

# DYSAUTONOMIA NEWS

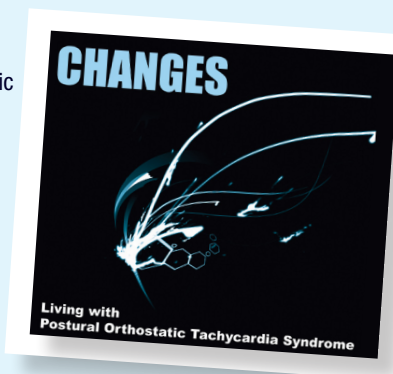
SPRING/SUMMER  
2009

## HOLLYWOOD HERE WE COME...

It has been over two years in the making, but DINET's documentary on POTS is done! We've titled it "Changes: Living with Postural Orthostatic Tachycardia Syndrome." The trailer is available for viewing at our website, [www.dinet.org](http://www.dinet.org).

DVD's will be available for purchase very soon. I would especially like to thank Alexia Anastasia, David Meiklejohn, Shannon Donegan, Autumn Austin, Dr. Charles Randy Thompson and Dr. Svetlana Blitshteyn for helping make my dream of a documentary a reality.

— by Michelle Sawicki



the documentary  
is complete!

## in this issue...

Syncope Counter Maneuvers	2
The Doctors Corner	4-5
The Patients Voice	3
Getting Up When You're Down	3

Dysautonomia News exists to inform and educate. The content should not be used as a substitute for professional medical advice, diagnosis or treatment. Readers are encouraged to con-firm all information with other sources and a physician. Please keep in mind that research is evolving and future discoveries may change or disprove some currently held beliefs.

## THE MEET OTHERS PROGRAM HAS RECEIVED AN UPGRADE!

Hello everyone! Great news! We've just performed a major upgrade to our Meet Others Program. We now have a database that automatically matches people by zip code rather than state boundaries. This will be very helpful to members who live close to their state's border and would like to be matched to people in the adjoining state. It will also greatly reduce Jane Bennett's time spent matching people. Previously Jane had to figure out each person's location and then send out emails. Wow...thanks Jane! Now our database emails people for us! We're excited about our upgrade and know our members will find it a valuable addition to DINET's services.

Ball State University is conducting an anonymous survey on POTS patients and caregivers. Click [here](#) to participate in this anonymous survey.

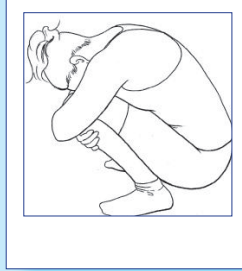
Dysautonomia News is a quarterly publication of the Dysautonomia Information Network. Subscribe to Dysautonomia News at [www.dinet.org/join.php](http://www.dinet.org/join.php)

# SYNCOPE COUNTER-MANEUVERS

The most effective way to avoid syncope is to assume a supine position immediately after the symptoms of pre-syncope develop. The counter-maneuvers listed below may help prevent symptoms of pre-syncope.

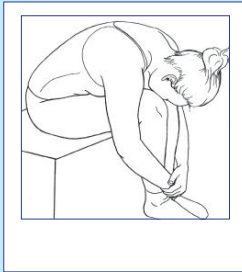
## THE SQUAT:

- Squat down with your feet flat on the floor about a shoulder's width apart.
- Wrap your arms around your knees in a hugging fashion.
- When you are ready to get up, tense your leg and abdominal muscles; remember to get up SLOWLY or you'll risk faint upon standing.



## THE CRASH POSITION:

- From a seated position, bend forward at your waist as far as is comfortable for you.
- Rest your head between or atop of your knees as you are able.
- Muscle tension is not needed.
- Remain in the position until you feel you are able to sit up.
- Give yourself time to stabilize in a seated position before attempting to stand.



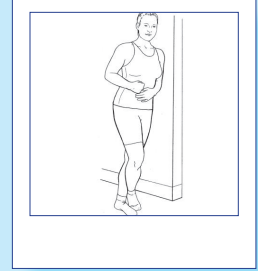
## ISOMETRIC ARM TENSION: (THE ANTI-HUG)

- Clasp your hands at the fingers (thumbs on top and bottom)
- Pull your hands away from one another as if to break your grasp
- At the same time push both hands away from your chest.



