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DINET is looking for a new President! Are you compassionate, organized, and interested in serving the dysautonomia community? Please consider helping DINET as our next President. Skills that would be helpful in this role include:

- Research skills (in order to keep DINET’s website and newsletter up-to-date on the latest medical research)
- A basic understanding of medical terminology
- At least a basic understanding of the various dysautonomias (POTS, NMH, syncope, etc) and their causes
- Able to spend at least 20 hours/week serving DINET
- Computer skills (email, web searches, social media skills, and maybe some website editing skills)
- Fundraising experience, including grant-writing (this isn’t essential, but could certainly be useful)
- Willing to adhere to DINET’s purpose of raising dysautonomia awareness and educating, promoting, and networking; willing to develop projects that perpetuate that purpose; and, willing to promote only evidence-based medical information

*If you are interested in the position of DINET President, please email Michelle at staff@dinet.org for an application
I live in a beautiful part of the US filled with scenery, wildlife and fresh air. However, it doesn’t have an abundance of sunshine during most months of the year. I’d been in a good trend of feeling a bit more human. I was dealing with my dysautonomia better during the summer months after I visited a specialist in dysautonomia. Yet I started to decline in the fall. This continued into winter as I mentioned in my article in the fall DINET newsletter. My primary care doctor suggested testing my B12 and vitamin D levels. It seemed like a good idea. I found old transcripts of a Cleveland clinic web chat hosted by Dr. Jaeger that stated “We frequently find vitamin D deficiency in patients who present with POTS type symptoms”. So why not test? Sure enough the results showed a vitamin D deficiency.

So, off I went to the health food store for vitamin supplements. How daunting! There were so many choices, tablets vs. drops, plain vitamin D or a combination? I stuck with plain vitamin D drops which can be added to water. In addition to the vitamins, I also looked into foods that are good sources of vitamin D. Milk is fortified with vitamin D, as are many ready-to-eat cereals and some brands of yogurt and orange juice. Cheese naturally contains small amounts of vitamin D. The list of good sources of Vitamin D includes lean meats, poultry, fish, beans, eggs, and nuts. I found a lot of info on the subject on the NIH website. http://ods.od.nih.gov/factsheets/VitaminD-HealthProfessional/

I feel nothing can really replace knowing your body. Getting to know your Dysautonomic or POTS body isn’t always easy but it is very important. If something is out of the “new” norm you have come to understand, then it is worth looking into. It may not solve the puzzle but finding another piece is a step in the right direction.

My unofficial tips for beating the winter blues:

1. Lighten up- literally and figuratively! If you can get outside
for a bit during the day, do it! Morning hours are the best. If you can’t go outside, consider investing in a full spectrum light or research the many products on the market today. Lighten up emotionally by lessening your stress.

2. Try new foods - look for veggies and protein or vitamin D rich foods. Try a new recipe. Look for a recipe that you can put in the slow cooker and take a walk while it is cooking.

3. Take vitamins - daily vitamins can be excellent supplements to your daily diet. Consult your physician for advice on vitamins that speak to specific deficiencies.

4. Exercise - recumbent bike getting you down? Try isometric exercise or swimming indoors at the gym. Always consult your physician before beginning any type of exercise.

5. Socialize - volunteer, visit or call family and friends, internet chat with your DINET forum folks.

6. Try a new hobby or interest - last year I took up knitting. This year I’m trying out aromatherapy.

7. Make resolutions - for your health and well being. Journal your journey. Record how far you’ve come and where you hope to go.

8. Don’t stop researching. Knowledge is power. We are our best advocates.

9. Share what you’ve learned/ your experience with docs, family and community. You never know who you could help. It’s what we can do if we can’t participate in research.

10. Breathe! The sun is still there and the next season will be here soon.
Editor’s note:
For this edition of Parenting Corner, regular columnist Rachel Faith Cox is joined by Alexis Pacheco. Together they provide a look at the impact chronic illness has on parenting.
When I began researching for this topic, I put the word out amongst my Facebook groups. I wanted to know what mother-guilt sounded like to others like me. I wanted to know if the things I’ve been listening to in my head are the same tracks playing on repeat in your heads too. Any of these sound familiar to you?

Cheryl: “I feel useless as a mum. Moms are meant to care for their kids, not the other way around; to protect their kids from scary stuff, not be the thing that scares them”

Zoe: “I would cry myself to sleep every night from the guilt of not being able to take care of my child”

Paula: “My guilt manifests in self talk like ‘you’re going to have to give these kids up’, ‘they deserve more’, ‘how am I going to keep doing this with no help?’ and even, ‘these poor kids are doomed having me as a mom’.”

