CVS appears on hit ABC drama Grey’s Anatomy.

Submitted by Carol Warner

What a week Nov 12th thru 16th proved to be for Chandra Wilson and CVSA. As most of you know Chandra plays “Dr. Bailey” on Grey’s Anatomy and is also our CVSA spokesperson. During that week Chandra had several interviews including an appearance on “The Talk” to promote the Nov 15th episode of Grey’s Anatomy, which Chandra directed and which included a patient that suffered from CVS.

Chandra was very excited about having the opportunity to direct this episode of Grey’s and gave this quote to us about her experience. “At the 2012 CVSA family conference, I was specifically asked by our sufferers to find a way to get CVS on to Grey’s Anatomy. Grey’s historically focuses less on the medicine of our patients and more on the lives of our regular characters and how they are impacted by the medicine and personal issues. Still, I made a pitch to my producers for a two episode arc of a 25 year old male character who repeatedly comes in to the ER with what we know are classic CVS episodes, vomiting bile, writhing in pain, dehydrated and no one there with him to speak as his advocate. He would eventually tell of how his school/work/personal life has been impacted by his illness, and begs to be taken seriously and for someone to figure out what’s wrong. Just as he is about to go through an unnecessary exploratory laparotomy as a last resort to see if something surgical was causing his episodes, he was to get diagnosed with CVS by Arizona Robbins who has CVS knowledge from working in pediatrics. But, I was offered Santa in a one episode arc. Weighing the pros, I decided that here was a vehicle to say the name Cyclic Vomiting Syndrome out loud on national television to up to 10 million viewers. Here was an opportunity to produce a Public Service Announcement to drive traffic to CVSA, its message board, and Facebook page. Here was a chance that, for all that would be missing in the Grey’s storyline, your comments and commentaries and posts would fill in the blanks for anyone coming to CVSA for the first time looking for validation or a name to take to their physician or a community of support that they never knew existed. We collectively accomplished that last night. Phones rang the next morning, hits were made to the website and comments were posted. Even the disappointed posts spoke graphically of the reasons why the content didn’t do enough justice to the experience of CVS way better than any episode of Grey’s Anatomy could portray. We need a Television Movie of the Week centered on a family affected by the CVS of one of the family members in order to accurately expose what our lives are like as sufferers and caretakers. Maybe I have earned the credibility to accomplish something like that now for us. Even as I write this, Sarina has just finished an 11 day stay in Children’s Hospital Los Angeles with one of her most violent episodes of relapsing CVS after almost 2 years of a break. I’m watching for every change in facial expression, keeping the trash can nearby, waiting for her gut to start regular motility again, eager for what is her normal energy level to return, praying that two days ago was indeed the end of this relapse so that she can go back to being a 19 year old college student with her whole life in front of her. That’s CVS.”

In true Grey’s fashion, the show was fast paced, had multiple storylines AND this episode included a message at the end—highly unusual for TV drama. One of the storylines was of a homeless man, who had been nicknamed “Santa” by the doctors because of his appearance and who was a frequent visitor to the Seattle Grace ER, suffering from severe nausea and vomiting and labeled as a “drug seeker”. A young female intern, who was assigned to the man’s case, would become frustrated after being puked on for the third or fourth time during the shift by this man but she also felt they were missing something about his condition. The intern showed compassion toward the man, who was very dirty, had long grey hair and a beard, by cleaning
CVSA Media Blitz is Huge Success
Submitted by Mary Rachael Barr

I am still trying to wrap my head around the events of the past week. For over 20 years, CVSA has been working to raise awareness about Cyclic Vomiting Syndrome. For the past 10 years that I have been on the board of directors, it has been a struggle to get any media coverage—much less coverage in the national media. And now, we have experienced in a week-long media blitz involving television, newspaper, magazine, and internet media coverage. It is truly astonishing how far we have come.

Before Chandra Wilson became our spokeswoman, our best media efforts resulted in local news coverage of an event such as CVSA walk or a human interest story about a child with an unexplained illness. Usually, this coverage was in the newspaper and not on television. For some reason, it is insanely difficult to persuade the media to write about vomiting—much less ridiculously intense, recurrent vomiting episodes with no known cause or easy cure.

For years, CVSA tried to find a national television show willing to address CVS. We approached House, Good Morning America, Oprah, and Mystery Diagnosis—to name just a few. We approached networks formally with official requests from CVSA and informally with letter writing campaigns by CVSA members. We were unsuccessful. Over and over, we were told, “Your best chance of getting any national media coverage is to find a celebrity willing to champion your cause.” It seemed like a hopeless quest. What celebrity would want to be associated with vomiting?

And then, CVSA and Chandra Wilson made contact following her appearance on The Talk in 2010 where she spoke about CVS. Her daughter Sarina is one of us, a fellow CVSer. I am so incredibly thankful that Chandra and Sarina are willing to speak out about CVS. Over my decade as part of CVSA, I have seen many families become involved with CVSA until their CVS is under control. Then they return to their life before CVS. It is hard to stay involved when you are well, because you do not want to remember how bad CVS can be. It would have been easy for Chandra and Sarina to take that road, but instead, they have chosen to use their connections and Chandra’s fame to tell others about CVS. I am so grateful.

Last year, Chandra appeared on the daytime television show, The Doctors, to talk about her daughter’s CVS diagnosis during an episode on misdiagnosis. (As our members can personally attest, many CVS patients are misdiagnosed before being correctly diagnosed with CVS.) It was the first time that CVSA had been mentioned on a national talk show. The office was swamped with telephone calls, e-mails, and inquiries. I was thrilled. I hoped that Chandra would be able to speak out about CVS and CVSA again on a similar show. I never imagined coverage like we have seen this week.

