

# At 9, learning to live a life less ordinary

By EMMA DANGERFIELD

**N**ine year old Jessica-Rose Boyd-Ruston looks and acts just like any other kid, but get talking to her and you realise she is very knowledgeable about her health and seems wise beyond her years.

The Woodbank School pupil has cystic fibrosis, a recessive genetic disease which affects the pancreas and in turn creates difficulty with the respiratory system including infections and trouble breathing.

Diagnosed at just five and a half weeks old, Jessica-Rose has spent her whole life managing the disease and has become quite the expert.

Because her body is unable to break down fat properly, she needs to take capsule medication known as creons, which do the job for her.

What she is eating determines how many creons she needs to take.

But this does not mean she has to avoid fat – far from it. She actually needs to eat more than her friends, including a high-carb and chocolate “diet”.

“Eating lots is fun,” she says. “But I actually do get tired of eating chocolate sometimes.”

To help her with her lung function, Jessica-Rose needs to do physiotherapy activities daily. This is particularly important in the mornings, to dislodge any built-up mucus in her lungs.

Her mum helps her with this by banging on her back and chest, sometimes for up to 30 minutes at a time.

Unfortunately, this routine means she has to get up early, sometimes even before 7am, which she is not that keen on.

Other daily routines include a saline treatment, which she has to inhale twice a day, and yearly injections, which she has just before her birthday in February.

“My present is needles every year just before my birthday, but it’s not a very good present.”

Jessica-Rose loves swimming, which is a great exercise for her

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Jessica-Rose Boyd-Ruston on her enviable dietary requirements

illness, and although she is not keen on running, she makes sure she takes part in that too because it’s good for her.

In fact, she makes sure she does just about every activity the other kids do.

Although Jessica-Rose lives in Kaikoura, she attends Woodbank School in Clarence, because it is a small school and therefore she is exposed to less bugs from other children.

She is also able to get more one-on-one time with her classwork because of the teacher-student ratio, something which is important when you have as much time off school as she does.

She often gets so sick she finds it hard to stop coughing, and has to go to hospital frequently, including for her “WOF” every year when she is hospitalised in Christchurch for two weeks. Last term she was off school for almost a month, so it is important she can catch up.

When in hospital she has a health school teacher who works with her for an hour each day, and has books to read and stories to write.

Last year, when she was in hospital before Christmas, classmates from Woodbank came for a class visit.

A sad fact of cystic fibrosis is that she cannot mix with other sufferers because they all have different bugs in their lungs. They have to wear masks when they are in the same room.

The same applies for children with cancer and Jessica-Rose has to be very careful who she comes into contact with.

She is the only child in Kaikoura with cystic fibrosis, which certainly makes her



**Tough cookie:** At just nine years old, Jessica-Rose Boyd-Ruston, centre, has a lot to contend with but she knows just what to do to manage her cystic fibrosis. She’s pictured with her Woodbank schoolmates, from left, Monique Graham, Maggie Lindstrom and Josh Beardmore. Photo: EMMA DANGERFIELD

special, and is coping very well with both the sickness and the ongoing treatment.

“I’m quite used to it now . . . but I get sick of it sometimes,” she says.

Cystic Fibrosis Awareness Week takes place every year in August, and this year’s theme was Bubbles Week.

The Cystic Fibrosis Association aims to raise awareness each year to help those affected by the disease.

Cystic fibrosis affects more

than 500 people and their families in New Zealand, however as it is classified as a rare disorder there is very little funding available from the government.

Jessica-Rose and her family and friends sell raffle tickets each year to raise awareness during the annual campaign, and each child with the disease gets a quilt every year.

■ To find out more about cystic fibrosis, including to find out ways to help those affected, visit [cfnz.org.nz](http://cfnz.org.nz).

## LETTER

### ‘Tapping’ seals with an iron bar

Maybe someone could enlighten me as to the difference between “tapping” a few seals on the head with an iron bar and “tapping unwanted” or purposely aborted calves on the head with an iron bar or hammer.

One is deemed legal, the other illegal. I do not condone either practice in any way.

Ann Hennessy