

13th CVSA International Family and Adult Conference

Submitted By: Michele Stamm and Michelle Vestal

Conference Overview

The 13th CVSA International Conference was held June 29–July 1, 2018, in Milwaukee, WI. It was a wonderful event! There were people that came from countries all over the world, including the USA, Canada, Japan, and India. Those affected by CVS, either directly or through their loved ones, came together to learn, encourage, and support one another. Many large group educational sessions were presented (see below for details). People had the opportunity to meet one-on-one with medical professionals as well, to discuss their individual situations. There were opportunities to meditate, to laugh, and to enjoy meals together — where else is “vomiting” an acceptable dinner topic?!? Perhaps the best part of the conference was being able to meet new people and say to each other, “You too? I thought I was the only one...”

B U.K. Li, MD

(Professor Pediatrics–GI, Director Cyclic Vomiting Program, Medical College of Wisconsin and Children’s Hospital of Wisconsin, has seen over 1300 CVS patients)

Dr. Li opened the conference with an overview of Cyclic Vomiting Syndrome (CVS), sharing a broad view of both diagnosis and treatment. He feels it is very important to discuss CVS and to educate the medical community about it, as CVS causes a disproportionate number of both Emergency Department (ED) visits and inpatient hospitalizations. These significant medical costs, along with the accompanying loss of productivity and missed hours at work and school, make it a very costly disease. And of course sufferers of CVS, along with their loved ones, experience a diminished quality of life. A unique medical challenge posed by CVS is that it crosses into multiple medical disciplines, including the specialties of gastroenterology (GI) and neurology.

While every CVS patient is different, the average age of onset is five years old. A typical person suffering with CVS may not receive this diagnosis for on average two and a half years, as there is no specific testing for this condition. One diagnostic complication is that so many people who suffer with CVS have other medical conditions, e.g. anxiety, depression, postural orthostatic tachycardia syndrome (POTS), etc. Treating these comorbid conditions can lead to improvements in CVS as well.

Another diagnostic complication is that there is such a variance of presentation patterns. Only about half of CVS sufferers have symptoms that present in a truly cyclical fashion. Otherwise known as “calendar” due to the predictability of the pattern. These patients are generally the most successfully treated. Other CVS patients can present with sporadic cycles or “cycles within a cycle” or long cycles, defined by episodes lasting greater than one month. These patients with long cycles are the most difficult to treat. Finally, patients can experience coalescence, having constant nausea or nausea between vomiting episodes.

Beyond the diagnostic challenges of CVS, there are unique treatment challenges as well. There is no one medication or treatment approach that works for everyone. A variety of approaches must be employed to successfully treat this disease. Lifestyle management is important; positive changes to nutrition, hydration, sleep patterns, stress management, and exercise, due to mitochondrial function, can be effective tools in managing this disease. Cognitive-behavioral therapy (CBT) can be an effective way to address these lifestyle factors in CVS patients. In those patients who have identified triggers that cause their episodes, avoiding these triggers is critical. Of course, there are many medications that have been used to effectively treat CVS as well. The unique challenge with meds is that a single patient will likely need different medications, depending on which phase of the disease they are currently in. There are **four phases of CVS**.

During the **well phase** or **inter-episodic phase**, when the patient is not experiencing symptoms, prophylactic/preventative medications are used. Dr. Li discussed Amitriptyline and Nortriptyline, sharing that they are both effective, especially when used in higher doses, but that they can have significant side effects in some patients. To limit the potential side effects, doctors should increase dosages slowly when prescribing these meds; Dr. Li feels this slow titration is the “key to success” with these drugs. Other preventative meds discussed by Dr. Li included Propranolol, Cyproheptadine, and Emend. Emend is a newer anti-nausea medication that is beginning to be used prophylactically. Mitochondrial-supporting supplements such as CoQ10 can be very effective during this phase as well.

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The **prodrome phase** occurs just prior to a vomiting episode, when a CVS patient can feel an episode coming on. The length and presentation of this phase, like any other, varies from patient to patient. Medications that Dr. Li discussed for potential abortive use during this phase include Sumatriptan, Zofran, Phenergan, rectal Valium, and Hydromorphone.

During the **episode** itself, rescue meds and procedures are implemented. Patients will do best in a quiet, dark room. They can be given IV fluids, including 10% dextrose. Anti-emetics and sedatives can be used. It is beneficial to have an ED protocol established prior to its being needed during this phase.