Margot: “I can’t keep up with them and I feel guilty that being with me is not fun or exciting enough”

Tanjil: “I even have ‘guilt at the gate’ waiting for the day they have their own children and I won’t be able to help”

In general, parenting guilt seems to affect our generation more than those before us. I don’t think my parents gave the thought “Could I be doing more?” much airtime. Before my Mom passed away, she murmured “I did my best”. It wasn’t an apology, or a defense. It was just a fact. She did her best. I hope that when my time is up, I can say with honesty and pride that I too, did my best.

“I even have ‘guilt at the gate’ waiting for the day they have their own children and I won’t be able to help”

Navigating our way through parenting with Dysautonomia, it is crucial that we take into account the context through which we parent. There are so many things we wish we could do for our children. Things that other parents might consider bare minimum parenting tasks. Although it is not a ‘normal’ situation to be ill for the long term, it is our normal.
How we approach the challenges we face as ill parents will have a significant impact on our families. But one thing we can always do is strive to do our best. Are you measuring your parenting achievements against the reality of your illness? Or are you comparing yourself to well parents? Or to yourself before you became sick? Your best will vary from day to day. Doing your best is not a fixed absolute, it is an achievable, variable, goal. On a bad day, your best might be managing a cuddle before school. On a good one, you might get some cookies in the oven.

If the roles were reversed and it was your child that was sick, what would your expectation be of them? Wouldn’t their ‘best’ be a yardstick that you shift based on their ability to achieve? I know I would make allowances for my kids. I love them! I would forgive them for not managing all the chores on the list. I would be lenient about how much of their homework got completed. I would be kind to them. Maybe it is time, as parents, we started being kind to ourselves. Take that load of expectation off our shoulders. Perfection is not attainable in parenting. And we did not ask to be sick. These are just the facts of our parenting life.

The purpose of guilt, from a psychological perspective, is to help us change. Guilt is an unpleasant, punishing thought pattern. It is helpful if the behavior you are thinking about is something that can be changed. As Kate reflects “I have to first acknowledge and explore the feelings of guilt, question why they are there and how valid they are. This way guilt becomes an indicator to things I can do better, instead of just a crippling spiral into negativity”. If it is a valid emotion, guilt can be a powerful motivator. But how much of your situation can you change? Is your guilt serving you, or bringing you down? The only part of the parenting-while-ill situation you can actually change, is how you approach the morass of guilty feelings about it. If your mother-guilt is not useful for you, it might be time to change the record.

Here are some of the ways other parents deal with parenting guilt:

**Communicate.**

“I find it helps to talk about the feelings and work through them so we can move on & focus on the good stuff, because the frustration and guilt that come from living with disabilities can’t help but come up from time to time. I find it important not to get stuck in it, at least, not for any longer than I can help!” Jem

Julie puts it this way, “As long as they (the children) know all my decisions are coming from a huge well of love for them, then I don’t sweat the little guilty niggles… I think all parents have a degree of guilt and if our kids knew how we felt they’d tell us not to worry so much”. Being open with your family and apologizing when you think it is warranted can be very healing too. “I am really good at apologizing to my children if I have yelled or I was in the wrong”, Sarah says.

Children usually respond positively to such honesty. They have finely attuned fairness ideals. Many parents find that through honest communication, their children become their strongest supporters. Understanding why things are different in your home will go a long way towards acceptance, for parents and for children. This becomes much easier as the children get older.

**Maintain Perspective.**

Pia finds it useful to put it all in context by talking with another adult she respects. “I talk to my friend who works in community services and also has a chronic illness, she helps me lower my standards and reassures me there are kids a lot worse off than mine”.

Sometimes, reminders like this can make an enormous
difference. Even with all the compromises, your children have something many do not. That is a powerfully comforting thought.

For Emily, it’s all about talking about it to someone you trust, getting off your chest, “I’ve been able to share with my husband, mum and good friends what is eating away at me at times and talking it through with someone other than the mean voice in your head really helps put parenting guilt in perspective”.

Zoe, applies Christine Miserando’s spoon theory. “I am constantly reminding myself that I’m NOT like other moms, I don’t have to be, I just have to use my spoons carefully”.

Releasing yourself from the expectations you hold and those of others is key to having some peace of mind.

