

CVS: Migraines, Mothers, Energy and Stress

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Submitted by Jackie Byrne, and reprinted with permission from CVSA UK

Dr. Li's presentation was dedicated to two mothers – Kathleen Adams, co-founder of CVSA USA, and to Professor Li's own mother who died recently.

Ten years ago, CVS was considered to be the 'cousin' to migraine but there were very few medical references to it. However, during the last decade several CVS associations have grown up, fostering thriving relationships between families and physicians, resulting in two international symposia. This has led to the condition becoming more widely recognised and diagnosed.

The dedicated CVS centre in the Children's Hospital, Chicago, headed by Professor Li, is a multidisciplinary clinic with a nurse co-ordinator, psychologist, neurologist, GI fellow, researcher and Chinese medicine doctors. It offers pre-review x-rays, lab tests and consultations. It has 701 CVS patients from 41 US states and 8 countries. Research is conducted on emesis including clinical data collection, studies on HPA axis and dexamethasone treatment. Here Professor Li and his team are light heartedly dubbed the Vicar of Vomit, Earl of Hurl, Baron of Barf, Duke of Puke, Queen of Quease or The Last Emperor of Emesis!

Professor Li gave us an impressive factual presentation. However space in the newsletter does not allow us to do it justice. Some statistics are listed here for brevity.

The top 5 CVS facts are:

- CVS is the most intense recurrent vomiting disorder;
- 58% patients require frequent IV;
- Misdiagnosis usually continues for 2½ years;
- High morbidity – 24 missed school days each year;
- High costs of care – on average £10,021 per year.

The mechanisms of CVS can be described as:

- Migraines – migraine headache connection;
- Mothers – maternal inheritance;
- Energy – energy deficits due to mitochondrial dysfunction;
- Stress – stress and corticotrophin-releasing factor (CRF).

Out of 480 patients, systemic symptoms include Lethargy 90%, Pallor 85%, Withdrawal 62%, Drooling 35%, Flushing 30%, Fever 30%.

GI symptoms include Vomiting 100%, Retching 82%, Anorexia, 81%, Nausea 81%, Abdominal Pain 78%, Diarrhoea 20%, Constipation 21%.

Neurological symptoms include Sleeping until well 58%, Headaches 50%, Photophobia 57%, Phonophobia 42%, Vertigo 28%, Seizures 4%.

When making a diagnosis, Professor Li said it is important to distinguish between two different patterns of recurrent vomiting. In the *chronic pattern* the child vomits a few times on almost a daily basis and the cause is usually found in the GI tract itself. In contrast CVS has a *cyclic pattern*, which is characterised by intense vomiting that occurs in distinct episodes separated by periods of normality. The cause is usually to be found outside the GI tract.

CVS is worse than viral (rotavirus) gastroenteritis as IV hydration is 75 times more likely, the patient is listless and semi-comatose (unable to walk or talk), patients adopt a foetal position (sensitive to light, sound and touch) and severe abdominal pain can mimic an acute abdomen.

42% of patients start an episode between 2 – 7 a.m., 49% of patients have a cyclic pattern with episodes between 1 – 4 weeks, 30% patients are affected by seasons and are better in the summer.

76% of patients (out of 480) had triggers including Psychological 50%, Exhaustion 40%, Infectious 42%, Menses 22%, Dietary 19%, Motion 12% and Atopic 6%.

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CVS can be identified by the history of the patient:

- Recurrent episodes (more than 3) 100%
- Normal in between episodes 94%
- Episodes similar to others 99%
- Absence of etiologic findings 97%
- Ill appearing (pallor and lethargy) 91%
- Family history of migraine headache 88%
- Intense vomiting (more than 4 an hour) 77%

Prophylactic therapies include anti-migraine agents (propranolol, cyproheptadine, amitriptyline), anti-epileptic agents (phenobarbital, topiramate, valproate) and GI prokinetic agents (erythromycin). Abortive therapies include anti-migraine triptans (sumatriptan, frovatriptan), anti-emetics and sedatives (ondansetron, chlorpromazine) and aprepitant and CRF antagonists.

CVS falls under a migraine umbrella together with abdominal migraine and periodic syndrome. In CVS, vomiting is predominant, in abdominal migraine, pain is the main symptom and in migraine headache, the headache is the worst feature. The development progression is CVS age 5, abdominal migraine age 9 and headache age 11. There is an overlap with 78% of CVS patients having abdominal pain and 52% having headache.

Clinical overlap in CVS, abdominal migraine and migraine headaches:

Symptoms	CVS	Abdominal Migraine	Migraine Headache
Vomiting	100%	39-72%	40-69%
Abdominal Pain	3-81%	100%	10-55%
Headache	38-59%	31-50%	100%
Associated Symptoms			
Pallor	90%	90-100%	23-88%
Lethargy	93%		
Anorexia	78%	91-98%	13-93%
Nausea	83%	73-91%	46-100%

CVS, abdominal migraine and migraine headache all have similar patterns and symptoms of pallor, nausea and listlessness. Most, but not all, CVS is migraine related. Many children grow out of CVS, but it is estimated that 75% will develop migraines. The migraine inheritance pattern indicates 63% of mothers have migraine compared to 16% of fathers, with both sides 20%.

To conclude – What is CVS?

- Like a diamond with many facets – as you examine each, you see something different – GI dysmotility, migraine, autonomic dysfunction, mitochondrial dysfunction, stressors, hormones.
- A migraine-related, maternally inherited, energy-affected, dysautonomia triggered by stress possible mediated by CRF.

Help Us With This Fun "Fun"draising CVSA Cook Book Project!

We have had several members ask us about a cookbook put together by our membership and their family and friends. After thinking about it for way too long ☺ we are moving forward with this great idea! So..... submit your recipes! We want them all! If you have a favorite salad, dessert or main dish, send them to us! Maybe you have the worlds best cookie recipe? Why not share it! Maybe it's a cool drink for the kids on a hot summer day, or something hot and warm for those winter evenings?

You can send us your recipe "in honor of" or "in memory of" a loved one. Or just because you know it to be one of the best and you want to share it with your extended CVS family! This book will be a loving tribute to children and adults, as well as their loved ones who face the challenge of living with CVS with courage and determination. So send in your recipes, help us get this project off and running, we cannot do it without you! Our hope is to see if we can have a cookbook ready for the holiday season!