The **recovery phase** is when vomiting stops and the patient begins to feel better.

Refractory patients are those considered difficult to treat, those non-responsive to treatment. There are many factors to consider with these patients. Is there an underlying undiagnosed disorder? Is there an unidentified trigger (psychological, chronic sinusitis, etc.)? Might the patient be missing/skipping some doses of their prescribed meds? Could the patient benefit from higher dosages of their current medications or by trying new meds altogether, or by combining meds? Might the patient be someone who metabolizes medications at a different rate (more slowly or more rapidly) than others? If these refractory patients are disabled and missing school, they may benefit from a rehab program that includes both physical and psychological treatment. For some patients, they will recover more quickly if they are participating in normal activity.

Dr. Li also discussed exciting new potential treatments on the horizon. These include auricular (ear) vagal nerve stimulator treatment as well as a variety of new medications — topical capsaicin, cannabidiol, Ketamine, sub-sedative Propofol, and a newer monthly injectable medication used for migraines.

In summary, Dr. Li suggested that many of us will find that we know more about CVS than the doctors who are treating us. He therefore encouraged us to educate and work *with* our doctors rather than fight against them. He advised finding a doctor who is willing to learn and partner with you toward finding the most successful treatment plan. Keys to success include getting a correct diagnosis and remembering that treatment is challenging, multi-faceted, and unique to each person. There is so much more to treating CVS than just stopping the vomiting.

***Note: Because “the basics of CVS” were reviewed in this summary of Dr. Li’s presentation, these same details will not be included in all presentation summaries.

Sally Tarbell, PhD

(Professor of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine Neuro-intestinal & Motility Program, Ann & Robert H. Lurie Children’s Hospital of Chicago, Pediatric Gastroenterology, Hepatology, and Nutrition)

Dr. Tarbell was invited to the conference to discuss her research, which was published in *Autonomic Neuroscience* in January 2017. In this study, Dr. Tarbell looked at anxiety and physiological responses to the Trier Social Stress Test in children and adolescents with CVS when compared to healthy control subjects. She concluded that heart rate variability may serve as a biomarker for evaluating stress as a potential trigger for CVS episode, but that more research is needed to evaluate differences between individuals’ stress responses and how such differences may influence their vulnerability to CVS attacks.

In her presentation, Dr. Tarbell discussed that we all have a stress threshold or “sweet spot,” and that while some stress in our lives is good, too much stress in our lives is bad. She discussed factors that can lower our stress “sweet spot,” such as trauma and adverse events in our early lives, as well as factors that can raise our stress “sweet spot,” such as a healthy lifestyle, strong social support, and learned coping skills. Questions to consider when looking at the relationship between CVS and stress are: Do those with CVS have a lower stress threshold or do they have a more robust response to stress when compared to others? Do people with CVS perhaps experience a constant low level of stress in their lives or perhaps perceive stress differently than others?

Meditation Session – Jyoti Sadhwani
(Integrative Nutrition Health Coach, Heartfulness Meditation Trainer, Heartfulness Institute)

Jyoti invited us to participate in a guided meditation session. For those who enjoyed the guided meditation session, she recommended heartfulness.org as a website to check out.

Essential Oils and Aromatherapy in CVS – Dr. Kim Trager, Holistic Chiropractor and Candace Lawrence, Licensed Acupuncturist

Dr. Kim Trager and Candace Lawrence taught about how essential oils could be used in managing CVS symptoms. They shared that nausea/vomiting can be positively affected by essential oils, as a person's dopamine and serotonin responses are affected by them. If a person's nausea/vomiting is affected negatively by scents, they recommended putting the oils on the bottom of one's feet, as the essential oils can travel throughout the body from there. They feel that the most effective essential oils for CVS are lavender, patchouli, fennel, peppermint, ginger, and chamomile. It is important to use oils that are certified pure and natural as well as using a carrier oil because many oils are too strong in their pure form.

Thangam Venkatesan, MD
(Associate Professor Medicine–GI Director, CVS Program for Adults, Medical College of Wisconsin)

Dr. V, as her patients lovingly call her, began by discussing the prevalence of CVS. It is more common than you might think, occurring in 1.9% of children in Scotland and Turkey, 2.3% of children in Australia, 2% of adults in the UK, and 3% of adults in the USA.