Sarah talks about reaching the point where she let go of comparison with other Moms. “I stopped looking at all the mommy blogs and started to listen to my own intuition. I knew in my heart I was doing the very best that I could do… at the end of the day all that mattered is that my children felt loved and secure. The rest would somehow fall into place.”

Take Heart.
Jo has found strength in what people from the medical community have said to her; “They’ve told me that most parents would not be coping as well as I have been. I don’t feel so much guilt now, I know at the end of the day the only thing that matters is that we are all still here, as a close loving family”.

The past three years have been extremely difficult on Cheryl’s family. Being misdiagnosed and not coping have taken their toll. “Yet,” she relates “I have also been able to help them recognize their feelings and help them through it which I may not have been able to do as well had I not been sick. Well, that’s the way I’m trying to look at it! I have good kids and I hope this has taught them more empathy and kindness and made them more resilient”.

I have left the last word for Aurora, who has been hospitalized for five of her children’s formative years. “I have just felt so sorry for both my children and myself. I missed not being there to tuck them into bed. I missed not giving them a cuddle when they fell over and grazed their knee. You can never get those times/milestones back. However, when you are well enough, that is the time to have quality time with your kids. I believe my kids have become more considerate of others, more understanding of people with disabilities, and certainly more understanding of variable illnesses”.

Like it is for so many of the symptoms of Dysautonomia, there is no magic pill that is going to make parenting while ill suddenly easy. There is no fast track solution, no fairy wand of fairness to take all the difficulties away. How we look at parenting; the lens with which we view ourselves, can make a big difference to the amount of guilt we suffer. Be kind to yourself today, Momma. You are doing a great job in trying circumstances. You are doing your best. And that, at the end of the day, is all any parent can hope to achieve. When you respond to your children with love, the greatest portion of your job is already done.
Growing up with Dysautonomia was never easy. As a child, I knew that something was different about me. Even my birth was not of the norm; my mother brought me into the world through a life-threatening C-section. At a hefty nine pounds and five ounces, I looked as though I had defied the odds— I was born with the illusion that I would be healthy.

My parents quickly learned that their “healthy” baby girl was not as she looked. I was born with a small hole in my heart, and endless trips to emergency rooms and cardiology clinics began to spin like a broken record for years to come. Growing up ill soon became a challenge for me. While my elementary school friends played sports, I was benched.

However, life goaded me in the third grade. The hole in my heart disappeared, and my cardiologist gave me his blessing to assimilate into the wide-world of children’s sports. For three years, I played softball and basketball, and although I was not a gifted athlete, I made sure that I enjoyed every minute of the sweat.

My sporting spree ended when I entered the sixth grade. I became deathly ill, and many days I could not bring myself out of bed without feeling as though I had run a marathon for which I was severely unequipped. I remember seeing my misery reflected upon my mother’s face, and little did we know that we had begun a long and painful journey together.

Dysautonomia devoured my life by the time I entered the seventh grade, and the depression of the disease engulfed me. Many nights my mother did not sleep as she monitored my deteriorating body and mind. She tried her best to remain positive, but I knew that beneath her strength she ached with fear for my well-being. I did not realize how my pain affected her. She never said it directly, but I knew that she inwardly blamed herself. As our journey progressed, she wondered if she had done something to pass such a horrid disease to her baby.

Nothing is worse than knowing that my mother felt guilty for my chronically ill body. I would rather suffer through unwarranted fainting than know that my mother blamed herself for a disease
that offers mercy to no one. How could the woman who repeatedly told me that I was beautiful, even with the ugly heart monitor cords hanging out of my shirt, think that she had anything to do with such a tortuous illness? How could the woman who drove me night after night to the emergency room feel guilty? If anything, my mother was a savior—a shining light in my world that has been vastly dim for the past fifteen years.

To parents with children who suffer from Dysautonomia: never blame yourselves. Never question things that you have or you have not done. Dysautonomia leaves plenty of questions unanswered, and what you must understand is that you are the answer for your children. While your child may have many friends at school, none of them will understand why your child cannot play certain games at recess or join their favorite sports teams at school. As your child grows older, people will not realize that even though your child looks healthy, he or she struggles daily with a chronic illness. When your child enters young adulthood and starts a career, he or she will be undeniably fearful of standing too long or doing something as simple as standing up from an office chair. Parents, no one can sympathize with a Dysautonomic child better than you. You are not to blame. You are the reason your children refuse to succumb to Dysautonomia, and you are the reason they fight to live.

