$255 Corporate Membership (one year)

Please sign me up as a scholarship member, I cannot afford dues at this time.

I would like to donate \$_____ in addition to dues to support ongoing efforts.

I would like more information.

Member Information:

Name: _____ Phone: _____

Address: _____

City: _____ State: _____ Zip: _____ Country (if outside USA) _____

Fax: _____ Email (required for access to Message Board): _____

How did you hear about CVSA? _____

Optional Information:

Patient Name: _____ Date of Birth: _____ Age at onset: _____

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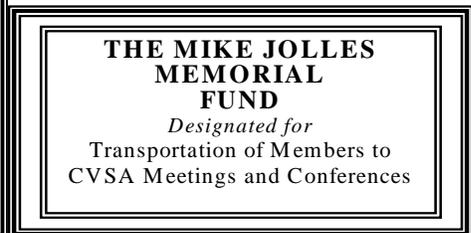
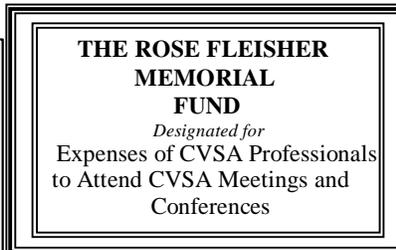
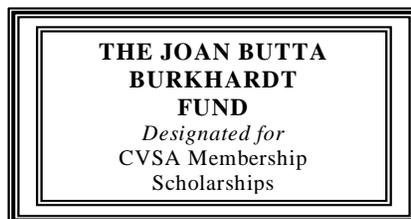
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Thanks to the generosity of our benefactors, CVSA has resources available to our members in cases of hardship. We thank these donors for their kind contributions.

For more information about applying for or donating to any of these funds, contact:

CVSA Executive Director, Debra Waites- Phone or Fax 1-614/837-2586 or email waitesd@cvsaonline.org



Cyclic Vomiting Syndrome and Cyclic Vomiting Syndrome Association

Cyclic Vomiting Syndrome (CVS) is an uncommon, unexplained disorder of children and some adults that is characterized by recurrent, prolonged episodes of severe nausea, vomiting and prostration with no apparent cause. Vomiting occurs at frequent intervals (5-10 times per hour at the peak) for hours to 10 days (1-4 days most commonly). Episodes tend to be similar to each other in symptoms and duration and are self-limited. The patient is generally well between episodes. CVSA is an association of patients, families and professionals who provide support for each other, promote education about Cyclic Vomiting Syndrome and fund research in nausea and vomiting in general. The CVSA Federal Identification Number is 39-1767509. All donations are tax deductible under the designation of a non-profit organization by the Internal Revenue Service under Section 501(C)(3).

Newsletter of the Cyclic Vomiting Syndrome Association-USA/Canada
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CYCLIC VOMITING SYNDROME ASSOCIATION – USA/CANADA

Regional and International Directory

CVSA Administrator / Ohio Headquarters

Debra Waites Email: waitesd@cvsasonline.org
3585 Cedar Hill Rd. NW
Canal Winchester, OH 43110
Tel. and Fax: 614/837-2586

Board Of Directors

President: Diane Babbitt, MI
Tel.: 269/968-6837
Email: babbitt@cvsasonline.org

Contact Ohio headquarters for contact information below.

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| | |
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The International CVS Program

Children's Memorial Hospital, Chicago, IL
Tel.: 773/880-4496 — Fax: 773/880-4036
Email: cvscenter@childrensmemorial.org

International Associations and Support Groups

For more information call or email Ohio headquarters

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