A QUALITATIVE STUDY OF THE EXPERIENCES OF FAMILIES WHOSE CHILDREN HAVE RETINOPATHY OF PREMATURITY (ROP)

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Report prepared for Prevent Blindness

April 24, 2026

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Contents

Beginning in 2023, the National Center for Children's Vision and Eye Health (NCCVEH) at Prevent Blindness developed resources to increase awareness about Retinopathy of Prematurity (ROP) for the general public in partnership with SPAN Advocacy Network, Hand to Hold, and the National Coalition for Infant Health. The work was funded by Regeneron and resulted in the creation of three fact sheets:

- What is Retinopathy of Prematurity (ROP)?
- How is ROP Diagnosed and Treated?
- ROP and Your Child's Lifelong Vision Health

A video series was also developed and is housed at Retinopathy of Prematurity (ROP) Videos - Prevent Blindness. These resources inform families about the ROP diagnosis and what to expect as the child grows, provide resources and support, and inform clinical practice. In addition, Prevent Blindness increased public awareness by establishing *ROP Awareness Week* held at the end of February each year.

Focus Group Background and Topics

In fall 2024 three focus groups were held, one with five early intervention providers, a second with five teachers of students with visual impairments/O&M specialists, and a third focus group with two mothers of children with ROP who had spent time in the NICU. The focus groups were designed to gather data to aid Prevent Blindness staff in the development of additional resource materials for families of children who have been diagnosed with ROP and educational offerings for the professionals who serve these families.

Key findings from the study included:

- Families in urban areas typically had better access to medical services.
- Families were less likely to seek routine ophthalmological care for their child and attend follow-up appointments when they had been told their child's ROP was "resolved."
- Having a child born prematurely, often with a number of medical conditions, was emotionally taxing and overwhelming to families both during the NICU stay and once the child came home.
- There was tremendous variability in the availability of early intervention services. When services were available, there may not have been staff who were knowledgeable about ROP, other eye

conditions, and the impact of blindness or low vision on a child's development.
- Referral systems and communication were often lacking in communities resulting in families and children not being connected with early intervention services.

As a follow-up to the fall 2024 study, in early 2026, Prevent Blindness initiated a follow up study including family members of children 10 years of age or younger who have ROP to share their experiences in a focus group. Details for the 2026 Focus Group Protocol can be found in Appendix A beginning on page 32.

Discussion topics included:

- Experiences families have had when their child has been in the neonatal intensive care unit (NICU) and been diagnosed with ROP.
- Families' journeys raising a child with ROP in relation to medical care, social/emotional support, and educational services.
- Barriers families experience accessing and attending eye care appointments for their child's ROP.

Participants

Nine mothers and one father participated in the focus groups. Two families were from Florida and one each from Alabama, Arizona, Indiana, Missouri, New Jersey, Oregon, South Carolina, and Virginia. Pseudonyms have been used in this report to protect the identities of participants.

Nine of 10 children included in this study spent between 78 to 185 days in the NICU, with an average stay of 120 days. Table 1, on page 31, provides additional information about the 10 children. Of note, Andrea's and Brenda's children were one of a set of twins with the other twin screened for ROP but not followed for this disease. Juniper's daughter was adopted at 27 months and did not spend time in the NICU in the United States.

When completing the registration form to sign up for a focus group, parents were asked, "Please describe your child's visual functioning at this time. How, if at all, is ROP impacting your child's development?" Six parents reported that ROP did not impact their child's development, stating:

- His visual functioning seems to be pretty good. Our ophthalmologist said he was farsighted during our most recent visit (back in the fall) and prior to that, said he was nearsighted. He said it can be common for them, when they are little, to fluctuate. He looks at books and whatever either up close or far away. He seems to have no issues. (Andrea)

- He received laser surgery treatment for ROP and sees wonderfully. (Brenda)
- As of now his vision seems fine but he still undergoes routine visits with his eye doctor every 8 to 12 months. (Cameli)
- His eyesight is tested annually, and his doctor says his vision is fine. He does suffer from light sensitivity and does not like bright sunlight or indoor lighting. (Darlene)
- My child's visual functioning is good at this time. He has yearly eye exams and there is no evidence of ROP post laser eye surgery. He has not needed glasses, as of yet. ROP has not affected my child's development. (Erin)
- Great so far. He had ROP while in the NICU and had the laser treatment immediately. (Hilary)

Two parents reported their child’s visual challenges were a direct result of ROP.

- My child currently has reduced visual functioning due to retinopathy of prematurity. My child has difficulty with distance vision, fine details, and depth perception. My child relies on close viewing, good lighting, and high contrast or enlarged materials to see more clearly. My child’s visual development has been delayed compared to age expectations, but my child continues to make progress. With ongoing eye care and appropriate supports, my child is able to use vision functionally for daily activities and learning. (Indigo)
- The doctors did not fully explain [ROP] and I did not put the pieces together myself until a few years later, just how much of an impact ROP would have on his life. He has very little to no peripheral vision all around both eyes. He walked into the post in the middle of a double doorway because he couldn't see it. Hand-eye coordination has been a big struggle. He gets a spoon near his mouth and then searches for it with an open mouth. We are fortunate the public school system is able to provide vision and orientation & mobility therapies. [Flynn’s son does not receive vision therapy nor vision rehabilitation. He receives services from a teacher of students with visual impairments.] It is also a pain because they require him to attend class there twice a week for half a day to get those therapies, so I have to leave work in the middle

> of the day to pick him up and transport him to his therapeutic preschool where he is the rest of the week. He recently started using a seeing eye cane [white cane] when out of the house and it has made a big difference. He is more confident about walking and running without running into things or tripping over curbs. When he was younger his eyes weren't able to work together, he would constantly turn his head to look at something with one eye and then the other. When he Facetimes grandparents or watches a show on his tablet, he generally wants it way to close to his face. Due to developmental delays and neurodivergences he has inherited, school will already be difficult. I worry that when he starts kindergarten this fall, he may struggle to see the board effectively or may focus too much on seeing everything instead of processing and absorbing what is being taught. (Flynn)

Two parents reported that their child's visual abilities were impacted, though they did not specify if the difficulties were a result of ROP, other conditions, or a combination. They shared:

- She wears glasses. Her right eye has little to no vision. Still inconclusive. (Gina)
- She has been diagnosed with a profound visual impairment. She reads and writes in braille, uses screen reading technology, and a white cane. Her rare disease, in combination with her complex visual impairment, has significantly impacted her ability to sustain grade level and chronological age-appropriate academic development. (Juniper)

The parents reported that the 10 children received routine eyecare. For these families there were no barriers to accessing eye care.

