

## Myasthenia Gravis Support Group of Central Texas

January 9, 2019

Linda Ann Joslin Facilitator Lee Higgins MGFA Rep Susan Larkin Treasurer  
Rachel Higgins MGFA Rep

### **Members in Attendance in January:**

Linda Ann Joslin Larry Joslin David Renfro Rachel Higgins Sallie Sassano Mary Beth Carter  
Albert Stowell Jim Kunkel Don Jones Dan Bealko Julie Afsahi Jonathan Simmons  
Gustavo Sanchez Katie Drimm Ray Johnston Joyce Brown Sandra Johnston  
Don Nichols (new) Barbara Nichols (new)

**Our 2019 Schedule: Spicewood Springs Library Branch 8637 Spicewood Springs Rd. 78759**

**Wednesday** February 13, 2019 at 7:00 pm to 8:00  
**Monday** March 11, 2019 at 7:00 pm to 8:00 Dr. Horvit  
**Monday** April 15, 2019 at 7:00 pm to 8:00  
**Wednesday** May 15, 2019 at 7:00 pm to 8:00  
**Wednesday** June 12, 2019 at 7:00 pm to 8:00  
**Wednesday** July 10, 2019 at 7:00 pm to 8:00  
**Wednesday** August 21, 2019 at 7:00 pm to 8:00  
**Wednesday** September 11, 2019 at 7:00 pm to 8:00  
**Wednesday** October 9, 2019 at 7:00 pm to 8:00  
**Thursday** November 14, 2019 at 7:00 pm to 8:00  
**Thursday** December 12, 2019 at 7:00 pm to 8:00

## **GET YOUR INFUSIONS AT HOME:**

 Katie Krimm, RN HPC Specialty Pharmacy (512) 571-6951

*Is getting to the doctor or infusion center too far to receive your IV?  
Do you work from home and going for an infusion is hurting your job?  
Are you more comfortable at home?  
Do you wish you could do infusions at night or on weekends?*

Katie stated that she will travel to your house to administer your meds. All you have to do is get approval from your doctor. Thank you, Katie for speaking with the MG Support Group.

### **HPC Patient Assistance Program**

HPC will assist our patients in the enrollment/qualifying process of the various patient assistance programs. These services help patients find the financial resources needed to live with chronic illnesses or conditions and a way to satisfy the expensive co-payment/deductibles.

Some of the programs include the Patient Access Network (PAN) Foundation and Patient Services Inc. (PSI) which are both nationally known, non-profit charitable organizations that provides a "safety net" for patients to alleviate some of the financial burden due from expensive premiums, high deductibles, and co-payments. Other non-profit organizations programs are utilized as well as the man factor co-pay assistance programs.

For more information, please contact **1-800-757-9192** or [patientassistance@hpcspecialtyrx.com](mailto:patientassistance@hpcspecialtyrx.com).

### **Questions**

- [Can I still work or go to school?](#)
- [How do I receive your services?](#)

- [How frequently does the home infusion nurse visit?](#)
- [Is home infusion service covered by insurance?](#)
- [What is infusion therapy?](#)
- [What is the advantage of home infusion therapy?](#)
- [When will service begin?](#)
- [Will they draw blood for tests in my home?](#)

### **Can I still work or go to school?**

Penn Home Infusion Therapy does not require that patients are homebound during their treatment. As long as your condition does not require you to be homebound, you will be able to work, run errands, and maintain your normal lifestyle for the duration of your treatment.

### **How frequently does the home infusion nurse visit?**

Each patient care plan is customized to the needs of the individual. Our nurse will discuss your care schedule with you during the first visit. At your initial evaluation, our nurse will determine the timing and frequency of visits based on your needs.

### **Is home infusion service covered by insurance?**

A nurse will contact you within 24 hours of your physician's referral. After evaluating your needs, we will determine a treatment and visit schedule. Services will begin based upon your physician's orders. Check with your insurance provider to ensure home infusion services will be covered.

### **What is infusion therapy?**

Infusion therapy involves taking medications intravenously into the bloodstream, spinal cord or under the skin. Infusion therapy is commonly used for:

- Antibiotics
- Chemotherapy
- Immune globulin
- Pain management
- Parenteral nutrition

Conditions often requiring infusion therapy include:

- Cancer
- Congestive heart failure
- Gastrointestinal disorders
- Hormone deficiencies
- Infections resistant to oral antibiotics

### **What is the advantage of home infusion therapy?**

Until the 1980s, infusion therapy was administered only at health care facilities, as an inpatient service. Individuals requiring lifelong therapy were not able to maintain normal lifestyle and work activities.