Would you like to become a DINET volunteer? Please email webmaster@dinet.org to learn more!
MEET THE MEMBER:
JESSICA’S STORY

Dearest reader, I would like to introduce you to Jessica. She is a woman who approaches dysautonomia with complete openness, an impressive self-awareness and a bottomless bag of tips and tricks. Unfortunately, her list of medical diagnoses is also, seemingly, endless. She has been clinically diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS), Neurocardiogenic syncope (NCS), Orthostatic Hypotension (OH), Inappropriate Sinus Tachycardia (IST), Gastroparesis, Colonic Inertia and Neurogenic Bladder. How does she manage? Optimism, balance and a healthy dose of that kind of quirk that forces a chuckle from the mouths of even the most sullen faces.

The symptoms of dysautonomia are so varied that some of us experience them for years without seeking medical help. In today’s world it is easy to dismiss dizziness, nausea, exhaustion and headaches as the byproducts of attempting to keep up with our ever-expanding schedules. For years, Jessica had excuses for her body’s aches and pains. Feelings of constipation and exhaustion were met with the thought, “I’m getting old.” She would say to herself, “I shouldn’t have had a protein shake today” when she felt nauseated. When she had morning dizziness she would think, “I’m just not a morning person.”

Despite her early symptoms, Jessica attests that she was one of the lucky ones. After fainting at age 34, it only took her 22 days and a few doctors to be diagnosed with POTS through a clinical examination and 30-day Holter monitor test. She
knows her life has been as full as possible with multiple chronic conditions, due in part, to her involved team of physicians. Her primary care doctor is particularly instrumental in helping Jessica find treatments that work for her. Together, Jessica and her primary discovered many of her medications were not benefiting her overall health. Under doctor supervision, she has recently weaned off six of her medications, and has begun using an integrative healing approach involving natural supplements and herbs. She has noticed improvements in the last six weeks.

Jessica, like all of you, knows dysautonomia is chronic. Sometimes, she tries to wish it away. Occasionally, she gets angry with her body. She grieves for her old self, she has moments of isolation, she analyzes too much, and she gets sad. But, overall, she works to fill the time between these tough moments with happiness and acceptance. Being open about her illness and beginning a support group in her hometown have been invaluable guides on her path to acceptance.

She also emphasizes the importance of maintaining a balance between body, mind and spirit. In addition to integrative therapy and a dedicated physician team, Jessica continually tweaks her workout plan and diet to better serve her sensitive body. Though her illness prevents her from having a traditional career life, she has found purpose by spreading awareness in her hometown through administrating a support group and working with local medical practitioners. Her efforts undoubtedly contributed to the fact that the mayor of her North Carolina town recently signed the Dysautonomia Awareness Month Proclamation, officially recognizing October as Dysautonomia Awareness Month. She maintains her strong spirit with the help of support group friends, her church and therapeutic practices like prayer, meditation, and music.

In the short moments I spoke with Jessica, I found her complete openness refreshing and delightful. Her turns of phrase were clever, quirky and made me chuckle more than once. Not least of all, she has some amazing tidbits on how to manage the everyday obstacles that are inherent to dysautonomia. It would be unfair not to share her wisdom with you, my dear reader.

Jessica’s Top 5 Tips

1. If you can’t find a local support group, start one. Online support groups are wonderful, but never forget the power of face-to-face interaction.

2. If isolation hits during the holidays, combat it by helping others. Volunteer at a hospital, faith-based organization or charity.

3. When dealing with gastric issues eat 6 small meals a day and avoid foods that may trigger your symptoms.


5. Work to understand others, both sick and well. “Could a greater miracle take place than for us to look through each other’s eyes for an instant?” -Henry David Thoreau
RESEARCH IN REVIEW

By, Laura Sabadini

POTS: IRON INSUFFICIENCY AND HYPOVITAMINOSIS D IN ADOLESCENTS WITH CHRONIC FATIGUE AND ORTHOSTATIC INTOLERANCE

Antiel RM, Caudill JS, Burkhardt BE, Brands CK, Fischer PR.

OBJECTIVES:
More than 10% of adolescents suffer from severe fatigue and/or orthostatic intolerance. Adult studies show correlations between iron insufficiency and fatigue as well as between hypovitaminosis D and non-specific pain. We sought to determine whether there were correlations between nutritional factors (iron status, and serum vitamin D levels) and chronic ill health.

METHODS:
We reviewed records of 188 adolescents with symptoms of fatigue and/or orthostatic intolerance and who underwent autonomic reflex screening.

