

MEDIA RELEASE

EMBARGOED: Midnight - Sunday 6 June 2010

PRIMARY DYSTONIA AWARENESS WEEK LAUNCHED TO HELP SERIOUSLY ILL SISTERS

Today, the national campaign 'Primary Dystonia Awareness Week' was launched by multi-award winning journalist Ben Fordham to raise critical funds to help Australia's only two children diagnosed with the painful and debilitating disorder, primary dystonia.

Leanna (15) and Bethany Mills (13), are the only two children known in the world to have been diagnosed with the rare, progressive, degenerative neurological disorder, featuring their unique combination of symptoms. There is no known cure and treatment is severe and often debilitating.

Leanna, Bethany and their family's plight was first made public on Christmas Eve 2004, when Fordham championed the cause on Channel 9's *A Current Affair* hoping to raise enough money to fund essential treatment and life-saving surgery in France.

"I will do whatever I can to help Bethany and Leanna. Despite the fact they make fun of me at every opportunity, I love them like sisters. We've managed to raise a lot of money for them over the years but they need assistance again urgently," Fordham said.

"When we first told the story of Bethany and Leanna's unique life threatening circumstances and the need to fund surgery in France, *ACA* viewers were so moved by the suffering of these two little girls and the severity of their rare disorder, that they were compelled to help. Now with Leanna's health failing, we hope they will want to help again," said Fordham.

In 2005, thanks to the generosity of Australians, the funds raised allowed both girls to undergo the high-risk surgical procedure known as Deep Brain Stimulation (DBS) which involved the implantation of electrodes deep in their brains.

Connected by wires to batteries implanted in the girls' abdomens, the electrodes send electrical impulses to specifically targeted parts of the brain aiming to minimise the excruciating muscle pain, excessive contractions, restricted body movement, tremors and spasms which cause their entire body to painfully twist in abnormal positions.

"For Bethany and Leanna, the DBS fuelled by batteries in combination with powerful drugs have had a short-term benefit with the outcome for Bethany being the most positive. However, Leanna's treatment has not been so successful," Fordham said.

"Having been recently diagnosed with Parkinson's on top of the affects of her primary dystonia, without help Leanna's outlook and quality of life is bleak," he said.

Michelle Mills, the girls' mother has been deeply moved by the compassion of Australians saying, "If it weren't for Ben's ongoing support and the many, many Australians who've helped us, Bethany would not be alive today.

"While Bethany still needs around-the-clock care, Leanna, is not doing very well at all. She's in a lot of pain and it's difficult for her to eat. Soon we'll have to start feeding her with a tube. Her ability to speak is also deteriorating which means it's very difficult for us to understand what she's saying which is very frustrating for her. She's so unwell and because she can't use her powered wheelchair in the house, the involuntary spasms are causing her to fall over all the time. Leanna's such a brave little girl but we're afraid that unless we get some help soon, one day, a fall will cause her serious and irreversible damage," Mrs Mills said.

The aim of this campaign is to once again appeal to the generosity of all Australians, individuals and businesses particularly in the lead-up to the end of financial year, to raise enough money to help cover the cost of care, ongoing essential trips to France and importantly, improve the quality of life the girls desperately need by providing them with a purpose built home that will accommodate their needs.

“With Leanna’s health declining rapidly, the family desperately needs funds to prolong and improve her life,” Fordham said.

“We hope to raise enough funds to purchase a block of land and build a home designed specifically around Bethany and Leanna’s needs which includes a hydrotherapy pool for daily treatment to help minimise their pain and improve their muscle function to give them as much mobility and independence as possible, for as long as possible.

“Channel 9 viewers have been amazing and always seem to dig deep when Bethany and Leanna need a hand. Let’s hope they get involved again!” said Fordham.

In the lead-up to the end of this financial year, all Australians have the chance to make a real impact in improving the quality of life of these two brave young girls and their family by making a tax deductible donation today.

Donations of \$2 or more will be gratefully received and are fully tax deductible.

Donate today to the ‘Leanna & Bethany Primary Dystonia with DBS Charity Foundation’.

