

Hi, I'm Robyn Lynn Snyder. I woke up with NDPH on 6/25/13. I was in grad school at the time and didn't have time for this. I was mostly bedridden with pain for the first several years. I wanted to find the cause, treat it, and get my life back. As we all do. About four years into this I got extremely frustrated over what was not available for us. While venting my anger to my husband I decided to do what I could to help the NDPH community and started one of the online support groups and had planned on doing a nonprofit concurrently as well. The nonprofit dropped to the wayside when my brother died, but we kept the support group going with the help of our moderators while I took time off to grieve. I'd like to thank Alan for picking up the mantle I dropped and continuing on to further research into our rare neurological condition.

I hate the pain, but absolutely love our community. I've met some of the most amazing people out of this. That aspect of this illness has kept me going and continues to do so.

I want to share some of the experiences from my own life that led to me starting the group, becoming active in the community, and what I try to do for our community.

First off, I was no stranger to chronic pain. My mom had breast cancer that metastasized to the bone and she lived in chronic pain. She was the strongest person I've ever met. When I first developed this, I was overwhelmed with thoughts that my mom would be ashamed of how horribly I'm handling my own illness. None of that's true, my mom would be the most understanding and extremely proud at what I've accomplished while sick. She would be telling everyone about the work I've put into helping members of our community while the community helps me just as much.

The second greatest influence in running the group was having several childhood friends who were disabled. Seeing them and their families adjust to meet their needs so they could live full lives had a big impact on my young life. One of my friends needed repeated surgeries and his grandmother would try to ensure that he missed as little school as possible. She would come to class while he recovered and would make games out of his rehab exercises. She would sometimes have his classmates help or set us in a circle and have us cheer him on when as she worked to get him stronger. I can still remember him laughing and us cheering him on. It was such an extraordinary way for her to handle the situation and they taught me a lot about perseverance.

The primary goal for the group has been to address as many needs of the community as we can. I've learned coping tools from our members and share them around. I also try and innovate new ideas to address our needs. We openly discuss our struggles and work to find ways of becoming more functional and live our lives to the best of our abilities. A lot of us have lost the ability to do things we used to do with ease and I encourage everyone to grieve what you've lost while striving to move forward and enjoy what you still can do.

I wasn't able to finish grad school and I'm okay with that now. Looking back, I'm not certain I would have been happy working in that field. I've taken up painting to help replace the hobbies I can no longer do and I love it. I'm currently trying to become stronger and learning how to become more highly functional with the intent of going back to school to become a therapist. I want to specialize in working with chronic pain patients. I'm not there yet, but I am working on it.