This summer at the conference, many members requested that Chandra get Grey’s Anatomy to incorporate CVS patient into an episode. She reported this to the board earlier this month, “I heard your requests at the conference this summer and am so pleased to report to the CVSA community that Episode #906 of Grey’s Anatomy entitled “Second Opinion” was directed by me and incorporated a character who is an adult sufferer with Cyclic Vomiting Syndrome into a storyline. My hope was that some undiscovered somebody out there saw themselves or a loved one and either picked up the phone to CVSA or explored the website, message board and Facebook page. I know the importance of having a name for what you are going through. Here’s hoping the countless undiagnosed or non-believers in the medical community will hear and take appropriate action for treatment.” You can read more about the episode on the front page of the newsletter.

Having a CVS patient appear on Grey’s Anatomy is a very big deal; Grey’s anatomy is watched by millions of fans each week. It is also the first time that CVS has been mentioned on a mainstream, primetime TV show. If all that had happened this week was the Grey’s Anatomy episode, it would have been a huge step towards CVSA’s goal of telling the world about CVS. But this week’s publicity has been so much bigger than a single episode of Grey’s Anatomy.

This week Chandra was able to tell others about CVS through many other avenues as a direct result of the Grey’s Anatomy episode. Chandra discussed CVS on Access Hollywood Live and The Talk. Then in primetime, she delivered a public service announcement about CVS after the Grey’s Anatomy episode. A public service announcement after a primetime TV drama is quite unusual and was a direct result of Chandra’s advocacy on our behalf. She was also able to use print media to help get the word out. She talked about CVS with TV Guide magazine, the Huffington Post, The Examiner, Lifescript, and The Hollywood Reporter to name a few. All of these interviews were publicized nationwide and have large distribution numbers.

Local TV media also covered CVS this week. Chandra was interviewed about CVS on two Southern California news channels (KTLA and KABC). Two of our members were also able to get their local media to cover their CVS story because of the Grey’s Anatomy episode. The Besnoff Family was able to tell others about their son’s Aaron’s experience with CVS in the Lancaster, PA newspaper, and Lynne Bussey and her daughter were interviewed by KRCR news in northern California. KRCR news also posted a link to CVSA’s website on their website. Overall, CVS and CVSA have received more mainstream media coverage this week, than during the previous decade.
We have seen a huge effect of this publicity at CVSA. By the end of the day on Saturday, over 400 people had e-mailed CVSA requesting information about CVS and more than 50 people called the office. Normally, we do not receive 50 new inquiry phone calls a month. On Facebook, we had 1,534 comments on our page at the end of the day on Friday. In contrast, on a normal day we average about 60-80 comments. We have also had an unprecedented number of people visiting the website and message board. This amount of activity is incredible.

By any standard, the media blitz has been extremely successful. If we take the most conservative view, 450 people contacted the office because they think they may be suffering from CVS. To put this in perspective, right now CVSA has 750 members. We also expect inquiries to continue to come into the office at a slower rate over the next week as people watch the episode on their DVRs. These 450 people are not just suffering potential CVS episodes but also from burden of an unknown medical condition. Most of us remember when no one could tell us why we were sick, when we were told "it's all in your head", or questioning pregnancy, to attempting to treat nerves/anxiety to environmental allergies. So, I just want to say THANK YOU, for partnering with ABC/Grey's, whoever...to spread the word! This really does give me hope.

The following are just a few of the comments we have received from people reached by the media blitz.

“Made me cry when I saw it. I had to call my hubby in to watch it and his jaw just dropped. He said that is u. Why did the Dr never ever bring it up. Thanks for this!!!!!”

“...this show may have been an answered prayer for my 17 year old.”

“My husband and I are in complete SHOCK!! Our son has these episodes where he vomits repeatedly for hours, says his eye hurts sometimes on a weekly basis. Then after a few hours and sleep he is usually fine again. We have been at a loss until we watched Greys Anatomy tonight and saw the patient and how it is usually found in children! We went to the website and it is 100% what he experiences!! Thank you so much for airing this and making us aware of what this could be!! We are going to print off this information and take it to our family doctor!! Again thank you so much!!!”

“This is a surreal night, watching Grey’s Anatomy, one of my favorite shows and they start talking about CVS…and there is a whole website and Facebook group. I have been living my whole life with CVS...It is so nice to know that there are people just like me dealing with this and that mainstream is starting to pick up on it.”

“We have finally a name for what my daughter has. We have spent years on a hamster wheel when it comes to what is going on.”

“I am very thankful to find out about this association due to last night show. My son’s GI Dr. wasn’t even aware there was one. At least now we can all support each other and learn from each other”

“I was thrilled to have heard about this on Grey’s. I was diagnosed when I was young and up until that episode I had NEVER heard anyone (outside my immediate family and doctors) talk about CVS and never knew about the website. I am thankful I found it.”

“It’s so surreal to me, still, to hear people talk about CVS as the horrible disease it is. I always feel like maybe I’m just a big baby, but this monster has had control of my life for 8 years now...”

“Quite emotional seeing Chandra discussing CVS. Sometimes you think you’re the only one eh!”

“[It’s] So weird to hear someone on TV talking about CVS, after years of struggle and even after diagnosis. Fantastic that Chandra is the spokesperson for CVS, hopefully now more people will be aware of this awful illness.”

“I'm just happy to learn that we are not alone. I never knew of this organization and I am so happy to find out about it. My son is 6 and has suffered his whole life with this. I am just thankful as a parent there is an organization trying to help.”

Thank-you Chandra and ABC for helping educate others about CVS!
and grooming him, so that he looked presentable. The intern went to her Chief of Staff, who wanted the man discharged because there was "nothing wrong with him", since all tests had come back negative and they needed the bed space. The intern stood up for the patient regardless. When the chief saw the patient all cleaned up, he backed off and allowed the intern to run one more test, a CT of the abdomen. There was actually a storyline within a storyline here, the patient was suffering from an unexplained illness but the perception of him was totally changed once he was cleaned up. The intern told her chief that the man would have been treated better if he had presented himself all cleaned up the first time and that as doctors they should treat all patients equally. While waiting to have the CT done, the man tells the intern of one more symptom (that he has migraines) and proceeds to puke on the intern once more. She leaves to meet up with another young doctor who had trained in pediatrics, and she vents her frustration about being puked on all day, the symptoms and not having a diagnosis. This young doctor takes the intern by the hand and they go back to the patient. He tells the man he has Cyclic Vomiting Syndrome, a condition that they see a lot in kids but that is also seen in adults. She also makes the connection to mitochondrial dysfunction. It is explained to the man there is no cure, but it can be managed. He is given medication to take with him and told to come back to one of the two doctors if he needs help and that they will look after him. At the end of the show we see the man, who had come into the hospital unclean and undiagnosed, leaving with an expression of satisfaction on his face. Now, he not only was cleaned up but had a diagnosis. At the end of the show Chandra did a 10 second public service announcement about CVS, CVSA and gave out the CVSA website address.

