

Media Release  
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*Unite and wear your colours with more than 300 million people living with a rare condition on Thursday 29 February.*

More than 2 million Australians have been diagnosed with a rare disease, it is a cause that is close to the hearts of many, and an important day for the Immune Deficiencies Foundation Australia (IDFA) community, using the occasion to educate people about Australians living with immunodeficiencies.

Local five-year-old Jude, (Lochinvar) was diagnosed with IRAK-4 deficiency at 14 months old. This genetic autoimmune disease is so rare that Jude is 1 of 75 people worldwide who have been diagnosed with this condition. This specific deficiency predisposes patients to recurrent life-threatening bacterial diseases, such as invasive pneumococcal disease.

Olivia Murdoch [Jude's Mother] emphasises the importance in raising awareness for all rare diseases. "We know that education about these kinds of illnesses will provide earlier diagnosis and treatment for people, with the aim to avoid potentially life-threatening situations, which we had to endure."

"Although the disease does not define my son, knowledge of rare diseases and their impacts goes a long way in helping people on their journey. We are so fortunate that Jude was able to receive the care he did during his early years, and we are grateful that we can highlight to others how to advocate and shed light on rare diseases," Continued Olivia.

This year, Jude was able to start kindergarten, which is a huge deal for the family, as assumed home schooling was their only option, if he survived through the early years.

Rare Disease Day is a global observance dedicated to raising public awareness for rare diseases and calling attention to the unique challenges that people and their families living with these conditions face. Rare Disease Day is observed every year on 28 February (or 29 in leap years)—the rarest day of the year.

**PO Box 742, Wollongong, NSW 2520**

This Rare Disease Day, IDFA is calling for all Australians to **#WearYourColours** to recognise rare diseases worldwide. A disease is RARE when it affected fewer than 1 in 2,000 people, and collectively, there are more than 6000 identified rare diseases.

Carolyn Dews, CEO of the Immune Deficiencies Foundation of Australia, shares, “With 70% of genetic rare diseases starting in childhood, Jude’s story is a powerful reminder of why it is so important to raise awareness about these rare, invisible and often life-threatening diseases.”

72% of the illnesses being genetic and almost 1 out of 5 cancers being classified as rare, this day is vital to highlight the challenges people may have to overcome. From diagnosis to treatment, each person found to have a rare disease has a very different path to follow – making it potentially lonely and difficult.

Rare Disease Day is patient-led, but everyone can participate in raising awareness and acting through various avenues, such as sharing your colours on social media, joining the global chain of lights, or hanging a poster.

For more information about IDFA and ways to get involved in Rare Disease Day, visit their website at [www.idfa.org.au/rare-disease-day](http://www.idfa.org.au/rare-disease-day).

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#### **About IDFA**

The Immune Deficiencies Foundation Australia (IDFA) is a national not-for-profit and leading peak organisation dedicated to improving the lives of those affected by immunodeficiencies. The organisation provides support and resources to individuals, families, and healthcare professionals and works to raise awareness about these conditions.

<https://www.idfa.org.au/>

#### **About Rare Disease Day**

Rare Disease Day is an annual observance that takes place on February 28<sup>th</sup> (or 29 in leap years) – and aims to raise awareness about the impact of rare diseases on patients and their families.

<https://www.rarediseaseday.org/>