Family turns to InfantSEE™ optometrist for answers to child’s photophobia

New parents Nate and Christie Burdek sensed that something was wrong with their infant son’s eyes. They just didn’t know what it was.

“From early on, Ben was sensitive to light,” said Christie. “When we were indoors, he wouldn’t want to be near the windows. When we were outside, he’d always tuck his head in our shoulders.”

Ben wanted to spend most of his time in his parents’ arms reading books, which he always held close to his eyes. He didn’t crawl around and explore on his own.

“He wouldn’t look at a lot,” said Nate. “He was always hiding when it was bright. But 7:30 p.m.—that’s his time.”

“It got to the point where we couldn’t spend time outside. We decided we were going to mention it to the pediatrician,” said Christie. “Prior to the 9-month exam, we decided if the pediatrician doesn’t find anything wrong, we would pursue it further.”

At the appointment with the pediatrician, the doctor looked in Ben’s eyes, but didn’t think anything was wrong. He explained that light sensitivity was common with fair coloring.

Although one of Ben’s grandmothers was sensitive to light, the Burdeks did not feel that was the only problem in his case.

“We knew something was not quite right,” said Christie. The Burdeks were unsure of what their next step should be until an opportunity arose in June when Christie’s father organized a family reunion.

Attending the reunion was St. Louis optometrist Tom Cullinane, O.D., a distant cousin of Christie’s.

“When we saw Tom, he told us all about InfantSEE™,” said Christie. “It sounded great. And finding out that it was a free program was even better.”

“I knew then, as soon as I saw him at the reunion, that this was something we needed to explore,” said Dr. Cullinane. The Burdeks brought Ben in for his InfantSEE™ assessment on June 17.

“He’s corneas were large and clouded,” said Dr. Cullinane. “And he was obviously a high myope.”

He determined Ben’s lens prescription power to be -12.00D.

“I was hoping to look in his eyes when they were dilated, but at this point Ben was very unhappy, and I knew he was going to see Dr. Goodrich ASAP,” said Dr. Cullinane.

Dr. Cullinane informed the Burdeks that Ben was nearsighted, but he decided to refer Ben for a definitive glaucoma diagnosis, though he was confident in the diagnosis considering all of Ben’s signs and symptoms.

Dr. Cullinane referred them to Steven Goodrich, M.D., a pediatric ophthalmologist, who also suspected glaucoma.

“I knew when I heard ‘glaucoma’ that it was serious,” said Christie. “I mean, you think of Ray Charles. I just never thought it was glaucoma. I was not familiar with it in a child. He was born with blocked tear ducts, but they were cleared. If anything, we thought it would be related to that.”

To confirm the diagnosis, Ben would need to be put under anesthesia and examined.

Dr. Goodrich rearranged his schedule for the next morning so that he could further examine Ben.

“He did new pressures, and said yes, it is glaucoma,” said Christie. When examined under anesthesia, Ben’s intraocular pressure (IOP) was 28 mm Hg.

Dr. Goodrich was very concerned about Ben and asked to meet with the Burdeks again the following morning, which was a Saturday. He gave them more information on glaucoma and reviewed procedures with them.

Dr. Goodrich referred them to Gregg Lueder, M.D., a pediatric ophthalmologist at Saint Louis Children’s Hospital, who was a congenital glaucoma specialist.

“Dr. Lueder performed goniotomy on Ben on July 19, just six days before Ben’s first birthday.”

“It’s amazing after the surgery—just the improvement. The day after the surgery, he started going to Christie’s parents much more readily. His comfort level was so much better. And when he got his glasses, he just started cruising,” said Dr. Lueder prepared the Burdeks for the possibility of multiple surgeries, but when Ben went back for testing in early August his pressures were within the normal range.

“He pressures were in the teens,” said Nate. “The doctor said the optic nerve looked like it had improved, and he didn’t need a second surgery at that time, which was great because success from the first surgery is not the norm.”

“We couldn’t have asked for a better outcome that day,” said Christie.

Ben’s cornea is fragile and relatively thin. He will continue to have exams under anesthesia every few months and may require examination every six months until he is 6 or 7 years old.

“If it wasn’t for the glaucoma, Nate and I thought he could have been walking or crawling earlier,” said Christie. “One good thing, if you could call it that, is that his speech is very developed. Glaucoma can show up at birth through whenever, and Ben’s case isn’t as severe as other cases that they detect at birth.”

“We’re really lucky we caught this early,” said Nate.

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“If we hadn’t found out about InfantSEE™, we wouldn’t have pursued this as quickly as we did,” said Nate. “I don’t know where we would have gone.”

The Burdeks were grateful to Dr. Cullinane and brought Ben to see him a few weeks after his surgery.

It was an emotional reunion for Dr. Cullinane, who was overwhelmed by Ben’s improvement and advances.

“I got a bit choked up,” said Dr. Cullinane. “If you could have seen where he was before and where he is now, the difference is just amazing. It’s unbelievable.”

The Burdeks hope pediatricians start promoting the InfantSEE™ program to other parents.

“It’s a perfect opportunity for a pediatrician when a parent has concerns, and the pediatrician doesn’t think anything is wrong, to send them in for an InfantSEE™ assessment,” said Nate. “It’s free and can put the parents’ minds at ease.”

The Burdeks want to make sure every parent knows about InfantSEE™.

“For Nate and I both, one of the first things we did after going back to work was share with everyone about the InfantSEE™ program,” said Christie. “In public, people react to his glasses and ask about them, and that’s a great opportunity to talk about InfantSEE™,” said Nate.

Dr. Cullinane was the first optometrist to sign up as an InfantSEE™ provider in Missouri and has performed 15-20 InfantSEE™ assessments since the program was implemented in June 2005.

“The InfantSEE™ program is a valuable tool for all infants around the country,” said Dr. Cullinane. “I urge more optometrists to get involved. Many think it’s difficult to do assessments at this age, but once you do a few, it’s kind of fun.”

For more information about the InfantSEE™ program, or to sign up as an InfantSEE™ provider, e-mail infantsee@aoa.org, call (800) 365-2219, ext. 4286, or visit www.aoa.org.

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