



Top Questions and Answers from NPF's "Ask the Doctor" Forum

Before you leave for summer vacation, make sure you visit the new and improved free online forum at www.parkinson.org. Login from the top right-hand corner of the home page and ask the National Parkinson Foundation doctors, surgeons, nutritionist, pharmacist and speech clinician your most pressing questions about Parkinson's disease. There are also open forums which allow caregivers and people living with young-onset Parkinson's disease to connect with others in the community. The following questions and answers from the forum all pertain to recent items in the news: removal of the Neupro patch from the U.S. market, dopamine agonist withdrawal symptoms, increasing uric acid levels in the blood as a PD treatment, and chewing gum to improve swallowing.

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Q What is the update on the Neupro (Rotigotine) dopamine agonist patch?

A Many patients with Parkinson's disease reported the patch concept to be desirable. The patch enhanced quality of life by reducing the need for continuous re-dosing of medications throughout the day. Although there are many dopamine agonist pill formulations available, many patients were extremely disappointed when the patch left the market. The patch issue that precipitated removal from pharmacies in the United States was an observed "crystallization" of the medication into what appeared to be "snowflakes" which appeared on the exterior surface of the patch. After scientific review, it was discovered that storage in a refrigerated environment was a potential solution. The patch underwent review by the FDA this spring, and a panel determined that to be re-approved, the drug would require reformulation. This reformulation process could take as long as a year or two (the patch is still available in Europe). In the meantime for those patients with Parkinson's disease who continue to wait for the patch, please see your doctor to discuss alternative strategies with the many tablet form medications.

Q What are dopamine agonist withdrawal symptoms (D.A.W.S.), and should I be worried about them?

A The team of Dr. Rabinak and Dr. Nirenberg coined the term D.A.W.S., reported in a recent article in the *Archives of Neurology*, which stands for dopamine agonist withdrawal symptoms. The doctors closely examined 26 Parkinson's disease patients who had their dopamine

agonist therapy tapered off or stopped for a variety of reasons. They identified in select patients a "severe, stereotyped cluster of physical and psychological symptoms that correlated with withdrawal in a dose-dependent manner, and this caused clinically significant distress or social/occupational dysfunction." It is important to note that only 19% of those who tapered off of dopamine agonists developed symptoms, and all of the patients with symptoms had some sort of impulse-control disorder prior to initiation of dopamine agonist therapy (compulsive gambling, shopping, etc.). The authors noted that "symptoms of D.A.W.S. resembled those of other drug withdrawal syndromes and they included anxiety, panic attacks, agoraphobia (fear of going out in public), depression, dysphoria (sadness), diaphoresis (sweating), fatigue, pain, orthostatic hypotension (dizziness when standing), and drug cravings." Parkinson's disease patients need to be aware of the potential for these symptoms to emerge if for any reason they are taken off of dopamine agonist therapy (leg swelling, dizziness, nausea, behavioral impulse control problem, etc.). If the dopamine agonist is taken away, patients and their physicians should be ready to address the potential withdrawal symptoms.

Q What do I need to know about uric acid, gout and Parkinson's disease?

A There has been a relatively recent observation that the levels of a marker in the blood called uric acid may be associated with the risk of developing Parkinson's disease. Uric acid is thought to function as an antioxidant, and

this effect may in some way decrease the risk of Parkinson's disease, or alternatively delay its appearance. When uric acid levels are high, people may develop angry, red, inflamed joints, and be diagnosed by their primary doctors with a disease referred to as gout. There is now an interest in examining whether increasing uric acid levels in the blood of patients with Parkinson's disease may be a useful treatment, and may even lessen decline. Massachusetts General Hospital has been leading an effort to study this effect in a well-designed clinical trial. Investigators have set out to study inosine, a nutritional supplement which raises urate levels in the blood (Schwarzchild and Ascherio). Parkinson's disease patients need to be aware that the safety of inosine needs to be established (make sure there are not side effects including the development of gout). It is best if patients either enroll in a clinical trial, or wait for the results of studies before trying to initiate treatment.

Q Does chewing gum really help swallowing in Parkinson's disease?

A A recent paper in the journal *Neurology* reminded us that the simple things in life can sometimes make a difference (South, Somers and Job). The study was based on the fact that Parkinson's disease patients have less frequent swallows, and that gum chewing may improve swallow

frequency. Twenty Parkinson's disease patients participated in this pilot study, which revealed that swallowing was indeed improved, and that this technique could in future studies prove to be a potentially effective management tool. Caution should be exercised as the

patients were only studied before and after five minutes of gum chewing, so longer term studies are needed. Patients included in their study also did not have severe swallowing problems, so this may or may not



benefit a more severely affected group. If Parkinson's disease patients decide to use this trick to decrease saliva/drooling or to improve their swallow, they should be careful to use sugar-free gum and to consult their dentist for advice on strategies for appropriate dental health. Also of note, many patients at the University of Florida have reported that gum chewing is an effective way to combat mild to moderate drooling.

The information published in this "Ask the Doctor" Forum is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Accordingly, please consult your own professional for all advice concerning medical, legal, or other matters published in connection with this Forum. NPF assumes no liability of any kind for the content of any information transmitted to or received by any individual or entity in connection with their use of the "Ask the Doctor" Forum on the NPF website, and NPF does not endorse or recommend any such information.

Quality Improvement Research Initiative Expanding to 17 Centers

After a successful pilot, NPF's Quality Improvement Research Initiative has expanded to 17 of our Centers of Excellence including the 6 centers from Phase I; 9 additional centers in the United States (Baylor College of Medicine, Beth Israel Deaconess, Johns Hopkins, Medical College of Georgia, Mt. Sinai, Muhammad Ali Parkinson Center, Parkinson's Institute, University of South Florida, University of Kansas); and 2 international centers in Israel and the Netherlands.

With over 2,200 patients in the registry, making it the largest clinical PD database, the data is now beginning to tell a story, showing how neurologists adopt various strategies to attack PD. Over the next year, NPF will be

identifying and adopting care quality initiatives and measuring their adoption through this initiative.

To date, the registry has shown that each center has very different approaches to care; for example, one may prescribe medication only, while others may combine medication with counseling. As we collect data, we will be able to say definitively whether one approach is better for patients or another, or if they are all equally good. As we establish these findings, we will publish them and promote them to ensure that these best practices are available to improve care for everyone, whether seen at a top movement disorders center or in primary care in the community.