

Rare disorder's a marathon battle

When Amy Bowen's son Christian was born two years ago it had been the "perfect pregnancy" and "perfect birth" for the first-time mum, and he seemed to be a perfectly healthy baby.

But alarm bells began ringing when Christian still had no neck control at four months old.

After 10 months of medical and genetic tests, Christian was diagnosed with an extremely rare neuro-developmental disorder called PURA syndrome.

"It was the hardest 14 months of my entire life,"

Mrs Bowen said. "No one could give me answers."

The Lilydale mum recently co-founded the PURA Foundation Australia along with Melinda Anderson, mother to Sarah, 15, and Rebecca Nunn, mum to Jack, 4, to support other families of children with the syndrome, which affects only about 600 patients worldwide.

The three mums are part of a team of about 60 runners and walkers competing in the Melbourne Marathon this Sunday.

To donate to the team, visit purafoundation.au



Melinda Anderson with daughter Sarah, 15, Amy Bowen with son Christian, 2, and Rebecca Nunn with son Jack, 4. Picture: David Caird