

# ***RUNNING FOR A CURE!***

## **Running a Marathon to raise funds to find treatments for Prader-Willi syndrome**

***Can you imagine feeling terribly hungry.... all day, all night, every day...no matter what you ate?***



On April 15, 2007, Mark Ranucci and David Stevens will run the Canberra Marathon to raise money to support research into effective treatments for the appetite disturbances of Prader-Willi syndrome. Mark's daughter, Charlie (14months) suffers from this condition.

As most people are not aware of this disorder, government grants or public appeals for research funding are unlikely to be successful. Families must raise funds themselves for research. Currently a small scientific team (mostly family funded) is working on this goal at The Garvan Institute of Medical Research, Sydney. We want to support this team further to both hasten and expand their research.

**We hope to raise sufficient funds to employ an additional scientist to this team at a cost of \$150,000 over a 3-year period.**

Prader-Willi syndrome (PWS) is caused by a random genetic error and occurs in approximately one out of every 20,000 births. It affects both sexes equally and all races.

One of the main concerns for people with this condition is that their bodies tell them that they are hungry ....all the time! Consequently, they will overeat if not supervised. This is not a behavioural problem, but a real physiological drive to satisfy their hunger. Along with a low metabolic rate and muscle weakness, this hunger impacts their health, emotional status, and severely compromises their ability to live independently. Currently, there is no cure; management involves complete control of food in all environments the person is in, requiring dramatic changes to family life.

In addition, other symptoms can be associated with PWS. Within the spectrum, symptoms vary amongst individuals. Children often attend mainstream school and become employed. The hunger, however, can prevent independent living and the enjoyment of regular social activities.

***Please help us beat the hunger!***

*"Our daughter has been diagnosed with Prader- Willi. As you can imagine, we are keen to ensure that research continues, targeted at identifying new treatments, not only for her, but also for all children with this condition.*

*In our society, food is central to social gatherings and activities. An effective treatment would enable these children to enjoy a healthy active life without being distressed by food, and allow them to live independently"*

