

# Surviving THE SILENT KILLER

Krystyna McIntosh never imagined that her robust toddler could die in his sleep, but Jordan fell victim to SUDC, the lesser-known face of SIDS



"He was perfectly healthy" says Krystyna McIntosh of her 18-month-old son.



"I don't like to hear my son cry," says Krystyna McIntosh.

**T**he morning of Aug. 22, 2006, was no different from so many that had gone before it. There was the usual bustle of a family of five dressing, packing lunches and having breakfast before everyone rushed off to work and school. Then, "we just said our goodbyes," says Krystyna McIntosh, who followed her routine of dropping her youngest child, Jordan, 19 months, at a relative's house before heading to her job at a law firm in Sydney's CBD. But at 2 PM, a frantic phone call from her husband, John, announced the unimaginable: Jordan had stopped breathing during his afternoon nap. Naïve from shock, McIntosh arrived at Baskarwan Hospital to find doctors trying desperately to revive her chubby-cheeked, mischievous boy, but to no avail, and the McIntosh family were plunged into an alien world of grief and confusion. "I was in total denial, just in a daze," recalls McIntosh, 42. "I just kept saying, 'It's not happening, it's not true.' I just couldn't comprehend how he could just die from nothing."

Though she's still no closer to an answer, McIntosh has learned that there's a name for what happened to Jordan: SUDC, or Sudden Unexpected Death in Childhood, which affects children aged over 12 months and is similar to SIDS (Sudden Infant Death Syndrome) but much rarer—one at 100,000 cases compared to one in 2,300 for SIDS. Most SUDC deaths occur between the ages of 1 and 3, but it has been known to affect children as old

as 15. "SUDC is a diagnosis of exclusion given when all known and possible causes of death have been ruled out," explains Dr. Henry Kraus, a world authority on SUDC and director of the SIDS/SUDC research project at San Diego School of Medicine. "I had never even heard of it," says McIntosh, also mum to Stephanie, 15, and Daniel, 12, with John, 44. The absence of a cause of death intensified the family's suffering: "When there's no reason, there's no closure," she says. "When you've lost a young child, you lose the future, you lose all your hopes and dreams and aspirations for that child... It's a very, very lonely road, sometimes."

**"When you've lost a young child, you lose the future"**

—Krystyna McIntosh

The days that followed were empty and surreal, recalls McIntosh, who credits her watertight marriage and caring friends and family with seeing her through. "I had to have people close to me," she says. "I think if I had kept to myself, I probably would never have come out from under the covers." Then, "once the shock wears off," comes another wave of grief. "I couldn't watch TV, I couldn't read a book for a good 18 months," recalls McIntosh. "I lost all enjoyment in everyday things. Every single morning that I'd wake up, I would just relive that day."

Bereavement counselling offered by SIDS and Kids NSW was another way out of the fog. "Without them, I wouldn't have been able to survive, I don't think. It was instrumental to my healing and my whole family's healing."

It was at a support-group meeting that McIntosh and her husband first learnt about SUDC. The coroner's report, which arrived 18 months after Jordan's death, >>>

Photograph by STEVE BACCION



Who Coping

**QUEST FOR ANSWERS**  
Through the Splash of Paul Foundation she set up with her sister Wendy Maloney and friend Linda Wilson, Krystyna McIntosh funds her husband, John, and children Daniel and Stephanie in Sydney on June 11. Has so far raised \$136,000.

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"The not knowing really breaks your heart," says Melissa Eason (left, in 2009 with Josh, daughter Olivia and twins Jacob and Noah) of Cooper (above, in July 2006, weeks before his death).

stated merely that there was no cause of death, so it was left to her and Josh to make the link to SUDC through their own research. "SIDS relates to safe sleeping, but for an older child it doesn't really apply because they're already moving around their bed. My son was already jumping out of his cot."

Melissa Eason understands her frustration only too well. Two weeks before Jordan died, Eason, 35, and her husband, Josh, 37, lost their son, Cooper, 22 months, to SUDC. On Aug. 5, 2006, "I put him to bed at 7.30 PM, then he woke up at 12.30 that night, and usually when he'd wake up in the night he'd have a night terror and cry and be upset, but he was babbling, he was lying in his cot having a chat, a bit of a giggle," she remembers. "Josh and I just looked at each other and thought, 'That's funny.'" Josh went to check on Cooper, offered his dummy and told him, "Go to nighties," says Eason. "And that was it. Then he found him at 7 o'clock the next morning."

"I just couldn't, and I will can't, understand how a healthy, happy, walking, talking, big, burbling boy could go to sleep and not wake up," says Eason, who'd known of the McIntoshes through mutual friends prior to their sons' deaths. The couples eventually met through the SIDS and Kids support network, where they learn of six other families in Australia affected by SUDC. "I think our first reaction was to reach out to other people who had been through something similar because I was confronted with a lot of people who had lost children during pregnancy or stillbirth or very early on, which as devastating as it is, it

just wasn't the same as my grief." As with the McIntoshes, the hunt for answers consumed the Easons: "We searched and searched, goodness, you should have seen my Google searches," says Eason, also mum to Olivia, 7, and twins Noah and Jacob, who were born two years after Cooper's death and are now 22 months. The toddlers sleep with motion monitors beneath their mattresses. "The monitors have been my saving grace," says Eason, who is expecting her fifth child in October, also the month Cooper was born. The pregnancy was unplanned. Says Eason, with a smile: "I think it's a gift from Cooper."

—Melissa Eason



Wiggles Anthony Field raises awareness—and his kids Amanda and Lucia (daughter Marie is on the floor).



"As a parent, the loss of infant and child death is so terrifying," says mum-of-two Sophie Falkner.

For McIntosh, whose son Jordan would have started kindergarten this year, the question of whether to try for another child is murky. She worries about having left it too late, and about the age gap between a new baby and teenagers. "We're just both not sure, and the biological clock is ticking," she says with a chuckle. The family, who go out on a "date night" to the cinema every month, love their new Maltese-poodle bundle of fluff, Rosco, and are as close as a foursome can be. But healing is a lifetime's work, says McIntosh. "The house is way too quiet," she says. "There will always be something missing in our home."

Alongside their love and unity, there's another reason to look ahead: June 25, Red Nose Day, will mark the fourth Splash of Red Ball held by McIntosh's charity, the Splash of Red Foundation, a volunteer-based nonprofit organisation. "Being part of the foundation is our way of moving forward and making a difference to other people's lives, and perhaps even attaining some meaning from our tragedy."

As well as raising funds for research and bereavement support services, McIntosh wants to increase awareness of SUDC. The foundation's logo is a dragonfly, McIntosh's symbol for her son. The insects are often around her, says McIntosh, fluttering their intricate, exquisite wings: "It's a sign that he's around, that he's watching over us," she says. The "cheerful, cheeky, spoilt" little boy known as "Mr Divine" is so much a part of his mum's life today as he was in life: "I always used to take Jordan on the merry-go-round," she says. "I can just remember hearing the music and looking at his smiling face. He used to love going round and round."

■ By Karina Machado

For more information, go to [splashofredball.com](http://splashofredball.com)

### STARS IN THE RED

More than two decades of Red Nose Day fundraising—this year it's on June 25—has helped SIDS and Kids achieve a 85 per cent reduction in SIDS cases in Australia. Yet, like SUDC, its causes are still unknown.

June 28, 2010

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