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LIVING

Searching for a miracle

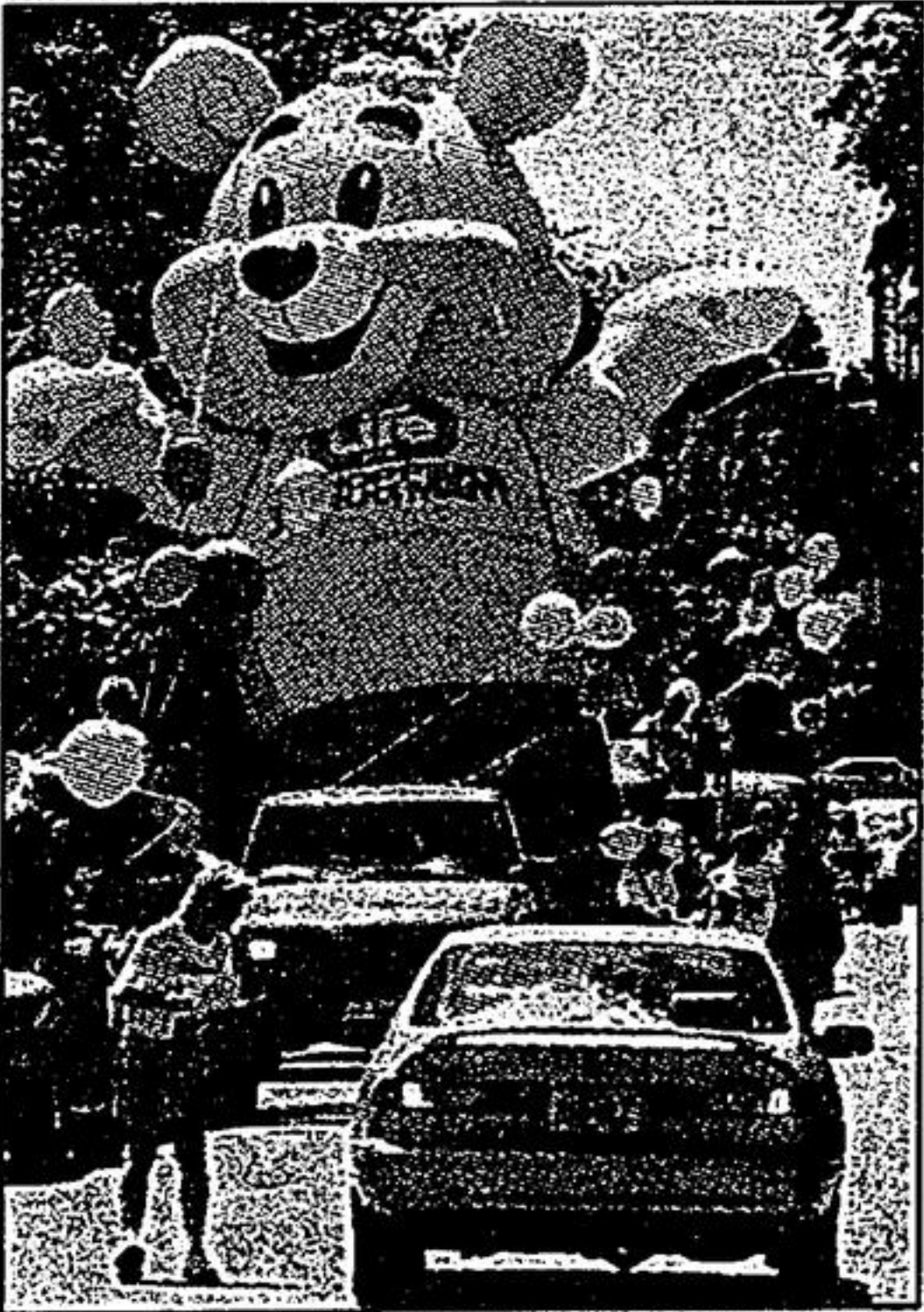
Brainchild support group extends a hand to children who have brain cancer and their families. Next Saturday, the group is hosting Summerfest, an annual fundraiser supporting brain tumour research.

BY JULIE CASPERSEN
STAFF WRITER

When Caryn Mohammed died of brain cancer in January 1993, her family and friends were determined to make something positive out of the devastating loss.

