

In insensitive Comments and Their Impact on Premie Mothers

An Inspire Premie Support Community Special Report

Introduction

By Brian Loew

We're pleased to bring you a report on the Inspire Premie Support Community survey, "Insensitive Comments and Their Impact on Premie Mothers."

"Parents of premies need compassion, not judgment," is how one mother put it. Another noted, "I hate it when people tell me, 'He had such a rough start,' or a 'rough life.' It makes me feel like it's my fault for giving him that "rough start."

The survey shows that mothers regularly face comments that upset them, but we also saw a number of encouraging findings and comments as well. Some mothers noted that the inappropriate comments diminished as they and their spouses educated their relatives and friends about the health realities of premies.



We hope that this survey sheds light on this important topic, which we see discussed regularly by community members. Thanks to all who completed the survey, and thanks for being part of such a vibrant and supportive [online community](#).

Special thanks to community moderator Deb Discenza, to blogger Jessi Bennion, and also to Keira Sorrells of the National Alliance of Premie Parents, who helped create this survey, and who wrote an excellent essay for this report, on [page 10](#). Lastly, we appreciate the contributions of Dr. Richard Shaw of Stanford University's Division of Child Psychiatry, who lent his expertise to this topic in the afterword, on [page 18](#).

A handwritten signature in black ink, appearing to read "Brian Loew".

Brian Loew
CEO
Inspire
brian@inspire.com

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Foreword

By Deb Discenza, Moderator, Inspire Premie Support Community
Author, The Premie Parent's Survival Guide to the NICU

Parent of premies are isolated in many ways. The birth, the NICU stay and even the homecoming set families up for long-term isolation.

The public, not understanding this scenario, is left to devise assumptions about the family's actions regarding the child. This further isolates the parents, breeding a sense of mistrust and ongoing isolation which has severe consequences on the health of the parents that is both physical and mental. Not having a strong support system can create issues of Post-Traumatic Stress Disorder, Postpartum Depression and more.

The public needs to be aware of not just the expenses of a premature baby being born and staying in the NICU but also the escalating costs that will come from as that child grows up. With this in mind, the extreme stress placed on the babies and their families will be felt for life unless they have support. The costs are physical, psychological and developmental on the baby's side of things but the parents' health, well being as well as their relationship is at high-risk for suffering irreparable damage.



What one preemie mom wrote in the survey underscores the stress that preemie regularly parents feel: “Relatives were giddy and happy and trying to do all of these ‘normal baby’ things like showing him around to all of their friends, and I just wanted to keep him home so he wouldn’t die.” The mother wants to celebrate the moment and yet feels a pull to alternately be polite to her relatives. But in reality she only wanted to keep her fragile son close to her. Giving the public a sense of the world of these families, from the tiniest of preemies to one just a few weeks early, will do a lot to educate the public as a whole.

This type of isolation creates a void for preemie parents so that when they encounter one another there is often an instant bond. Hence you could say that groups like our community on Inspire fulfill a special need for this community, creating a link between these families that more than likely have never met in person.

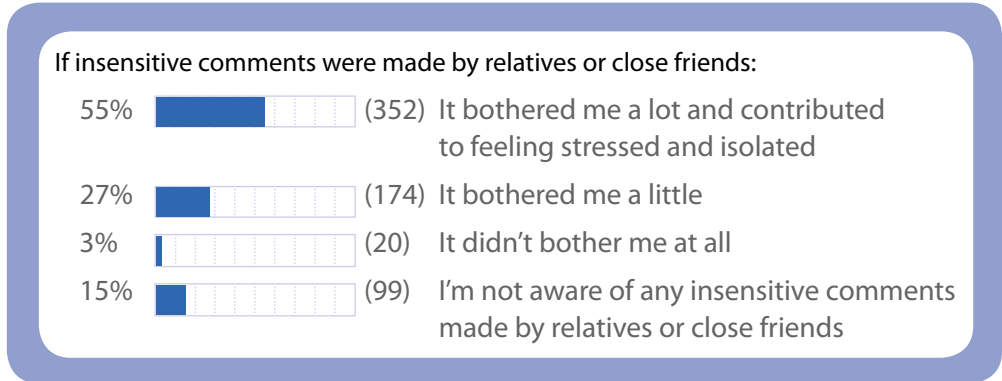
Key Findings at a Glance

- Over 630 completed online responses from mothers of preemies.
- Insensitive comments made by relatives or close friends resulted in stress and isolation in about 55% (350 respondents) of the mothers.
- About 20% (130) said insensitive comments resulted in lost relationships with one or several people who were “very important” to them.
- More than 40% of respondents said that more often than not they heard people tell them that the babies “are fine when they are home from the hospital and that Mom is just being overly protective” in expressing concern for the preemie’s health.
- More than half of respondents said they have heard comments that show lack of understanding that child development in a preemie is far different than that of a normally developing child and it is not just “a matter of time and waiting” before things happen.