Methods

During each focus group, the interviewer audio recorded the session and sent the audio files for transcription. Transcripts were reviewed multiple times and themes were identified, as well as quotes that represented the themes. After all the themes were identified, the transcripts were reviewed again to ensure accuracy. Prevent Blindness staff reviewed the draft report providing input prior to the report being finalized.

Please see Appendix A, beginning on page 32 for the focus group moderator script. Not all questions were asked of all participants based on the flow of the conversation.

Results

Eight themes evolved from two focus group discussions. Quotes from participants are used to illustrate key points. Nine of the parents had a traumatic birth experience as their children arrived between 23 and 28 weeks gestation and remained in the NICU from 78 to 185 days. Though each of their experiences were unique, there were commonalities in their NICU and post-NICU experiences related to their child's ROP.

Theme 1: Hearing the Diagnosis of Retinopathy of Prematurity

Nine of the parents shared what they recalled when learning of their child's diagnosis of ROP while their child was in the NICU. Often the diagnosis was shared after the ophthalmologist completed a weekly screening. ***Hearing that their child had ROP was an emotional experience.*** Indigo described her reaction.

> *"I appreciated that [the ophthalmologist] was very clear and straightforward, but emotionally it was still overwhelming. We're already processing so much [information], alarms, oxygen levels, feeding progress, and then to hear that there was a condition that could potentially affect my child's vision long-term was really heavy."*

The amount of detail and the quality of the doctor's bedside manner experienced by the families varied. Andrea explained the challenge of having different ophthalmologists screening her twins.

> "The first time the explanation [from the ophthalmologist] was lacking. It was like, 'Hey, we're just checking for this." It's kind of this thing, but it's just something that we do for premature babies.' [Later my baby] had a second exam done with the ophthalmologist who would later do the Avastin injections and his laser surgery. He was the one who ultimately, we wanted once we were out of the NICU, because he came in, he took so much time, he explained everything, and he had research to back him up…. It just didn't seem clear to me until he really took the time to talk about the zones and to talk about the idea of regression and how it could be a slow

> process and all of these things. [Some ophthalmologists] were a lot clearer in the fact that lasers still probably [would be] a likelihood on down the road. And others were, I wouldn't even say optimistic, but they were like, 'Yeah, we'll see.'"

For some families, the ROP diagnosis was yet another diagnosis their child received while in the NICU. Brenda described some of the health challenges her son experienced while in the NICU.

> *"Our son had had a seizure and had IVH (intraventricular hemorrhage) grade 3 bilaterally… and the diagnosis from the doctors was, 'With an injury of this size, he will probably never walk. He'll probably never get out of bed. He'll probably never speak.' We were digesting that. Our days in the NICU were day by day. He also had lung issues. My poor little guy…. In between all of that we got the ROP and I was like…another diagnosis, here we go. How do I translate this to my concerns?"*

Though all the parents wanted to make decisions that would benefit their child's health, they often did not have a full understanding of the potential long-term impact of ROP on their child's development. This was often coupled by believing that the doctor knew best and what was needed. Flynn shared his thinking when he learned his son had ROP and would need to begin injections.

> *"They [the ophthalmologists] are the doctor. I had a general idea that it [the injections] were for his benefit and that it had to do with the way the veins [blood vessels] in his eyes were growing. So that part I think was relatively clear. The part that I guess I didn't understand in general was the impact the surgery would have on him.... They mentioned that he would lose some peripheral vision and that's better than potentially going blind, which I thought was a real possibility. But he has really no peripheral vision all the way around both eyes. I don't think it was explained to me that well, and I never really understood that [at the time]."*

Hilary received a call at home from the ophthalmologist who reported that her son had ROP stage 3 and that she would like to perform laser surgery immediately. She explained her and her husband’s reaction.

> *“We're shocked and really don't know what it [ROP stage 3] means. We started asking a lot of questions. And they explained about how he has the potential to lose some peripheral vision, and also if we don't do the surgery that there's a risk that he could go blind. When you hear that, obviously you don't want to hear that. So, you're going to do everything you possibly can to prevent that from happening.”*

For Juniper, learning of her adopted daughter’s visual impairment was very traumatic. She described her experience.

> *“We thought that her diagnosis was nystagmus [a jerky movement of the eyes] and we Googled that. [I took her to the ophthalmologist] and reported something is a little off. [I told him] she seems to be bumping into things a lot…. He looked in her eyes, and I can still remember, he pushed his little rolly chair back and he said, ‘I'm sure you've heard by now she's hopeless and I'm not touching her.’ And I said, ‘What are you talking about?’ And he said, ‘She's blind.’ That was my first encounter with medical ophthalmology.”*

Juniper took her daughter to another ophthalmologist who examined her daughter under anesthesia. The second ophthalmologist said:

> *“’It's not a hopeless situation. She will be okay. We just have to figure out what works best for her, just like for every child.’ That's what we've been doing ever since that day.*

Theme 2: The Eye Exam Experience in the Neonatal Intensive Care Unit

Few of the parents were present in the room when their baby underwent an eye exam to screen for or monitor ROP progression. Often, nurses or other personnel advised them not to be present as observing the exam could be difficult. Though Darlene had a nurse that explained what to expect during the exam, she found observing her son's first ROP screening was going to be too difficult.

