

Robyn Norris had both of her breasts removed so she didn't have the expense of travelling three hours a day for cancer treatment

NEWS

# Heal the Bush: We need action to fix rural health in NSW

SUE DUNLEVY THE SUNDAY TELEGRAPH  
JULY 13, 2014 12:00AM

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Robyn Norris, 48, with her son Liam, 18, and daughter Bronnagh, 21.

The cost of accessing medical treatment for her daughter's leukaemia has so far cost Wagga mum Jodie McKnight almost \$1000

NEWS

# Heal The Bush: 'We're sick of paying to get treatment'

SUE DUNLEVY NATIONAL HEALTH REPORTER  
THE SUNDAY TELEGRAPH JULY 27, 2014 12:00AM

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SAVE THIS STORY



Wagga's Shannon McKnight, 17, and her whole family has uprooted to be with her in Sydney for the next six months as she battles leukaemia. Picture: Cameron Richardson

The town  
that won't  
let its  
residents  
die

NEWS

# Molong has raised more than \$1 million in the past decade for anyone in the town who falls ill

JANE HANSEN THE SUNDAY TELEGRAPH  
AUGUST 03, 2014 12:00AM

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Dotty Compt is enjoying a much happier life with her granddaughter Anna after receiving treatment for a brain disorder with funds raised by the Molong's residents.

The Unified Voice for all Australians living with a rare disease

rare voices  
A U S T R A L I A

## The Australian Experience of Living with a Rare Disease



personal stories

Megan Fookes  
Executive Director, Rare Voices Australia  
[www.rarevoices.org.au](http://www.rarevoices.org.au)

## Kerry's story

Living with Ehlers Danlos Syndrome, rural NSW

**Kerry tells her story.**

**It took 48 years to diagnose my rare disease.**

I am now 56 years old. We believe my late father died from this same rare condition and was never diagnosed.

My Ehlers Danlos is most pronounced on my face. I have found little empathy from my doctors. I have had people, including doctors, say that I was just ugly. It was years before an eye specialist worked out that I had ED. My local GP didn't really understand what this was and showed little empathy or interest in finding more about this rare condition. This has made things difficult, especially since I live in a rural town with access to only one GP.

But I have met some fantastic doctors who have been on this learning journey with me.

One of those I met on a plane as I returned from another specialists' appointment in Sydney. He was a doctor at the Concord Hospital.

We chatted about lots of things. I found it liberating when I said I had been to many specialists who charged too much money to simply send me to someone else.

The doctor was honest with me, saying: 'I can see that your face is not normal and you have some form of connective tissue disorder.'

He referred me to a doctor at the Concord burns unit. He did some research into this rare disorder but could not find another ED person who had had face work. Although initially hesitant to work on me, he soon realised my different appearance had affected my whole life. He operated three times. I will never look like "normal" people. But without bumping into a very kind doctor on my plane flight and being referred to a one who was prepared to take a risk with me, I would not feel this good about my face.

**I will be grateful to these men for the rest of my life!**



# KIMBERLEE FRANCIS - RARE VOICES AUSTRALIA

<https://www.youtube.com/watch?v=4WsIXPdPOCE&feature=youtu.be>