



## Parent Working Group

### Introduction

We would like to extend a warm welcome to you from the Parent Working Group (PWG); a subcommittee of the PR-COIN Collaborative. We are pleased you have expressed interest in joining our group as we work to help improve the outcomes for children with JIA. We hope that you are as excited about this opportunity as we are and that you find all of the information you need to make your decision in this introduction.

By now, you probably already know that PR-COIN stands for the Pediatric Rheumatology Care and Outcomes Improvement Network, a group of pediatric rheumatology clinics teaming up to improve care for children with juvenile idiopathic arthritis (JIA). PR-COIN's mission is to dramatically improve the outcomes of care for children with rheumatic conditions. While drugs and treatments for JIA have gotten better over the years, doctors still need to know more about which methods work best. By sharing information and best practices, PR-COIN clinics can find better ways to reduce pain, improve how well joints work, increase children's ability to play, get better treatment results, and so much more. Additional information and resources are available at [www.pr-coin.org](http://www.pr-coin.org). If you are not already familiar with PR-COIN, please take ten minutes to watch this Prezi (<http://bit.ly/prcoinprezi>) created by one of our parent representatives.

The Parent Working Group (PWG) is a subcommittee of PR-COIN comprised of one or two parent representatives from each PR-COIN member center. Formally, the PWG is charged with supporting the development of family focused activities and initiatives, informing PR-COIN with a variety of patient and parent perspectives, actively contributing to PR-COIN's mission and initiatives, advocating PR-COIN membership to parents engaged with non-member centers, and endorsing PR-COIN to other organizations.

Participation takes an estimated fifteen minutes per week on emails and 1 to 1 ½ hrs per month on the monthly PWG call. The time and day for the monthly call changes annually based upon PWG member feedback. It is currently held the second Monday of each month at 8:30 PM Eastern.

Additional time would be required if you choose to attend the Action Period Calls, participate in other PR-COIN subcommittees, participate in PR-COIN projects, or prepare and attend presentations for the Learning Sessions. PR-COIN has monthly Action Period Calls (APCs) to provide updates and information about new projects. These calls last an hour and occur during



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the work day. It is not a requirement that you attend these calls, but we do encourage parents to try to attend. The APCs provide a lot of information, and it's great to see how the measurements they track are progressing. Parents are also welcomed on the Data, Informatics, and Research subcommittees of PR-COIN. If you choose to participate in one of these subcommittees, the meetings are during the work day once a month for an hour. Finally, PR-COIN has Learning Sessions twice a year, typically in May and October in Cincinnati, OH. It's a two-day conference where the teams come together to discuss new projects, data, grants, and share updates on their goal progress. PWG members are invited to not only attend the conference but to also present in various sessions at the conference. If you attend a conference, there would obviously be the additional time commitment of traveling and attending the two days of sessions. Plus, there would be additional time required in the month leading up to the conference to work on the presentation(s).

PWG members also contribute to projects at their local centers. The amount of time required for these activities vary by center as some teams are more receptive to parent involvement than others.

PR-COIN is an amazing network. Being a PR-COIN parent representative is an exciting opportunity. It does require a time commitment, but it is wonderful knowing that you are helping to improve the outcomes for children with JIA. If you want to be a parent representative but are unavailable at the time of the PWG calls or unable to make the time commitments, there is an option to have a second parent representative for your site. The two parent representatives would work together, but at least one parent representative for each site is required to attend the call each month.

We hope this information helps with your decision to join our group. If you have any questions that we have not answered, please reach out to us at [prcoinparents@gmail.com](mailto:prcoinparents@gmail.com).

Sincerely,

The PR-COIN Parent Working Group representatives