> *"[The nurse] told me what was going to happen…. The doctor [ophthalmologist] comes in and sees all the babies. Every baby is scheduled at a specific time. [I go into the room] and I see that plate [tray]…with the little utensils and those little metal things [eyelid speculum] that are horrible. I'm looking at that [tray of tools wondering] what are they going to do with that?... I felt kind of prepared in a way. But I left because I was, you're scaring me with what this is going to be. [After the exam] I walked in and there was a piece of paper explaining what ROP was, an educational flyer. On the paper was written zone 2. [The paper] was left there at his bedside and I picked it up and was reading it. [I was wondering] what the heck is this? So that was my first introduction to what is ROP…. I asked my [baby's] primary [doctor], 'What is this number? What does this mean?'… She was the one who really explained it [ROP] to me, not the doctor [ophthalmologist]."*

Theme 3: The Emotional Toll on the Family When a Child is in the Neonatal Intensive Care Unit

At some point during the focus group, each of the 9 parents whose child had spent time in the NICU described feelings of being overwhelmed, isolated, uncertain, and/or worried. Brenda's thoughts were echoed by several of the parents.

> *"I think the most frustrating thing is when they [doctors] are like, 'Well, we don't know. Will they walk? Will they talk? Will they have vision? Who's to say, alright, see you, bye.' And you're just sitting there feeling like you got hit by a truck."*

Brenda then went on to speak about her children's ophthalmologist who did not pressure her and her husband to have their son undergo laser surgery.

> *“It's on the parents to understand and digest and grieve. The attitude of the provider, [them] being able to give you stats, options, and thoughts as plainly as possible in a kind and hopeful way is amazing.”*

Later in the focus group, Brenda spoke about her husband’s experience of having premature twins and a wife who had a very difficult delivery. She told the group that her husband was “very masculine” and worked in a profession where counseling was not viewed positively. Yet, her husband did join a NICU support group for fathers, and this was beneficial to him and their marriage.

Camile and her husband, recent immigrants to the United States, both had immediate family that still lived in their native country. Though their families were supportive virtually, they had no one to physically provide them support when their son was in the NICU, nor when he came home. Camile reported that they are a religious family and spent a lot of time praying to God during her son’s time in the NICU.

Indigo noted that the nurses went beyond explaining information.

> *“Most of the supports I received came directly from the medical staff and nurses especially. They were honestly the biggest social encouragement because they would explain things, reassure us, and sometimes just sit with us when things felt overwhelming…. Everything was happening so fast and our focus was really on my daughter's stability and getting through each day…. Looking back, I do think connecting with other parents who were going through similar things could have been helpful emotionally.”*

In some NICUs there was support for new parents, though not all parents found the support helpful. Andrea reported her experience.

> *“In theory there was a NICU support group, but it was not heavily attended. It was not super helpful.”*

In his son's NICU Flynn shared that there was a parent volunteer who he believed had a child in the NICU the year before. She was someone available for new parents to talk to and to provide them with emotional support.

> *"I don't remember exactly what was going on at the time [with my son's health], but there's always something you're worried about. [The volunteer] was there to tell you, 'Oh, it's going to be no big deal. They turn out fine.' [I was thinking] I kind of hate you right now. I don't really want to talk to you. That's not helpful…. I don't know that I could have survived the whole experience without the nurses."*

Theme 4: Education and Support for Families

Gina and several other parents noted that families often do not realize that they need support yet admitted now that as parents of premature infants they lacked emotional support. Gina shared:

> *"I feel like it would've been helpful to have more mental health support and stuff like that. I think you're just in a routine so that you don't realize what your needs are. You're just focused on your kid."*

Hilary received considerable support during the NICU experience. Her and her husband now serve on a board for an organization that provides support to families with children in the NICU. She explained the types of support she received while her son was in the NICU.

> *"I had a dedicated social worker who would reach out to me, probably daily in the beginning, just to check up on me and see how I was doing. [The social worker would ask if I] needed any sort of support or resources. My hospital had the March of Dimes NICU support program, which had a lot of parent resources as far as educational materials, pamphlets, etc. They provided food and scrapbooking stuff for parents to distract them a little bit. We also could reach out if we needed*

> *somebody to talk to. They did have a lot of resources. I was fortunate enough to experience that."*

Darlene's hospital also provided a lot of support for families.

> *"They have a wonderful nonprofit [ICU Baby] that is inside the hospital that assists [families]. They are there all the time. [Those with the nonprofit] have a uniform on. They come around to the bedside to all the [babies] in level two and level three NICUs. They have weekly dinners for the moms there in a special dedicated room for NICU parents, activities, and online support. They give you baby bags full of things. They have somebody that contacts you by phone and text. It's a really wonderful program. And then they also follow you post discharge to see if you need help in any areas or resources. They're absolutely wonderful and I still keep in contact with them to this day…. Between the nurses and the coordinator with ICU Baby, that's what made all the difference."*

Indigo explained her feelings and recommended follow-up from the NICU after discharge.

> *"When we first came home, I think what would've helped me most was more emotional support and connection with other parents who had gone through something similar, especially parents of children with ROP. Medically, we had the appointments scheduled and we knew who to follow up with, but emotionally, I don't think I was fully prepared for the transition. The NICU is intense, but you are surrounded by professionals. Once you come home it can feel really isolating. I was happy to be home, but I was very anxious. Every little thing felt big. I think a structured follow-up call from someone in the NICU could have helped. Even if it was once or twice, it would have meant a lot. Just someone to check in and ask how we're all doing."*

Though not every family wants to or can participate in a support group, some parents felt that in-person and virtual support groups would be helpful, with families taking a lead role in developing the support groups, rather than the support groups being developed by professionals. Erin reflected on what she saw as the benefits to families of having support groups.

