

It's 'Sixty Five Roses' month



Ellis Miles. She's 5 and has cystic fibrosis

by Sarah Martin

A bright little girl has inspired a fundraising effort with a very personal story at Somerled Wines.

In most ways Ellis Miles is like other 5-year-old girls - she has boundless energy, is a spark of fun and inspiration and has a wild imagination.

What is different about Ellis is she has Cystic Fibrosis, a genetic condition that primarily attacks the digestive system and lungs and is the most common regressive gene condition among Australian children.

Every day Ellis has physiotherapy and a nebuliser treatment which puts saline solution into her lungs to break up mucus, as well as handfuls of tablets containing digestive enzymes taken with every meal to assist with the breakdown of fats and proteins.

Her mother Neala Miles works at the Somerled Cellar Door and often takes Ellis in to meet the staff there, including owner and manager Lucy Moody.

"Ellis is so tiny, with an enormous personality and she takes all of the treatments and clinics in her stride," Lucy said.

"It's true to say she doesn't know any different, but she spends an awful amount of time in hospital, has daily treatments and takes medication that no other kids do."

When Neala told her that May is 'Sixty Five Roses' month, the major fundraising month for Cystic Fibrosis Australia, Lucy was keen to do what she could to get involved.

"It is nicknamed 'Sixty Five Roses' month because a young boy mis-heard the name of his sister's condition, which is why the rose is the symbol of the CF foundation," Lucy said.

"We knew immediately that we

wanted to be involved with 65 Roses month just to do our little bit because it is so close to us."

Lucy decided to donate \$6.50 dollars from each bottle of Somerled Sauvignon Blanc sold during May directly to Cystic Fibrosis South Australia.

"We really felt it was the least we could do," Lucy said.

"We hear about how different amounts of government funding can help or hinder because whether Ellis can have treatment at home or hospital makes a huge difference to them as a family.

"Recent changes mean that some no longer have funding at home, which means more time in hospital and overnight stays.

"We just want to do anything to help make a difference in their day to day life."

When Neala was told about the fundraising effort she was thrilled.

"I was overwhelmed," Neala said.

"I just feel so grateful to have fantastic employers who are willing to jump on board and help out any way they can.

"They are amazing - not just with fundraising but in accommodating for Ellis' clinic days and extra treatments.

"They are happy to help whenever they can."

Neala said her family have received seemingly unlimited support from Cystic Fibrosis South Australia to try and make their daily lives easier to manage, not just for Ellis but for the entire family.

"Cystic Fibrosis South Australia gives us so much support as a family.

"They organise events for the children to participate in such as Christmas picnics, fun days and sibling camps.

"For some families it is a real hardship so it is very important to get people supporting one another in the community.

"They also offer support in sourcing medical equipment and recently they helped us access some funding through the Little Heroes Foundation. It enabled us to receive a brand new nebuliser which we never would have been able to afford on our own."

Neala said Ellis doesn't really understand what Somerled is doing for her.

"She is five so she is very self-centred," Neala said.

"She hasn't quite grasped the concept but what she knows for sure is that she is the star of the show."

Somerled Wines will be supporting the Sixty Five Roses campaign for the month of May and encourages people to make an order online at somerled.com.au or by phone on 8388 7478.