

Remembering Nebyu

"I wanted to do something to remember him."

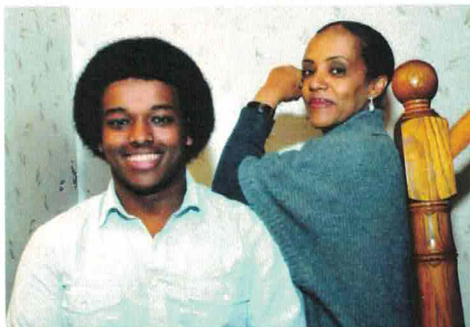
When Anna Argaw's son, Nebyu Taddese, was diagnosed with epilepsy it came as a shock. He was in Grade 10 and his seizures appeared suddenly. Even more shocking was his unexpected death from SUDEP only a few years later at the age of 19.

To hear Anna talk about her son is to learn a little about an amazing young man. A hockey player and President of his student council, he dreamed of being a sportscaster and was studying media and communications at the University of Toronto.

More than that, by all accounts he was an incredibly friendly, caring person. After he passed away friends and classmates described his willingness to lend a kind word or a supportive hand when someone was going through a hard time.

Nebyu refused to let epilepsy be an obstacle. He wasn't ashamed of his epilepsy and didn't try to hide it. His medications seemed to be working. He was a good student and was working at his summer job the same day Anna arrived home to find him in bed. He wouldn't wake up.

Making the loss worse for Anna was the feeling



Nebyu & Anna

that she had never prepared herself for the possibility that she could lose her son to epilepsy.

"I never heard that he could die from epilepsy, how serious it was. I was worried about the medication, or if he was going to be slowed

From Making Sense of SUDEP by SUDEP Aware

www.sudepaware.org

Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of a person with epilepsy, without warning and where no cause of death could be found.

Recent studies estimate the rate of SUDEP at about one death per 1,000 people with epilepsy per year.

The cause of SUDEP is unknown. It usually occurs at night or during sleep, and this makes it hard to find out exactly what happened during the last moments of life. There is often, but not always, evidence of a seizure before death. A seizure at the time of death is not needed for diagnosis of SUDEP.

The strongest risk factor for SUDEP is having frequent generalized tonic-clonic (grand mal) seizures. The more frequent these seizures are, the higher the risk of SUDEP.

The best way to reduce the risk of SUDEP is to have as few seizures as possible.

- Keep regular appointments with your healthcare provider.
- Take your seizure medications regularly and reliably. If you have concerns about side effects, it is important not to make changes to your medications without talking to your healthcare provider.
- Identify and avoid triggers for seizures (such as lack of sleep, drinking too much alcohol or using recreational drugs).
- Ask your healthcare provider about other epilepsy treatments (such as surgery) when medications are not enough to control seizures.

down," says Anna. "Maybe the doctors don't want to scare people but I think it's good for the family to know there is death from epilepsy; you'll be prepared for it. Doctors should let you know that it can happen."

OUR FALLEN SUPERMAN:



REMEMBERING
NEBYU TADSESE

Yearbook Memorial

Now Anna wants to help to keep Nebyu's legacy going. She's become very involved with Epilepsy Toronto, helping to raise awareness for Purple Day and organizing a team of walkers for Team Epilepsy Toronto at the Scotiabank Waterfront Marathon.

"When my son passed away I was shocked. Now I'm just missing him; it's hard to

accept," she say.

"We need to educate people about epilepsy."



Hockey Star



Changes to the Epilepsy Program at the Krembil Neuroscience Center

The Epilepsy Program at Toronto Western Hospital continues to offer patients many of the newest therapies and treatments for controlling seizures. Our commitment to ongoing innovation and excellence in patient care has led to a number of recent changes within the Epilepsy Program.

The Krembil Neuroscience Centre has been previously known for the only adult epilepsy monitoring services in Toronto, consisting of a 5 bed Epilepsy Monitoring Unit (EMU) for continues video/EEG monitoring of patients being considered for surgery and those requiring accurate diagnosis of epilepsy. Our program is delighted to announce the expansion of its existing EMU as of July 2014. The EMU has doubled in its capacity, making it the largest adult EMU center in Canada. Since the admission capacity to the EMU has doubled, our wait times have dramatically decreased.

We have expanded our multidisciplinary team by adding new members with specialty in epilepsy care including a new epilepsy surgeon, neurologist (with special interest in women's health), nurse practitioner, EMU nurse coordinator, EEG technologists, social worker, neuropsychologist, and administrative support staff.

The Krembil Neuroscience Center Epilepsy Program is committed enhancing care by providing access to best-practice management and shortening wait times for diagnostic testing and treatment of individuals living with epilepsy.