



press clip

Buying a rose for Charlie

CYSTIC FIBROSIS

BY PERRI POLSON

FIFTEEN-MONTH-OLD Charlie Blackwood from Bunbury, on Western Australia's south coast, is one of around 4000 children and young adults who live with Cystic Fibrosis (CF) in Australia.

Charlie was flown to Perth Children's Hospital (PCH) for emergency surgery straight after birth, and his diagnosis was a shock no one saw coming.

Charlie was diagnosed with CF at 11 days old and his family spent almost six weeks in intensive care recovering from the surgery.

All of Charlie's treatment has to be done in Perth, and the family will regularly make the two and a half hour trip every three months.

Marlene expressed her disappointment with the lack of care available in Bunbury.

"CFWA is amazing, and the support we get from PCH is also amazing, but funding in our healthcare system, especially for regional hospitals is needed."

COVID-19 has posed a particular threat to sufferers of CF.

"We were happy living in our little bubble, then the borders opened. It's been a stressful time," Marlene said.

"Last year we spent just over four months in hospital between winter viruses. If a regular cold puts us in hospital for six weeks, I'm really

terrified to see what COVID will do to him."

Between hours travelled

and time spent in hospital, there is the day to day management of Charlie's condition.

A nebulizer treatment is administered three times a day, with physio and differ-

ent medications also now a part of their schedule.

Cystic Fibrosis affects many organs, but particularly weakens the lungs, putting many CF sufferers at greater risk during the pandemic.

The month of May is globally recognised as Cystic Fibrosis awareness month, with 65 Roses Day on May 27 marking the annual fundraiser.

CFWA created the virtual initiative to host 65 Roses Day in 2020, to allow people to continue to support patients and their families.

Fresh roses are still available for purchase and delivery to show support for loved ones living with CF, will be available at Bunbury Centerpoint and the Mandurah Forum.

"Despite the challenges, once again we will work within the parameters of this pandemic with our priority to keep the CF community safe," CFWA chief executive Lisa Bayakly said.

"But we also need to ensure our CF community still celebrate their day of awareness and this vital fundraiser.

"It is so important for these families to be recognised and

to have the opportunity, just one day of the year, to stand proud and work together to raise awareness and funds for CF."



Mandurah Mail
Thursday 26/05/2022

Page: 10
Section: General News
Region: Mandurah, AU
Circulation: 32000
Type: Regional
Size: 481.00 sq.cms.



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Baby Charlie and Mum Marlene after Charlie's emergency surgery at Perth Children's Hospital. Picture supplied.