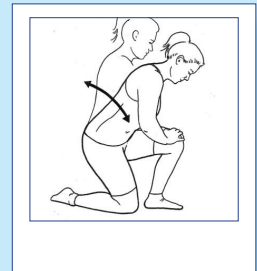
## LEG CROSSING/TENSING: (THE COCKTAIL PARTY POSE)

- While standing, cross one leg over the other at the knee and SQUEEZE both legs together. Tighten your abdominal and buttocks muscles (like you are trying to hold a coin between your legs/buttocks).
- Squeeze your arms into your body and alternate squeezing of each leg if necessary.
- For more stability you may want to do this as you lean against a wall or other sturdy upright object as available.



## GENUFLECTION/ CONTRACTION:

- Move from standing to kneeling on one knee.
- Shift the body back and forward at the waist while contracting the legs, buttocks and abdominal muscles.



## BENDING/ CONTRACTION:

- While standing, bend at the waist and lean against a cart, counter or other sturdy object.
- Bend one knee and squeeze the muscles of the supporting leg, buttocks and abdominal muscles
- Alternate legs



## RESOURCES:

Krediet CT, de Bruin IG, Ganzeboom KS, Linzer M, Van Lieshout JJ, and Wieling W. "Leg crossing, muscle tensing, squatting, and the crash position are effective against vasovagal reactions solely through increases in cardiac output." J Appl Physiol 99: 1697-1703, 2005.

Krediet CT, van Dijk N, Linzer M, van Lieshout JJ, Wieling W. Management of vasovagal syncope: controlling or aborting faints by leg crossing and muscle tensing. Circulation. 2002;106(13):1684-1689.

Brignole M, Croci F, Menozzi C, et al. Isometric arm counter-pressure maneuvers to abort impending vasovagal syncope. J Am Coll Cardiol. 2002; 40(11):2053-2059.

Grubb, Blair P., McMann, Mary. The Fainting Phenomenon. (Futura Publishing Company, 2001), 108-111.

© 2009 DINET.ORG all rights reserved

# Getting Up When You're Down

## Finding YOUR Silver Lining: The Good that Comes from Living with Dysautonomia

When storm clouds are gathering and the sky is dark and threatening, it's sometimes hard to find the silver lining in those clouds. That's how it is with dysautonomia. At first most people are so overwhelmed by symptoms and the grief for all that is lost that it is impossible to find any positives. But after the initial blow we can step back and see the good (yes- GOOD!) that comes from living with a chronic illness. Our forum members recently shared the positives that dysautonomia has brought to them.

Their thoughts ranged from pragmatic to philosophic. From a practical perspective, one member was quick to mention the housekeeping help that her family found necessary to bring in since she became ill. On the other end of the spectrum, another discussed being truly grateful when she was well enough to do the dishes. Other members were happy to have time to devote to their passions: quilting, jewelry design and making greeting cards. Because her illness forced her to be home more, one member was able to find the time to write and publish a book.

Some members had more philosophic silver linings to share. Several focused on their deepening relationships with spouses, children, and other family members. Their illness gave them concentrated time to spend with loved ones. The guilt at being unable to do so many things didn't disappear, but they were able to focus on the greater gift of "downtime" spent together, which ultimately strengthened their relationships.

Many DINET participants mentioned their increased ability to be empathetic toward others who are suffering. One member said, "Things are not always as they appear. I never look at people anymore and wish I had what they have because I know now that I have no idea what their life is really like, or the difficulties that they face." Many took that empathy a step further and mentioned their renewed ability to help others. They saw their illness as an opportunity to help identify other sufferers and offer them aid.

Several of our members mentioned the gift of being able to sort through everything in their lives to ultimately find what's really important. With limited energy, it's imperative to focus on the important stuff and not be overextended by extraneous stuff. This prioritizing also extended to friends. One member mentioned the gift of being able to sort through real and "convenient" friends. Real friends checked on them and offered support. The others who didn't probably weren't friends at all.

