

POSITIVE VOICES-MAY 2011

Your Newsletter by Positive People for Positive People

TRANSITIONS IN CONSUMER ADVISORY COMMITTEE/CAC

Brian Wieder

On May 10, 2011, STAP will be present at the monthly CAC meeting to watch and participate in the changes of leadership that will occur on that day. As Chair of the CAC for the last two years, it has been very clear with my continued health issues that lead me to believe that I no longer can fully commit and bring continuous leadership as I have in the past. On May 10, Will Z, who has been the Co-Chair for the past year, will become the new Chair of CAC. For those who have not met Will, he is very bright, articulate, and sensitive with a strong sense of whom he is and what he believes in. Always flexible to the CAC members suggestions, he is a great problem solver and a great voice for all our clients living with HIV/AIDS. Please feel free to attend the meeting and meet Will. There will also be a new Co-Chair and a Secretary chosen, so this is a great time to get involved with the group.

For me, this has been an incredible joyous period of my life, making terrific friends that care for and look after me, people who I trust and know that they always have my best interest at heart when I ask for advice or need assistance. Really, STAP was the biggest player at the table, so to speak, as every issue that the CAC brought to them that affected the clients, their services and care, they stepped up and did what they could do to resolve those issues. STAP and all the wonderful friends that I have met there, thank you for your support, energy and action taken when needed. Will is our gift to you.

March 28, 2011/POZ.com

Pooled Trial Results Suggest Capsaicin Patch Relieves Neuropathy Pain

The pooled results of two clinical trials suggest that a skin patch with the chili pepper-derived chemical capsaicin could relieve HIV-related neuropathy pain by about 30 percent. These trial results, presented at the annual meeting of the American Academy of Pain Medicine (AAPM), were **reported** by the website Medpage Today.

Chili peppers and mustards have been used for centuries in topical balms to treat chronic pain. Only during the past few decades, however, have scientists figured out how capsaicin—the chemical that gives chilies their pungency—works as an analgesic: It depletes a neurochemical called substance P responsible for transmitting pain.

NeurogesX, based in San Mateo, California, has spent several years testing capsaicin in skin patches to treat a variety of chronic pain conditions. The company now has a skin patch made up of a gel containing 8 percent capsaicin, called Qutenza, which is approved by the U.S. Food and Drug Administration (FDA) to treat pain from shingles and from diabetic neuropathy. Qutenza is applied for one hour in a single application and the pain-relief lasts for about three months.

NeurogesX has also conducted trials of Qutenza to treat HIV-related distal sensory polyneuropathy (neuropathy), a condition marked by nerve damage, which can cause pain, tingling and numbness in the extremities and sometimes lead to permanent disability.

“To date, medications used to treat neuropathic pain have yielded disappointing results in large randomized controlled studies among HIV-associated neuropathy,” Steven Brown, MD, from the AIDS Research Alliance in Los Angeles, told Medpage Today.

Brown, who presented the results of the two trials at the AAPM conference, also noted: “The only substances that have shown any impact on the pain appear to be the [Qutenza] patch, smoked cannabis and recombinant human nerve growth factor, but none of these treatments has yet been approved by the FDA for that use.”

Two clinical trials of Qutenza for HIV-related neuropathy conducted before 2008 had **mixed results**, with one showing improvements in neuropathy pain and another finding that Qutenza wasn’t significantly better than a gel patch containing a miniscule amount of capsaicin. A 2009 article in *Wired* magazine **detailed** how the placebo effect—whereby patients’ symptoms can significantly improve just by thinking they are getting a real medicine, even if they receive only a sugar pill—is particularly strong in trials of pain medication. This means that a medicine often has to be quite potent to show a statistical difference.

At the recent AAPM conference, Brown presented data on an analysis that pooled the results of two newer studies. The studies compared 239 people who received a single application of Qutenza (8 percent capsaicin) with 99 people who received a single application of a control patch containing only 0.04 percent capsaicin.

Brown and his colleagues found that those receiving Qutenza had a 27 percent decrease in their neuropathy pain compared with a 15.7 percent decrease in those who received the control patch. The improvement was highly statistically significant, meaning that the difference between Qutenza and the control was too large to have occurred by chance.

What’s more, when Brown’s team looked at those who received a higher degree of pain relief—a 30 percent or more reduction in pain scores—36 percent of those on Qutenza saw this higher level of relief compared with 22 percent on the active control.