Survey Summary

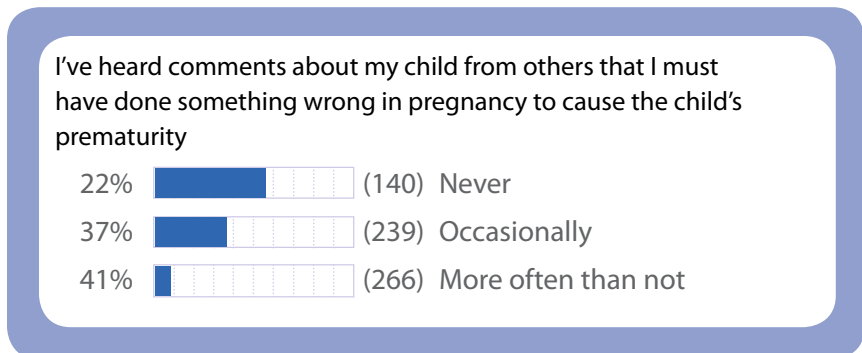
With over 630 respondents in less than two weeks, the response to the online survey, *In insensitive Comments and Their Impact on Premie Mothers*, showed a great interest in providing information to the Inspire community to help educate others.

This summary breaks into the following areas which all contribute to the premie mother’s feeling of isolation from the parenting community and the public at large:



Given a sense of being an “odddity”

In each question that related to scenarios relating to abnormality of the child or something the parent did “wrong” in the pregnancy, the responses within the “occasionally” field at an average of over 40% suggested that an undercurrent of criticism that is often a part of the general parent community though this is more of an outright rebuke. The implied sense here is that the public does not understand that pregnancies can end



early without a parent doing anything wrong. Within this, parents did not see a criticism of their taking up taxpayer money in the form of Medicaid, county therapy programs and more which suggests a real lack of understanding as to how those children in need are helped to reach their potential.

Given a sense of the parents being too protective once the baby is home

Parents expressed the biggest issue for them related to scenarios after the baby comes home from the Neonatal Intensive Care Unit (NICU). Consistently survey respondents revealed overwhelmingly that they were often the targets of criticisms regarding being over-protective about germs and the child's health in general.

I've heard comments about my child from others that show lack of understanding that child development in a preemie is far different than that of a normally developing child and it is not just "a matter of time and waiting" before things happen.



Little to no public understanding of what having a baby early means within the NICU and at home and growing up

The parents found themselves having to educate others about having a preemie and the long-term effects which overwhelmingly fell on deaf ears relating to the NICU stay and parents emotions. The largest disconnect comes with the public at large relating to the differences of the development of a full-term baby versus a preemie. There is a consistent myth that once the baby is discharged from the NICU that everything is suddenly "OK." (This is a topic explored in this report by Keira Sorrells and Dr. Richard Shaw, on pages [10](#) and [18](#).) In addition to this situation, parents reported a shocking insensitivity of 74% to mothers who gave birth early stating that they were somehow "lucky" that they didn't have to deal with the "uncomfortable" last stages of pregnancy.

The end result is preemie moms felt distinct stress at 82% when the commentary came from a relative or close friend. This was fairly similar for casual acquaintances though not as stressful and less so when dealing with strangers. In all circumstances, though, people were dealing commentary from others that were insensitive.