Others mentioned personal growth. After facing very challenging physical symptoms, they found out just how much they could survive. The future felt less frightening. After all they'd been through, they felt like they could handle anything.

One member poignantly brought up the confirmation that her diagnosis brought to her. "I learned to trust MYSELF more. I learned that I am NOT lazy or insane... my body simply will not function like a "normal" person's will." The ultimate silver lining for her was gaining the ability "to distill the important things in life down to a small, rich cordial and skim out all of the distractions and energy wasting sludge."

Chronic illness is never fun and not something we at DINET would wish on anyone but, as the above examples show, it can lead to personal growth. Just visit our forum at [www.dinet.ipbhost.com](http://www.dinet.ipbhost.com) and you will find that, in facing chronic illness, many of our members have developed thought processes far beyond their years.

-by Julie Gregory ("Mack's Mom")

## the Patients VOICE

I sit staring out my window again  
Stuck in this room  
By an illness that won't let me free

I look out at the rain  
And feel

Blue with sadness for  
All that was, is and never will be

Red with frustration and anger  
Hating the pain and endless days

Green with envy  
Because everyone's life has moved on  
While I am stopped here since that  
fateful day

Yellow with fear  
That this is the way  
It will always be

Then he calls  
Come look out this window  
And I see  
A rainbow stretched across the sky

The colors transform  
Into Hope

-by Stacey Yount

Does your place of business or family give to charity? If so, please let them know about the Dysautonomia Information Network, [www.dinet.org](http://www.dinet.org). DINET is completely funded by member's donations and can't exist without them. THANK YOU!

# doctorscorner



**Q:** Dear Doctors,

I have had Postural Orthostatic Tachycardia Syndrome (POTS) and Neurally Mediated Hypotension (NMH) for at least ten years and am allergic to latex. These conditions are not waning and I cannot see them waning in the near future. I was told by one doctor a few years ago that we should just wait to start a birth control regimen when these conditions started to get better but I need to start one sooner rather than later. What are my best options? Is there one that will help my dysautonomia?

Margaret  
Nashville, Tennessee

**A:** Dear Margaret,

*It is difficult to answer this question without having details as to the reason why you and your doctors are considering starting birth control regimen in the first place and what other reasons might be at play for your doctor to postpone starting these until your conditions improve. If you are desiring contraception purely for birth control purposes, waiting until POTS and NMH improve is not necessary since POTS and NMH are not a contradiction to oral contraception or other forms of birth control.*

*To my knowledge, latex allergy is a lifetime problem and is not expected to improve, and as such, you may want to consider barrier contraception methods with non-latex products (i.e. non-latex condoms). Remember that for many women, POTS and NMH can get worse either before or during menstruation, so using oral contraception with the purpose of stopping or decreasing the frequency of menstruation might be a viable treatment option for some women.*

*You may want to discuss this issue further with your gynecologist who can suggest the type of oral or other form of contraception that would best suit your needs.*

**Dr. Svetlana Blitshteyn**  
Kinkel Neurologic Center, LLP, Buffalo, NY

**Q:** Dear Doctors,

Since my POTS started I have severe facial flushing. I know a lot of POTS patients have this but mine is so bad that even in winter I have to have a fan blowing on me/windows open for at least half the day. I cannot bear even slightly warm temperatures and even damaged my skin because of using icepacks to cool myself down. It prevents me from doing most things but only occurs in my face and ears. My skin feels like it is on fire. I couldn't cope with a sweat test and clonidine had no effect. Are there any other options left? Is there a known cause for facial flushing in POTS?