> *"I think being able to connect families that may have similar experiences is really important because there's so much going on when you're in the NICU. There are so many different diagnoses, procedures, and everything else. It's very easy to get caught up in all of that. And you don't know what the outcomes are going to be in the future. Some kids will go on to have fine vision, and some kids may lose their vision. If you have people who you can talk to who are going through something similar, it's just nice to have someone to relate to. Maybe they've gotten different information than you've gotten, and you can share ideas and things that have helped your child."*

Some families appreciate having someone visit them and their baby in the NICU. Individuals in this role must be knowledgeable about ROP and other conditions experienced by premature infants.

Flynn explained the value of having someone he could touch base with about typical child development.

> *"What was also really helpful was that one of my wife's friends had a baby a few months before [our son was born]. We just texted fairly often. [I would ask questions such as] 'Does your baby do this?' It was reassuring just being able to talk to another parent who was [raising a young child]. Their daughter didn't go through the NICU, but she was still a newborn baby. We were able to talk about what they were doing or what was happening. It was just reassuring."*

Like Flynn, Brenda found it helpful to compare her son's development to that of a typically developing baby.

> *"It was helpful in terms of all development [to check the website] Pathways.org. That's just kind of how I tracked [my twins' development]. That [website] was recommended by everyone in our NICU in terms [of a resource to use] to keep an eye on [typical development. For example,] can he reach out and touch something? Can he identify something? So Pathways.org was my biggest resource."*

Many families use social media to obtain information. Camile shared that she and her husband found support through a Facebook group for families who had children in the NICU at their hospital.

> *"We were grateful that the NICU had a Facebook page where you can post about your children. You can post if you have any questions or if you want family support. The doctors and nurses [were on the Facebook page] and encouraged each and every person."*

No one has a crystal ball to know the long-term impact of prematurity and ROP on any one child. Yet, some families appreciate receiving information about the potential long-term impacts of ROP on children. Hillary shared:

> *"My biggest concern is what might happen 2, 3, 5, or 10 [years from now]. I cringe every time [my child goes to their annual ophthalmological appointment] because I'm afraid years down the line [his vision] might regress or the retina might detach. I do ask those questions, and the ophthalmologist is very optimistic and gives positive answers."*

Gina also shared her perspective.

> *"It's really hard to be told exactly what's going to happen in the future. It helps to have other people who are going through the same thing to kind of feel like you're not alone, especially after being in the NICU. I think that [the NICU and*

> *ROP] is just not a common experience. A lot of people don't understand why you're a helicopter parent and why you're so, I don't know, on top of everything. [Families] just [need] support and resources."*

Finally, parents want a trusted source to whom they can ask medical and developmental questions and from whom they can receive accurate information. As Darlene explained:

> *"We're just relying on Google and the things we read. There's just so much conflicting information. [How do we know] what's accurate, what's not accurate? What does the research say? What is factual?... [What are] things to look out for? What are questions you might want to ask?"*

Theme 5: Preferred Ways to Receive Information and Judging the Accuracy of the Information

Depending on the type of information being provided and an individual's learning style, the ways in which they prefer to receive information varies. Often people do not have just one preference. Indigo shared her thoughts.

> *"For me, the best way to receive information about ROP was a combination of written materials and videos. Written information is really helpful because I can go back and really carefully take my notes and really process the details at my own pace. Written information would be useful for understanding the medical aspects, things like treatment options and what to watch for as she grows. But I also find videos very helpful, whether on YouTube or other platforms because they explain a concept visually. I think videos would be good for demonstrating strategies for supporting a child with therapy. So short, clear videos that summarize key points are really ideal for me."*

Erin preferred written information about ROP and had a strong aversion to videos about ROP treatments. She explained her perspective.

> *"I think seeing videos about ROP might be a little triggering from a mental health standpoint. I remember seeing what they did to look at the baby's eyes in the NICU and those images have not left me."*

In considering information they encounter, parents were quick to point out that they found conflicting information on the internet. Therefore, they sought information from reputable sources such as medical organizations (e.g., National Eye Institute), hospitals, or research studies published by reputable sources. Several parents shared that medical professionals had cautioned them not to conduct Google searches. As Andrea noted:

> *"Google is a scary place when you don't really know all the terrible things that exist out there."*

Juniper noted that she not only appreciates medical information, but also information from those with lived experiences.

> *"I like to see people with blindness and low vision telling their lived version of what they're experiencing and milestones that they had. I really value that component, that perspective. [I appreciate them] sharing their journey and what has worked [for them] and kept their hope alive."*

Theme 6: Discharge from the Neonatal Intensive Care Unit and Adjusting to Life at Home

The nine parents reported that there was planning with hospital staff leading up to their baby's discharge from the NICU. Flynn was in a unique situation as his wife died within a few days of childbirth, so he was a single father of a baby who spent 99 days in the NICU. He shared one of the things that the NICU staff did that prepared him to care for his son on his own at home.

> *"They let me spend the night in the NICU the night before discharge. We had our own room. They have someone on call in case something happens, but it's really just trying to give you that at-home experience of what it's going to be like."*

Andrea shared the lead-up to discharge for her son and how the need for oxygen added to her concerns about the progression of his ROP.

> "We met with a social worker, we had different trainings, and we met with a doctor. But the thing I remember most is when we got discharged, they are saying, 'You're going to have a lot of appointments.' I still don't think I quite knew what that meant, the degree to how many appointments we would actually have, and how sometimes how redundant they felt. We came home with my baby on oxygen. So that was also affecting our baby's ROP growth, the growth growing out of the zones. It was constantly this battle of he needs this oxygen, but I know his eyes aren't fully [developed so that oxygen is] not helpful for his eyes."