The three-month improvement in neuropathy pain doesn’t come without side effects, however. David Walk, MD, of the University of Minnesota in Minneapolis, who has used Qutenza for non-HIV pain care, told Medpage Today, “This treatment can be painful. Even with the lidocaine that is delivered before the patch is applied, patients report some pain associated with the patch for as long as a week afterward, so we usually send them home with analgesia to cover that period.”

NeurogesX reports on its web site that it is still working to seek FDA approval for Qutenza for HIV-related neuropathy.

Note from the Editor: I have been fortunate enough to be part of having Qutenza applied to my feet two times and the difference in pain is incredible. They only do this in NYC and if you need the doctor’s number, please contact me at 607-724-1272.

FROM THE MEDICAL ADVOCATE

Spring is in the air, and our thoughts turn to fitting into last year's bathing suit and where we should go to show off our girlish (or boyish) figures! But for some of us, there's more to worry about when traveling than getting the table closest to the ocean (where everyone can admire our bathing suits). The following are important tips on how to travel with your medications and what you should have with you to make that easier.

Travel Tips

- Pack extra medicine and supplies when traveling in case you are away from home longer than you expect or there are travel delays.
- Carry a copy of your prescriptions in your carry-on, purse, or wallet when you travel.
- If you are taking injectable medications (e.g., Fuzeon, insulin, testosterone) you must have the medication along with you in order to carry empty syringes.
- Do not remove syringes or medicines from the original packaging with printed labels and manufacturer's information. Packaging is a good way to help airport security identify your medicines. Opening packages or taking pills out of their prescription bottles will delay your time in security.
- Show copies of your prescriptions and/or your medication bottles you have in your carry-on when you present to airport security. If you have any problems, ask to see a supervisor.
- You can ask for and are entitled to a private screening to maintain your confidentiality.
- With recent security concerns, the amount of liquids you are allowed to carry-on is limited and in some cases prohibited. The following guidelines about liquids are the most current provided by the Transportation Security Administration:
 1. 3-1-1 rule for carry-ons = 3.4 ounce (100ml) bottle or less (by volume); 1 quart-sized, clear, plastic, zip-top bag; 1 bag per passenger placed in screening bin. One-quart bag per person limits the total liquid volume each traveler can bring. 3.4 ounce (100ml) container size is a security measure.
 2. Be prepared. Each time TSA searches a carry-on it slows down the line. Practicing 3-1-1 will ensure a faster and easier checkpoint experience.
 3. 3-1-1 is for short trips. If in doubt, put your liquids in checked luggage.
 4. Declare larger liquids. Medications, baby formula and food, and breast milk are allowed in reasonable quantities exceeding three ounces and are not required to be in the zip-top bag. Declare these items for inspection at the checkpoint.

In some cases, the airline may ask the on-board staff to store your medicines and syringes during flight. Keep your medicines, syringes, and supplies together in a carry-on case or travel case to make passing them to and from the flight staff easier with less chance of losing medications or supplies.

- If traveling abroad, become familiar with the laws, restrictions, and requirements of the countries you are traveling to. The US requires all passengers to declare medicines and syringes when traveling abroad.

Preventing Infections and Illness When Traveling

When you travel, you risk coming into contact with germs you might not find at home. Many of these germs can make you very sick. For people with special health needs such as people living with HIV, travel can be risky to their health. Travel, especially to developing countries, can increase your risk of getting opportunistic infections. The best thing you can do when you travel is to know the medical risks and to take steps to protect yourself.

Before You Travel

- Talk to your doctor or an expert in travel medicine about health risks in the area you plan to visit. They can tell you how to keep yourself healthy when you travel to places where certain illnesses are a problem. They also can tell you about places that might not be safe for you to visit. Ask them if they know of doctors who treat people with HIV in the region you plan to visit. Plan in advance for problems that might come up.
- *Traveler's diarrhea* is a common problem when traveling abroad. Your doctor can prescribe certain antibiotics to take along with you in the event you get diarrhea. A common drug for traveler's diarrhea is ciprofloxacin. *Important note: make your doctor aware of any allergies you may have to antibiotics (e.g., sulfa drugs) before taking any medicines.*
- Insect-borne diseases are also a major problem in many areas. Take a good supply of an insect repellent that contains 30 percent or less "Deet" with you. Plan to sleep under a mosquito net, preferably one treated with permethrin, in places where there is malaria or dengue fever. Unless you need to go there, avoid areas where yellow fever is found.
- Ask your doctor if you need to take medicine or get special vaccinations before you travel. He or she will know which vaccines are safe for you. Your doctor will also know the best ways to protect you from such things as malaria, typhoid fever, and hepatitis. Make sure all your routine vaccinations are up to date. *Important note: people infected with HIV can't take live vaccines. Check with your doctor before taking any vaccine.*
- If you are leaving the United States, make sure you know if the countries you plan to visit have special health rules for visitors. These rules can include vaccinations that may not be safe for HIV-infected people to take. Your doctor or local health department can help you with this.
- If you have medical insurance, check to see what it covers when you are away from home. Many insurance plans have limited benefits outside the United States. Very few plans cover the cost of flying you back to the United States if you become very sick. Make sure your paperwork is in order, and take along proof of insurance when you travel.