A brain tumour ended the 14-year-old's life, a little over a year after she was diagnosed with cancer.

Around the same time, another Markham couple was struggling to cope with a similar nightmare when a tumour was discovered in



STAFF PHOTO/SJOERD WITTEVEEN

The Brainchild parade passes through Unionville Main Street last Saturday to promote the Aug. 8 Summerfest at the Markham Fair Grounds.

EARLY DETECTION IS IMPORTANT

Brainchild offers some symptoms that could be the early warning signs of tumors or cancer in children:

- headache
- double vision and visual disturbances
- morning nausea and vomiting
- weakness or paralysis in any part of the body
- personality changes
- hearing disturbances

According to Brainchild, there is a five to 10 per cent increase in pediatric brain tumors each year. And after leukemia, brain tumors are the most common malignancy in children. Families and friends of children with brain cancer are invited to the support group meetings that take place on the second Thursday of each month at 7 p.m. at the Hospital for Sick Children, 555 University Ave., Toronto.

the brain stem of their oldest daughter.

Jennifer Green is now 17, living a normal, healthy life, and is celebrating her sixth year in remission.

The two families, who attend the same Markham church and who practically lived at the Hospital for Sick Children during their daughters' illnesses, vowed Caryn won't have died in vain.

"We decided to start the group the day Caryn died," said Jennifer's mom Karen Green.

And that's how Brainchild was born. The group exists for three reasons:

- to support children, their families and friends;
- to inform people about the importance of early detection;
- to provide funds for research into causes and treatments of brain tumours.

"Brainchild came out of the need to do something out of the helplessness," Karen said.

When Jennifer was diagnosed with medulloblastoma in Aug. 1991, it was sudden and it was terrifying.

She was 10 years old, and had been swimming and riding her bicycle that day. She complained to her mom about a headache around 4 p.m. Karen originally thought Jennifer had heat stroke, but it quickly became apparent that something was seriously wrong with her.

"One hour later she didn't know who I was."

Jennifer was taken to Markham

Stouffville Hospital where a CAT scan sent warning signals about a problem in the girl's brain stem. By 8 p.m. Jennifer was admitted to the Toronto hospital.

Within six weeks she'd lost her sight. Over the next eight months she endured nine operations. The following year was filled with radiation treatments.

It was during this time that the Greens and the Mohammeds leaned on each other for support, wondering how other families get through the nightmare.

"Helplessness is not having a clue what to ask, who to call," Karen said.

Karen said the tragedy was compounded by isolation — the vast majority of parents don't have to deal with cancer in their children; most people would rather dismiss the fact that childhood cancer exists; most people shy away from the subject of cancer when talking to a family dealing with the illness.

