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DAVID McLAIN/Buffalo News



Stroke victim Gerry Andrzejewski meets a new friend at picnic.

Parents, disabled children celebrate life at 1st picnic

THEY ARE PART of the world's uncounted and countless "sleeping children," and this was their day in the sun, their first picnic.

Over the happy, noisy play of their brothers and sisters who tossed water-filled balloons and eggs, you could hear the drone of battery-powered motors pumping formula food to them through tubes. And you also could see mothers diapering children who were long past the age of diapers.

Still, it was their day, a celebration by parents of the lives of children whose days and nights are spent in a comatose state. It was a day when, with help, a mother or father could guide a limp hand to touch a cow, pet a lamb and feel the fur of a newborn kitten — a day to reach out from darkness and discover a piece of life.

For them, there was no laughter, no wide-eyed wonderment. It was, as the mother of a 7-year-old boy said, only an outing — "but if you take this day away, how would it differ from his being in prison?"

They came to this Marilla farm by different routes — some as a result of birth defects, some through strokes and disabling diseases and heart attacks. And all of them were severely and multiply handicapped. They came as sleeping children.

Separately, they came from all over Erie County. Collectively, they came from the Center for Handicapped Children at 777 Maryvale Drive — a six-room schoolhouse where there is no such thing as reading, writing and arithmetic, but where, with parents and staff, they are part of an extended family, their lives tailored to an awesome reality.

Gerry Andrzejewski, 8, for example, is learning not to pull his hand away when someone touches his arm. It has been an extended and, at times, a frustrating teaching process.

"In time," says his mother, Donna, "Gerry may learn to turn his head to indicate a 'yes' or a 'no,' but that's a long, long way down the road."

Gerry is a stroke victim, and in June 1986, when he "graduated" from a special class for exceptional children, his mother videotaped what were to be Gerry's last spoken words. "I love you very much, Mom," he said. Soon after, he was left paralyzed and barely-conscious by another seizure.

The school and working for it with the parents of other children has been her living lifeline ever since, Mrs. Andrzejewski said.

Of her son, Nathan, 7, also left comatose by prolonged cardiac arrest, Mabel Janiga said she knows — "as only a mother does" — that Nathan can experience pleasure.

"I want to see him happy. I love it when he smiles and seems to experience pleasure," she said.

Picnic: Parents seek small signs of happiness

Continued from Page C1

"The school has given me hope, friendship and support," she said. "As parents, we all have something in common: We want what is best for our children under whatever circumstances prevail."

Though it was a picnic for children, it was an unusual one. And throughout the day, the parents and guests played the usual picnic games. But they also spent a lot of time scanning the faces of their sleeping children, searching for the smile or slight turn of the head that would say, "I'm having fun." And some found it; others didn't.

For Mr. and Mrs. Jon Knapp, there was no face to search, no child's glance that would signal them that their 13-year-old daughter, Kristine, was having a good time. Kristine died a month ago.

"This is our family now," Mr. Knapp said, "and that means we're not alone."