RESULTS:
Of the 188 patients, 130 patients (69%) had excessive postural tachycardia (PT) with a heart rate (HR) change of ≥30 bpm. 62 patients (47%, n = 131) had iron insufficiency with low iron stores, and 29 patients (22%, n = 131) were iron deficient. HR change did not correlate to ferritin level (P = 0.15). 21 patients (22%, n = 95) had hypovitaminosis D (25-hydroxyvitamin D ≤20 ng/mL). There was a significant association with hypovitaminosis D and orthostatic intolerance (P = 0.024).

CONCLUSION:
In patients presenting with chronic fatigue and/or orthostatic intolerance, low ferritin levels and hypovitaminosis D are common, especially in patients with PT.

PubMed PMID: 21886073
GYNECOLOGIC DISORDERS AND MENSTRUAL CYCLE LIGHTHEADEDNESS IN POSTURAL TACHYCARDIA SYNDROME.


OBJECTIVE:
To assess differences in gynecologic history and lightheadedness during menstrual cycle phases among patients with POTS and healthy control women.

METHODS:
In a prospective, questionnaire-based study carried out at Paden Autonomic Dysfunction Center, Vanderbilt University, between April 2005 and January 2009, a custom-designed questionnaire was administered to patients with POTS (n=65) and healthy individuals (n=95). The results were analyzed via Fisher exact test and Mann-Whitney U test.

RESULTS:
 Patients with POTS reported increased lightheadedness through all phases of the menstrual cycle phases as compared with healthy controls. Both groups experienced the greatest lightheadedness during menses, and a decrease in lightheadedness during the follicular phase. Patients with POTS reported a higher incidence of gynecologic diseases as compared with healthy controls.

CONCLUSION:
The severity of lightheadedness was found to vary during the menstrual cycle, which may relate to changes in estrogen levels. Patients with POTS also reported an increase in estrogen-related gynecologic disease.

PubMed PMID: 22721633;
PubMed Central PMCID: PMC3413773.
Full text: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3413773/

SLEEP DISTURBANCES AND AUTONOMIC DYSFUNCTION IN PATIENTS WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

Mallien J, Isenmann S, Mrazek A, Haensch CA.

Many patients with postural tachycardia syndrome (PoTS) suffer from fatigue, daytime sleepiness, and sleeping disturbances. The objective of this study was to compare subjective and objective sleep quality of PoTS patients with a group of healthy controls. All patients completed a Pittsburgh Sleep Quality Index questionnaire and the Epworth Sleepiness Scale. The patients sleep architecture, heart rate, and heart rate variability (HRV) measurements were taken during one night at the sleep laboratorium. All data was collected at the Sleep Unit, at Helios Klinikum Wuppertal. Thirty-eight patients diagnosed with PoTS were compared to 31 healthy controls, matched in age and gender. Patients with PoTS reached significantly higher scores in sleep questionnaires, which means that they were more sleepy and had a lower sleep quality. Polysomnography showed a significantly higher proportion of stage 2 sleep. The results of HRV analysis in different sleep stages confirmed changes in autonomic activity in both groups. PoTS patients, however, showed a diminished variability of the low-frequency (LF) band, high-frequency (HF) band, and LF/HF ratio in different sleep stages. It can therefore be gathered that PoTS could be considered as potential differential diagnosis for sleep disturbances since PoTS patients had a subjective diminished sleep quality, reached higher levels of daytime sleepiness, and showed a higher proportion of stage 2 sleep. PoTS patients showed furthermore a reduction of LF/HF ratio variability in different sleep stages.

PubMed PMID: 25071706;
PubMed Central PMCID: PMC4083342.
Full text: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4083342/
DYSAUTONOMIA (GENERAL):

DYSAUTONOMIA: PERIOPERATIVE IMPLICATIONS

Mustafa HI, Fessel JP, Barwise J, Shannon JR, Raj SR, Diedrich A, Biaggioni I, Robertson D.

Severe autonomic failure occurs in approximately 1 in 1,000 people. Such patients are remarkable for the striking and sometimes paradoxic responses they manifest to a variety of physiologic and pharmacologic stimuli. Orthostatic hypotension is often the finding most commonly noted by physicians, but a myriad of additional and less understood findings also occur. These findings include supine hypertension, altered drug sensitivity, hyperresponsiveness of blood pressure to hypo/hyperventilation, sleep apnea, and other neurologic disturbances. In this article the authors will review the clinical pathophysiology that underlies autonomic failure, with a particular emphasis on those aspects most relevant to the care of such patients in the perioperative setting. Strategies used by clinicians in diagnosis and treatment of these patients, and the effect of these interventions on the preoperative, intraoperative, and postoperative care that these patients undergo is a crucial element in the optimized management of care in these patients.