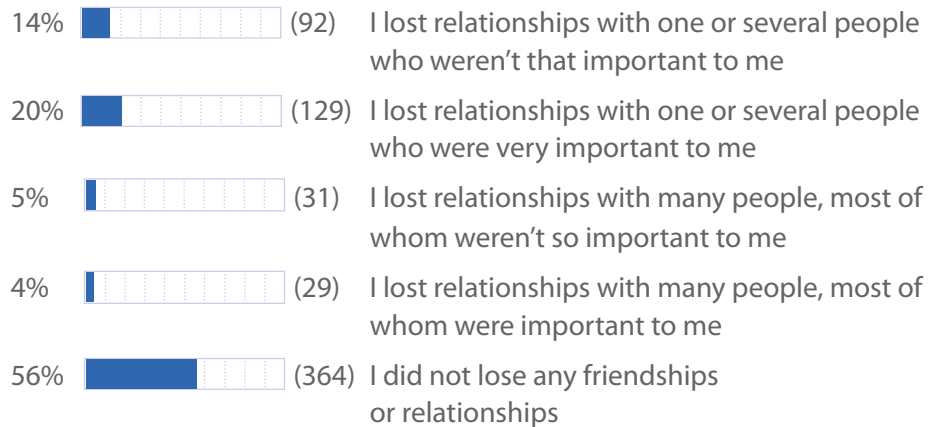
This leads to the theory that as these parents endure inappropriate understanding and/or commentary from others, they are going to feel more isolated which can not only relate to their ability to communicate with others, seek out help for this problem, and even potentially to affect the child's stress factor.

While the insensitive comments were indeed

hurtful regardless of the connection to the mother, it does show an interesting impact. About 20% of the respondents noted that they lost relationships with one or more people were indeed quite close to them. While disturbing, the good news is that 56% said that while affected by the comments they did not lose any friendships or relationships over this issue. This suggests that the mothers, in need of further connection with others were willing to push aside the frustration in hopes of taking a higher road and maintaining harmony. However, as hurtful as the comments get it can be hypothesized that these parents' relationships with others did change in some manner instead of a complete cut-off.

About two-thirds of the survey respondents are between the ages of 30 and 39. Twenty-two percent were between 20-29, and nearly 20% were 40 or older. The gestational age ranges of the babies at birth were as follows:

To what extent did you lose friendships and/or relationships with family members due to the lack of understanding by others of the preemie parent life? Choose the best answer.



Lessons Learned

One would hope that these findings would help medical and therapeutic professionals work to provide an outreach to the public in order to educate the on these babies and thereby creating a bridge of understanding. Doing so should take a two-pronged approach in order to connect with people in a variety of ways:

Professionals Educating Immediate Family/Friends

The issue at hand is that family and friends often only hear the details about the premature baby from the stressed parent. The ongoing stress of that parent can easily look like the parent is overreacting. Beyond this the family and friends are often confused by the preemie coming home because it may be a bit smaller but still look much like the average newborn. To them, then the baby is now just like any other baby and is fine. Having professionals educate the family and friends on what having a preemie is like and that this does not all end with the discharge, would be most useful. As the professionals are very busy and likely a discharge class could not accommodate this effort, then it might be useful to create a brochure or letter that can be handed out to others. That way the parent is backed up and therein better understood.

Professionals and Parents Educating the Public

As the general public may only see a premature baby as “just a smaller version of a newborn,” it is important that they be educated on this matter. Having public service announcements that provide quick tips on helping families with preemies through times ahead such as RSV season, developmental delays and more will go a long way to helping these families be less isolated.

Essay

Keira Sorrells

**Executive Director, National Alliance of Premie Parents
President, Zoe Rose Memorial Foundation**

Unless you work in the NICU or are a parent of a premie yourself, you cannot begin to imagine what living there day after day is like. A constant state of fear exists as you watch your child struggle to live.

Many parents of healthy newborns will express feelings of fear in bringing their baby home for the first time; they will get up in the middle of the night to make sure the infant is still breathing; they will wonder if they can decipher what their child needs based on their various cries. That fear is increased exponentially for a parent of a premie because these parents have actually watched their children struggle to live, they have seen their child turn shades of gray and blue as the current form of respiratory support is failing to help them breathe, or they've been told that their baby is so sick they are maxed out on all mechanical and medicinal support and all they can do now is wait and see if their baby will turn the corner. When you live in a constant mode of survival, the energy needed to educate those around you who do not understand what you are going through can be in short supply.



By virtue of necessity for the health of the babies, the NICU is an isolating place. Two of my girls were in the NICU for 4 months while the third remained for an additional 5 ½ months. I isolated myself from others as a way to protect myself from comments that were hurtful. I could not stand to hear another mother complain about having to wake up in the middle of the night to breastfeed her baby when my babies weren't even big enough to eat by mouth and I was awakened at night by calls from the hospital. This trend of isolation I set remained for a very long time as my focus was solely on the health and well being of my children. I just did not have the energy for anything other than caring for my three fragile babies.