Dr. V discussed Cannabinoid Hyperemesis Syndrome (CHS), as this is a new and common topic in the news and is being increasingly blamed in true cases of CVS. A frustration for CVS doctors and patients alike is that when asked, 90% of ED physicians didn't know that CVS was an actual disorder, but they are VERY aware that cannabis can be an issue in vomiting. There is unfortunately a lot of misattribution of CHS in cases of true CVS. CHS is most definitely not the same as CVS; the two syndromes therefore need to be distinguished from one another. One potential reason for the confusion is that 40% of CVS sufferers do use cannabis, especially young males. This is likely because cannabis is an antiemetic. To fully distinguish between CHS and CVS, patients would need to stop using cannabis for 3–6 months, to be certain that it is out of their systems. Any remaining vomiting cycles could then be safely regarded as CVS.

Dr. V shared research that she is presently conducting with Dr. Boles, looking at certain genotypes that can predict the risk of CVS or its response to different therapies. She also discussed some newer treatments for CVS, including Ketamine and Emend. She also discussed the positive effect that stress-reduction, therapy, and meditation can have on CVS.

David J. Levinthal, MD, PhD
(PhD Assistant Professor, Director, Neurogastroenterology and Motility Center, Department of Medicine, Division of Gastroenterology, Hepatology, and Nutrition, University of Pittsburgh Medical Center)

Dr. Levinthal's focus is on the neurological control of the GI system and more specifically, on CVS. He noted that other disorders present with four distinct phases like CVS does, including migraines, epilepsy, and panic disorder. Knowing these are all similar disorders in that way, they can provide clues to us about CVS, in both diagnosis and treatment. They are all neurogenic disorders that involve multiple systems of the body; CVS likely involves neural circuitry and neuronal excitability as well. Exploring the idea that CVS is a brain-based disorder, he pointed out that areas of the brain that control the core of the body are the same as those that control the adrenals that stress can affect, which could explain why meditation and yoga can positively affect CVS.

Triggers common in CVS include fasting/hypoglycemia, sleep deprivation, acute physical stress, and mental triggers. It is interesting to note the circadian patterns with CVS attacks, in that a majority of CVS attacks occur in the early morning when cortisol levels are higher. Dr. Levinthal discussed the "CVS Threshold" as a disease model, sharing that one effective treatment approach is to use prophylactic medications to raise this threshold and another approach is to avoid triggers, to keep the patient below this threshold, thereby avoiding episodes.

Dr. Levinthal concluded with a discussion of Ketamine, which appears to potentially be a very effective treatment to abort CVS episodes. To achieve a positive response, Ketamine generally needs to be used in higher dosages than is typical, although the optimal dosage would be based on patient response.

Richard Boles, MD

(Director CNNH NeuroGenomics Service, Medical Geneticist in private practice, Chief Medical and Scientific Officer NeuroNeeds)

Dr. Boles explored the topic that one's genetic sequence can predispose them to disease, and that genetic testing can therefore lead to improved treatments in patients with CVS. He reported on a few specific patients that he has been able to treat more effectively by learning their specific genetic variants.

Dr. Boles also discussed CVS as a functional condition. Much testing that is done to diagnose disease looks at the structure of the body and its cells instead of their function; this testing therefore cannot accurately diagnose CVS, because it is a functional disease. No one specialty can treat CVS in isolation, because it involves multiple systems of the body.

Dr. Boles discussed CVS as a mitochondrial dysfunction. He feels that treating the mitochondria with supplements can lead to positive results. He recommends the "Mito Cocktail" of supplements. He also has developed a supplement called Spectrum Needs, which contains 33 active ingredients that can help promote mitochondrial energy metabolism. He concluded by emphasizing that CVS is a treatable disease, and encouraged us to not give up!

Katja Kovacic, MD

(Professor Pediatrics–GI, Medical College of Wisconsin, Children's Hospital of Wisconsin)

Dr. Kovacic began by discussing how the autonomic nervous system (ANS) is involved in mediating signals between the brain and the gut. She reported that CVS can be considered an imbalance between the sympathetic and parasympathetic nervous systems in the body, a chronic autonomic dysfunction. We should consider targeting the ANS dysfunction in treating CVS. Many CVS patients present with a lower vagal tone, which is related to anxiety.