Camile was the only parent who reported she made all the follow-up appointments for her son. None were made by the hospital staff for him. With her OCD (obsessive compulsive disorder) she appreciated being in control of scheduling. Camile's experience was the opposite of Brenda's. She explained that all of her son's appointments were made for him prior to discharge.

> *"We weren't in the NICU anymore, but we still had the NICU mindset…. You feel so helpless in this space for so many months…. [You appreciate when you're told] this is what you're doing. This is your plan. These are the days you're coming back [for appointments]. I was actually pretty grateful for [being told the appointment schedule]."*

Camile also reported that upon discharge, she and her husband were provided with a telephone number that went directly to the NICU. Once home, they were able to call this telephone number to speak with nurses and doctors who had cared for their son and were able to answer questions they had.

Following discharge, the emotional rollercoaster continued for the parents. Not only were they having to manage the care needed by all newborns, they also were having to juggle the complexities and demands that come with prematurity. Darlene articulated these demands and their emotional toll.

> *"It was an hour and a half to two-hour drive to the ophthalmologist's office every week. The ophthalmologist appointment can't conflict with the pulmonology appointment…trying to schedule all of these appointments in a way where it made sense. Then throw in the feedings. My baby had a lot of reflux. I was pumping. He was on reflux medication. We were mixing the calorie formula and the breast milk and measuring and doing all these crazy things. It was just the complexity of all the things that were required. Then not forgetting about yourself as a parent, I feel like all the focus is always on the baby. And then mom goes home, dad goes home, well, what about us? We're barely hanging on here for life. So, it was shocking when we came home and it was a little overwhelming."*

Erin shared that her situation was complicated by COVID as her son was born late in 2020 and came home in early 2021. As she, her husband, son, and immediate family maintained their "bubble," she sought support online.

> *"Project NICU, dear NICU mama, and different communities of families with parents going through similar things [was helpful]. I could talk to and relate to others in some way…. Project NICU had a mentorship program where I was actually partnered with another mom whose daughter was born at a similar gestational age to my son. She had gone through similar things. Just being able to talk to someone who had been there, even if I didn't know them personally, was a really good resource at an isolating time."*

Though Juniper’s daughter did not join their family until she was 2 years of age, she and her husband had an adjustment period with this new child in their home. They were living far from either of their families in a state that was not familiar to them.

> *“I quit pretty much everything [including my job] to attend to this child and figure out this whole blindness thing. Not to sound dramatic, but I was very depressed. [My depression] probably lasted a good 2 years…. The [in-person] support was non-existent, and no one could understand [what we were going through] because here we have this almost 3-year-old who is presenting as a 12-month-old.”*

Theme 7: Ophthalmological and Other Medical Follow-Up Appointments

The parents described the need their baby initially had for ongoing ophthalmological care both in the NICU and once discharged. Darlene recalled that for a long time she was taking her baby for weekly exams and for her and her baby “those exams were awful.” She explained the progression moving from weekly exams to monthly exams and then to exams every 6 months.

> *“It got to one point where he [the ophthalmologist] said, ‘Okay, he's not getting worse, but he's not getting better. We're just going to follow him to see what happens…. Then it [the ROP] did start receding. [The ophthalmologist] said it's improving. And then the exams were stretched out.”*

Most of the parents continued to have their child see the ophthalmologist who cared for them in the NICU or the ophthalmologist who the NICU staff scheduled them to see following discharge. Cameli traveled for over an hour for her son to see the assigned ophthalmologist but then switched ophthalmologists. She explained why this switch was made.

> *“We had a bad experience with the doctor [ophthalmologist] that they [NICU staff] sent him to. It [the doctor’s office] was very far from us, but that's the doctor that they told us to see.*

> *He was very rude and [told us] 'He's okay.' He doesn't really tell us what to do [for our son]."*

Not surprisingly, the parents had a lot to keep up with as multiple specialists were following their babies. Indigo's experience was typical.

> *"We left [the NICU] with a pretty detailed discharge plan…. It felt overwhelming at first because suddenly we went from having nurses and doctors around 24 hours a day to being responsible for managing appointments ourselves. After those initial appointments were set up, it became our responsibility to stay on top of the scheduling…. As a parent, I quickly learned that we had to be organized and proactive. I kept a calendar just for the medical visits. The transition home was really intimidating…. The moment we left the NICU, that chapter felt technically closed."*

The importance of follow-up with the ophthalmologist and other specialists was stressed to the parents. Darlene described her feelings and concerns.

> *"There was the multitude of appointments where every day there was a visit, cardiology, pulmonology, ROP [ophthalmology], pediatrician, etc. You felt like you were living in this circle of appointments where God forbid you don't take them [baby to the appointment], then someone's going to call DCF [Department of Child and Family Services] on you. It becomes so overwhelming. I will never forget when we left [the ophthalmologist's office], and he said, 'Do not miss your appointment with me. I will call social services…. [B]y missing these appointments, your child can go blind…and you're scared into oblivion…'"*

Few parents received any follow-up from hospital staff after discharge. Darlene was one of the few who had follow-up.

> *"We had a social worker who called and basically went through the list of appointments. So, while that was nice, I [could] see that list on my fridge. I was very aware of what those appointments were. [The calls] felt supportive, but they also felt like one more thing I had to check off my list. I have to talk to this person who's going to tell me all those things that I already know. It wasn't like a mental health or a support sort of check-in as much as it was like a, 'Hey, this is all the things you have coming up.'"*

Once Juniper's daughter came under the care of the ophthalmologist who conducted her exam under anesthesia and other doctors at the same hospital, things improved for the family. Juniper explained.

> *"The doctors gave us their cell phone numbers and were in constant communication with us. They were deeply interested in long-term outcomes for our child. And I would like to think that over the years they've displayed the same type of interest and care…. Our daughter's medically complex. She has a lot of other medical concerns from being born prematurely and the whole team…work in tandem."*

Juniper shared that now, each time they see the ophthalmologist, the doctor is surprised by the activities her daughter is doing as the doctor does not typically get these types of reports from families who have children with limited vision and complex needs.

