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Putting a smile on sick children's faces

The loss of a child led to the formation of a society that seeks to fulfil the wishes of children with terminal or life-threatening illnesses.



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AFTER his dream meeting with Tun Dr Mahathir Mohamad, there was a marked difference in Mohd Nur Nazari Mohd.

The 15-year-old, who was fighting cancer, had a spring in his step and a dogged determination that had never been seen since he became ill, relates his mother Rohani Kadir Gani.

He started talking more and even managed to walk further, albeit at slow speeds, says Rohani from Seberang Prai, Penang, and she adds: "He fought (the illness) until the very end."

Dr Mahathir had told her boy to keep up his spirits and not to think about his condition too much, says Rohani. "That visit changed him and he was more resolute."

Her only son, Nur Nazari passed away a month or so after the meeting with Dr Mahathir. "But he did not look sickly at all when he died," she recalls.

Nur Nazari's meeting with the nation's fourth prime minister was arranged by the Child's Wish Society of Malaysia (CWS), a charity that is dedicated to fulfilling wishes of children stricken with life-threatening or life-limiting diseases.

He had initially wanted go on a pilgrimage to Mecca but because of his condition, he was advised against making the arduous journey. He then asked to meet with Dr Mahathir.

Rohani only has praise for the CWS which, she says, made her son's final days more exciting. "I am really proud of what they were able to do, raising my son's spirit"

Since its inception in 2008, the society has granted about 110 individual wishes. It tries to grant wishes of those below 18 years old who are stricken with life-limiting diseases.

According to CWS secretary Nik Rozana Nik Hassan, anyone can refer a wish to them. The wishes will then go through a panel of doctors who decide if they can be granted.

Awareness of the society is growing, with about 3,000 members on its Facebook group receiving constant updates about its activities. "We want to reach out to more children," says Rozana.

The CWS had initially focused on children with life-threatening illnesses but this was expanded to include those with life-limiting diseases.

Most of the wishes are for electronic devices such as mobile phones, iPads and laptops, but there are some that are very simple and innocent

One girl wanted a pink teddy bear while another girl wanted a bicycle.

There are also those who wish to see animals such as orang utans, parrots or elephants.

Last year, leukaemia patients Mohd Nur Adha Sariffuddin, 12, and Intan Mariysa Eilya Maryanzam, five, from Perak and Perlis, respectively, got their wish to ride on an elephant at the Lok Kawi Wildlife Park in Sabah fulfilled.

Then there are those who want to meet their sports heroes.



Moment to cherish: Nur Nazari, who had his wish fulfilled, talking to Dr Mahathir during their meeting earlier this year. - Picture courtesy of CWS

For Muhammad Anas Sadiq Aminuddin, 15, who has been suffering from Duchene Muscular Dystrophy (DMD) since he was a child, meeting Manchester United legends Bryan Robson and Andy Cole was on his wishlist. (DMD is a recessive X-linked form of muscular dystrophy that results in muscle degeneration, difficulty in walking and breathing, and death.)

The wish was granted when Anas met his heroes who were in Kuala Lumpur in March for the EPL Masters tournament.

His mother Siti Nazriah had contacted the CWS via Facebook and upon confirming with Anas' doctor in Muar, the society granted his wish.

According to CWS vice-president Teoh Teik Hoong, the society was formed when two of its current board members lost their nine-year-old daughter to leukaemia.

While in hospital with their daughter, they saw that many other children were suffering from all kinds of diseases.

"Overseas, it is not uncommon to hear of children's wishes being granted," says Teoh, who describes the setting up of the society as an informal affair and that it is run entirely by volunteers.

In its first case, the CWS gave a portable DVD player to a bedridden boy in Petaling Jaya who had Down Syndrome and was suffering from leukaemia.

There is a cap to the wishes and the family's background is also taken into consideration.

If the wish is from a wealthy family, it will still be considered as there are wishes that money can't buy, says Rozana.

"Money won't be able to buy them a visit to the Prime Minister's residence, for example," she says.

Mohammad Nur Aliff Omar, 11, who suffers from DMD, was treated to breakfast by Prime Minister Datuk Seri Najib Tun Razak and wife Datin Seri Rosmah Mansor last October.

"There were no formalities and it was all very casual," says Teoh, adding that Najib subsequently named his Arowana fish after Nur Aliff.

In case there are some people who think they can fool the CWS with fraudulent wishes, Teoh says they are able to tell if the wishes

have been instigated or choreographed. They once received a wish purportedly from a 13-year-old hospitalised girl asking specifically for a Playstation console and a 32-inch television set.

"We can tell when a wish is genuine or not," Teoh adds.

The society conducts its own fund-raising event once a year and accepts donations from people and corporate partners.

AirAsia, for example, sponsors flights for the children and their families.

The society does not accept personal donations for individual cases as they want contributions in a pool to reach as many recipients as possible. As such, they don't accept donations in kind but rather in cash.

"We emphasise that time is not on our side and if we have funds, we can immediately purchase the required in an instant," says Teoh, explaining that some of the children were living on borrowed time.

Teoh also says that many play their part to make the wishes of the child come true. He likens these people as jigsaw pieces that come together to put a smile on the children's faces.

"At the end of the day, the real heroes are the children who suffer in silence. Despite their pain and illness, they can still afford to smile," he says.

For more information on the CWS, log on to cwsmalaysia.com or call 03-5632 4941.

Eat durians to raise funds

IF you happen to be in Subang Parade on July 3 and the smell of durians overwhelms you, don't be alarmed. Six tonnes of Malaysia's most loved King of Fruits will be brought in specially from Mantin, Negri Sembilan, for an all-you-can-eat session, which is part of the Child's Wish Society of Malaysia's annual fund-raising event. Tickets are priced at RM20 for a one-hour durian-eating session (there will be four sessions). For more information, call 03-5032 9778 or drop by Subang Parade's guest services counter to purchase your tickets.