CASE STUDY

SOPHIA'S WORLD

Carol-Ann Oragano accepts her daughter is permanently disabled, says **Joy Orpen**, but she has had the help of other brave parents and found laughter to be the best medicine

Four-year-old Sophia Oragano must be one of the happiest children in the world. She seems to find everything incredibly funny and she laughs constantly. Her laugh is so infectious that people are instantly captivated by her. Yet Sophia, of the long, curly locks, has many disabilities. Because of brain damage that occurred before she was born, she is almost totally deaf, is wheelchair-bound, and has several other debilitating problems.

Her mother, Carol-Ann, 39, says Sophia's delivery at the Rotunda Hospital was without incident and that her Apgar score — the measure of a newborn's general health — was high.

However, the next day she saw her baby turn blue and though it was only for a second or two, she had a doctor check her out. Finding nothing wrong, the doctor nonetheless moved the infant to the neonatal intensive-care unit (NICU) for observation. Staff initially suspected a chest infection but, when that proved not to be the case, blood tests were done. These were soon followed by an hour-long brain scan.

By day three, Carol-Ann, a nurse, and her English-born husband Sean — a building surveyor who has Irish and Italian antecedents — were getting seriously worried. "I hadn't slept a wink the night before," says Carol-Ann. "Then the neurologist told us Sophia had congenital cytomegalovirus [CMV]." Congenital means the condition was present at birth. "He showed us the scan. It was completely obvious," she says. "There were calcifications all over the brain and oedema, while the brain itself was smaller than normal."

It now seems likely that the baby fell victim to the virus when Carol-Ann suffered a minor cold just six weeks into her pregnancy. She explains that CMV is a very common herpes-type virus — many people have it and display no symptoms. But, when an immune system is compromised for whatever reason, then danger looms.

"That was the worst possible time for Sophia to get an infection like that. At six weeks her brain was just developing, while she wouldn't have had a proper immune system yet," Carol-Ann explains. "If I'd been into my second trimester, her hearing might have been the only thing affected. And, had it been in the final stages of pregnancy, then she would probably have been completely fine. Although I only had what I thought was a tiny cold, the timing couldn't have been worse for the baby."

It was all heartbreaking for the Oraganos. "When we got the diagnosis, I was in a ward with all these happy mothers and their perfect babies and I was so upset I said to the nurses, 'Get me the hell out of here,'" Carol-Ann recalls.

She was moved to a room for mothers whose children were in intensive care. "I was then with different parents who were upset, worried and crying and I felt more comfortable there," she says. Those same parents were, in spite of their own troubles, very supportive and Carol-Ann still sees some of them.

Shortly after, the Oraganos were told that, while Sophia probably wouldn't die, she would have lifelong severe mental

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and physical disabilities and she might prove to be blind and deaf.

"The deaf-and-blind bit was the worst for me," says Carol-Ann. "I hated the thought that she would be trapped inside her body."

Soon after Sophia's birth she was given aggressive anti-viral therapy in the hope that some of her hearing might be saved. So the pair remained in the Rotunda for more than six weeks. As time passed, it emerged that Sophia had partial hearing and that she could see — the first piece of good news the Oraganos had had since her arrival.

This initial period is somewhat hazy for Carol-Ann. "I was just limping from day to day," she says. "For the first six months I had a horrible sinking feeling in the pit of my stomach. I also got shingles soon after Sophia was born and I'm sure it was caused by stress."

Carol-Ann is a very strong, optimistic woman and eventually she rallied. But she has no illusions about her daughter's future. "She is definitely going to be permanently disabled at a profound level for the rest of her life — unless a miracle occurs," she says.

Carol-Ann says because of her many disabilities, Sophia requires 24-hour care. "She can only swallow liquidised food and she suffers from chronic constipation and reflux. It takes ages to get her dressed, fed and ready for school. Then there are the two boys, Sam and Charlie, to get ready as well. Mornings in this house are a bit of a nightmare," she says.

On weekdays, Sophia is at St Michael's in Baldoyle — a school for people with intellectual disabilities — until mid-afternoon and, by all accounts, she is a great hit with everyone.

Carol-Ann says of her good-natured daughter: "She is like a doll in a box — so sweet. She's very placid and laughs constantly. She even wakes up in the middle of the night laughing at God-knows-what for about an hour, before she goes back to sleep. She's gas."

Sophia's wonderfully big-hearted and intuitive brother Sam says of his little sister: "When she came out of the tummy, her brain didn't work. I am sad that she is missing out on all the amazing things we do. But she's special, because she is the only girl in our family and I think she is really pretty. And it's so good that she can see and make sounds. I love it too when she laughs — she just loves hugs and kisses."

The entire Oragano family says they are also blessed by the generosity of the Laura Brennan Charitable Trust which aims to help children such as Sophia, especially those in the Malahide area. The trust was set up by Pat and Nuala Brennan in memory of their daughter Laura, who died following a short illness when she was just 16.

Thanks to them, Sophia has crucial occupational therapy twice a week and, also thanks to them, Carol-Ann was able to take her daughter to Brainwave in England for two days of intense therapy and follow-up exercises at home.

"Because of the current cutbacks it's hard to access services, so the Trust really fills a gap for us," Carol-Ann says. "While Sophia is receiving vital stimulation during physio and occupational therapy, I can forget about her and concentrate on the two boys and that is also really important.

"I'm just so grateful to the Brennans — they are such amazing people."

The Laura Brennan Charitable Trust is holding a fund-raising gala evening on February 11, tel: (01) 845-0621, or see www.laurabrennan.org