Home infusion is a safe and effective alternative to inpatient care for many patients. Penn Home Infusion Therapy performs a thorough patient and home assessment to ensure that home infusion therapy is an appropriate method of treatment.

### **When will service begin?**

A nurse will contact you within 24 hours of your physician's referral. After evaluating your needs, we will determine a treatment and visit schedule. Services will begin based upon your physician's orders.

### **Will they draw blood for tests in my home?**

Penn Home Infusion Therapy will draw blood in the home as part of a patient's ongoing plan of care; however we will not come to the home for the sole purpose of drawing blood.



**Jackie McSpadden is one of our members provided this article.**

Pacing: The Chronically Ill Person's Best Friend

## ***Five effective strategies for pacing when you're sick or in pain***

Posted Jun 15, 2016 Source: Pixabay

Pacing refers to spacing out your activities during the day so that you're able to stay within the limits of what your body can handle without exacerbating your symptoms. Another way to think of it is that pacing is a way to keep you inside your "energy envelope"—the envelope that contains your energy stores for any given day.

First, an admission: Even though pacing may be the single best “treatment” for me, I have a [love-hate](#) relationship with it. On the one hand, I love pacing because it keeps my symptoms from flaring. On the other hand, I hate pacing because it keeps me from doing everything I want to do.

To complicate matters, I'm much better at pacing when I'm at my best, as opposed to when I'm at my worst. This means that when I'm feeling intensely sick or in pain, I tend to ignore pacing and overdo things which, of course, only exacerbates my symptoms. Why in the world would I do this? Because doing things distracts me from my symptoms. In other words, activity keeps me from tuning in to how my body feels. Of course, this always backfires. The time comes when my body imposes itself on the situation and tells me in no uncertain terms: “That is *enough* for now.” Then, when I do give in and lie down to rest, I have to deal with feeling worse due to all that extra activity. When will I learn?

This tendency of mine is the exact opposite way that “pacing failure” is usually described. It's usually described as overdoing it when you're feeling good, and then having to pay for it later, often by being confined to bed for a time. This is called the “push and crash cycle.” I can do that too, but in this complicated relationship I have with pacing, I could call my tendency to overdo it when I'm already feeling terrible a “crash and crash cycle”!

I'm pretty sure I'm not alone in doing this.

The odd thing is that I'm generally a very disciplined person, so because pacing takes discipline, you'd think I'd be good at it. But I'm not. I admit that one reason for writing this piece is self-interest: I need to work on my pacing skills and writing about it will inspire me to do so.

Here are some ideas for pacing that have worked for me when I'm being “good” and following them:

### ***1. Alternating activity with rest. This is the essence of pacing.***

In my experience, the best way to do this is to write out a schedule for the day that incorporates rest in between each activity you want or have to do, be it mental or physical. This way, you're dividing your activities into manageable chunks of time.

Here's the secret to success with this: if you don't stick to your schedule exactly, don't abandon it. This is a common mistake. When I was teaching, I recommended that students create a schedule during finals period in which they set out what subjects they'd study on any given day and time. Then I gave them this final piece of advice: “Stuff happens that can keep you from sticking precisely to your schedule. Don't throw it out. Revise it and start from your new spot.”

This approach to scheduling has helped me tremendously since becoming chronically ill. For example, if I put on the schedule for the morning, “10:00-10:30: work on blog post,” but then wind up working until 11:00, I

revise the schedule and move on with the day. Simply having that schedule in front of me keeps me from deviating from it too much. Without set time-frames, I'm likely to lose track of time and work for several hours straight; then of course, I have to suffer the consequences. Some people find it helpful to set a timer; when it goes off, they know it's time to stop the activity and rest for a while.

## ***2. Slowing down when performing tasks.***

I tend to do things quickly. This causes my heart to begin racing and it can even make me dizzy. Slowing down is an excellent way to pace. And so, when I catch myself going faster and faster, for example, when I'm folding laundry or doing the dishes, I consciously tell myself to slow down. Not only do I save energy this way (and so I'm pacing), but I enjoy the task much more.

