



Dear prospective PR-COIN site:

Greetings from PR-COIN's Parent Working Group (PWG). We are represent parents from all PR- COIN member hospitals and are thrilled that you are considering membership in the collaborative. This letter offers some encouragement from the perspective of patients and their families.

First, here's a little more about the PWG and what we do. Each PR-COIN site nominates one or two parents to be representatives to the network and actively participate in co-production. We meet via phone and webinar once a month, plus attend the monthly Action Period Calls when we're able. We are instrumental in helping to plan the semiannual Learning Sessions and present there alongside providers. We work with the PR-COIN Coordinating Center staff and providers on various projects for the network. Several PWG members serve on PR-COIN's subcommittees, such as Research and Informatics. At the invitation of our sites, many of us attend and contribute to regular quality improvement meetings with our local team. Also at the local level, some have had the opportunity to help begin parent groups, the goals of which are support both families and our pediatric rheumatology departments.

One of the chief reasons we want to be involved with PR-COIN is that we clearly see the value of working within a co-production model as a way to maximize resources. Ultimately, parents and providers are working toward the same goal of giving our JIA kids the best life possible, so it makes sense to join forces. We recognize that these ideas represent a huge paradigm shift for many providers, but those that have "taken the leap," so to speak, have found that their efforts are enhanced by parent participation.

When a site becomes a part of the PR-COIN network and patients' families learn what that means, it tends to increase the families' confidence in their pediatric rheumatology department. The idea that their children's doctors are a part of this collaborative which is working toward the common goal of better disease management can be incredibly reassuring. In addition, it is encouraging and empowering as a caregiver to know that your child's provider sees you as a partner, a part of the team. One parent articulately sums up how we all feel by saying this: "I am proud that my site is a member of PR-COIN. It shows my site is willing to take the extra step in their commitment to improve the quality of life for my child and the other children. Their membership demonstrates how they value the patient and family perspective and how this connection can lead to greater and more meaningful improvements. Knowing that my site is collaborating with other well-known and highly regarded sites gives me, as a parent, more confidence that my site is providing the most optimal treatment to attain the best outcomes for all patients."

We in the PWG count it a privilege to be included in this incredible venture, and do not take lightly our role in co-production. It is energizing and exciting to be collaborators in the quest to improve best practices and outcomes for children who have JIA; we hope that you will feel the same way and throw your hats in this ring with us! In closing, here are some words of encouragement from PWG members:

"Imagine if all kids with JIA had the same level of care and remission success rates as the best hospital in the world – PR-COIN can make that happen."

"PR-COIN membership may involve some extra effort, but the results outweigh the time in that it offers a more collaborative and patient-centered approach to improving care."





“PR-COIN membership provides the tools and resources to help you on your journey of quality improvement, but the real value comes from learning and leveraging the great ideas from others who are on the same journey!”

Thank you for taking the time to read this letter. If we in the Parent Working group can be of further assistance to you and your team as you consider membership in PR-COIN, please do not hesitate to contact us at Prcoinparents@gmail.com. We look forward to working with your team!