Chandra’s goal for this episode was to raise awareness about Cyclic Vomiting Syndrome. Having watched her two TV interviews and the Grey’s Anatomy episode, I can say that I believe she did just that. While the Grey’s Anatomy show may not have followed the story line that she wanted, she was able to use the episode to talk about CVS during multiple TV interviews which aired nationwide and to spread the word about CVS in written media articles (e.g. the TV Guide). She was also able to deliver a public service announcement at the end of the Grey's Anatomy episode (a very unusual event). For the first time ever, CVS was talked about on a medical drama that is viewed by millions of people around the world. I know there will be sufferers who saw themselves in Chandra’s words this week. Let’s hope they reach out for help.

To Chandra, on behalf of all CVS sufferers and CVSA, once again I say a huge thank you for all of your efforts to see that CVS was included in a Grey’s episode and for all you do to help raise awareness about CVS. You are making a difference in a way not possible for the rest of us!

**New therapies for CVS to be studied**

Submitted by Kathleen Adams

A collaborative team of researchers received a one-year, $50,000 grant from the Clinical and Translational Science Institute of Southeast Wisconsin (CTSI) to study possible new therapies for cyclical vomiting syndrome, a chronic disorder that affects children and adults.

The project title is “Serum Endocannabinoid Concentration and Salivary Cortisol in Patients with Cyclic Vomiting Syndrome.” The primary investigator is Thangam Venkatesan, MD, Associate Professor of Medicine (Gastroenterology and Hepatology) and gastroenterologist at Froedtert Hospital; co-primary investigators are Cecilia Hillard, PhD; and Hershel Raff, PhD.

Cyclic vomiting syndrome (CVS) is a chronic disorder that is characterized by episodic nausea and vomiting interspersed with symptom-free intervals. Treatment is mostly based on alleviating symptoms when the episodes occur, and there are no consistently effective therapies or preventive measures available. The goal of this study is to learn more about the relationship between stress and endocannabinoid concentrations in the body, and how that factors into CVS. This new data will pave the way for developing new therapies to treat CVS.

This is one of 19 pilot projects being funded in 2012 through CTSI. The goal is to create synergy through collaboration, and studies are specifically designed to lead to major future research support. The projects explore findings that have the potential to be translated into clinical practice and community health, and are led by investigators at the CTSI’s eight partnering institutions: the Medical College of Wisconsin, Marquette University, Milwaukee School of Engineering, UW-Milwaukee, Froedtert Hospital, Children’s Hospital of Wisconsin, the VA Medical Center, and the Blood Center of Wisconsin.

CTSI is part of a national consortium of top medical research institutions. Working together, the CTSI institutions are committed to improve human health by streamlining science, transforming training environments and improving the conduct, quality and dissemination of clinical and translational research. The CTSI program is led by the National Center for Advancing Translational Sciences, part of the National Institutes of Health. Support for the Pilot Award Program comes from Advancing a Healthier Wisconsin (AHW), the National Institutes of Health (NIH), the Biotechnology and Bioengineering Center (BBC) and the John and Jeanne Byrnes CTSI Award.
Help Protect Rare Disorder Research Funding

The National Organization for Rare Disorders (NORD) has asked us to join them in asking Congress to protect funding for rare disease research.

“We are writing to alert you to a situation that could have a major impact on rare disease programs at NIH, FDA, and other federal agencies. Under the Budget Control Act of 2011, federal programs face an across-the-board funding cut of nearly 8 percent in January 2013 if Congress hasn’t reached agreement on a budget deficit reduction plan. These across-the-board cuts could have a devastating effect on research and other programs of major importance to the rare disease community. . .

Last week, the White House Office of Budget and Management (OMB) released a report on the possible effects of these funding cuts, known as "sequestration", on federal agencies. The cuts could result in the loss of 1,200 FTEs at FDA alone. They could negate much of the anticipated benefit from this summer’s FDA Safety and Innovation Act.

At NIH, the result would be equally devastating. The cuts would slice $2.5 billion from a $30 billion budget, resulting in the loss of the ability to fund about 2,300 new grants or reduced commitment to existing grants.

These cuts are not acceptable! No action in Congress is expected until after the elections in November, but there is value in beginning to make our case now.

In recent weeks, NORD has been meeting with other organizations concerned about these potential cuts, including the Coalition for Health Funding http://publichealthfunding.org. It is our fervent hope that Congress and the President will reach agreement on a deficit reduction plan before January so that the cuts won’t be implemented.

But in the meantime, we encourage you to submit a letter to your elected officials through NORD’s Legislative Action Center to let your elected officials know that Non-Defense Discretionary (NDD) programs, including medical and scientific research, education, public health and more, have already borne more than their fair share of responsibility for deficit reduction. We encourage you to personalize your letter by including information about how a rare disease has affected you or your family.”

To put the above information into perspective, the approximately 2,300 new grants that NIH would be unable to fund represent a quarter (25%) of the new/competitive grants. This would greatly decrease our professional member’s chances of receiving research funding to investigate new treatments for CVS. CVSA would like to encourage our members to join with other rare disease sufferers and NORD to let Congress know how important rare disease research is to us.


"Dear Senator/Representative X,

As a constituent, I am writing to urge a balanced approach to deficit reduction that does not include further cuts to Non-Defense Discretionary (NDD) programs, which have already done their part to reduce the budget. NDD programs – the core functions government provides for the benefit of all, including medical and scientific research, education, public health and many more – support economic growth and strengthen the safety and security of every American.