> *"I guess since we're first-time parents, we never told her [our daughter] 'no.' When she asked, 'I want to ride a bike.' We're like, 'Sure, let's figure out how.' We always just try to figure out how to make it [the activity] accessible for her. She navigates very well with what little functional vision she does have."*

Theme 8: Early Intervention and Special Education Services

Early intervention services are available to children from birth to 3 years of age. Juniper’s daughter, who was over age 2 when adopted, did not receive early intervention, nor did Hillary’s child who is currently between 6 and 7 years of age. Only three parents (Cameli, Flynn, and Indigo) reported that a teacher of students with visual impairments was part of the early intervention team. It should be noted that all three parents referred to these professionals as “therapists,” not as teachers which is a common issue in the early intervention arena.

Cameli reported that her son’s teacher of students with visual impairments had accompanied them to ophthalmology appointments and that she found this to be valuable. She also shared that she and her son were invited on community outings (e.g., zoo, farm) with other families and she thought this was beneficial for both her son and her.

In reflecting on early intervention services, Brenda shared:

> *“[Early intervention is helpful because] you don't know what you don't know about…next [developmental] steps and ROP. [Our state has] got a lot of problems, but fortunately for us early intervention there was not a huge backlog. We got in right away with our social worker, with our case manager, and just set up everything. And that included vision counseling [it was not clear what Brenda meant by vision counseling] and just keeping an eye on his development.”*

Brenda reported how well her son who has ROP and his twin are doing as 2-year-olds.

> *“They're both thriving like crazy. They’re walking, going in different directions. It’s beautiful. I couldn’t be happier.”*

Indigo shared that a teacher of students with visual impairments was part of her daughter’s early intervention team.

> *"[The teacher of students with visual impairments] worked closely with us and our family. She shared strategies to [help us] support her visual developments. She helped us understand how to make the environment more accessible. We also had therapists who worked on fine motor skills, daily living skills…. We kind of had support, although we could have used more."*

Five of the seven children over age 3 currently receive special education services while Darlene's and Hilary's children do not. For Juniper educational services provided support as she did not find support in the community. Because of her experience, Juniper is now a teacher of students with visual impairments and orientation and mobility specialist.

> *"[Through my training I am] educating our family. We could then speak the truth to what is really going on in our family and educate our family members. [For example,] my dad said, 'Don't worry, she'll grow out of it [blindness].' And we're like, 'No, she's blind. You can't grow out of blindness.'"*

Flynn explained how special education services are supporting his son's development.

> *"Through the school system, he's getting vision therapy [his son is not getting vision therapy, rather he is getting services from a teacher of students with visual impairments] and orientation mobility. They started him using a [white] cane that helps him [when walking]. Last night he tripped over a curb getting out of the car when walking onto the sidewalk. [He tripped] because he held the cane up in the air. If he was using it right, he would've noticed the curb."*

Recommendations

Based on the focus groups and the evaluator's vast knowledge and experience in the field of blindness and low vision, recommendations are offered.

Support Families When Their Child is in the Neonatal Intensive Care Unit and Assist Medical and Educational Staff to Better Understand Retinopathy of Prematurity

The experience of premature birth and having a child in the NICU is emotionally taxing. Families often need a variety of support as they navigate the challenges they are experiencing.

- Non-medical support is important for families. Often a listening ear is all that is needed, especially if that listening ear provides emotional support. It is imperative that medical professionals treat each child and family with respect, meeting them where they are currently at on their journey. **Prevent Blindness may wish to partner with medical schools, schools of nursing, and other groups to offer joint in-person, hybrid, or online training that focuses on non-medical support.**

- **Prevent Blindness and other collaborators can work with local groups, whether affiliated with the hospital or not, to plan events for families.** During the NICU stay events may include a nice meal, space and supplies to scrapbook the family's journey, journals, access to a therapy dog, massages, music, or other relaxing events.

- Though not all families want support, many families do want and appreciate support. **Prevent Blindness and other collaborators can develop both in-person and online support groups.** These groups need to be developed with input from families.

Provide Support to Families Once Their Child is at Home

The need for support does not end when a child is discharged from the NICU. Continued support can take multiple forms.

- Once the child is home from the NICU, support to families may include telephone calls, texts, and/or emails to check in with the family. These should be arranged ahead of time with the family to find out their preferred method of communication and desired frequency. Support may also include access to respite care, transportation assistance, help locating local services, a photo shoot for the family, massages, etc. **Prevent Blindness and other organizations can work together to establish support systems and options within local communities.**

- **Prevent Blindness and other collaborators can provide education to families and information about developmental milestones that are adjusted for the baby's developmental age**. Presenting information in easily digestible chunks, perhaps with the use of bulleted lists, may make the material more accessible to families. Creation of an app specific to children with ROP and developmental milestones and other relevant content may be appreciated by families.

- **Prevent Blindness can coordinate with other organizations that are focused on prematurity and the NICU experience.** By building alliances with other organizations, Prevent Blindness may find it easier to spread their word.

- **In collaboration with other organizations, Prevent Blindness could create a family mentorship program specific to families who have a child who is spending/has spent time in the NICU and is experiencing blindness or low vision.** Such a program will need to be designed with input from families at every stage of development. The program will also need to include a screening process for mentors.

- **Prevent Blindness may want to develop a website specific to families whose children are being monitored for ROP or have been diagnosed with ROP.** Prevent Blindness can partner with NICU support organizations to provide information on ROP for parents of children who are born prematurely and do not know what to expect regarding eye exams and ROP.

Provide Opportunities for Families to Learn Skills to Advocate for Their Child

It is important that families have the skills to advocate for their own child. Often it is those with lived experiences that take a key role in advocating for legislation and the development of programs that benefit families.

