



# The *Gathered View*

National Newsletter of the Prader-Willi Syndrome Association (USA)



Mackenzie Rose Beverage  
Australia

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## Donations for Research

As of 3/31/07:

**\$93,899**

## A Life Less Perfect

By *Lisa Peters*

Before my son Nicholas was born, my life was perfect.

I ran in an invisible race with neighbors and friends. A race to see who had the greenest lawn, the smartest kids, the whitest teeth. I was a member of an elite group, devoted to raising elite children. We spent our time at barbecues and soccer games, tallying our points in the quest to grab that glittering gold ring of perfection.

As we admired our children and our lawns, we never stopped to realize that on our faces we wore rose-colored glasses and in our hearts we felt an emptiness that searched for a deeper meaning to our lives.

On January 18, 2002, like a thin layer of glass, my perfect life came shattering down by the purest sound of six horrifying words... "Your son has Prader Willi syndrome."

And suddenly I could not breathe.

I sobbed for my poor, weak, little child.

I sobbed for myself.

I sobbed for the perfect life we would never have together.

There were no flowers, no cards, no congratulatory notes from family and friends. My son entered the world in silence. No smiles, no laughter, no fanfare. No one welcomed him. Everyone was sad.

Where in a perfect life would this little child fit? It was as if his very existence threatened to tarnish this utopian world we had created. My tiny son was a giant monster of truth that threatened to expose the meaninglessness of a life built out of playing cards. And all who lived in these fragile card houses could not understand how to celebrate the birth of this little child.

My son lay limp upon his bed. A yellow feeding tube was taped to his cheek and traveled up his nose and into his stomach. Taped to his tiny skull another tube pumped antibiotics into his fragile veins. Around his floppy body a brace made of thick straps and stiff velcro held his weakened hips in place. IV poles and feeding machines surrounded him like quiet metal soldiers standing at attention. Everywhere alarms sounded... a constant reminder that this was hell and we now lived in it. Around me in the



Nicholas Peters at birth

NICU, I saw only despair... parents with children struggling to live.

Like my newly born infant, I was abruptly and cruelly removed from the warmth of my womb-like perfect life. I was thrust head-first into a cold and terrifying imperfect world.

This was my new home. I felt sick.

Every movement I made felt unnatural and awkward. My mind was frozen. My body moved like a robot. I did not want to look around me, for everywhere I looked, I saw pain. I felt like a soldier on the battlefield, frozen by the ghastly sight of the slain, bloody carcasses at his feet. And yet, like this soldier in a war he did not create, I too could not escape my fate.

*Life continued on page 13*