Together, these programs represent the second smallest share of the federal budget. They are not the drivers of the debt. And yet, they are always the most vulnerable to cuts, and have already been slashed in the name of deficit reduction.

Members of Congress and the President must work together to achieve a balanced approach to deficit reduction. Only through balance can we avoid sequestration and put our nation on a sustainable fiscal path.

My particular reason for writing to you is that I am concerned about rare disease programs at FDA, NIH, and other federal agencies and I urge you to protect such programs from the effects of the sequester.

Funding to support discovery of potential therapies and cures for rare diseases is essential to protecting our nation’s competitiveness in the life sciences, and is vital to ensure that millions of Americans affected by rare diseases continue to benefit from the promise of biomedical innovation.”

It is also helpful to tell your Senator or Representative how CVS (or other rare diseases) have affected you and your family. Please include your name and address at the bottom of the letter so that your representatives know that you are from their district. It reminds them that they were elected to represent you! Please join us in writing to your representatives so that we can preserve research funding for rare disorders like Cyclic Vomiting Syndrome.
CVSA launches new teleconference support groups.

Finally, a way to meet people without having to leave your home! In response to many members' request, CVSA started having AccuConferance Support Group Meetings in early October. These calls are a fantastic way to meet other families struggling with CVS, to exchange tips of how to fight CVS, and make new friends without leaving your house! CVSA is thrilled to finally offer this type of member support and early feedback from attendees has been very positive!

It is extremely easy to join one of these calls. Upcoming Support Group meetings are listed on the website under the current events tab (click on the “Support Groups” link on the left hand side of the page). At the appointed time of the meeting you will dial the number 1-800-977-6002. You will then be asked to enter the participant code which is: 5429554#. You will be asked to state your name and then you will be joined to the call. (If you call in early before the moderator is on, you will be put on hold and then joined to the call once the moderator has joined the call.) Each call will last approximately 1 hour. At present, leaders try to schedule calls every 4-6 weeks. Contact information for each group’s leader is available on the website.

Currently we have leaders in nine different states (Colorado, Illinois, Iowa, Michigan, Minnesota, New York, South Carolina, Oregon, and Washington St). While we encourage members to call into support groups near your geographic area, you are welcome to join any call that is convenient. If there is not a call in your area of the country, please just pick a group to join. We are encouraging members to call into a group in their particular area (if possible) for several reasons. First, we hope that these teleconference groups will connect people who can also support each other in person—either by hosting an official in-person support group meeting, by making informal plans to meet up with another CVSer that they met through the calls, or even helping another CVS family when an episode strikes. Second, we hope that members will be able to share concrete information about their experience with particular doctors, hospitals, emergency rooms, or clinics. This information will be much more helpful if you are in the same geographic area. Finally, we hope that these groups will lead to a critical mass of CVSA members in a community to help spread the word about CVS and educate our communities. We really want to encourage our members to take advantage of this new resource.

We are also recruiting more members to lead these teleconference support groups. Eventually we would love to have a group in each state. You do not need any particular background or training to become a support group leader. If you are interested, please contact Ruth Novak at the CVSA office (cvsa@cvsaonline.org or 414-342-7880).

Please see the report from Washington’s first Accu-Conference Support Group below to get a glimpse of what occurs during one of these support groups teleconference calls.

Report from Washington's first teleconference support group
Submitted by Marie Pierce

I am proud to report Washington's first Accu-Conference Support Group was a success. Thank you to those that called in. Without you, this group would not have been possible. I believe bringing this type of support to our members will prove to be a valuable asset.

Being an adult sufferer I have spent the past few years trying to find some form of support here in Washington and kept coming up empty handed. The feelings of hopelessness, depression, isolation, and fear slowly began taking over. When I found the CVSA’s website I felt a sense of belonging, the isolation began to lift, the depression wasn’t as dark, and for the first time in years I felt there was hope. I began thinking what a wonderful opportunity it might be to bring CVSA here to Washington, and decided I would volunteer my time to make that happen.

I began placing brochures at the local library, doctors’ offices, even trying for a face to face group, but as sometimes happens with each of us living hours apart, the face to face proved a bit harder than initially planned.

Then the idea of offering a telephone support group was presented and I saw that proverbial light bulb go on and thought what a perfect opportunity. I had been a receptionist in my working days, though I am now unable to work, but that didn't mean I couldn't offer my time and love of people and of course the phone to offer support to others.

The date was set and away we went! We covered a lot of topics, some of which are listed below:

We discussed what things we had identified as triggers for our episodes. Episode triggers seem to be specific to the individual. Spicy foods, emotional stress, trauma, alcohol, tobacco, and marijuana were all mentioned as identified triggers by at least one person on the call.

We also talked about the rate in which individuals are misdiagnosed. One member that attended the conference mentioned...
that some doctors are diagnosing patients with Crohn's disease, when in fact it may be CVS.

We discussed several new treatment possibilities including:

FSM (frequency specific micro-current) which uses mini-currents aimed at the Medulla Oblongata to regulate CVS episodes.

Enterra ™ Therapy (also known as Gastric Electrical Stimulation, or GES) which uses what is more appropriately labeled as a gastric neuro-stimulator, although it is commonly referred to as a “pacemaker.” The electrical energy delivered to the stomach during Enterra ™ Therapy is high frequency and low amplitude; generally not sufficient to make the stomach contract or even empty better in many cases. Some GI Doctors believe this maybe an effective treatment for CVS as well.

As you can see we shared some very valuable information with each other. I even learned of some possibilities in new therapy options and after some research found the GES is offered in the Seattle area!

All in all, I would chalk this up to a complete success and look forward to the next meeting. I hope to have more members give it a try. If there's not a current group leader in your area, you can join one of the areas already holding groups and maybe even consider becoming a volunteer leader for your area.

Have you ever wondered what a CVS episode feels like?