PubMed PMID: 22143168;
PubMed Central PMCID: PMC3296831.
Full text: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3296831/

NCS/PAF/MSA:

PREMOTOR SIGNS AND SYMPTOMS OF MULTIPLE SYSTEM ATROPHY

Jecmenica-Lukic M, Poewe W, Tolosa E, Wenning GK.

Diagnostic criteria for multiple system atrophy are focused on motor manifestations of the disease, in particular ataxia and parkinsonism, but these criteria often cannot detect the early stages. Non-motor symptoms and signs of multiple system atrophy often precede the onset of classic motor manifestations, and this prodromal phase is estimated to last from several months to years. Autonomic failure, sleep problems, and respiratory disturbances are well known symptoms of established multiple system atrophy and, when presenting early and preceding ataxia or parkinsonism, should be regarded as evidence of premotor multiple system atrophy. An early and accurate diagnosis is becoming increasingly important as new neuroprotective agents are developed.

PubMed PMID: 22441197
The study aim was to assess sympathetic vasomotor response (SVR) by using pulsed wave Doppler (PWD) ultrasound in patients with multiple system atrophy (MSA) and correlate with the tilt table study. We recruited 18 male patients and 10 healthy men as controls. The SVR of the radial artery was evaluated by PWD, using inspiratory cough as a provocative maneuver. The response to head-up tilt was studied by a tilt table with simultaneous heart rate and blood pressure recording. The hemodynamic variables were compared between groups, and were examined by correlation analysis. Regarding SVR, MSA patients exhibited a prolonged latency and less heart rate acceleration following inspiratory cough. Compared with the tilt table test, the elevation of heart rate upon SVR was positively correlated to the increase of heart rate after head-up tilt. The correlation analysis indicated that the magnitude of blood pressure drop from supine to upright was positively associated with the SVR latency but negatively correlated with the heart rate changes upon SVR. The present study demonstrated that blunted heart rate response might explain MSA's vulnerability to postural challenge. PWD may be used to predict cardiovascular response to orthostatic stress upon head-up tilt in MSA patients.

PubMed PMID: 22262954; PubMed Central PMCID: PMC3259486. Full text: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3259486/
NCS & POTS:

ASSESSMENT OF THERAPEUTIC BIOMARKERS IN THE TREATMENT OF CHILDREN WITH POSTURAL TACHYCARDIA SYNDROME AND VASOVAGAL SYNCOPE

Lin J, Jin H, Du J.

BACKGROUND:
Postural tachycardia syndrome and vasovagal syncope are common causes of orthostatic intolerance in children. The supplementation with water, or salt, or midodrine, or β-blocker was applied to children with postural tachycardia syndrome or vasovagal syncope. However, the efficacy of such medication varied and was not satisfied. This review aimed to summarise the current biomarkers in the treatment of the diseases.

DATA SOURCES:
Studies were collected from online electronic databases, including OVID Medline, PubMed, ISI Web of Science, and associated references. The main areas assessed in the included studies were clinical improvement, the cure rate, and the individualised treatment for postural tachycardia syndrome and vasovagal syncope in children.

RESULTS:
Haemodynamic change during head-up tilt test, and detection of 24-hour urinary sodium excretion, flow-mediated vasodilation, erythrocytic H₂S, and plasma pro-adrenomedullin as biological markers were the new ways that were inexpensive, non-invasive, and easy to test for finding those who would be suitable for a specific drug and treatment.

CONCLUSION:
With the help of biomarkers, the therapeutic efficacy was greatly increased for children with postural tachycardia syndrome and vasovagal syncope.

PubMed PMID: 24774832
Q

If someone with dysautonomia has a MTHFR A1298C or C677T gene mutation and a GCH1 gene variant, both of which result in lower levels of tetrahydrobiopterin (BH4), would it be advisable to take a BH4 supplement of some kind? How can BH4 levels be increased?

Vera from VA

A

I have no first-hand experience but there is a BH4 replacement called Kuvan used for phenylketonuria that can be tried. I believe that BH4 deficiency occurs most commonly with production of peroxynitrite, in which case vitamin C can be helpful.

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