## ***3. Following the 50% rule.***

With this pacing tool, given how you feel on a particular day, you decide what you can comfortably do and then *only do 50% of it.*

One reason this is a great strategy is that I tend to overestimate what I can comfortably do, so this keeps me safely within my energy envelope. I also recommend that you think of that unexpended 50% as a gift you're giving yourself to help you feel less sick and in less pain.

## ***4. Using a metaphor to help allocate available energy.***

Many of you are familiar with the "spoon theory" by Christine Miserandino and find it very helpful. Here's a link to it: [The Spoon Theory](#).

I use a "marbles in a bowl" metaphor because it works better for me. When I wake up in the morning, depending on how I feel, I imagine that I have a certain number of marbles in a bowl. They represent the available energy I have for that day. It might be 50 marbles on a good day...and 10 marbles on a bad day.

Then, before I start an activity, I estimate how many marbles it will use up and subtract that number from my total. When there are no more marbles in my bowl, it's time to "shut down" for the day. Initially, I had a lot of success with this strategy. Unfortunately, several years ago I stopped doing it. (Note to self: start thinking about marbles again!)

Don't forget that mental and emotional activity use up marbles too. In fact, [stress](#) is a marble gobbler. For this reason, if an unexpected source of stress arises, you may suddenly find your bowl empty. That's the time to make a commitment to rest as much possible for the remainder of the day.

## ***5. Using a pedometer or a heart rate monitor.***

These are inexpensive devices. A pedometer counts the number of steps you take in a day. A heart rate monitor keeps track of how fast your heart is beating. Once you figure out your limits—how many steps you can take or how high your heart rate can become before you feel the energy draining out of you—you keep your eye on the pedometer or the heart-rate monitor; when they get to a certain reading, you know it's time to rest.

The reason I'm not using either at the moment is that, in my case, I can overdo things without taking a single step, for example, working too hard on my writing even though I'm reclining on the bed. Nevertheless, I know from others that these two devices can be valuable pacing tools.

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A final word. Expect the unexpected, meaning that no matter how carefully you've planned your day for perfect pacing, as John Lennon wrote: "Life is what happens while you're busy making other plans." Stuff happens that may keep you from sticking to your pacing [goals](#). When that happens, don't abandon your pacing plans and don't blame yourself for getting off-course (that's a useless waste of your limited energy). Instead, revise your schedule and then try again. In an earlier piece, I referred to this as keeping a "Try Mind."

If you have a particular pacing strategy that works well for you, I hope you'll share it in the comments section below.



*Albert Stowell is one of our members that provided this article.*

### **Scientist explores the '7th sense' — the link between the immune system and the brain**

HAMPTON — The immune system is a marvel, working to keep the organs in the body healthy.

Until recently, though, scientists thought the immune system was less proactive with one particular organ — the brain, or central nervous system.

"The understanding was that the two systems don't interact with each other — or should not interact with other — and they would only interact with each other in pathologies," said Jonathan Kipnis, head of the Department of Neuroscience at the University of Virginia in Charlottesville.

"So, if there is a problem, the immune cells will get into the brain and will attack the brain, and then you have pathologies such as multiple sclerosis."

But Kipnis and his international research team at the university's Kipnis Lab are turning this notion on its head.

Their recent findings suggest that not only are the immune system and the brain more closely linked than believed, but the immune system's sensory role for the brain is so key that Kipnis considers it a "seventh sense" — after sight, sound, touch, smell, taste and sense of movement.

In fact, Kipnis believes that a healthy brain and healthy immunity are so interdependent that replenishing an impaired immune system could actually restore impaired brain function — and even give a little boost to aging brains.

The implications are immense for possible treatments for neurological disorders and diseases from autism to Alzheimer's to PTSD to MS.

Kipnis was scheduled to talk about his work in a free public lecture Tuesday evening at the Virginia Air & Space Center in downtown Hampton.

Because his appearance is sponsored by NASA Langley Research Center, however, the continuing federal government shutdown is forcing Langley to reschedule to another date still to be determined.

C. Michael Holloway, a senior research computer engineer at Langley, suggested Kipnis for the center's monthly Sigma lecture series.