“What does an episode feel like?” is one of the most common questions that people ask CVS patients. For those of us who suffer from CVS, episodes are very difficult to describe in a way that non-CVSers can understand. Recently two poems were brought to the attention of the CVSA office. The first one, Days of the Dark, was written by Loryn Eagleson, a 14 year old pediatric sufferer. The second one (on the right) is untitled and is written by Keith Harris, an adult CVS patient.

We hope these two poems give our members with CVS encouragement that they are not alone in their suffering and our members without CVS insight into what CVSers experience during an episode.

Days of the Dark
by Loryn Eagleson

Nothing only repeating forever pain
Stuck in a never ending maze
No bright sun only dark rain
To only sit quietly and silently gaze

No choice in the path
Only to sit and let it be
I’ve now felt its terrible wrath
But, no, I won’t have it over throw me

I choose how to spend my day
I will see the shining light
I will have only my way
I’ll turn wrong to right

An Untitled Poem
By Keith Harris

I lie in my bed unable to sleep.
My mind racing between pain and nausea.
My legs are in constant motion.
Fueled by the gut shot feeling in my stomach.
With each breath...another shot of pain.
It’s time! Another hour has gone by.
I roll off my bed onto the floor.
Then it begins...
Explosive vomit escapes my mouth.
One wretch after another.
My body writhes and jactitates each time.
As if my body seeks to decontaminate,
The poison saturating my body.
The vomiting continues,
Until my pores start to flood.
My wet clothes stick to me as I stand.
Bloody spider webs encompass my bulging eyes,
As if the strangler finally releases his grip.
I look down at clear liquid everywhere.
At least not eating for four days,
Keeps the carpet clean.
I then see the cup of blood on the floor.
Oops! I must have tore my esophagus again.
I towel off and slide back into bed.
My mind and legs start up again.
The hours start to merge.
My poor wife looks at me.
Empathy in her eyes,
Knowing there is nothing she can do.
Eventually sleep takes over.
A few hours later my eyes start to flutter,
As the morning light hits them.
My mind swims trying to comprehend.
The realization floods back to my conscious.
Anger builds...
Why do I have to awaken?
Fore every night of this,
I pray it’s my last,
And my eyes will cease to flutter!
10th Annual Connecticut Walk to “Stop the Cycle”

The 10th CT CVS Walk had a beautiful backdrop of the Long Island Sound with grey but beautiful clouds above. The magnificent breeze made the warm day feel very comfortable. Approximately 90 people, including 13 with CVS, attended and shared in the food, companionship, fundraising, and spirit of the day. This year’s CT Walk has netted over $13,300, making the total for the CT Walks close to $189,000. Thank you to all that contributed! The Koch Family greatly appreciates your participation!

Here are the thoughts from some of the attendees…

“It was only my second walk, but I hope to attend many more as we all fight "the monster" and the havoc he wreaks on us all. It is such a positive experience for me to commiserate with others in the same situation and to share stories and remedies as we all try to help each other through the trying times. God bless you for what you do and for bringing us all together to try and find some positives in a medical condition with so many negatives. I appreciate all that you do!!!”

-Lisa Walega

“I have had the honor of joining the CT Walk To Stop The Cycle, otherwise known as the CVS walk, for the past 4 years. The first year my youngest son Samuel was in the middle of a CVS cycle and did the walk while being pulled in a wagon. Some friends wondered why I'd bother to “put him through that” but I knew that if anyone understood it would be others at the walk. When we arrived, people there immediately flocked to him and knew exactly what was wrong. I knew then that I had found an extended family!!

Since that first walk I have joined the walk yearly with Samuel, his twin sister Jennifer and older brother Benjamin. It is something our family, and especially Samuel, has looked forward to each fall. Samuel is quite the character and immediately took to Kristin Koch. She is the CVS’er that the walk was started around. Samuel now calls her his “girlfriend” and brags to everyone who will listen about not only “his” walk but also about his college girlfriend Kristin!!

This year was the first year that Samuel was joined in a red shirt by his older brother Benjamin. Samuel has had CVS since he was around 2 years old and was only recently, around age 6, discharged from GI. We are some of the lucky ones in that Samuel’s episodes can be broken by Zofran. This allowed him to no longer have to take any daily preventatives!! Benjamin is even luckier than his brother in that while he has CVS, he has a very mild form and at age 9 he has only had 5-6 total episodes.

During these 4 years I have often struggled with how to raise funds for the CVS walk. Some years I have outright asked for donations and other years I have just donated money myself. None of the years did I feel as if I was doing enough, so this year I started making retractable ID badge holders out of medicine vial caps that I get from work. I am a nurse so they are

CVSA Blog

CVSA blog is brought to you by CVS sufferer, Kristyn Rein! As part of our efforts to educate people about CVS as well as to increase awareness about the disease we will be launching our first blog! Learn more about events, tips, and stories related to CVS and CVSA when you visit http://cyclicvomitingsyndrome.wordpress.com/

-Submitted by Kristyn Rein
readily available and many with CVS end up in the ER or hospitalized receiving the same medications I am using the caps from. What better way to raise money? I sold these badge holders for $5 and all profits were given to the CT CVS walk. Coworkers went crazy for them and I was able to easily raise $800!! If you wear a badge for work, want a badge holder for yourself, and want to support CVS research, then please feel free to visit my etsy shop. You can find it at: http://www.etsy.com/shop/flutterbysforhope.

The CT CVS walk is such a fun time that my family always looks forward to. I am glad to have found such a great extended family.

-Tracey Arnold

I have been going to the walk at Sherwood Island, in CT., since the beginning, which is now celebrating its tenth year of helping raise money for research and awareness. An excellent success, don't you think? For me, the most rewarding aspect is meeting new people who have either, just learned about CVS or have been recently diagnosed, and listening to their stories. There are some great successes that I have heard over the years, and a few not so happy ones along the way too.

I remember walking with Kathleen and her daughter Molly, and discussing with her how she started the organization. I learned how tough it is to find a cure with limited funds, awareness and knowledge. It made me realize how important the CT walk is in spreading awareness and knowledge and raising much needed funds.

