

*Sammy-Joe
Moonchild, Survivor*

Sammy-Joe Liistro loves riding his bike and when he is not in hospital, when he is well, he will ride for hours. His giggles are as musical as those of the average Aussie kid and his parents smile broadly; they are watching their child at play. They sit in the backyard of their Craigieburn home, revelling in the sight of their happy son, while the average Australian family sleeps. It is night and Sammy-Joe plays under the light of the moon because he cannot play by day. For Sammy-Joe, the sun, the daylight, is fatal.

Sammy-Joe has a deadly congenital disorder. There is no cure for Trichothiodystrophy (TTD), and no treatment available in Australia due to a lack of funding. At sixteen years of age, Sammy-Joe has earned the foreboding accolade of oldest survivor of TTD in this country. He is one of only thirty-three TTD carriers worldwide and Mr. and Mrs. Liistro are desperate to return to America where Sammy-Joe was first diagnosed with the disorder. Sammy-Joe Liistro will continue to deteriorate if he does not receive the life-saving treatment currently being offered in the US.

TTD is a rare congenital condition causing high sensitivity to light and ultra violet rays. Sammy-Joe cannot venture into daylight without the protection of six layers of clothing and three hats. The ultraviolet light breaks down his DNA and kills cells, which culminate in the destruction of the immune system. Other symptoms of TTD include brittle hair due to sulphur deficiency, stunted growth, poor weight gain, mental retardation, cataracts, dental abnormalities and autism. The skin blisters and hair loss Sammy-Joe suffers after only the briefest exposure to the sun are merely a prelude to a host of life-threatening reactions to UV rays.

Mrs. Liistro, who currently battles her own health issues, speaks of her campaign to bring awareness to the plight of TTD sufferers. In a letter to parliament, Mrs. Liistro pleaded for increased funding into genetic research. 'I just don't want any other families to go through what we have with Sammy-Joe,' she said.

The Liistro's are disillusioned by the Government's failure to address the issue of funding for congenital disorders such as TTD. However, they are deeply touched by the generosity of many Australians who have made donations ranging from cash, to the supply and installation of UV free lighting for the Liistro home. At a recent charity auction, the Melbourne Markets Lion Club raised a substantial sum to add to Sammy-Joe's trust fund, which will contribute to easing some of the many hardships this condition imposes. Mr. and Mrs. Liistro and Sammy-Joe's younger brother, Christian, rely on their faith to overcome the next battle – to acquire the airline tickets, and the accommodation that will enable their family to travel to various states of the US for tests and treatment that may save Sammy-Joe's life. The Liistro family are hoping to travel to the US in the near future. Sponsored flights and accommodation would ensure their departure and Sammy-Joe's chance at continued survival.

Mrs. Liistro's tired smile animates when she talks of her son, 'the moonchild, the survivor.' She braves a broader smile to repeat Sammy-Joe's promise—'I'm not going to die, Mum.'