ROP follow-up: through hell and high water

Devon Schuyler

WHEN nurse Debbie Neff returned to Tulane Hospital in New Orleans several weeks after Hurricane Katrina, the Neonatal Intensive Care Unit where she worked was in complete disarray. The hasty evacuation – which involved carrying the infants up eight flights of stairs to the heliport – had left the floor filled with a haphazard maze of cribs and bottles of mouldy formula.

So it came as a surprise when she reached her desk at the end of the floor, slid open the drawer, and was able to retrieve the precious folder that contained all her contact information for the New Orleans participants in the ETROP (Early Treatment for Retinopathy of Prematurity) study. Neff is the study's New Orleans coordinator.

Over the following months, she would track down all 10 of the study participants – most of whom came from the most heavily-hit areas of New Orleans, such as Eastern New Orleans and the Lower Ninth Ward – and make arrangements for them to be seen at one of the study's 25 remaining centres. The result is that not one of the New Orleans patients missed their annual follow-up exam. By contrast, follow-up for the study's other 391 participants was approximately 90 per cent.

"Quite frankly, I had already contacted the coordinator in Houston and I pretty much said, 'I think my part of this study has ended because every study patient has vanished and I'll never be able to track them down,'" said Neff. "I just saw doom from where I was."

Courtesy of National Eye Institute, National Institutes of Health

A paediatric ophthalmologist uses an indirect ophthalmoscope to examine an infant for signs of retinopathy of prematurity (ROP)

Her home was liveable but damaged, with a soaked carpet and a mangled roof, and she didn't know whether she had a job.

"Tulane was continuing to pay us, but we were told that they didn't know how long that would continue. So at this point, I was considering myself jobless," she said.

But she took her folder home, picked up her cell phone (her land line was not working), and started calling the families of the study participants.

"When they entered the study, I told the parents that I needed the phone number and address of anybody they could think of who was in a stable environment, so if they happened to move, I could contact this person and they would be able to put me in contact with them. Every patient gave me at least three addresses, and even more phone numbers."

She continued calling cell phones, relatives, and friends of participants, either getting leads or leaving messages when possible.

"One patient had a grandmother in Alabama, so I was able to contact her that way. Another patient's family was in Houston; they had lost everything and were staying there."

When she had exhausted the phone numbers, she sat down and started writing letters to every address she had for the missing participants.

Four patients needed to be seen in the early months after the hurricane to avoid missing their window for follow-up; she arranged for three of them to be seen in Houston and one in Los Angeles. Neff also tracked down the remaining six patients; five of these have been seen for follow-up. The remaining patient had been seen shortly before the storm, so her follow-up window re-opened only recently.

"I don't know how I was so lucky to find every single one of them," said Neff.

She attributed most of her success to the fact that she had built strong personal relationships with all of the families – to the point that one of them even had her on speed dial.

"I've always felt that it goes beyond what I need to do as a study centre coordinator to make my patients feel that if they needed anything, even outside of the study, they could call me," she said.

Robert J Hardy PhD, the study's principal investigator at the coordinating centre in Houston, agreed that Neff's personal relationship with the families made all the difference, and commended the work of Neff and Robert A Gordon, the principal investigator in New Orleans, for their work in locating the infants and their families and arranging for them to be seen.

"They did it by developing phenomenal relationships with their patients from the very beginning," he said.

William V Good MD, the ETROP Study Chair, advised other investigators to "get good people involved in your research, who form helpful as well as scientifically oriented relationships with the families… that's what forms the groundwork for being able to have follow-up in the extremely unlikely event of a disaster."

The initial results of the ETROP Study, released in December 2003, demonstrated that premature infants, who are at the highest risk for developing vision loss from ROP, will retain better vision when therapy is administered in the early stage of the disease. Follow-up continues at 26 participating centres in the US.

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