Another year, I remember meeting a young man who was 19 years old. He was sick all the time and his girlfriend was pregnant and expecting their child soon. It was tough to listen to how ill he was, how financially he was not able to provide for himself and his girlfriend because of his illness. He was always battling to keep his weight up. I don't know what happened to him, but I hope for the best.

About three years ago I remember meeting a couple whose son was in college in Florida and he was going to the hospital once every two to three weeks. As with any freshman in college, you might enjoy yourself a little too much and wear yourself out. Come to think of it, I do remember all that studying did take a toll. Being the father of a two and half year old, I understand how you want to do anything and everything for your child, especially when they are not well.

Every year it is nice to hear that some of the younger sufferers, who over time, are getting less and less episodes. It also is nice to hear about adults who haven’t been ill for over a year or so, where they used to be hospitalized frequently. Now they have been able to stay out of a hospital for a considerable amount of time.

The most memorable year, and the one that showed me how tough CVS suffers are was when Kristin Koch showed up in a wheelchair. She was holding a hospital basin that looked all too familiar. She was feeling miserable but she showed up. How’s that for dedication to the cause? The Koch’s should be commended for doing an amazing job every year for spreading awareness and raising funds, but that's another article.

It’s really funny when you describe what CVS is to someone who doesn’t know. My story is I vomit for thirty hours or so, while being hospitalized. I get treated and then get paroled. As most of you know, everything is fine in between. How ridiculous is that??? But you know what, it’s not that bad. I have met people who feel nauseas all the time. They will go on for days and sometimes weeks feeling miserable. I realize that as far as this illness goes, I am lucky.

So for me, the walk is therapy and reinforces how I want to live my life. I hope that by telling my story and what I go through, that I have conveyed that CVS is only a part of how I live. That when I get ill, it is only a small issue and that the secret to dealing with CVS is to live your life to the fullest when you are healthy. As a result of that thinking, I have travelled and visited hospitals in seven states and three countries. Talk about taking the show on the road. I am heading to Montreal for a hockey tournament in November, so I might have a fourth country to add to the list, hope not though, but it will not stop me. Am I right Kristin? At the very least, I can tell some new doctors and nurses about CVS.

So that’s my story, and I am sticking to it.

-James P. O’Reilly
Golf Outing Raises $1500
Submitted by Anthony J. Destribats

On August 23, 2012, the Princeton Bar Association (PBA) hosted its first annual golf outing at the prestigious TPC Jasna Polana golf course in Princeton, New Jersey. The course is on the former estate of John Seward Johnson, an artist and grandson of Robert Wood Johnson (co-founder of Johnson & Johnson).

Profits from the PBA golf outing were to be allocated for a charity chosen by the PBA Board of Trustees. As a PBA Trustee, I nominated CVSA as the charity of choice for the 2012 golf outing. The choice of CVSA as the 2012 charity was an easy decision for me. And, after disclosing my health condition to the Board, the decision to donate our profits from the golf outing to CVSA was unanimous.

I have suffered from CVS for over 18 years. Before I attended the 2012 summer CVSA conference in Milwaukee, Wisconsin, I never met another person who had CVS. The conference was an enlightenment to me. Not only did I meet many other adults and children with CVS, I learned that I am not alone and, unfortunately, many others suffer from CVS much worse than I do. The 2012 CVSA conference also enabled me to meet a number of physicians who have been instrumental in prescribing medications to me which have aborted every CVS episode I have had since I left Wisconsin. That in and of itself is a miracle for me and my family! For the aforementioned reasons, I am truly grateful to CVSA and the work that it undertakes.

The golf outing was a success and we were blessed with beautiful weather. Members of the PBA had the chance to golf at one of the top courses in the Northeast while raising a modest amount of money for the work that CVSA does. James O’Reilly (another CVS sufferer) from New York City, also attended the event as my guest. We all had a great time (except when we had to add up our total strokes after 18 holes). I look forward to and truly hope that I can organize future fundraising events for CVSA. A special thank you to the CVSA Board of Trustees for the work they have done, do and will continue to do for all of us. I would also like to thank Matthew S. Barndt, Esq., President of the Princeton Bar Association., and all of the PBA members who attended the event. God bless you and your families.

CVSA patient donates allowance to CVSA
Submitted by Liz Saarie

Maddy Saarie has had CVS since age 8 months. She was diagnosed at 2 or 3 and is now almost 13, with no signs of growing out of it. Her cycle only occurs every 3 months or so, so she is a lot luckier than some kids, but as you know CVS is one horrible disease to experience. Our kids are required to give part of their weekly allowance to charity. They choose the charity and we match the amount. Well, she certainly saved up for awhile this time! Years! She chose CVSA,. We matched it and sent the $568 donation in. I'm sure it makes her feel good to know that she can help in some way, to find a cure for this violent condition.

Memorial for Susan Hass

Susan Hass was born on May 5, 1959 in Kansas City, Missouri, the daughter of William and Donna (Bumgarner) Swanson. She graduated from Winnetonka High School in 1966 and went on to receive her Bachelor’s Degree in Business Education from Missouri Western State University. Susan loved teaching and spent many years helping children learn. Susan suffered with CVS for about 30 years before finally being diagnosed by an ER nurse. After the nurse told her about CVS, she found CVSA and Dr. McCallum. $640 was sent to CVSA in her honor after she passed away after knee replacement surgery.

She leaves behind her husband, Mike Hass; daughters, Celeste Perkins and husband 2nd Lt. Brett Perkins, and Stephanie Hass; sister, Linda Anderson and husband, John, all of Liberty Missouri; and her mother, Donna Swanson of Kansas City, Missouri.

Save the Date for these Upcoming Fundraisers!

“Little Black Dress for CVS” Fundraiser on May 11

Mark your calendars and get those cocktail dresses cleaned and ready to go. Following on the heels of our successful cocktail party in NYC to raise funds for CVS, we’ve set a date for our next fundraiser. The “Little Black Dress for CVS” will be held at the home of Victoria McCabe in Westfield, New Jersey on May 11, 2013. The evening will include dinner, music, dancing, a short presentation about CVS, and raffle all to benefit CVSA. Suggested donation of $30 is requested. For more information, to volunteer, or RSVP contact Victoria (victoria.mccabe@gmail.com).
Winter is a great time to try new things!

