

Hi, I'm 17, and I'm part of the PR-COIN Patient Advisory Group. The children are not just your patients, they are also a key resource in assisting you to find the best possible patient care and treatments. We know all about the everyday aches and pains, and we also know what it feels like to be in a full flare. We know what it's like to have five different appointments in five different departments in one week, sometimes even more than one per day. We live with this disease every day, and we try hard to find ways to rise above it.

For patients, this is about far more than just enduring the pain; far more than having to learn to accept missed opportunities due to illness; far more than having to spend more time with medical staff than with friends or even family on some days. It IS about working together to try to figure out what interventions might successfully help each of us reach remission. And once we have found the answer, we will take the world on by storm, because, as you know, we don't like to be held back from what we want to do!

The interesting thing about PR-COIN is that every child involved is at a different point in their life, and in their phase of illness. We have children just entering elementary school, leaping into middle school, nervously starting high school, and kids like me that are graduating this year and starting college, and making plans that will likely affect the rest of our lives. Each patient's focus and treatment goals are varied. For example, a smaller child might simply wish to be able to play at recess the whole time and not regret it the next day. A high-school-aged patient might want to be able to play with his or her full level of ability in "the big game", and a young adult might worry about finding a university that is not too far away from the family, friends, and the medical staff who offer them support in so many different ways. Each one of us is a uniquely different person, with different needs, and different goals. But there is one major goal that we all have in common, and that is to find a treatment that will get us one step closer to remission.

In order to do that, we have to work together, not continue on individually. We can't remain strangers. We have to get to know each other. The patient group is still very young, but its members are strong-minded, ambitious, and they truly want to make the rheumatology world better for future patients. We share our experiences, and are creating new friendships. We are taking the steps to get to know one another. Truly, everyone in this room is taking the first step in the process simply by sharing their data, and their stories.

Now, I want you to imagine how beneficial it could be if we were able to take in even more members, and actually collected data and stories from people who live in other areas, as well as our own. It would be interesting to find out what treatment therapies have worked for them, what things did not work for them, and it could even help us to assess how specific situations may have somehow been handled in a better way, for better overall outcomes.

What if we no longer remained strangers to each other, and instead, we all came together as a family to support each other, and to assist the medical team as they work to find a successful treatment path for each of us? Yes, we are each very different, and very unique, yet, we are all essentially reaching out for the same thing. Let's work together!