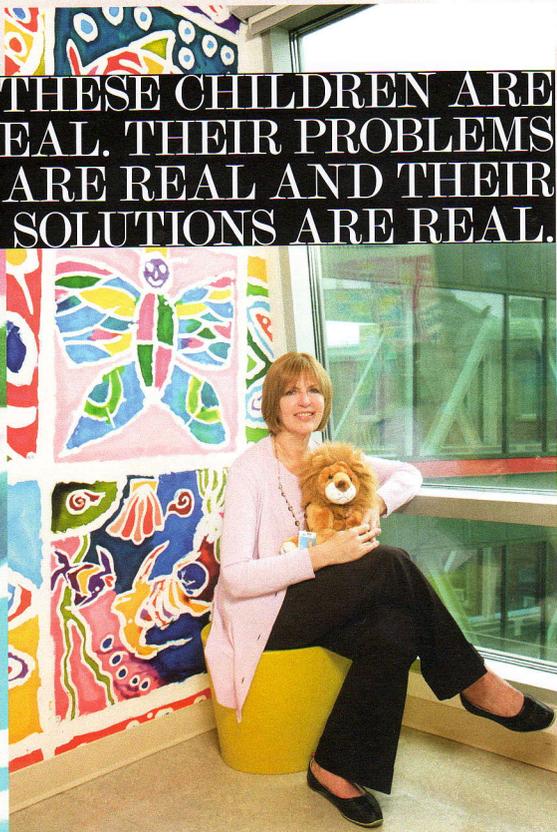


# HELPING

THESE CHILDREN ARE REAL. THEIR PROBLEMS ARE REAL AND THEIR SOLUTIONS ARE REAL.



## The Ontario Parents Association for Children with Cancer (OPACC)

**LAUGHTER BOUNCES** off the colourful, hand-painted motif covering the window-lined walls. On pint-sized furniture sits a small group of children. Their little hands eagerly roll out the brightly pigmented Play-doh, moulding and contorting it into various shapes.

At first glance, you wouldn't guess that this open and inviting space is the clinic in the oncology section of Toronto's Hospital for Sick Children. It's only upon further inspection that you begin to observe the stream of doctors and nurses moving through the hallways, and the engaged smiles of the child life specialists, equipped in matching purple shirts.

Off to the side stands a long wooden booth filled with brochures and pamphlets. This high-trafficked station is the responsibility of Susan Kuczynski, the parent liaison for the Ontario Parents Association for Children with Cancer (OPACC).

Although Susan has an in-depth background in healthcare, her role here at the oncology clinic is strictly non-medical. As a parent liaison, she helps provide a voice for families and serves as a source of support; assisting them in identifying members of their healthcare team and ensuring that they are aware of the resources available to them in Ontario. However, what truly makes Susan's role so invaluable and rare is that she is privy to an inside knowledge base not commonly shared among hospital staff.

Susan has been here before—when her own daughter was a patient.

At 10, Susan's daughter was diagnosed with renal cell carcinoma. As her daughter welcomes her 27th birthday, Susan now helps walk other families down the long and tumultuous road she once traveled herself, providing crucial support to families in their greatest time of need.

"When my daughter was diagnosed, I wasn't as uncomfortable as some parents were, and I realized early on that families need to feel a bit of empowerment," says Susan.

It was clear then that there was a distinct need for the development of a role like this at SickKids. With the support of her daughter's oncologist, Susan traveled throughout the States and spoke with various centres that had initiated a parent advocate role. Working closely with the hospital, she helped establish a program doing just that, and within the past few years, it has received the vital funding it needs.

From day to day, the parents of a child stricken with cancer can teeter on a fine edge, as the diagnosis places an unquestionably heavy emotional and financial weight on a family. It doesn't just impact the individual; it also affects the family in entirety and the consequences of that can be everlasting.

"A lot of times, at least one parent loses their job, so you have single income parents who didn't intend to be single income parents. You have parents who are coming from far distances and need a place to stay. The financial impact on families is huge and takes years to recover."

OPACC works diligently to create opportunities for activities and events, aimed to help keep families connected at no incurred expense; providing activities such as picnics, fairs, and children's camps that can be enjoyed together. As Susan explains, "I know it sounds sort of weird, 'Oh I found this great picnic,' but being able to offer families the opportunity to be a family at no cost, being able to help them find the resources that they might need to be able to build themselves up, is really important."

However, what is truly rewarding for Susan is the knowledge that she has helped a family—perhaps with an action as simple as giving a parent a health planner to keep track of her child's medical records, or as personal as being a shoulder on which to lean on a difficult day—and seeing that sense of relief wash over them.

"I feel it's a privilege every day when people talk to me and share their story with me or ask me questions, because I know how hard and vulnerable every one of us is. There isn't a parent I have met that has said, 'No, I know I didn't do anything wrong. I know it wasn't my fault.' Every single parent, everyone I have ever met, in some way feels responsible."

OPACC offers that unique understanding and support that can only come from a parent who has had a child with cancer. Perhaps most importantly, it offers families in their darkest hours the simple knowledge that there is someone there, wanting, waiting, and available to help them.