When You Travel

- Food and water in developing countries may not be as clean as they are at home. These items might contain bacteria, viruses, or parasites that could make you sick. To be safe, drink commercially available bottled water when possible.
- Do not eat raw fruit and vegetables that you do not peel yourself, raw or undercooked seafood or meat, unpasteurized dairy products, or anything from a street vendor. Also, do not drink tap water, drinks made with tap water, or with ice made from tap water, or unpasteurized milk.

ON GOING MEETINGS AND COMMUNITY SERVICES

JOIN CONSUMER ADVISORY COMMITTEE [CAC] MEETINGS

The STAP Consumer Advisory Committee is a committee facilitated by and made up of consumers (STAP clients) who welcome other consumers and their significant others, caretakers and family members to join them on the second Tuesday of each month. This collaborative effort provides a confidential space for clients to make recommendations regarding STAP client services and other programs in a non-judgmental environment.

The meetings are held following the Friends Dinner at 6:15 at Trinity Memorial Church (on the corner of Main & Oak Streets) in downtown Binghamton. Call 1-800-333-0892 for directions or more details. If you cannot attend these meetings, mail your opinions or suggestions to STAP, 122 Baldwin Street, Johnson City, 13790, Attention CAC. CAC is encouraging consumers in other counties to organize monthly meetings in their area. Contact your case manager or Brian Wieder at 607-724-1272 to discuss developing CAC in your community.

DRAGON SLAYERS

Hepatitis C and Co-Infection Support Group. Meetings at 6:00 - 7:00PM on alternate Tuesdays at Trinity M, 44 Main Street, Oak Street Entrance in Binghamton. For information, call (607) 798-1706.

FRIENDS DINNER

Friends meet every Tuesday evening for a time of fellowship and good food. Join us at Trinity Memorial Church (on the corner of Main & Oak Streets) in downtown Binghamton. Doors open at 5PM and dinner is served between 5:30 & 5:45. No charge, just come with a smile and a friendly attitude - ready to meet and greet friends and have a hearty meal.

Parking is available on Oak Street behind the Church Annex. Use the Oak Street entrance for the cafeteria. Free bus passes are available for STAP clients! Call your case manager for details. Bus passes available for transportation to/from the Friends Dinner only. For more information call Bill at 607-724-0103.

FREE ANONYMOUS RAPID HIV TESTING

Walk-in *Anonymous* testing is available in our STAP Johnson City office every Monday from 1:00-4:30PM and Thursdays from 1:00-3:00PM. *Confidential* testing is available in our STAP Johnson City office Thursdays from 9:00AM - 12:00PM. STAP's office is located at 122 Baldwin Street Johnson City, NY 13790. Walk-in *Anonymous* Testing is also available at STAP's Ithaca office located at 501 S. Meadow Street, Ithaca, NY 14850 on Tuesdays from 9:00AM-11:30AM, and *Confidential* testing can be scheduled Thursdays, 9:00AM-11:30AM. For more information and other testing opportunities available throughout the month, please call (607)798-1706.

Blogging Anyone???

Anyone interested in blogging messages is welcome to join in at thecubebinghamton.tumblr.com or contact ethan@thecubebinghamton.org for more information.

ASK THE MEDICAL ADVOCATES

Have general questions or concerns regarding HIV?
Want to better manage side effects of your HIV medications?
Concerned about interactions between your HIV meds and other meds that you take?
Want to better understand the results of your blood work or other lab tests?
Concerned about HIV exposure risks to your negative partner?
Interested in alternative or complementary therapies for HIV?

Kelly Conroy/Medical Advocacy Coordinator/.607-206-3418.

HOPE DISPENSARY OF THE SOUTHERN TIER

The Hope Dispensary of the Southern Tier, a service provided by Lourdes Hospital, is a new program designed to provide medications to those that are uninsured or underinsured and have a limited income. Here is how you qualify:

You must have no prescription coverage

Have a photo ID or Social Security Card

Bring one of any of the following as proof of income: Pay Stubs or Bank Statement, SSI/SSD paperwork or Unemployment or Pink Slip form from employer.