I isolated myself from others as a way to protect myself from comments that were hurtful.

We hear many times over from families that coming home from the NICU is the most difficult part. One mom once said it was like being dropped off in the middle of the ocean as you are no longer surrounded by the NICU staff and are left to now care for your medically fragile baby yourself. After enduring the emotional, psychological, and physical strains of being in the NICU, you hope that once home you can begin to breathe a little easier. This couldn't be farther from the truth in many cases, as the baby's care is now up to you.

In Their Own Words

Members of the Inspire Premie Support Community responding to the survey wrote about their personal experiences. A sampling follows:

I've even had insensitive comments made by NICU nurses and other medical providers. It would be nice to have counseling done for parents while their child is in the NICU so that we could be better prepared to handle insensitive comments that are bound to happen. It would have been nice to have been armed and better prepared. It would also be nice to have some training for grandparents and other close relatives so that they realize first hand from the mouths of medical professionals how severe prematurity is and to be aware of the impact of their comments.

—Charlene Fronczek
Annandale, VA
Son born at 31 weeks gestation

We had a great support group of friends and family. However, none had experienced a premature birth before. We essentially “taught” them and dispelled many myths and misperceptions about premies and pregnancy complications.

—Melissa Irwin
Thornton, CO
Son, Gabriel, 4

It has been almost four years since I have spoken to my paternal aunt and grandmother. Everyone in my family knew that they had to have their flu shots by a certain date, or they couldn't come to our house. My aunt came for a visit and I asked her if she had received her shot yet. When she replied that she hadn't I told her that she wasn't going to be able to stay. So, they have remained mad at me for “kicking” her out of my house.

—Rebecca Bond
Clayton, NY
Twin sons, born at 25 weeks gestation

Although I understand people's ignorance, I do not understand people's willingness to express their ignorance in such a cruel manner. Misconceptions abound about prematurity and its effects on families. The media portrays the birth of a child as a wonderful time in people's lives and for many it is. Unfortunately, it isn't for everyone. For me it was a life threatening and altering time. Parents of preemies need compassion not judgment.

—Lynn Taylor
Oxford, CT

Twins, Victoria and Ron, Jr., born at 27 weeks gestation

For the most part, people's intentions are good. It's a very unfamiliar situation for most people. My preemie has global long-term issues and it's confusing to people who want a diagnosis or complete explanation. I just tell them the sky is the limit for her and only time will tell!

—Jill Hamblen
Phoenix, AZ

Daughter, 5, born at 26 weeks gestation

Unfortunately people just aren't going to understand unless they've been there. I learned long ago to take it with a grain of salt because people just don't know what to say. Of course my preemie is a happy, healthy four-year-old now so the hurtful comments have faded over time.

—Heidi Mattson
St. Cloud, FL.

Daughter Coral, 4, born 10 weeks prematurely

I was very bothered by comments from strangers about my son's size. Because he is so small, I often had people act very odd when I told them his real age, and sometimes even resorted to lying about his age to avoid the comments that would upset me so.

—Tina Brown
Rockford, IL

Son, 17 months old, born at 28 weeks gestation

In Their Own Words

I found the least understanding to come from those closest to me. I can't count how many times I asked my mom if her hands were clean when she wanted to hold the baby, she told me yes, and then I asked her when the last time she washed them was and it was before she left her house.

—Anonymous
California
Mother of a now-five-year-old preemie

I found everyone to be very supportive and understanding even though my son was "only" 6.5 weeks early and didn't have any major health concerns.

—Colleen Goldstein
Chelmsford, MA
Son, born at 33 weeks

I had several pregnant moms say to me that I was lucky I didn't have to gain a lot of weight and be uncomfortable. My sister-in-law, who was pregnant at the same time, kept telling me how jealous she was and how miserable she was while she was still pregnant (she had a pretty rough pregnancy and was vomiting a lot) and I was visiting my 25-weeker in the NICU every day. It upset me greatly and I swore to her I would rather go through being sick at the toilet everyday, being overdue, hot, uncomfortable a million times over than to have to be watching my son be poked and prodded and struggling to survive every day. People just don't understand the facts involving premies. I will always remember what we went through and am so grateful to be celebrating my son's fourth birthday this month!

