

# What makes it a Peanut Butter & Jam Sandwich?

Both sides together = Always Together!

Always Together Care: Families on their own do amazing things. Health Care Providers on their own also do amazing things but it isn't OPTIMAL NICU Care\* until both sides are put together (just like a piece of bread with PB or J isn't a sandwich, until it is put together).

## Background:

The IWK NICU Parent Partner Program began in 2013. It was visioned and created by two NICU moms and two NICU Social Workers. Since then, the program has oriented 37 volunteers (all NICU parents), has created a comprehensive psychosocial support network for current NICU families and volunteers, has active connections with over 300 NICU families who have been discharged, offered consultations to programs across the country and in various units, presented internationally & has collaborated on various research projects. Our volunteers are in the unit, on interview panels, on committees, involved in research projects, host online and in-person events and support groups; all within the safety of an Always Together (PB & J) model. How did we create safe and healthy engagement? The tenets of Always Together Care are foundational to our Parent Partner Program and are currently being employed more widely throughout the NICU...As you read our recipe, highlighting a few of our values, consider how this could be more broadly applied across our healthcare system!

### Skip pre-meetings

I know, it's tough. You want to be prepared. It is SO tempting to pre-plan before families are invited in. RESIST THE URGE! To authentically partner with families, means putting on the brakes until everyone is present. For our Parent Partner Program, it meant beginning from the ground level. All brainstorming, all pioneering was with Social Workers and families together from the start.

In NICU, this kind of Always Together (PB & J) Care, looks like inviting families to the table or being invited to the table by families to collaborate on ALL aspects of the plan of care.

### Rethinking Schedules

For our Program, this meant being flexible and colouring outside of the lines. When we were having meetings, potty training was also happening ("can I put you on speaker phone while baby runs to the potty?"). It took patience, persistence and creativity. It took genuine respect for the expertise that each of us brought to the table. It took evening meetings, tears, loooong explanations and compromise.

In NICU this looks like collaborating on scheduling all forms of care, not dictating the timing. It looks like a shift from "educating parents" to being willing to learn from and with each other.

### Slowing it all down

NEC, ROP, AOP, SGA....WTF??? In order for volunteers to have an equal voice at the table, the pace needs to be slowed down. We found on committees especially, we needed a Health Care Provider there who would ensure that context was given to our volunteers and the hospital-ese could be interpreted.

Did it slow down our meetings? **BIGTIME.** Did it allow families to contribute in a meaningful way? **BIGTIME.**

In NICU, this looks like changing what rounds looks like. This looks like instead of asking, "Why aren't parents...(fill in the blank)? To now asking, "What do we need to change as a team to invite families to...?"

### Being Trauma Responsive

NICU changes families. It doesn't end at discharge. It lives on in our thoughts and hearts for a very long time. We offer our volunteers a pre-brief and a debrief every time they volunteer. We walk with them in their ongoing medical journeys with their children. We give space to laugh together, cry together and be together.

In NICU, this looks like following family's unique preferences, meeting a family where they're at, having open conversations and supporting the family's way of being.



IWK Health



For more conversation,  
connect with us!

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\*There are many studies that conclude that partnership between patients and families is "optimal care" however, there is no consistent definition of partnership. Additional research pending.