



NEWSLETTER

A **B**IOlogic drug safety and effectiveness inter**N**ational pharmacoepidemiologic **I**C study in pregnant women with autoimmune disorders or asthma and their children (BIONIC).



Newsflash

Patient Partner Meetings

Patient Partner Discussion Circles taking place in January 2025

Study Findings

Our team recently undertook a study on patient partner engagement methods. See **results highlights on page 2**.

Funding

While we were not successful in our last funding submissions, **BIONIC received high scores by reviewers, and we plan to resubmit** in February 2025.

BIONIC OBJECTIVES

In women with AD or asthma, who continue versus discontinue biologic use in pregnancy, compare the risks of:

- 1) Maternal complications in, and worsening of disease during, pregnancy.
- 2) Complications in their infants and children.

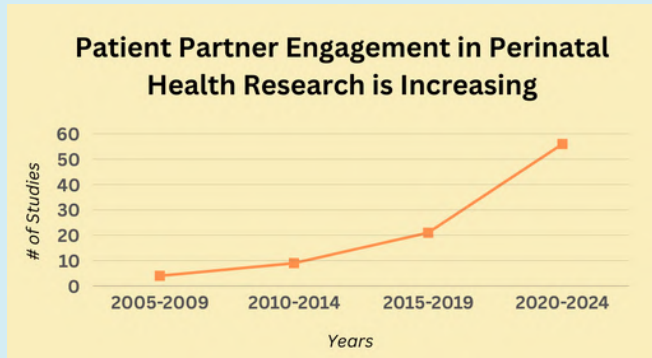


We hope you and your loved ones enjoyed a restful holiday season.
All the best for 2025!!

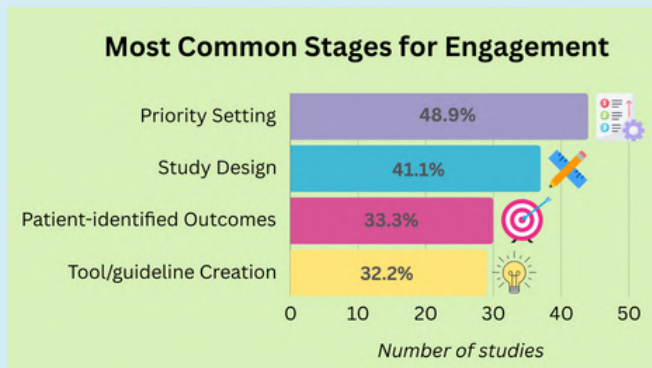
RESEARCH STUDY FINDINGS

Patients as Partners in Perinatal Health Research: A Scoping Review

Lucy Zhao, medical student in Dr. Sonia Grandi's lab, recently conducted a scoping review to examine how patient partners are engaged in perinatal health research, and the results are in!



Graph 1 shows the trends of patient engagement in perinatal health research over time.



Graph 2 shows the stages of a research study in which patients were most commonly engaged.

Standardized reporting of patient partner engagement is lacking

Using GRIPP2, an international tool for reporting patient and public involvement in health and social care research, can increase effectiveness of patient partner engagement.

Interested in our other studies?

See results from Dr. Grandi's study on [Patterns of Aspirin Use for Preeclampsia \(PE\) Prevention](#). We conducted a Town Hall discussion with PE survivors to gain feedback on study results.

25 studies reported challenges to keeping patient partners engaged



Challenges related to engagement after enrollment due to loss to follow up are common in health research. However, our study also highlighted *unique* challenges to keeping patients engaged in the perinatal health context, as outlined below:



Benefits seen by patient partners included **feeling empowered**, knowing they can **help someone else**, and a **cathartic experience** from being heard

Recommended articles which were included in the scoping review: [Chambers et al.](#), [Mackintosh et al.](#)



Graphic recording of the town hall discussion

Meet Natalie (Sparacio) Hayde

BIONIC Patient Partner Spotlight



Access blog:
[Lights, Camera, Crohn's](#)

Natalie is a former TV news anchor and reporter whose mission in life is to advocate for those battling inflammatory bowel disease. She was diagnosed with Crohn's disease in July 2005, two months after graduating from Marquette University. Her award-winning blog, *Lights, Camera, Crohn's*, which launched in July 2016, spans more than 400 articles and covers everything from overcoming struggles to celebrating small victories throughout all parts of the patient journey from diagnosis and beyond.

Along with her blog, Natalie is part of the Patient Advisory Board for IBD Moms and IBD Social Circle (#IBDSC), on the Patient Engagement Research Council for Janssen Pharmaceutical, and serves on the Patient Leadership Council for the Social Health Network. She's also a patient advisor for the PIANO (Pregnancy Inflammatory Bowel Disease and Neonatal Outcomes research project), and a contributor to Everyday Health.

Natalie was selected as the IBD Research Insider and Patient Reporter for the Crohn's and Colitis Congress happening in February 2025. She is also an active volunteer and spokesperson for the Mid-American chapter of the Foundation, she emceed the Chapter Gala in November for the third year in a row. She was chosen to be a Social Media Ambassador for the Crohn's and Colitis Foundation this fall.

Natalie has been featured by Women's Health Magazine, CBS This Morning, Wall Street Journal, Prevention Magazine, Self Magazine, The Mighty, and on several podcasts. Natalie was honored with the Social Health Award's Community Cultivator Award in 2022 and was recently the October Cover Story for Health Monitor Magazine.

She was the U.S. Patient Ambassador for the first-ever Global Consensus Conference for Pregnancy and IBD and spoke as a panelist for the FDA regarding safety of biologics and small molecules in pregnancy. She is also a part of the Patient Partner Advisory Committee for the BIONIC study which aims to explore the use of biological medications in pregnant women with autoimmune disorders or asthma, and their potential impact on both maternal and infant health outcomes. As an IBD mom of three children, Natalie hopes her story can comfort, educate, and inspire fellow patients and caregivers.

Share Your Thoughts

Let us know what you think of the January BIONIC Newsletter, or tell us what you would like to hear about in the next edition [here](#).

How to get in touch with us

Sonia Grandi, (PI): sonia.grandi@sickkids.ca

Cristina Longo, (PI): cristina.longo.1@umontreal.ca

Yanara Marks, patient partner engagement:

yanara.marks@sickkids.ca or call 416-813-7654 Ext. 309361