—Anonymous
Lionvia, MI
Son born at 25 weeks gestation

In Their Own Words

I think being a premie mom has humbled me and I am a different person for it. I try to think of people hurtful comments about my twins, and think, "If I haven't gone through this with my babies, would I have said something like that?" But no matter how much I try to justify it on their behalf it still hurts. My twins are now 20 months and are doing well, but I still to this day have anxieties about what we have been through and how much people really don't understand what it's like to have a premie and have a child fighting to survive and to miss all the happiness and excitement that child birth normally brings. I finally feel like I need to talk about all the traumatic details and it's like no one wants to hear me. Everyone says to look at them, they're perfect, why bring up the past? I think awareness needs to be higher.

—Samantha Blackburn
Chino Hills, CA
Identical twin girls, born at 28 weeks gestation

I was very lucky that everyone in my circle understood the germ factor, not hard to do when we are bringing a baby home who had four surgeries. Part me thinks I didn't actually see comments as insensitive until other moms on the site started to point it out. In general I don't mind people asking questions, it helps educate everyone. Not many people have been exposed to a baby with such a young birth age (thank goodness). The friend I "lost" I didn't really lose but our relationship did change. She is still a good friend but I see her differently. I had two friends cry when I showed them photos. One shed a few tears and managed to pull it together, realizing it was not about her but about me, and I was OK. The other friend did not pull it together and we ended up having to give her some time alone with her husband. It was about her. It definitely changed my views about her and the friendship.

—Michelle Mackenzie
Katy, TX
Daughter, born 24-5/7 weeks gestation, a surviving twin

In Their Own Words

With my second child, born at 24 weeks weighing 1 lb., 5 1/2 ounces, it was heartbreaking for us to watch what she had to go through to be in this world and then when she came home from the NICU 97 days after birth, we then had to endure hurtful comments from people, both strangers and family who didn't seem to be aware their comments were hurtful.

Four months after bringing her home from the hospital (her actual age was 7 months, but corrected 3 months), we decided to venture out as a family to the grocery store. Waiting for the checker to finish scanning our groceries, she became interested in our daughter, still connected to oxygen and very, very tiny. She asked me how old she was. A question I dreaded because she looked like a newborn and I always struggled with actual age or corrected age. I chose this time to tell her actual age and she looked horrified like we were terrible parents. She wanted to know why she was so small and I launched into an abbreviated version of what happened. Even after I told her I had an incompetent cervix, she asked, "What did you do?" My husband shook his head at me, as if to silently tell me, "Don't take it personal, she doesn't get it." But I couldn't help but take her question, no matter how innocent, as a personal insult. She didn't know this but, I did everything in my power to get her to a viable gestation, practically standing on top of my head in Trendeleburg for 16 days never once getting up to use the bathroom, until I was told I had developed chorioamnionitis and I had no choice—she had to be born by C-section right away. I would have stayed that way until she was full term if my body would not have given out on me.

The experience has prompted me to start writing a book, including people's insensitive comments, our heartbreak as a family, and our newfound awareness of what is important in life. The experience has made me a stronger person, but the last 3 years have been very, very tough. My identity as a whole has been changed forever, our family has been changed forever, and life will never be the same.

—Christine Rinebarger
Colorado Springs, CO

Daughter, Mackenzie, born at 24 weeks gestation

In Their Own Words

The only time I got a comment from a stranger was out to breakfast one morning and someone asked, “What’s wrong with her?” Some people are a little insensitive when it comes to her vision although many can’t tell that she is legally blind, they mostly comment on her curly hair. I also work with a great group of people that have been very supportive over the last three years as I have dealt with all of her medical issues. My family has been beyond wonderful, in providing all of the support, love and care that I’ve ever needed in caring for my VIP.

—Diane
Dunwoody, GA
Daughter, 3

It is very sensitive to all the moms who had preemies being looked upon as if they did something wrong while they were pregnant. General population fails to understand that there is no perfect pregnancy, and mothers with preemie babies didn’t choose to have preemie babies. We should be thankful that our babies survived and educate the people who don’t understand what it takes to take care of a preemie baby or babies.