Dr. Kovacic discussed the importance of neuro-modulation in treating CVS. She mentioned some drugs that are producing very positive results, including tricyclic antidepressants. Other therapies discussed by Dr. Kovacic include CoQ10, ginger, topical capsaicin, Pyridoxine (Vitamin B6), acupuncture at the P6 acupoint, and CBD (cannabidiol). Like the other physicians at the conference, she believes that lifestyle modifications are important to the successful treatment of CVS patients as well.

Dr. Kovacic also shared about her current research project, using auricular neurostimulation units with their electrodes placed on the external ear to affect four cranial nerves. She conducted an earlier research study in which these units proved successful for treating patients with abdominal pain, and has now begun clinical trials using these units in CVS patients. These units are not yet covered by insurance, as they are still under clinical trial for treating CVS. While the study is still in its infancy, early results are promising. Only two patients have been enrolled so far, but they both appear to have benefitted from this treatment, anecdotally.

Julie Banda, APNP

(Advanced Practice Nurse Practitioner, Pediatric Nurse Practitioner-GI, Children's Hospital of Wisconsin, Milwaukee)

Julie Banda was invited to the conference to discuss her area of expertise, Dysautonomia/Postural Orthostatic Tachycardia Syndrome (POTS). She noted that there are many comorbidities shared between CVS patients and POTS patients. Per a study conducted by Dr. Venkatesan, approximately 85% of CVS patients experience Dysautonomia-type symptoms. The autonomic nervous system (ANS) controls heart rate, blood pressure, and digestion — so it is a logical conclusion that a dysfunction of the ANS system could certainly lead to the symptoms found in both POTS and CVS.

Typically, POTS first presents itself in adolescence. Patients may benefit from diagnostic testing when they are experiencing symptoms of dizziness, heart rate changes, or chronic nausea with position changes and/or fainting episodes. Diagnostic testing includes a tilt table test and sweat-measuring tests.

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Treatment for POTS includes intake of a high volume of fluids (3–5L per day) and avoiding diuretics such as caffeine and alcohol. Patients may benefit from drinking 16 ounces of water before even rising from bed or allowing themselves a slower time to rise in the morning, to allow their system to adapt. Another suggestion is to elevate the head of the bed, so that a POTS patient will not have so far to adjust when rising in the mornings. Support/compression stockings may be helpful. Patients may also benefit from strengthening their leg muscles and doing isometric leg exercises before rising.

Salt is a mainstay of treatment for POTS. The first medication considered in POTS is Fludrocortisone; when used in conjunction with hydration, salt, and exercise, it is usually quite effective. She discussed medications that can help POTS symptoms that include the "Mito Cocktail". Julie discussed the importance of keeping POTS patients safe if they have a risk of fainting, especially when they're in the shower. She also discussed the importance of keeping POTS patients actively involved in their own lives, and said that they should be encouraged to return to normal activity even when their symptoms are not fully under control. POTS patients may benefit from psychology services, not because POTS is psychogenic, but because these patients may benefit from learning coping skills for their disease process.

Praveen Goday, MD **(Pediatric Gastroenterologist, Children's Hospital of Wisconsin)**

Dr. Goday is a nutrition expert at Children's Hospital WI. He discussed the varying needs of the CVS patient, depending upon which phase of the disease they are currently experiencing.

During the prodromal phase, medications should be the primary focus, rather than nutrition. If the patient can tolerate fluids, they could be beneficial at this stage.

During the actual vomiting phase, the initial concern is keeping the patient properly hydrated. If the patient comes to the ED or needs to be hospitalized, Dr. Goday recommends a 10% dextrose solution, given at a higher rate than is typical for patients with other diagnoses. Nutritional supplementation needs to be considered in longer episodes. NG tubes cannot effectively work in someone who is still vomiting, so other methods must be considered. Dr. Goday argued that NJ tubes are safer to use than are central IV lines, because of the increased complications and risks of infection with central IV lines.

In the recovery phase, the goal is to get the patient back to a regular diet as soon as they can tolerate it, once the episode ends. He cautioned against Pedialyte, as it does not contain lipids and also against Gatorade, as it contains too much sugar.

Dr. Goday had a few recommendations to consider during the inter-episodic phase. He said to avoid fasting and cautioned the CVS patient against coffee, alcohol, and cannabis. He recommended keeping a food diary, to help a patient learn if anything food-related may be triggering their episodes. He also discussed the importance of maintaining a healthy weight, as many of the medications used to treat CVS have weight gain as a side effect. In conclusion, he recommended the 5-4-3-2-1-0 Diet (5 veggies & fruits a day, at least 4 meals eaten together as a family per week, 3 meals a day, 2 hours max screen time, 1 hour physical activity per day, and 0 sugar-sweetened beverages — unless they are needed due to management of CVS symptoms).