"Professor Kipnis and his associates had made a textbook-changing discovery of a physical connection between the central nervous and immune systems in humans — two systems that had long been thought to be in nearly complete isolation from each other," Holloway said.

"By itself, this discovery is fascinating. But what makes the discovery especially worthy of a Sigma series public lecture is the potential for enabling new approaches for finding effective treatments, or perhaps even preventers, of diseases ... affecting the brain."

### **Running at peak**

Kipnis's most recent findings build on his 2015 breakthrough that the brain is surrounded by lymphatic vessels. Until then, such vessels were thought not to exist.

That discovery was voted one of the biggest breakthroughs of the year by the journal Science.

Kipnis now believes that the lymphatic vessels help maintain brain function by flushing away waste that brain tissue produces to the lymph nodes, considered the command center of the immune system.

As we age, the lymphatic system can start to deteriorate, affecting brain function. But Kipnis' team found a way to reverse some of those effects by targeting the lymphatic vessels.

They applied a gel containing a growth factor to the skulls of aged mice, and as a result those mice outperformed their peers in memory and learning tasks.

The gel worked by rejuvenating the lymphatic vessels, causing them to enlarge and drain waste from the brain better.

There is a caveat though: Such treatments can't work miracles and create brand new Einsteins.

"You cannot take a Fiat and turn it into a Mercedes, because it's a different engine, it's a different car," Kipnis said.

Instead, he said, think of a healthy immune system as a pit crew that can help an individual machine run at its own peak level.

In another experiment, the team found that a healthy immune system alleviated stress in mice that were exposed to cat urine — a big trigger for mice. It even went a long way toward preventing post-traumatic stress disorder.

According to Kipnis, 70 percent to 80 percent of mice with impaired immune systems developed PTSD in stress experiments, compared to only 10 percent to 15 percent of mice with healthy immune systems.

"There is a lot of research still yet to be done in order to understand what is happening," Kipnis said.

But their ongoing work at the molecular level continues, and one day could lead to new drugs or medical treatments for a host of neurological ills, he said.

"I think everybody in biomedical research is dreaming that his or her discoveries will impact human health," said Kipnis. "At the end of the day, that's why we're here."

**Tamara Dietrich, 757-247-7892, [tdietrich@dailypress.com](mailto:tdietrich@dailypress.com), DP\_Dietrich**

#### **Support Groups in Texas ----- LET'S GO TEXAS!!!!!!!!!!!!!!**

Central Texas MG Support Group meets at the Spicewood Springs Library 8637 Spicewood Springs Rd Austin 78759  
Linda Ann & Larry Joslin, Facilitators Started in February 2007 [www.mg-centraltexas.org](http://www.mg-centraltexas.org)

Alamo MG Support Group meets in San Antonio on the 2nd Health Link Fitness Center, 288 W. Bitters Rd San Antonio 78216  
Elroy and Gail Tschirhart, Facilitators Started in February 2007 [www.mgsouthtexas.org](http://www.mgsouthtexas.org)

Houston MG Support meets in Houston every 2nd Saturday. Trini Mendenhall Community Center, 1414 Wirt Rd. Houston 77055  
Meena Outlaw or Sarah Ricks, Facilitators Started January 2017 <https://mghoustontx.org/>

Northwest TX/DFW Support meets in Dallas Every 2nd Sat contact Facilitator to confirm location  
Karon & Jerry Faught, Facilitator Facebook: [DFW Myasthenia Gravis Support Group](https://www.facebook.com/DFW-Myasthenia-Gravis-Support-Group)

Southeast Texas MG Support (also servicing Southwest Louisiana) 2nd Thurs in Beaumont - Howell's Furniture Community Rm  
Tracey Young, Facilitator Started November Facebook Page

Corpus Christi Texas MG Support Meets 3rd Saturday confirm location Robert Harvey, Facilitator Started January 2017  
[https://www.facebook.com/Myasthenia-Gravis-Support-Group-of-Corpus-Christi-Texas-630868910390981/?ref=page\\_internal&qsefr=1](https://www.facebook.com/Myasthenia-Gravis-Support-Group-of-Corpus-Christi-Texas-630868910390981/?ref=page_internal&qsefr=1)

Deep South Texas MG Support Harlingen Karen Mau  
San Angelo Texas MG Support Ralph Rumph <https://www.facebook.com/sanangelomg/>

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