—Cathy Talongwa
Mountain View, CA
Son, 4

The hardest thing for me is that now that my preemie is six years old, I am still dealing with the stress of having gone through such a traumatic experience and the years afterward following up on his medical care. People don’t understand how scary it is and how long it lingers because moms have to be strong for their babies and families and we don’t always get a turn to be comforted and to process our own emotions.

—Amanda
Halifax MA
Son, 6, born at 32 weeks gestation

In Their Own Words

Afterword

by Richard Shaw, MD
Professor of Psychiatry and Pediatrics
Division of Child Psychiatry
Stanford University, Palo Alto, CA

The fact that 630 parents responded to an on-line survey indicates the importance of this issue. The survey is also of interest given the choice to explore the impact of comments made by friends and family members. In my experience, this is a very understudied topic. While there is certainly interest in the psychological reactions of parents to their birth and hospital experiences, little attention has been paid to how parents are affected by such comments.

The birth of a premature infant is an extraordinarily stressful and often traumatic experience in the life of a family. Several of the respondents made reference to the trauma of having a premature infant.

Unfortunately, while the concept of postpartum depression is now very well recognized in the medical profession, the concept of a premature birth and a NICU hospitalization as a trauma is not one that is commonly thought of by health care providers. Research at our institution has suggested that as many as 40% of mothers may develop posttraumatic stress symptoms within the first few weeks of their child's birth. Our research, and that of others, has also shown that these symptoms, if not recognized and addressed, may last many years, and have an impact on the well being of both parents as well as on their developing child. Respondents in this survey also made reference to the long-term nature of the effect of a premature birth. Such data stress the importance of recognizing that the experience of



having a premature infant is not one that is short lived, or that will necessarily pass or ameliorate with time. Unfortunately, over 80% of the respondents in this survey reported comments from friends and family members that showed a complete lack of understanding of this issue.

There are many sources of stress in the NICU environment specifically, and more generally for all parents of premature infants. Some of the respondents in this survey made reference to insensitive comments made by NICU nurses and other medical providers, the one group that we might assume would be most sensitive to the experience of a new mother. However, parents in other settings, for example, parents of terminally ill children have also commented that some of the most hurtful and enduring memories of their hospital experiences are the casual, although perhaps not ill-intentioned comments, made in passing. The results of this survey, and others, confirm the importance of educating health care professionals about the potential impact of such statements.

This survey raises awareness of the potential effect of other comments made by friends and family members, most of which appear to come more than anything else from a place of ignorance of the issues. Forty-two percent of the sample reported that they heard comments implying that they as mothers were in some way responsible for the premature birth. Our own research has shown that mothers of premature infants have a tendency to look for a cause and more often than not will pin the blame on things that they themselves did or didn't do during the pregnancy. Most of these explanations of course are spurious. This tendency to self blame and recrimination has its own adverse effects on the well being and sense of worth in mothers and has the potential also to influence their parenting patterns. This survey suggests that innocent but hurtful comments by friends and family members may further aggravate to an unnecessary degree these feelings of shame and self-blame. The survey also suggests that the perception of being misunderstood by close relatives and friends may lead at times to irrevocable harm to important relationships at a time when these relationships are most needed.

The findings of the survey also highlight another issue for parents of premature infants. The birth of a premature baby with possible concomitant medical issues or implications for future development is its own trauma, that of the loss of the “idealized infant.” This realization is often associated with profound feelings of loss, and mourning — at times a form of traumatic grief — and a complicated relationship with the child itself. Respondents in this survey reported numerous comments made about their child being “wrong” or “abnormal.”

Our own research has shown that mothers of premature infants have a tendency to look for a cause and more often than not will pin the blame on things that they themselves did or didn't do during the pregnancy.

Comments of this nature, particularly ones made by close friends and relatives were particularly bothering to survey respondents and contributed further to their feelings of stress and isolation.

Finally, respondents in the survey had much to say about what parents believe would have helped with their specific experiences. Many commented on the need for education and increased awareness of the issues affecting parents of premature infants. Sadly, such efforts are lacking, not only in clinical settings where these babies and mothers receive care, but also in the research literature. This survey highlights an important deficit in our system of care as well as a need to advocate more strongly for this parent community.

About Inspire



Princeton, N.J.-based Inspire creates safe, moderated online communities, organized by medical condition, for patients to share information and to support one another.

Inspire builds and manages these communities in partnership with more than 70 national patient advocacy and support organizations. For more information, go to www.Inspire.com, or email team@inspire.com.

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