Website: mycause.com.au/millssisters

Phone: 4032 7145 (from anywhere in Australia)

Mail: PO BOX 8005, Marks Point Post Office, Marks Point Road, Marks Point NSW 2280 Australia

For more information about Bethany and Leanna please go to: www.primarydystonia.org.au

ENDS

Interview opportunities include:

- Parents: Nick & Michelle Mills
- Bethany & Leanna Mills
- Ben Fordham
- The Mills Sister’s Australian doctor

To request an interview or photographs please contact Insight Communications

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JOURNALIST NOTES

Family History

1998 - Aged two, Bethany’s first symptoms appeared

1998 - Aged four, Leanna was admitted to hospital suffering a bout of pneumonia when first symptoms began with her arm twisting involuntarily behind her back

1998 - Nick Mills forced to quit work to help take care of the children

1998 - Sold family home for around \$140,000 to help fund trip to England to take the girls to see Dr Robert Surtees in order to diagnose their symptoms

1999 - Travelled to England to see Dr Robert Surtees. Both girls were diagnosed in theory with a cross medical condition called primary dystonia/Parkinson's. To date, Leanna is increasingly affected by Parkinson’s whereas Bethany suffers from primary dystonia only

2000 -Travelled to New York to see a specialist

2004 - First met Ben Fordham and A Current Affair (ACA) who filmed a story about Bethany and Leanna

2004 - On Christmas Eve their story aired on ACA, raising about \$140,000 in donations

2005 - In March Bethany travelled to Montpellier, France and underwent Deep Brain Stimulation surgery

2005 - In November Leanna underwent Deep Brain Stimulation surgery in Montpellier, France

2009 - 1 February – the Australian Taxation Office endorsed the Bethany and Leanna Mills Primary Dystonia with DBS Charity Foundation has having charitable tax concessions status

Leanna and Bethany Mills - The Mills Family Story

Australian born sisters Bethany (13) and Leanna Mills (15) are the only two children in the world known to have been diagnosed with the rare progressive degenerative neurological disorder, primary dystonia featuring their unique combination of symptoms.

Forced to give up work to provide full-time care for his daughters, Nick Mills and wife Michelle sold the family home in 1998 to fund an exhaustive international search to diagnose their daughters' condition and to find a treatment and hopefully a cure. Nick and Michelle also have two other daughters, Olivia (11) and Katey (17).

As a family, the Mills have struggled on a day-to-day basis to fund care and treatment.

Bethany and Leanna's unique symptoms are a painful combination of cerebral palsy and Parkinson's disease resulting in excruciating muscle pain, excessive contractions, restricted body movement, tremor and spasms which cause the entire body to twist into abnormal positions.

After exhaustive tests in Australia and overseas, primary dystonia was diagnosed by experts at London's Great Ormond Street Hospital in 1999. There is no cure and doctors are yet to pinpoint a genetic cause.

In 2005, Leanna and Bethany underwent 'deep brain stimulation' involving the implantation of electrodes into the brain which are connected to batteries implanted under the skin.

Given the unique nature of this procedure on children, the Mills family had to fly to the specialised paediatric neurosurgery department at the Center Hospitalier Universitaire de Montpellier in France.

Leanna and Bethany are the only children in Australia known to have undergone the incredibly complex procedure, deep brain stimulation (DBS) for their condition.

Each year Leanna and Bethany require ongoing maintenance including battery changes and the Mills family undertake the costly task of travelling to France multiple times a year. Maintenance often requires surgery which adds to the stress of the children and their family.

Nick and Michelle Mills and sisters Olivia and Katey have now lost the possibility of communicating with Leanna. She now struggles to eat or drink and is closer to requiring tube feeding to stay alive.

Leanna and Bethany are in danger of seriously injuring themselves due to involuntary spasmsmodic contractions and require wheelchairs for mobility – Leanna is mainly confined to a wheelchair. Their condition being what it is, a powered wheelchair provides means for the girls to have the independence of mobility.