Winter can be a tough time of year for people with CVS. CVS patients often have more episodes during the winter months for a lot of reasons. Physical activity can help CVS patients stay healthy. Staying physically active improves mitochondrial function which helps prevent CVS episodes. It can be hard to stay physically active during the cold months of the year. However, there are lots of fun activities that can only be done during the winter like sledding, skiing, building snowmen, and playing ice hockey. What new activity would you like to try this winter?

Winter Weather Gear

Word Bank
Boots
Carrot
Gloves
Hat
Hockey puck
Hot Cocoa
Ice skates
Scarf
Skis
Sled
Snowboard
Snowshoes

What is your favorite winter activity?

Drawing is an activity that sometimes helps people express how they feel, and can be a great way to relieve stress.

In the space below draw something related to your favorite holiday tradition.
Join Chandra Wilson of Grey’s Anatomy at the 2nd Pasadena Rock ‘n’ Roll Half Marathon on Sunday, February 17, 2013 in Pasadena, CA. CVSA has again been invited to participate in the event by CureMito! It will be our second year to participate in this well-known “Competitor Group” charitable run. We want to thank Chandra Wilson, her daughter Sarina, and Dr. Richard Boles for including us in this event.

Donations to “TEAM CVSA” will be divided to benefit CVSA and CureMito!. CureMito!, a non-profit charity, benefits patients with mitochondrial functional disorders, including Cyclic Vomiting Syndrome. This “sister” charity to CVSA is also advised by Dr. Richard Boles who directs the CCS Center for Metabolic & Mitochondrial Disorders at Children’s Hospital in LA. The Center integrates diagnosis, treatment and research. Dr. Boles has been a Primary CVSA Medical Advisor since 1999 and continues to do extensive research on Cyclic Vomiting Syndrome.

This year a 5K run has been added to the event so runners can choose between the two races. Consider lacing up your shoes to run (or walk) for Team CVSA. To register for the race go to http://curemito.donordrive.com. Click on “Register Now” Under Run/Walk. Sign up as a “Team Member” and Select “Team CVSA”.

To donate to Team CVSA, go to http://curemito.donordrive.com. Click on “donate now” (top right), “Make donation”, type in “Team CVSA”, donate now OR send check/money order payable to “California Community Foundation” WITH “CureMito! Team CVSA” IN MEMO LINE. Mail to: CureMito! 1005 South San Rafael Ave Pasadena, CA 91105

Attention Holiday Shoppers!!!
GOODSEARCH, GOODSHOP, and GOODDINING to benefit CVSA

Submitted by Debbie Conklyn

Did you know that you can conduct internet searches, or shop online, and raise money for CVSA at the same time? Up to 30% of your purchase will go to CVSA. All you have to do is go to www.goodsearch.com.

GOODSEARCH
Type Cyclic Vomiting Syndrome Association in the box that says Who do you Goodsearch For? Then search the Web as you normally would and a small donation goes to CVSA.

GOODSHOP
In addition to Web searches, you can click on a link to search for coupons, free shipping offers, and shop at hundreds of popular stores Up to 30% of your purchase price will go to CVSA.

GOODDINING
If you’re not already a member of the GoodDining program, please consider enrolling. Register your credit or debit cards. Then, simply dine out at a participating location on the days when donations can be earned and use a registered card to pay. A donation of up to 6% will be made to your selected charity or school at no additional cost to you. There are no membership cards to carry, coupons to print or numbers to remember.
The Canadian Connection
Submitted By Carol Warner

The fall is in full swing and the holidays will soon be upon us, but the work for CVS and CVSA never stops. This version of the Canadian Connection brings to you a professional update, as well as a personal one.

Dr. Bob Issenman, our Canadian CVSA medical advisor, continues to work tirelessly, to develop a treatment plan (as reported in a previous article) that will hopefully be used in the future, in all emergency departments. This plan will help ER doctors recognize CVS and give them a baseline treatment plan that can be used for patients that do not have a personal protocol to follow. Just recently Dr. Issenman told me “they have instituted a rapid recognition/rapid treatment CVS/Migraine paradigm in the McMaster Children’s hospital ER department”. This is another step forward for Dr. Issenman’s vision of having the treatment plan come to fruition.

The weekend of Oct 20-21st Dr. Issenman and Carolyn Jeon, a medical student at McMaster, “presented a poster on the McMaster results, in treating CVS, as if it were Migraine headache, at the NASPGHAN” meetings in Salt Lake City, Utah. This was another opportunity, to not only share the results from McMaster but to also bring more awareness of CVS to large number of physicians. We once again thank Dr. Issenman for all he does for his patients and for CVSA.

On a personal note, this fall was very exciting for our family, as we celebrated the marriage of our youngest daughter, Stephanie, to the love of her life, Camron Murphy, Sept 1st. The ceremony took place in the field on our dairy farm, as Steph and Cam, were surrounded by loving family, friends and a few of Steph’s beloved Holstein cows. It was a perfect end of summer day, under a blanket of beautiful blue sky and fluffy white clouds, filled with warmth and sunshine. Our oldest daughter, Lacey (our CVS'er) stood proudly beside her sister, as one of two maid-of-honors. I am so happy to say that Lacey made it through all the excitement V free! In the week leading up to the wedding, we tried extra hard to keep Lacey's routine normal and did increase her meds slightly and it worked. She had so much fun and that made the day even more special.

As many of you know, it has become custom, to tinkle your glass with your spoon during the dinner portion of the reception, so the bride and groom will kiss. Steph and Cam decided to use this opportunity to raise funds for CVSA, in honor of Lacey. They placed a small glass flower vase in front of them and anyone who wanted them to kiss had to put money in the vase. The money would then be donated to CVSA. I am happy to say, $450 was raised. We had the money turned into a US money order, which actually grew to be $452.22, with the exchange, and sent it off to the CVSA office. When some wonderful friends heard what Steph and Cam had decided to do with the money, they very kindly matched the donation, so that little vase raised $904.44!

