

## Thank you CVSA

“Thank you ever so much for providing me with such a comprehensive list of the specialists... I sincerely appreciate your help with this issue.”  
*Sabina, New York*

“Great suggestions... Thank you for your time and patience.”  
*Patricia, Louisiana*

“Thank you so much for the information and getting back with me. We are looking forward to learning as much as we can to help and support her... We appreciate everything and are happy to know we have resources and support at CVSA.”  
*Heather, Florida*

“Thank you for pulling and sending this list. We feel more hopeful knowing who we should turn to now. Thanks a million!”  
*Kelly, Maryland*

“You can’t imagine how grateful I am to the CVS Association, this is such an emotional relief to finally know what my wife has been dealing with for the past 15 years.”  
*Simon, Colorado*

## What You Can Do

- Help raise awareness with families and professionals you know
- Join CVSA and volunteer as you are able
- Contribute articles to the newsletter
- Donate generously
- Help fundraise

For more information on CVS or CVSA please contact the CVSA office at [cvsa@cvsaonline.org](mailto:cvsa@cvsaonline.org) or call (414)342-7880

For more information on volunteering for CVSA, please contact: [cvsaprogramassistant@gmail.com](mailto:cvsaprogramassistant@gmail.com)



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Do you know  
someone  
who has  
unexplained,  
severe,  
stereotypic  
episodes  
of vomiting?

Is the person  
well between  
episodes?



Cyclic Vomiting Syndrome Association  
HOPE STARTS HERE.

Founded in 1993, CVSA raises awareness and provides education and support to those affected by cyclic vomiting, abdominal migraine and related disorders while advocating for and funding research.

## Cyclic Vomiting Syndrome

### What Is It?

CVS is an unexplained disorder of children and adults that was first described by Dr. Samuel Gee in 1882. The condition is characterized by recurrent, prolonged attacks of severe nausea, vomiting and prostration with no apparent cause. In some there is severe abdominal pain. Vomiting occurs at frequent intervals for hours or days (1-4 most commonly). The episodes tend to be similar to each other in symptoms and duration and are self-limited with return of normal health between episodes.

### Occurrence

CVS begins at any age. It can persist for months, years or decades. Episodes may recur several times a month or several times a year. Females are affected slightly more than males. The person may be prone to motion sickness, and there is often a family history of migraine. There is a high likelihood that children’s episodes will be replaced by migraine headaches during late adolescence.

### Symptoms

Episodes may begin at any time, but often start during the early morning hours. There is relentless nausea with repeated bouts of vomiting or retching. The person is pale, listless, and resists talking. They often drool or spit and have an extreme thirst. They may experience intense abdominal pain and less often headache, low-grade fever and diarrhea. Prolonged vomiting may cause mild bleeding from irritation of the esophagus. One mother aptly described her child’s state during the episode as a ‘conscious coma’. The symptoms are frightening to the person and family and can be life-threatening if delayed treatment leads to dehydration.

### Diagnosis

CVS has been difficult to diagnose because it is infrequently recognized and is often misdiagnosed as stomach flu or food poisoning. There are currently no blood tests, x-rays or other specific procedures used to diagnose the disorder. The diagnosis is made by careful review of the patient’s history, physical examination and lab studies to rule out other diseases that may cause vomiting similar to CVS.

### Triggers

Although some patients know of nothing that triggers attacks, many identify specific circumstances that seem to bring on their episodes. Colds, flus and other infections, intense excitement (birthdays, holidays, vacations), emotional stress and menstrual periods are the most frequently reported triggers. Specific foods or anesthetics may also play a role.

### Treatment

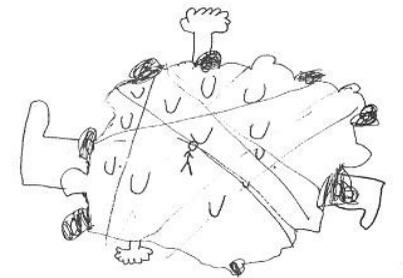
Treatment is generally supportive with much importance placed on early intervention. A dark quiet environment is critical for sleep. Hospitalizations and IV fluid replacement may be necessary. Medication trials often succeed in finding something to prevent, shorten or abort episodes. Links have been made between CVS and mitochondrial disease supporting the use of CoQ10, L-Carnitine, and other supplements can be beneficial. It is important to work with a physician who does his/her best to understand CVS and is supportive.