Denise Bellcock, RN **(GI Nurse, former ER Nurse)**

Denise Bellcock was invited to the conference to help attendees learn more about navigating the emergency department (ED). She reviewed with us the definitions of the different levels of emergency departments, from Level I to Level IV. She also reviewed the Emergency Severity Index (ESI). Patients needing truly emergent, life-or-death care are ranked lowest, at an ESI of Level 1. Those not needing resources to be stabilized are ranked higher, at an ESI of Level 5. CVS patients would typically present as an ESI of Level 3-4, needing one or more resources to be stabilized, but without their vitals presenting in a "danger zone".

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Denise shared that the primary goal of any ED is “to get the right patient to the right resources in the right place at the right time.” Since patients with CVS are usually not presenting in a life-or-death situation, they will generally receive better service in the ED if they come prepared. You should bring with you a list of your meds and allergies, including the times your medications were last taken. You should also bring an overview of your health history, including any past surgeries and procedures and any recent test results. If you have a CVS treatment plan, that should be brought as well. You should be prepared to share what has/has not worked in the past. We are our own best advocates. If your family member with CVS is very ill at the time of arriving at the ED, you can advocate for treatment to begin ASAP, especially when you know how effective that treatment has been in the past.

The goal of the ED is to rule things out and to stabilize a patient before admitting them to the hospital or discharging them home. Blood work may be done, and you will likely have to wait for the results before discharge. If you do not feel ready at the time the ED doctor suggests discharge, you should speak up and tell them why, whether it is because you still feel sick or because you don't have a plan in place for follow-up care. Denise suggests working closely with your CVS specialist before, during, and after ED care for CVS. She mentioned that outpatient infusion centers are becoming more common and might be a good alternative place for CVS treatment when the ED is not warranted.

Michael Williams — Story of Hope

Michael Williams is a young man who shared with us his journey with CVS. He became ill at 10 years of age, and was diagnosed with CVS after seven frustrating months of various incorrect diagnoses. Like many of us, his journey with CVS has had many ups and downs. His cycles changed over time, in both length and severity, eventually changing over from vomiting to primary migraines. He tried various medications that did not work. He tried Amitriptyline when he was first diagnosed; while it did not work for him at that time, it is working for him now.

Michael met Dr. Li when he was 12 years old; his relationship with Dr. Li is what led him to want to be a physician someday. Michael is currently enrolled at the University of Illinois, Chicago and will graduate in the spring of 2019. He is majoring in pre-med and biochemistry. He hopes to work in a lab and then return to medical school to become a doctor, one of the “good doctors” who listens to his patients and works with them. He continues to experience 4–5 migraines per month, but is working through those to be a successful student. Michael shared that “it's not easy, but it's possible!”

Jenny and Eleanor Johnson — Story of Hope, “Redefining Hope”

Jenny Johnson (AKA Mama Bear) and her 12-year-old daughter Eleanor (AKA Eleanor the Great) presented together about their journey with CVS. Eleanor's CVS began during her preschool years. Her first longer episode occurred during second grade, resulting in a five-day hospitalization. Eleanor received multiple incorrect diagnoses along the way, including food poisoning, dairy sensitivity, and eosinophilic esophagitis (EOE). Even with a now-correct diagnosis of CVS, their up and down journey continues. Jenny noted that as soon as you think you have your CVS figured out, it changes. Currently, Eleanor's episodes last about three weeks at a time.

Both Jenny and Eleanor feel fortunate to have found an amazing doctor in their community, Dr. Biank. While Dr. Biank does not specialize in CVS, he was willing to partner with them, to research, and to learn. Jenny recommends finding a doctor who is willing to partner with us in a similar way. Another positive part of their journey was establishing a 504 plan with Eleanor's school. Her teachers follow this plan to help her manage her schoolwork through her illness. Jenny highly recommends that students with CVS work with their schools to establish a 504 plan; because they are federally mandated, the school cannot deny students with CVS from having them.

