



# Who cares wins

Ordinary families are capable of extraordinary things, writes **Cheryl Critchley**

**R**AISING kids is hard enough when they're healthy. Try to imagine what it is like for families who have to cope with a disabled child.

I met two families who are coping with very different problems. Each is doing an amazing job in trying circumstances.

Sammy-Joe Liistro, 20, is one of only 10 Victorians with trichothiodystrophy (TTD), an extremely rare genetic disorder that causes brittle hair, skin problems, physical and developmental disorders, stunted growth and light sensitivity.

His mother, Maria, 43, set up the Friends of Sammy-Joe Foundation to help others like him and is on the Genetic Support Network of Victoria committee to raise awareness of the condition.

His dad, Joe, 45, a storeman, and brother Christian, 16, also offer much support.

Sammy-Joe has a reduced life expectancy and his intellectual age is about four. He cannot go outside during the day.

But he more than makes up for all that with love and enthusiasm.

Maria won funding for a project co-ordinated by Delfin and Naturform last year to build a large pavilion at the back of their three-bedroom home for Sammy-Joe and others like him to play in.

In the early days Maria had no social life, gave up working as a hairdresser and integration aid and even developed a Vitamin D deficiency from lack of sunlight.

She never complains and is over the moon with the new pavilion.

"I can even leave the back door open," she says. "I used to have to keep it closed. We feel so connected now to everyone around us, it's amazing. I am able to run the groups here and keep working on raising awareness."

And the rest of us complain if our footy team loses or our kids spill milk on the kitchen floor!

**M**ARIA'S selflessness is typical of those who face such hardship. The Moore family is another example.

Son Grayden, now 27, almost died from severe head injuries after a skateboarding accident in 2004. But his amazing recovery and the determination of his nurse mother, Laurelei, doctor father Derek and six siblings helped him beat the odds.

Despite improving, Grayden still lives in a nursing home and is the face of the Building Better Lives initiative to provide age-appropriate accommodation for 150 young people.

This family has been through hell, but still works to help others. Grayden's next step is a transitional living centre, then semi-independent accommodation.

"It's a great concept," Laurelei says. "He left home 10 years ago — he doesn't want to live with us, anyway."



▲ **Light relief:** Maria Liistro set up a foundation to help others like her 20-year-old son, Sammy-Joe.



▲ **Building hope:** skateboard accident victim Grayden Moore, with parents Derek and Laurelei, is the face of the Building Better Lives initiative.

These families are an inspiration to those faced with similar life-changing news.

Very Special Kids and interACT, a group for parents with special-needs children, have produced a great starting point: *There's no Such Thing as a Silly Question*.

This guide for families who have children with chronic illness, disability, mental illness and life-threatening conditions is a godsend.

It contains practical advice on how to cope and to educate others, useful contacts and helpful comments from parents who, like Karen, have been there.

"Remember to enjoy your child for who they are and what they can do, rather than for what they can't do," she says.

#### WHAT DO YOU THINK?

Email  
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**Net links:**  
www.buildingbetterlives.org.au,  
www.vp-it.com.au/sammyjoe/

**The Friends of Sammy-Joe Foundation will hold a three-course dinner dance with drinks in Campbellfield on Saturday, June 20. Tickets \$65. Contact sammyjo2@bigpond.com.au**

## COPING WITH A SERIOUS DIAGNOSIS

- Make sure you have a good, supportive GP.
- Visit the Health for Kids Network website: [www.healthforkids.net.au](http://www.healthforkids.net.au)
- Use the internet wisely. It can be helpful but there may also be inaccurate information.
- Consider an open letter to family and friends explaining the condition, telling them how they can support you and what to avoid.
- Consider using the answering machine to screen calls.
- Choose who to tell about appointments or you may be overwhelmed with calls.
- Look after yourself and your immediate family and let others support extended family and friends.
- Consider taking a form letter to service providers to cut down on having to repeat your child's history.
- Consider setting up a website about your child for friends and family.
- Identify helpful supports such as key friends and family who will be there unconditionally.
- Take each day as it comes and try not to think too far ahead.

Source: *There's No Such Thing as a Silly Question. A Practical Guide for Families Living with a Child with Chronic Illness, Disability, Mental Illness or a Life-threatening Condition.* (interACT/Very Special Kids).

Every weekday  
there's something  
extra



Herald Sun