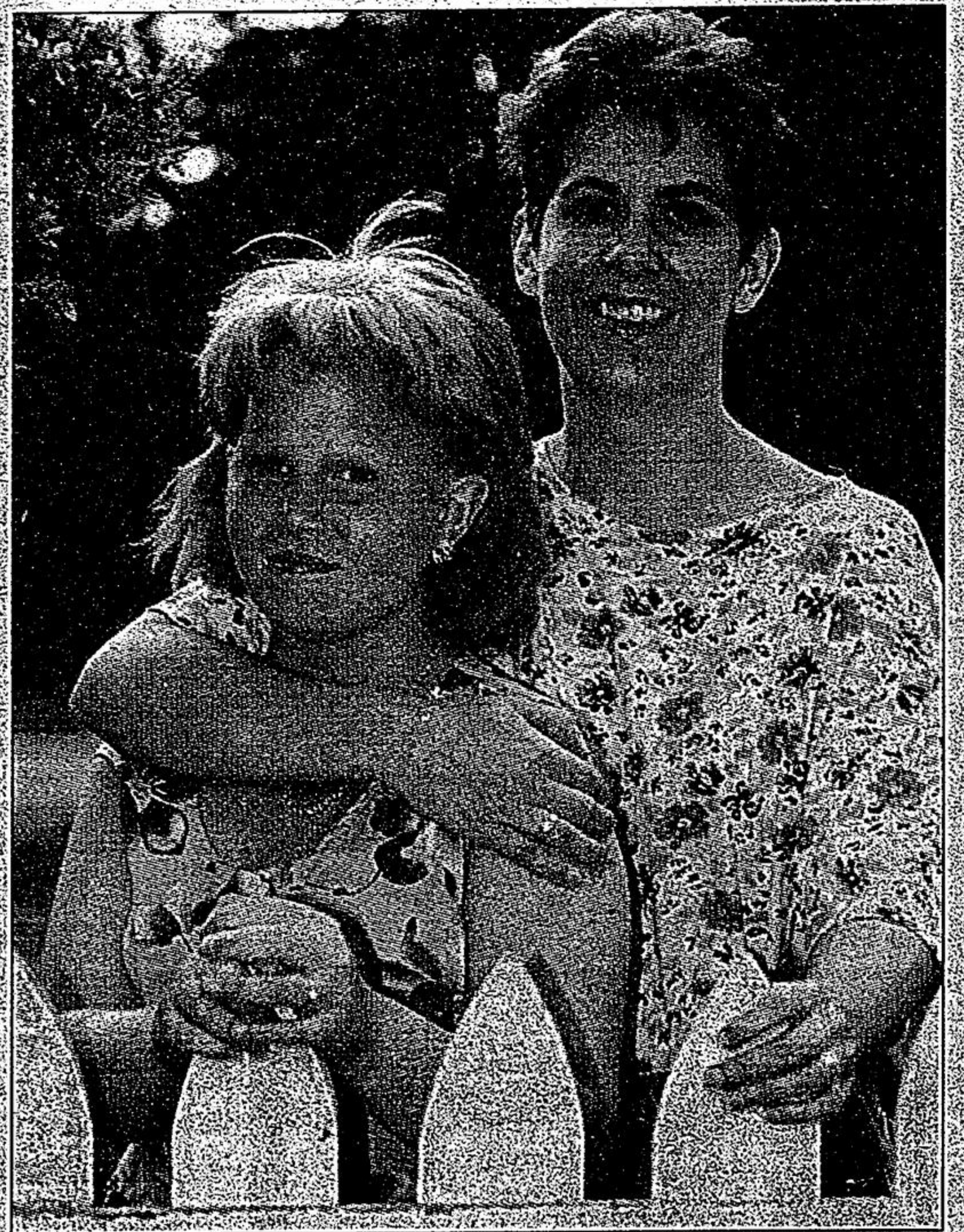
But for the Greens, dealing with cancer became part of their normal life, although Karen said she felt her family was "running parallel" to everyone else.

Karen said despite the suffering and the terminal nature of the disease, the children living with cancer rarely complain, and try to take each day on its own. "Brainchild is a memorial to their courage, a memorial to their dignity."

And out of the nightmare, she and her family learned a lesson: "We never take anything for granted," she said, giving Jennifer a hug. "Every day you wake up in the morning is a gift."

The existence of Brainchild is like a gift to families with newly diagnosed children, pairing them up with others who have been through the cycle, hooking them up with bereavement support groups, letting them know they are not alone.

Last year alone, the number of new cases of brain tumours diagnosed at the Hospital for Sick Children was between 60 and 100. Their cause is unknown, and there is no way to predict or prevent them.



STAFF PHOTO/SJOERD WITTEVEEN

Karen Green, right, helped launch Brainchild after her daughter Jennifer was diagnosed with a brain tumour in 1991.

Brainchild is holding its fourth annual Summerfest, a fun family carnival held in Markham, in order to raise much needed funds for research as well as to enhance patient care.

Last year's event raised \$40,000 through raffle tickets, silent auction, and donations. Brainchild has provided ambulatory pumps for terminally ill children to allow them some mobility at the hospital, and ensured there is a VCR in every patient room in the neuro-surgical unit.

This year's Summerfest is on Saturday, Aug. 8. There will be helicopter rides, jumping castles,

games, a corn roast, a hot air balloon (weather permitting), and appearances by children's favourite TV and movie characters. The activities also include a silent auction, live bands, and a car show.

There are still opportunities for vendors with craft booths to join in, for a \$25 donation.

Admission is \$5, and this includes a raffle ticket for a chance to win a Honda Civic hatchback.

For more information on Brainchild call (416) 813-7974. For details on Summerfest, call committee president Gary Kisilowski at (905) 764-0922, or the Mohammeds at (905) 471-1294.



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