The task of day-to-day living is made extremely difficult as their current housing commission family home is unsuitable for powered wheelchairs. If they wish to use their powered chair they are confined to one room otherwise require assistance with their manual chair.

Caring for Leanna and Bethany involves enormous costs, not only for regular brain surgeries critical for Leanna and Bethany's survival, their medications and allied health requirements, but also for the family's travel to France. These financial concerns add enormous stress to the already traumatic and emotional lives of the Mills family.



Symptoms Of Bethany & Leanna's Primary Dystonia

- Both Bethany and Leanna suffer severe and painful disabilities
- Both are reliant on 24 hour care and mobility support including wheelchairs
- Leanna has extreme difficulty with eating and drinking and is losing her ability to communicate
- Bethany has serious pain in her shoulders, which is escalating as the condition continues to develop

Both girls experience:

- Painful muscle contractions affecting their entire bodies
- Uncontrollable and spasmodic limb movements
- Restricted body movement and extremely stiff limbs
- Twisting and distortion of body parts
- Shaking and tremor
- Voice and speech difficulties (particularly in Leanna)
- Muscle deterioration

What is Dystonia & Who is Affected?

- Dystonia is a chronic and disabling neurological disorder in which sustained muscle contractions cause the spasmodic distortion of the body
- Dystonia has multiple causes and can affect different parts of the body, making diagnosis difficult
- Primary dystonia has prevalence mainly in young people. The average onset of dystonia is approximately 12 years, with the median age between 9 and 11 years
- Primary Dystonia is presumed to be genetic in cause, though no genetic links have been proven by specialists in Leanna and Bethany's case

What are the Symptoms of Primary Dystonia?

- Involuntary contractions affecting either a single muscle or a group of muscles such as those in the arms, leg, neck or the entire body
- By causing tendons to shorten, dystonia can lead to permanent physical deformity
- Twisting of the body parts
- Uncontrolled and often painful movements
- Shaking or tremor
- Voice and speech difficulties

What is Parkinson's Disease?

- Parkinson's Disease is a neuro-degenerative movement disorder characterised by tremors, limb stiffness, posture instability and delayed movements. It is a result of the degeneration of cells in one movement-control area of the brain.





Ben Fordham

Ben Fordham met the Mills family in 2004. He has been a significant supporter, following their story on *A Current Affair* and encouraging the community to make donations to assist the family.

Fordham, an investigative reporter with Channel 9's *A Current Affair*, is a multi-award winning journalist who's broken countless stories, both in Australia and overseas.

His coming-of-age in journalism came before he celebrated his 21st birthday. Then a political correspondent with Sydney's 2UE, Fordham won a Walkley Award — Australia's top award in journalism — for his coverage of the Thredbo landslide tragedy. He also won a Raward — the top accolade in the Australian radio industry — for excellence in journalism. He became the youngest reporter in history to win a Walkley-Raward double and was honoured on Australia Day with a Young Citizen of the Year Award.

Fordham made the switch to television in 1998 by joining Sky News Australia. He was soon reading national news bulletins and anchoring live coverage of major breaking stories. Less than 12 months after joining Sky News, he was recruited by the Nine Network.

His investigations have uncovered multi-billion dollar scams, leading to arrests in Australia, Britain and Ireland. In 2003 he exposed the cover-up of child abuse by the Catholic Archbishop of Tasmania — a story that led to the conviction of a high ranking priest. His exclusive exposé of former property high-flyer Cameron Donald led to national media coverage when Fordham was physically attacked and hospitalised while pursuing the Sydney businessman. Fordham's stories have also been broadcast in the United States on the respected ABC Nightline program. He has covered both Commonwealth and Olympic Games and interviewed numerous Hollywood celebrities including Tom Cruise, Charlize Theron, Nicole Kidman and Drew Barrymore.

In 2006 Fordham achieved a lifelong dream by filing his first report for 60 Minutes. To get the story, he trekked for 10 days into the wild jungles of West Papua to discover the last living tribe of cannibals. It was the highest rating story on 60 Minutes for 2006.