- Prevent Blindness has a successful ASPECT Patient Engagement program that focusses on building participants' advocacy and storytelling skills. Though some family members of children have taken part in the program, the program is geared to adult participants (age 18+). **Prevent Blindness may wish to develop a track within the ASPECT program specific to supporting families in building their advocacy skills so they can more effectively advocate for their child's medical and educational services in addition to advocating with legislators and others to ensure legislation and programs that impact children with visual impairments are comprehensive and funded.** Within this track, families can also learn skills that will better position them to guide their children as they grow so they can tell their own stories and advocate for themselves.

Educate Professionals About ROP and How to Care for Families

Prevent Blindness and other collaborators can educate both medical and educational professionals about ROP.

- **To benefit children, Prevent Blindness and other collaborators can offer webinars, fact sheets, pre-conference and post-conference sessions about ROP to both medical and educational professionals.** By pairing with already established organizations, Prevent Blindness will potentially have a deeper impact on children and their families. Providing continuing education units (CEUs) for any offering may result in attracting a greater number of medical and educational professionals.

- **Prevent Blindness and other collaborators can sponsor training so that professionals and volunteers have the knowledge and skills to answer questions from families in the NICU.** Often nurses and other staff do not have in-depth knowledge about ROP and other vision conditions, and/or they do not have the time to sit with a family and answer questions.

- **Prevent Blindness can partner with early intervention agencies to offer webinars, fact sheets, pre-conference and post-conference sessions to medical professionals to assist them in understanding what early intervention services involve and the benefits of these services to families.** Medical professionals can connect families with early intervention services in their area. Too often families are told by ophthalmologists and other medical professionals that "There's nothing we can do." Though from a medical standpoint, this may be true, from an educational standpoint it is not. Early intervention is designed to support not just the child, but the family.

- It is imperative that early intervention providers have knowledge of the impact of ROP and other eye conditions on a child's development. These professionals must be equipped to share information on how to raise a child who is blind or has low vision, especially if the child has complex medical and learning needs. **Prevent Blindness and other collaborators can sponsor training for early intervention professionals so that they gain knowledge about the impact of blindness and low vision on a child's development and practical strategies that can be shared with families.**

Conclusion

This study was undertaken to gather information to answer three questions:

- Experiences families have had when their child has been in the neonatal intensive care unit (NICU) and been diagnosed with ROP.
- Families' journeys raising a child with ROP in relation to medical care, social/emotional support, and educational services.
- Barriers families experience accessing and attending eye care appointments for their child's ROP.

Participants described several challenges and supports when their babies were in the NICU, being examined by the ophthalmologist, and diagnosed with ROP. The participants also described their journeys in parenthood caring for their child with ROP.

Through two focus groups, eight themes were identified.

- Hearing the diagnosis of ROP
- The eye exam experience in the NICU
- The emotional toll on the family when a child is in the NICU
- Education and support for families
- Preferred ways to receive information and judging the accuracy of the information
- Discharge from the NICU and adjusting to life at home
- Ophthalmological and other medical follow-up appointments

- Early intervention and special education services

Notably, nine parents did not identify barriers impacting access to eye care for children following discharge from the NICU. All 10 parents reported their child was seen at least annually by an ophthalmologist. Future research is needed to examine barriers families experience to eye care access. Recruiting participants for this type of study will be challenging, but it is necessary. If barriers are not identified, then solutions and support mechanisms cannot be developed and offered.

The parents who participated in this study offered a multitude of suggestions for ways Prevent Blindness, hospitals, and other professionals can improve the education and support for families of children with ROP. These include:

- Providing families with support options both while their child is in the NICU and once the child is home. Supports can take the form of:
    - Providing a knowledgeable individual who can provide a listening ear and answer questions.
    - Working with families to develop support groups and/or mentorship programs.
    - Creating a website specific to families who have a child with ROP or who are being monitored for ROP. The website can have information on often asked questions and a chat room for families to connect with others. k
    - Providing tangible comforts and activities (e.g., dinners, massages, access to scrapbooking materials, respite care).

- Providing families with information can better prepare them to meet the demands of parenting a child who is born prematurely and has or is monitored for ROP. Information topics include:
    - The impact of ROP on a child's development taking into account the child's adjusted age.
    - The benefits of early intervention and the role of members of the early information team.
    - The importance of advocacy and how to tell one's story. As Prevent Blindness has a successful ASPECT program, creating a family-track is a potential way to share this information.

- Providing medical and educational personnel information that will better position them to support families. Information topics include:
    - The impact of ROP on a child's development and strategies to support a child's development.

    - An overview of early intervention, local early intervention resources, and the benefits of early intervention on a child’s development.

In conclusion, the 10 parents who participated in this study shared a wealth of information. It was clear that each parent loved their child deeply and that they were committed to ensuring their child had access to medical care and educational services that would allow their child to thrive. The range of experiences in the care of their child(ren) varied widely, which led to diverse experiences, understanding, and access to support.

The recommendation set forth in this report are ones that Prevent Blindness and collaborators can consider as they continue their efforts to ensure that children born prematurely who are being monitored for or have ROP have access to both medical and educational services that will support their development. Recommendations in this report not only encompass the child’s needs, but those of medical and educational professionals, and most importantly the family.

Table 1 Children's Demographic Information

Parent's Name	Child's Age in Years	Gestational Age in Weeks	Time in NICU	Received Injections	Received Laser Surgery	Early Intervention Services Received	Receive Spec. Ed.
Andrea	1-2	24	185 days	Avastin	Yes	OT, PT	N/A
Brenda	2-3	28	130 days	No	Yes	DT, OT, ST	N/A
Cameli	2-3	24	117 days	No	No	DT, FD, OT, PT, ST, TVI	N/A
Darlene	3-4	25	78 days	No	No	PT	No
Erin	5-6	25	90 days	No	Yes	OT	Yes
Flynn	5-6	25	99 days	Yes, UN	Yes	OT, PT, ST, TVI, O&M	Yes
Gina	6-7	23	150 days	Yes, UN	Yes	DT, OT, ST	Yes
Hillary	6-7	26	140 days*	No	Yes	None	No
Indigo	8-9	27	90 days*	Yes, UN	Yes	OT, PT, TVI	Yes
Juniper	9-10	Unknown	Unknown	-	-	None	Yes

*Parent reported months, so the number of days is an estimate.