With the wedding over we can now settle into getting ready for winter and continuing our efforts for CVSA. From our family to yours we wish everyone a happy and V free holiday!

CVSA T-shirts are now available
Spread the Word & Support Our Cause!

T-shirts come in children and adult sizes, and are available in 2 new designs (small & large logos). All shirts are blue with white writing, and cost $13.00 including S&H, regardless of size. Orders can be placed via phone (414) 342–7880, and online at www.cvsaonline.org.
Greetings from the office. . .
Submitted by Ruth Novak

I am so grateful for and excited about the national media coverage that we are getting through the hard work of Chandra Wilson, our National Spokesperson. She is helping us to get the word out about CVS in a way none of us could have hoped for two years ago! Her dedication to the cause and to her daughter Sarina is powerful and we thank her, the staff of Grey’s Anatomy, and the network for helping us to bring CVS to the forefront. Please write into the show to give them your thanks for the wonderful exposure that CVS was given.

AccuConference Support Group meetings have started! In fact by the time you read this, some groups will have had a second meeting. We initially advertised the groups by geographic zone so that we did not overwhelm any one group as the calls started. While the groups are still organized geographically, you are welcome to call into any group that meets at a convenient time for you, just be sure to look at the time zone for the meeting so that you call in at the correct time. There is an up to date list of all the meetings scheduled on the website under Support Groups which is found under the Current Events heading. The leaders are excited and hope to schedule calls about every 4 to 6 weeks and the members who have joined the calls have had only positive things to say! Please consider giving the teleconference support groups a try. I know they will be such a blessing to many in our community who feel alone in their battle with CVS—particularly those who are unable to join us at the family conferences. (You can read more about the teleconference support groups on page X.)

As time goes on, we will need more leaders to come forward. If that is something that you would like to do for CVSA, please call me at the CVSA office or drop me an email. I will be happy to share with you how it works and get you started if you decide to give it a try. We also have meetings for our leaders which are done by phone so that we can all grow and learn from each other. I hope that someday, we have a leader in every state in the country and that we will need two in some states when the groups get too large for one call!

If you have questions or concerns that you would like to discuss or if you have news to share, we are here to listen. You can call me at 414-342-7880 or email me at cvsa@cvsaonline.org. Best wishes to all of you.

CVSA Board of Director Candidates for the 2012 Election

In accordance with the bylaws of CVSA, elections for seats on the Board of Directors are held each year. Members of the Board of Directors serve staggered terms of three years each. This year there are three current board members seeking reelection. Please cut out your ballot, complete it, and mail it to the address on the ballot by December 30, 2012.

Pursuant to CVSA’s bylaws, in January 2012, the Board of Directors will elect the new officers of CVSA from the members then serving on the Board. The results of this election will be announced in the Spring 2013 edition of Code ‘V.’

Term beginning January 1, 2013 - ending December 31, 2015

Connie Hill
Connie Hill lives in Lee’s Summit, Missouri with her husband Alan. They have two children, Christopher 33 and Amanda 27. Both of their children are CVS sufferers. Amanda since she was 8 and Christopher is an adult onset sufferer. They have been members of CVSA for at least 15 years and have been serving on the CVSA board since 2010.

Connie is very active in their church serving on several ministry teams and she enjoys serving on mission trips twice a year with her church. Connie is very excited about the direction CVSA is going and wants to serve in any capacity the board needs her to serve. She is very committed to helping others deal with this illness and to help bring more awareness to the awful disease.

Ballot: Members-at-Large

______ Connie Hill

If you are a member of CVSA, please cut out this ballot, vote, and mail to:

Ruth Novak
10520 W Bluemound Road, Suite #106,
Milwaukee, WI 53226
Recent References for CVS and Abdominal Migraine

Boles R: High degree of efficacy in the treatment of cyclic vomiting syndrome with combined co-enzyme Q10, L-carnitine and amitriptyline, a case series. BMC Neurology;11:102, 2011
Lippincott Williams & Wilkins, 2011
PRIMARY MEDICAL ADVISORS

Richard G. Boles, M.D., Children’s Hospital of Los Angeles
Phone: (323) 361-8600 Fax: (323) 361-1172

David R. Fleisher, M.D., retired

Robert M. Issenman, M.D., McMaster University, Hamilton
Ontario, Canada Phone: (905) 521-2100, ext. 75637 Fax: (905) 521-2655

B U.K. Li, M.D., Medical College of Wisconsin, Children’s Hospital of Wisconsin, Milwaukee, Dept. of Pediatric GI
Phone: (414) 266-3690

Bhanu Sunku, M.D., Mount Kisco Medical Group; 110 South Bedford Rd.; Mount Kisco, NY 10549 (914) 242-1580

Sally Tarbell, Ph.D., Medical Psychologist - Children's Hospital of Psychiatry and Behavioral Sciences affiliated with University of Colorado Denver

Thangam Venkatesan, M.D., Medical College of Wisconsin, Milwaukee, Division of Gastroenterology and Hepatology
Phone: (414) 955-6836 Fax: (414) 955-6214

Sumit Parikh, M.D. Center for Pediatric Neurology
Cleveland Clinic Main Campus Mail Code S71
9500 Euclid Avenue Cleveland, OH 44195 (216) 444-5559

CVS Treatment Programs

Clinic for Cyclic Vomiting Syndrome - Wisconsin
Medical College of Wisconsin Pediatric GI
Children’s Hospital of Wisconsin in Milwaukee
Phone: (414) 266-3690

Clinic for Cyclic Vomiting Syndrome for Adults - Wisconsin
Medical College of Wisconsin Department of Gastroenterology
(414) 955-6836

CCS Program for Metabolic & Mitochondrial Disorders
Children’s Hospital of LA
Los Angeles, CA
(323) 361-8600

Clinic for Cyclic Vomiting Syndrome - Ohio
Cleveland Clinic, Cleveland, OH
Phone: (216) 444-5559