Anonymous

**A:** *There is a subgroup of patients with POTS that we see who have abnormally sensitive white blood cells that are called mast cells. These cells are critically important in the body's response to foreign substances and in allergic reactions. They release substances like histamine and prostaglandins that can cause flushing, vasodilation, hypotension or even hypertension (due to excessive activation of the sympathetic nervous system).*

*There are patients that seem to trigger their mast cells to degranulate (release their chemicals) without an obvious cause. We refer to these patients as having a "Mast Cell Activation Disorder". This is typically associated with episodic flushing (turning red) with spells, followed by profound fatigue. Usually we have seen this in the whole body. We test for this by getting a 4 hour urine collection at the time of a severe spell and assessing levels of 9-methylhistamine (a stable urinary histamine metabolite). To "enrich" the urine, we ask patients to void and discard their urine right at the beginning of the spell prior to the 4 hour urine collection. If the concentration of the methylhistamine is elevated, then we may target therapy at this problem. Treatments might include combined antihistamines (H1 and H2 blockers), high dose aspirin, or a central sympatholytic such as alpha-methyltyllopa. It is worth noting that most cases of flushing are NOT due to Mast Cell Activation disorder, but given the different approach to treatment, we feel that it is worth looking for this problem in the correct clinical context.*

**Dr. Satish Raj**  
Vanderbilt University Medical Center, TN

**Q:** Dear Doctors,

My 18 yr old daughter was diagnosed with POTS 2 months ago. It came on acutely. Within 2 weeks she was (and still is bedridden..) sitting only to 30 degrees before onset of dizziness/syncope. On tilt tables her heart raced, her blood pressure dropped only slightly and she passed out after 1 minute. Her EEG was normal whilst testing. We are back to see the consultant in 2 weeks time. What tests should we ask/expect to determine which subset of POTS she has in order to determine the best form of treatment? She has low blood pressure.. normally 88/56 average. She is experiencing tachycardia on sitting and sometimes lying down (with chest pain.) Will the treatments control the tachy/syncope? She is currently on Ivabradine 2.5mg daily, which is not even close to controlling the tachy (pulse goes from 70 to 140+ on sitting up) but has lowered the pulse rate slightly (maybe 10 bpm supine). We are doing 2.5 liters fluid and salt tablets in the meantime.

G. Robinson  
Durham. UK

**A:** Dear G. Robinson,

*Has she some form of more generalized autonomic failure? Rare but sometimes seen in kids. Prolonged bedrest causes severe orthostatic intolerance. My subsets are probably changing. Please see a neurologist to go over potential aspects of autonomic failure.*

**Dr. Julian Stewart**  
New York Medical College

**Q:** Dear Doctors,

With POTS there can be marked polyuria (frequent urination) that is often misdiagnosed as Diabetes Insipidus. Is this misdiagnosis based on urine volumes or on urine osmolality? After overnight (12-hours) fluid deprivation, do POTS patients concentrate their urine as well as normal individuals? Is there any time that you have seen increased serum osmolality with decreased urine osmolality in POTS patients and it has NOT been Diabetes Insipidus?

Jennifer Cook  
Georgia

**A:** Dear Jennifer,

*I have not done all these tests although calculated osmolality and urines, when we have obtained them is usually normal. I have had interaction with a patient recently who sounded like DI but may have been from excessive water drinking, and*

*I have had interaction with a patient recently who sounded like DI but may have been from excessive water drinking, and I do not have the results of water restriction in that patient. In those patients who are hypovolemic, I have not noted abnormalities in renal or hypothalamic function suggesting DI, nor vast diuresis.*

*Have you evidence for increased daily urine output?*

**Dr. Julian Stewart**  
New York Medical College

**Do you have a question for one of DINET's medical advisors?**

**Click [here](#) to ask your question today!**



**Get yours today at**  
<http://dinet.org/tshirts.htm>

**And a special thanks to...**

**Michelle Sawicki, Editor**  
**Judith Pettibone, Editor**  
**Staci Friedman, Art director/Designer**  
**Forum members "Earth Mother" and "AJ4055",**  
**for the counter-maneuvers document.**

# SOME OF THE MANY FACES OF THE MEMBERS OF DINET...



**DVD  
COMING  
SOON TO  
DINET.ORG**



**...THAT YOU WILL SEE IN  
OUR FIRST DOCUMENTARY**

**"CHANGES: LIVING WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME"**