### Long-Term Treatment

The foundation of long-term management involves a responsive collaborative doctor-patient-family relationship, sensitive to stresses caused by the illness and to triggers such as feelings and attitudes that may pre-dispose individuals to attacks. Consistent, accessible physician care by a care coordinator who understands and communicates the nature of CVS, regardless of specialty, is vital to the family’s well-being. Connections with the Cyclic Vomiting Syndrome Association, a family and professional network, does a great deal toward healing a family that has been in doubt and despair for years.

### Related Terms

abdominal migraine, bilious attacks, periodic syndrome, recurrent vomiting, intractable vomiting



The “Puke Monster” by Caitlin, age 10

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## From the Patients

“As the attack progresses the nausea becomes constant. Nothing will relieve it, I can only describe it as absolute hell. I feel so awful that I honestly want to die. As well as the constant unrelenting nausea, I am utterly exhausted. All I want to do is sleep.”  
*Fiona, 17, England*

“The nausea is controlling, unrelenting and consumes every ounce of strength. I always sensed, real or imagined, that everyone thought I should be able to stop vomiting on my own. But sheer will does not control these attacks, a fact that’s hard to articulate—sick or well. I knew my parents were worried, exhausted and even angry at times. I felt very guilty about not being able to stop vomiting and that made me feel even worse. That’s a big burden for a child! I can say it’s very important that parents don’t doubt their child about CVS and its effects.”  
*Jennifer, age 27, Illinois*

## From The Professionals

“We’re up against it here with CVS. As doctors and parents, we’re struggling together as equals against a common problem. The collaborative model for the doctor-patient-family relationship is critical in the management of this disease.”  
*D. Fleisher, MD*

“...cyclic vomiting, though not fatal or progressive, or productive of permanent organ damage... appears to be one of the most frustrating and elusive of childhood chronic illnesses. Because of the frightening unpredictability of episodes, the lack of known etiology, and lack of a clear treatment regimen or prognosis, conditions for maximum family stress are created. Although the disease may ultimately remit, one runs the risk of leaving a child and family permanently psychologically scarred.”  
*K. Longeway, PhD, clinical psychologist*

“The mother of the patient on account of anxiety and loss of sleep, presents a pathetic figure as the curtain drops on the trying drama. The attending physician is subjected to the embarrassment of his conscious futility in answering the parent’s question as to what measures may be taken to prevent the next occurrence.”  
*P. Smith, MD, 1934 medical article on CVS*

## From The Families

“...you wonder when you wake up—is this another bad day? And then I hold my breath each morning until she appears. We are so thankful to learn of other people with CVS. For many years we thought it was just a strange thing with our child—now we know it’s a ‘real disease’ with a ‘real name’.”  
*Linda, Idaho*

“I hate this disease! - not knowing when it will rear it’s ugly head and take our daughter away, sometimes for as long as 10 days. She is so sick she doesn’t speak or even want to be read to. It is so painful to see someone you love suffer so much and not be able to stop it.”  
*Nancy, Pennsylvania*

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## International Network

Our worldwide network continues to grow. We have either professional or family outreach contacts providing support and education on CVS in over 30 countries. This includes our ongoing relationship with the other five CVS associations in Germany, Italy, Japan, Nordic countries, and the United Kingdom.

## Membership and Renewal Application

Your membership dues help CVSA to fund research, scientific symposia, conferences, and outreach programming. Member benefits include:

- Code “V” newsletter 3 times per year
- Members - only discounts for conferences and other CVSA sponsored events
- CVSA Membership Card
- Early notification of upcoming events

### Membership Options

\$75 U.S. Funds - Full- Priced Individual/Family Membership (1 year)

\$130 U.S. Funds - Full-Priced Individual/Family Membership (2 year)

\$35 Discounted Membership (1 year)  
(Because we understand that CVS makes it difficult for some to afford a full-priced membership) Please note: benefits are the same as a full membership.

### Additional Donation:

Enclosed is a donation of \$ \_\_\_\_\_ to support the work of CVSA.

Name (please print) \_\_\_\_\_

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### Total Amount Enclosed

\$ \_\_\_\_\_ Please make check payable to CVSA, Inc.

Visa, MasterCard, and Discover Card accepted

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