Jenny and Eleanor had a lot of encouragement for us, sharing their thoughts about HOPE.... “Having hope is not always sunshine and flowers.” “Hope means not giving up when you feel desperate and scared.” “Hope means learning to ride the waves without freaking out too much.” “Hope means celebrating that you made it through and the growth it caused in you.” “Hope means that the light will eventually come back, despite the darkness.” “Hope means being willing to ask for help and leaning on a community when things get hard.” Jenny talked about how beautifully their community has supported them, and suggests that we all make a list of our villagers, those who can hold us up when we cannot do so. She encouraged us to be our own biggest advocates, even when we might feel hopeless. She encouraged us to practice positivity even amidst the misery, to be resilient and to never give up.

Shun Emoto **CVSA Japan Update**

Shun Emoto came to the conference all the way from Japan, to share with us his personal experience with CVS and to share an update about CVSA Japan. Shun began experiencing unexplained vomiting in 1997 at the age of seven, and was not diagnosed with CVS until he was nine years old. Even once diagnosed, his disease was very misunderstood. At the time, there was no knowledge of CVS in Japan... there were no CVS doctors, no CVS medications, no CVS treatments. Even though he was extremely ill, people would talk about his CVS being “fake” and “psychosomatic.” It was an extremely discouraging time, leaving him and his family feeling lonely, powerless, and socially isolated. Happily, by age 16, the intervals between Shun’s episodes started increasing and eventually his CVS disappeared altogether.

Motivated by his own struggles and wanting no one else to feel as alone as he did with his CVS, Shun established a CVS support group in 2012 and founded CVSA Japan in 2014. Shun shared that Japan now has one pediatrician who specializes in CVS, Dr. Toshiyuki Hikita. Presently, Shun is a PhD candidate at the University of Tokyo, studying public health, looking specifically at how to promote the research of rare diseases. Shun is working to bridge the gaps between patients, universities, hospitals, and pharmacies for clinical studies and trials of rare diseases. These rare diseases include, but are not limited to, Distal Myopathy, Replacing Polychondritis, Russell-Silver Syndrome, Marfan Syndrome, Isaac’s Syndrome, Mitochondrial Diseases, and Cyclic Vomiting Syndrome.

Shun serves on the Executive Committee of Rare Disease Day, Japan and works with the organization, Rare Disorders Without Borders. Shun has been honored with the “Symbol of Tomorrow” prize from the Emperor for his work. It is Shun’s goal that no one be isolated with his or her rare disease the way he was as a child. He wants people who struggle with CVS and other rare diseases to be able to say, “We are not alone any more.”

Dr David Fleisher, the “Grandfather” of CVS

Dr. Fleisher closed the presenter portion of the conference by sharing his thoughts with us. Dr. Fleisher was one of the founding members of the CVSA, along with Kathleen Adams. He remains involved with the CVSA as a mentor to our current medical advisors. He shared with us the “Five Things that Every CVS Patient Needs”:

A good doctor, one who has first-hand knowledge about CVS or is willing to listen and learn about CVS and who is also willing to partner with the CVS patient to provide a continuum of care.

Medications that work. There are now so many medications that are available; a patient should not give up on finding something that can effectively treat their symptoms.

An institution (hospital) that “gets it”, one that will listen to the primary care doctors who are treating the CVS and will implement the plan implemented by these doctors.

A rational treatment plan with defined goals and strategies. This plan should include specifics for each of the four phases of the disease. Sleep is extremely important during the episode itself. He noted that sleep is the only escape from the horrific nausea; “when you’re sleeping, you’re not puking.”

Contact with others suffering with CVS so that folks don’t feel alone. This is why the CVSA is so very important!

Update from the CVSA Leadership:

Blynda Killian, CVSA President and Debbie Conklyn, CVSA Program Director

Blynda and Debbie concluded the conference by answering our questions and by sharing more about what they are currently working on within CVSA. They anticipate publishing the Adult Guidelines for CVS in a publication of the ANMS (American Neurogastroenterology and Motility Society) by the end of 2018 or in early 2019. These guidelines will be published with open access, so that they will be available to anyone and everyone. They plan to work on updating the pediatric guidelines next. They continue to work on recruiting new doctors to the referral list, and requested our help in doing so, if we have had a good experience working with a doctor in the treatment of our CVS.

2018 CVSA Conference Testimonials

Have you ever considered attending one of the CVSA Family & Adult Conferences but just weren't sure if it was for you? Well you are in luck, as we have some of the testimonials from this year's attendees. We hope that you enjoy reading their testimonials...

