



ADVOCACY ALERT

June 10, 2009

Hello Everyone ~

It's June, the month that holds the summer solstice. I have always loved the summer because when I was a child everything slowed down. But, as an adult, nothing ever seems to slow down. Why, just when you're gearing up for all that stretching out in the sun and looking for fireflies in the evening, the summer solstice shows up and the days begin to grow shorter again. But, back to "sunnier" thoughts.....the summer solstice, June 22, 2009, is the longest day from sunrise to sunset. I tried to research how many hours of sunshine you would enjoy on the 22nd, but I couldn't read the Gregorian calendar table with universal time, daylight-saving-time and leap-year calculations. However, I did do much better researching some new information about a common practice called "therapeutic substitution". But, first things first.

We're still in the News! In April we made the cover of *Newsweek*. In May, music legend Prince spoke for the first time about his childhood epilepsy in a television interview. Speaking to US talk show host Travis Smiley of "Late Night on PBS", the 50-year-old revealed that he was born with epilepsy and how his parents struggled to cope with his illness. And now, we made it on MSNBC and had "Today Show" coverage. See what happens when we **TALK ABOUT IT** © !

The MSNBC coverage was about "therapeutic substitution" and the roles you, your doctor and your pharmacist make in decisions that affect your health care. It is a lengthy article with lots of information that you can find at www.msnbc.msn.com/id/30627962/ but I will attempt to hit the highlights for you: Some pharmacists legally switch a drug prescribed by a doctor in a common practice called "therapeutic substitution". The new drug is in the same class as the old drug and treats the same condition, but it is not precisely the same medication. This is a common practice that can result in potentially deadly consequences. Your pharmacist can legally switch a drug prescribed by your doctor without telling you or your physician. Usually, pharmacists replace a brand-name drug with a generic formulation of the exact same medication. The new drug is in the same class as the old and treats the same condition, but it's not precisely the same medication.

In one way, at least, patients can benefit from substitution ~ smaller co-pays. But two-thirds of people who reported having medications switched in a National Consumers League survey said they were not consulted. Of those, 40% said the new drug was not as effective and a third said it had more side effects. "It's not okay for your insurance company or pharmacist to change your drugs without your knowledge," says NCL Executive Director Sally Greenberg.

Unfortunately, therapeutic substitution is here to stay. What does this mean to you? What can you do? You need to be on the lookout to make sure you are not harmed by this practice. Here are common reasons you could end up with a less effective drug and the steps you can take to ensure you get the medication to treat your condition properly.

1. If your pharmacy tells you that they "legally" have to make the switch, please know that no state mandates therapeutic substitution, and even out-of-state mail-order houses must comply with the laws in your state. NO STATE says the pharmacy can change your medication without first checking with you first!
2. Get the right drug: If your doctor believes their drug of choice should not be switched for another, ask them to write "Medically necessary", "may not substitute," or "DAW" for "dispense as written" on the prescription. That obligates the pharmacist to check with you and your doctor before making any switches.
3. If a pharmacy tells you the law requires a substitution, find out which substitutions your state allows and challenge the switch with your pharmacist. To get the information to see about your prescription, you can contact the state board of pharmacy at www.nabp.net . (I went to this website and was going to check on the AEP's in the state of Louisiana but there is a fee associated with any searches, so I intend to check with our office in New Orleans and see if they already know which drugs, if any, are on this list. When I find out, I will send that out to everyone.)
4. Pick a pharmacy you like and stick with it. That way your pharmacy will have a long record of your prescription history and know if a drug didn't work for you.
5. Ask your pharmacist to put a blanket statement in your records that you DO NOT want any medications switched unless you and your doctor approve. This is a way to get your pharmacist's attention. The pharmacist is a part of your medical team. They want to know more so they can do a better job advocating for you.
6. The insurance company will often say that if you request "name-brand" when you could have "generic" then they will require higher co-pay or not cover the cost. You can ask your doctor to submit documentation justifying why the insurance company should cover the "name-brand" instead of making a substitution. If the doctor persuades the insurance company that a particular drug is medically necessary, the insurer may cover it after all.
7. Pharmacies make drug switches because profit margins are higher on cheaper substitutes. Pharmacies are directly reimbursed by insurance companies and make more money from generics even though the costs for brand-name drugs are higher. The switch to a cheaper substitute can be motivated purely by profit.

Please know that I am not against "generic" drugs. According to the Congressional Budget, generic drugs save consumers \$8 billion every year. I just want you to be aware of the risk associated with generic drugs. Amy Detrick, a former social worker in Grove City, Ohio waited months while her doctors fine-tuned the precise cocktail of medication to keep her from having seizures. When her condition was finally under control, she filled a prescription for Tegretol and shortly afterward had a seizure while riding her bicycle. She fell, broke her leg and had a hairline fracture in her left eye socket. While in the hospital being treated for her injuries, her doctors noticed that the blood level of her medication had declined. Her pharmacist had exchanged her Tegretol for a generic that had worked a little differently. "Just imagine what could have happened had I been behind the wheel of my car," she says.

I'm sorry this month's note is so wordy, but there is still so much to disclose on this subject. Please let me know if you have had an experience with your/or your loved one's medication being switched without your consent. If so, how did you address the switch with your pharmacist or your doctor? Do you take a generic AEP? If so, how is it working for you? Would you like to be contacted about your experience? Would you be willing to speak to, write to or make telephone calls to legislatures concerning your experience? Would you be willing to let us document your experience for data only? If so, please contact me at amy@epilepsylouisiana.org .

Wow, that was a lot of questions! Hopefully, I'll get some responses. But for now, get up.....stretch your legs..... and walk around in the sunshine.....

Until next month,

Sincerely,

Amy Nichols

*Great is the sun, and wide he goes – Through empty heaven without repose;
And in the blue and glowing days – More thick than rain he showers his rays.....
~Robert Lewis Stevenson~*