DT = Developmental therapy, FD = Feeding, OT = Occupational therapy, O&M = orientation and mobility, PT = physical therapy, ST = speech therapy, TVI = teacher of students with visual impairments, UN = parent is unsure of the name of the medication.

Appendix A: Focus Group Protocol

Hello, my name is Penny Rosenblum and my company, Vision for Independence, has been hired by Prevent Blindness to serve as their research evaluator. Specifically, I am assisting the organization to gather information about your experience of having a child who spent time in the neonatal intensive care unit (NICU) and has been diagnosed with retinopathy of prematurity (ROP). The information you share will assist Prevent Blindness as they continue to develop materials to support families of children with ROP.

Thank you for agreeing to take part in today's focus group that will last approximately 60 minutes. You will receive a $75 Amazon gift card for your participation. I will share your name and email address with Prevent Blindness staff, and they will send the gift card to you in approximately 1 month. I will be preparing a report using information learned through this focus group and another focus group. Though I will not refer to you by name in the report, if I use a direct quote from you, it may be possible for others to deduce who you are. Please know I will make every attempt to maintain your confidentiality. To that end, I ask that you not share with others what we discuss during the focus group. I will share a copy of the final report with you.

Please identify yourself by name when you speak so everyone knows who is speaking. If there is a question you prefer not to respond to, that's fine. Please just say "pass". I'll rotate who I call on first to answer a question, but please feel free to make follow-up comments.

Do you have any questions before we begin? [Answer questions]

With your permission, I'd like to record today's session so I can refer back to the recording for data collection purposes and ensure that I accurately hear what each of you shared. Thank you for providing a media release. As a reminder Prevent Blindness may quote you on the website but will identify you as a parent/guardian.

[Obtain verbal permission to record.]

1. Please introduce yourself and tell us briefly about your family's journey with ROP and how old your child is now.

2. Tell us about your experiences and feelings when first learning your child had ROP?

- Who made the diagnosis?
- How did the individual explain ROP to you and your family?
- Did you receive information on ROP?
- Were you connected with a parent support organization?
- Did your child undergo any procedures in the NICU, if so tell us about them?
- As your child prepared to come home, were any appointments made for your child to follow up on their ROP? If yes, who made the appointments? Were you consulted about the time, date, and location of the appointment?
- Were the appointments made for your child made at or near the hospital where your child was in the NICU or were they made for locations closer to home?
- Was there any follow-up from NICU staff or someone else at the hospital to ensure your child kept appointments and received ROP eye care after leaving the NICU? Tell us about the follow-up.

3. Can you share information about the information on ROP you received when your child was diagnosed and receiving care in the NICU? Please also share information on support you received and from who? Were you connected with a parent support organization?

4. What were some of the needs for support you experienced (e.g., mental health, peer support, encouragement to "keep it going" in the face of a challenging situation) when your child first came home from the hospital?
    - Are there any resources you found helpful?
    - How have your needs changed over time?
    - Are there resources that would have helped you with these needs? If so, what might these resources look like?

5. Can you share information about the eye care your child has received after their NICU stay?
    - Did anyone from the NICU follow up to see if your child kept appointments made prior to discharge?
    - How often is your child seen by an ophthalmologist? Optometrist?
    - How do you get your questions answered about ROP including diagnosis, treatments, and follow up care?
    - What are your main questions about ROP and eye care in general?
    - Do you have a different process for getting information about your child's other health issues?
    - Are there any resources you found helpful?

6. How do you prefer to receive information about ROP or your child's other eye conditions (e.g., written material, text, Tik Tok)?

- Where do you first go when you're looking for information?
- What websites or Facebook groups do you use?
- What do you consider when deciding if information is accurate or trustworthy?

7. Have you found peer support, for example from a parent group for children with disabilities or an organization that connects parents with mentors?
    - If so, please tell us about your experiences with peer support?
    - Who first told you about this option for peer support?
    - Are there informal ways you have found peer support, for example through your child's teacher who introduces you to another parent? Please tell us about these connections.

8. Did/does your child receive early intervention services? (moved from being #4)
    - If yes, how were you referred to early intervention services?
    - If yes, what did the team share with you to help you understand the impact of ROP on your child's development?
    - If no, did anyone discuss early intervention services with you?
    - If no, why did you opt not to have your family participate in early intervention services?
    - What vision services did your child receive in early intervention? Did your child receive a functional vision assessment at the beginning and/or end of early intervention?

9. If your child receives special education services in preschool or elementary school, tell us about the services they receive.
    - Do you believe the teacher of students with visual impairments serving your child is knowledgeable about ROP, why or why not?
    - What accommodations does your child receive at school because they have a visual impairment?

10. How can Prevent Blindness and other organizations help support families as they seek follow-up eye care upon their child's release from the NICU?

11. What are some challenges that your family faced during early childhood (after your baby came home from the hospital) in terms of healthcare, eye care and early intervention?
    - Are there any resources you found helpful?
    - Are there resources that would have helped you with these challenges? If so, what might these resources look like?

12. We have a few more minutes. Is there anything else you'd like to share that will help Prevent Blindness as they work to support families of children with ROP and other eye conditions?

Thank you for taking the time today to take part in the focus group. This has been a rich discussion! I will be sharing your name and email address with Prevent Blindness and within the next month you will receive a $75 Amazon gift card via email. If you think of anything else that you want to share with me, please feel free to email me. When I finish my report, I will send you a copy.