Tom Cannek

I thought things went very well. Food was good and coffee was great.

Susan Rhein

Attending the conference is a must! A lot of new information since the last conference. The networking, camaraderie and sharing reminds me that I am not alone in this and that there are medical professionals dedicated to improving the lives of CVSers.

I can't wait to share the new information with my physician!

Lexy Jollimore

I am a Canadian registered nurse and mother of an adult daughter with CVS. About eight years ago, my daughter Christina started having bouts of vomiting with abdominal pain. The vomiting episodes would last up to seven days during which time she was violently ill and unable to do much more than moan and vomit. She ended up in the hospital repeatedly with each doctor saying something different but none was able to tell us what was actually wrong with her. Sometimes she was admitted but just as many times she was not. After sitting in the ER for several hours curled up in a chair vomiting, she would be given IV antiemetics and then sent home.

She had several scopes and tests which did not provide any insight as to what was going on with her. This went on for several years until one day when I was at work, I had a patient who was admitted with vomiting. While assessing my patient, he told me that he had cyclic vomiting syndrome. I had no idea what that was; it was the first time I had ever heard of it but as he was describing his symptoms, I noticed the similarities between his symptoms and my daughter's. I then researched CVS and found a link to CVSA. I took all the information that I had found to my family doctor who diagnosed her with CVS.

Although we have had a diagnosis for some time now and through research, had a general understanding of what CVS is, she had never been on any medication for it or had a treatment plan. Attending the CVSA conference was invaluable. We learned so much, not just about CVS, but also about treatment. We have now been to the doctor and she has been started on Amitriptyline and we have hope that there is a light at the end of this very dark tunnel.

I have talked to the clinical nurse educator at my hospital, who did not know what CVS was, and am planning on bringing the information that I learned at the conference to the nurses and doctors at my hospital so that our patients with CVS can be treated more efficiently.

Along with the hope that we brought back with us, is a lot of frustration at the lack of knowledge and resources about CVS in Canada. I know there are other Canadians with CVS but Christina had never met anyone else like her until we traveled to Milwaukee to attend the conference.

I want to thank you at CVSA for giving us this hope.

Why have I attended the CVS conference three years in a row?

Submitted by: Kiersten Wood

June of 2014 was the first CVS conference that I attended. When my Mom and I signed up we weren't sure of what to expect, but we knew that this was something we needed to attend because we were on the search to find anything to help my chronic CVS and migraines. We went in with an open mind. Little did we know that we would meet life-long friends and receive information that would be life changing.

I remember the feeling after the first 15 minutes of the initial "meet-and-greet." I had horrible anxiety and didn't know if I was going to be able to stay much longer. I was truly overwhelmed. Having everyone ask me questions such as "Who is the sufferer?" "How long have you had it?" "What are your triggers?" It was a lot to take in at first. However, it was also comforting knowing I was finally around other people that understood. Could this be real? Was I really meeting other people that had experienced what I had experienced and could relate to me? It was overwhelming at first. However, after the initial overwhelming feeling went away I started to feel comfortable. I was finally in a crowd of people that "understood" me. I knew I could share my trials and tribulations and not have them look at me with an expression of "huh?" They really knew what I meant.

We learned so much great information at the conference and took home so much knowledge. However, I think the best thing we took home were the life-long friendships that we developed in the short week-end that we spent 1,750 miles away from home. I knew that I would probably not see these friends for at least another two years but I knew they were all only a text, phone call, or Facebook message away if I needed them. Since our initial conference in 2014, my Mom and I have attended two more conferences. I can honestly say that at every conference we continue to learn so much about CVS. We learn about new findings from the medical advisory board, we learn of new stories of hope from the most amazing and most brave CVS warriors that I have met, and most of all, we are able to see our old friends and make new friends that truly understand what we have been through.

If you have never attended a CVS conference, I highly encourage you to look into attending the next conference in June of 2020. And to those of you that have attended a conference and think that attending another one is not necessary because there is "nothing new to learn" or you're just not sure you will benefit from another conference, I highly encourage you to attend again. Our amazing medical advisory board is continually working on finding new things that we will all benefit from, and if you don't feel as though you will benefit from new or repeated information, I can guarantee you WILL benefit from the friendship and companions you will gain from the conference. Take the risk and attend a conference!

Let's all continue to have HOPE and spread AWARENESS!!!

