

## *Moose Notes 2011 (Highlights of the Year)*

**Jean** started the year on a good note: by starting a **new job**. She's working at Brookside Gardens in the adult education department. She loves it – being around plants and beautiful, well-kept gardens, working with knowledgeable people, and with a low-key boss that she gets along with well. It's also motivated her to do more on her own garden.



Jean and I hike nearly every week, although I was out of commission in May and June with a bum leg.

I've had an exciting year: **I started a non-profit organization, [Circadian Sleep Disorders Network](#).**

As many of you know, I've suffered all my adult life with Delayed Sleep Phase Disorder (DSPD, also known as Delayed Sleep Phase Syndrome, DSPS). This is a neurological disorder in which the body's clock is delayed relative to the external day/night cycle. The result is an inability to fall asleep until the wee hours, and a corresponding difficulty getting up until late in the day.

For the past ten years I've participated in an email list, with a few hundred other people who also suffer from DSPD, or the even more debilitating Non-24-Hour Sleep-Wake Disorder (Non-24). Last May I attended an NIH meeting of a committee developing a sleep research plan. There I met two other people from our email list, and became aware again of the need for a national organization to represent us, to promote awareness of our condition, to obtain accommodations at work and school, to provide support for people with these disorders, and to encourage research. We had discussed this on the list before, but it hadn't gone anywhere. So I decided that, since I was now retired and had some free time, I was in a good position to get this going.

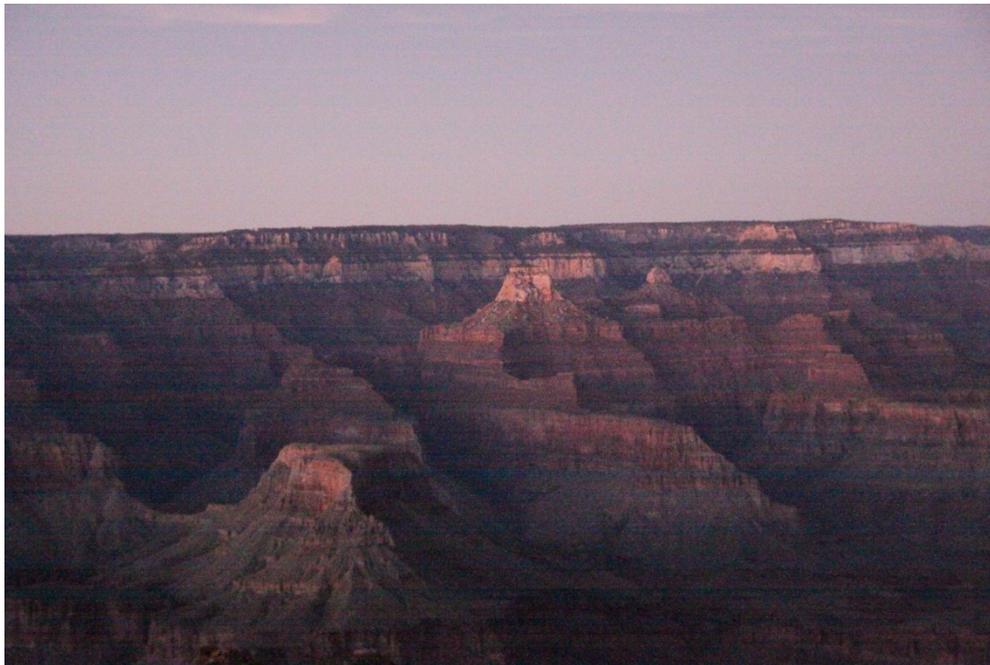
I contacted other people whom I had known on the email list, and we assembled a board of directors and an advisory panel. We incorporated in August as the *Circadian Sleep Disorders Network*. That name was chosen in order to include both DSPD and Non-24. I studied some books on organizing a non-profit, and set up a web site at [www.circadiansleepdisorders.org](http://www.circadiansleepdisorders.org), with the shortcut [csd-n.org](http://csd-n.org). It includes content from others as well as myself, and we still want to add a lot more content. I modified



standard bylaws to account for our unique situation: our board members are not all awake at the same time. So our board discussions are now conducted via internet forum.

We recently added more people to the board, and elected officers: I've been elected president. We are now discussing dues and benefits for memberships, and expect to open the organization to members shortly. We also plan to apply for IRS 501(c)(3) tax-exempt status. I had hoped things would move more quickly, but there was a lot to do behind the scenes, and all the interaction has to be done via email or forum.

In October I attended the Narcolepsy Network conference. The Narcolepsy Network is another organization advocating for a sleep disorder, with many of the same goals as ours, so I wanted to learn how they organized and how they went about pursuing those goals. As long as I was in Las Vegas, I took a few days on my own to hike in the Grand Canyon. A photo from that trip is on this year's holiday card, and another, taken just after sunset, appears below.



The most recent news from Jean's family is that her younger daughter got engaged, and will be married in January.

*Have a happy holiday season!*