Bring proof of residency - one piece of mail with your name and address, such as a phone bill, NYSEG bill or cable bill.

Bring the prescription with you

If you need assistance with providing this information to determine eligibility, they have an onsite Social Worker who can help you with the process. There is a monthly income level that you cannot exceed. The information is listed on the next page.

Family Size and Monthly Income

1 = \$1,805	2 = \$2,428
3 = \$3,052	4 = \$3,675
5 = \$4,298	6 = \$4,922
7 = \$5,545	8 = \$6,168

The Hope Dispensary will verify your information onsite and the Social Worker that is present each day they are open will also provide screenings for financial assistance to access 50% discounted up to possibly free healthcare in the Lourdes network. This is great information!!!

Hope Dispensary does not carry all medications. They do cover HIV medication as well as antidepressants. They do not carry any controlled substances or birth control. If they do not have the medication that you need, they have programs developed so that you might qualify for free medication directly from the pharmaceutical corporations. They use medication samples and generic medications. They are located at 477 State Street in Binghamton and their number is 607-584-9376. They are open Monday through Friday from 10AM - 6PM.

New LGBT Information Site Launched

www.asaging.org/larc

The American Society on Aging has created a Lesbian, Gay, Bisexual, and Transgender (LGBT) Aging Resources Clearinghouse that holds information related to and resources for people aged 50 and older. The site's searchable resources span several categories: education and training; health and mental health; housing and support services; populations and communities; and public policy, advocacy, and legal issues. Also available are annotated listings for service providers, community and professional organizations, information sites, reports and articles, and links for ordering DVDs, books, and other useful products.

FREE CELL PHONES CHANGES

There are now two government sponsored program available that can provide you with a free cell phone and 68 free minutes per month. Eligibility is based on your participation in one of several State or government programs like PUBLIC HOUSING, FOOD STAMPS, MEDICAID and more. There is also a limit to the amount of income you receive each month. This program is called LifeLine Assistance and you can find out about it through safelink.com or calling 1-800-378-1684. If you need help with the application process, please call your STAP case manager for assistance. The other program is called Assurance Wireless, which offers 250 per month, but you cannot roll over your minutes per month. Their number is 888-321-5880.

NEWS FROM CANDACE ABOUT EVENTS

I have tickets to the Madrigal Choir, series "Something Old Something New". They are good for one performance of any of the following:

[All's Fair: Songs of Love and War](#)

[Sunday May 22, 2011 -4:00pm](#)

[First Presbyterian Church - 42 Chenango Street Binghamton NY](#)

Candace Phelan/Phone: 607.798.1706 ext. 225

CALL FOR PEOPLE LIVING WITH HIV

When: Southern Tier AIDS Program, Inc. is having a meeting on
May 17, 2011
1:00 PM to 2:30 PM
RSVP May 12, 2011

Where: In the Johnson City Office
122 Baldwin Street
Johnson City NY 13903

What: A meeting of all current Speaker's Bureau participants
and people that want to be future speakers, to tell their story.
Updating the current information
Signing on new Speakers
Training

For more information and for a reservation, call Candace at (607) 798-1706 ext. 225 or 1-800-333-0892

FROM KAREN AT THE MEDICINE SHOPPE PHARMACY

Our article this month centers on the medication Viramune. Viramune (Nevirapine) is an NNRTI (non-nucleoside reverse transcriptase inhibitor). As with most of the other medications we've studied, it must be taken in combination with other anti-HIV drugs to lower viral load and increase CD4 cells. This medication can be taken with or without food and the starting dose is one 200mg tablet once daily for two weeks, then one tablet twice a day thereafter. The reason that we start with only one tablet per day is to reduce the chance of a rash developing. The most serious adverse event seen with Viramune is hepatotoxicity, which can be severe and life-threatening. It is most commonly seen in women with high CD4 counts and its risk is greatest in the first 6 weeks of therapy. Patients should watch for signs of liver toxicity including fatigue, nausea, anorexia, jaundice, tenderness, and rash. Other less serious side effects including diarrhea, headache and fat redistribution have also been observed. Viramune should not be taken with Reyataz or Intelence due to increased risk of toxicity. It should also be avoided with certain antiarrhythmics, antibiotics, antifungal agents, and even over-the-counter Tagamet. Check with your pharmacist if you are taking Viramune and make sure they have your full list of prescription and non-prescription meds.

The manufacturer of Viramune is offering a Co-Pay Savings Card for those of you that are using private insurance. Unfortunately, it cannot be used for your Medicare or Medicaid co-pays.