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Media Release

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Young Warrior Austin Sparks Awareness for Rare Disease Day

More than two million Australians live with a rare disease, and on February 28, 2025, the Immune Deficiencies Foundation Australia (IDFA) is calling on communities to come together, spread awareness, and have the conversation about rare diseases like immunodeficiencies.

Meet Austin: A Young Warrior with a Rare Disease

In the vibrant city of Warner Queensland, five-year-old Austin McCormack shines as a beacon of joy and resilience. Austin was recently diagnosed with pan-hypogammaglobulinemia, a primary immunodeficiency. Despite facing monthly IVIg infusions and ongoing health challenges, Austin's adventurous spirit shines through. His mother, Samantha, shares how their family navigates life with a rare disease—balancing medical needs with the joys of childhood.

"He knows the routine now—he's brave at every appointment, even when it gets tough," Samantha [Austin's Mother] says. "Austin's resilience inspires us every day." She hopes their story encourages other families to trust their instincts and advocate for their children's health.

Samantha's journey as a mother has been one of persistence and advocacy. After encountering multiple doctors who dismissed her concerns, it took two years before Austin received a proper diagnosis. The turning point came when they were referred to a specialist at the Women's and Children's Hospital in Adelaide, confirming what Samantha had suspected all along. "Trust your instincts," she advises other parents. "Doctors are experts, but no one knows your child better than you do. Make sure their voice is heard."

Why Rare Disease Day Matters

Rare Disease Day is a global movement dedicated to raising awareness for the over 6,000 known rare diseases, many of which are life-threatening and often invisible. With 70% of genetic rare diseases starting in childhood, IDFA CEO Carolyn Dews highlights the urgent need for awareness and support.

"Austin's story is a powerful reminder of why we must continue advocating for those with rare diseases," she says. "No one should feel alone on their journey."

With 72% of rare diseases being genetic and nearly 1 in 5 cancers classified as rare, this day is a crucial opportunity to start conversations about the challenges of diagnosis, treatment, and daily life for those affected. By talking openly, we can help break down misconceptions, support better healthcare access, and foster a stronger community for those living with rare diseases like immunodeficiencies.

Colour a Zebra for Rare Disease Day and Win a Family Trip to the Zoo!

To mark this important day, IDFA has launched an exciting Colour a Zebra Competition, inviting primary school children across Australia to showcase their creativity by colouring in a zebra—an animal known for its unique stripes, just like rare diseases are unique. By participating, children will learn about the importance of rare diseases while also going in the draw to win a family trip to the zoo! Simply submit a photo of the coloured zebra for a chance to win.

Join IDFA in celebrating Rare Disease Day by:

- Encouraging primary school children to enter the Colour a Zebra Competition for their chance to win a family trip to the zoo
- Having conversations about rare diseases like immunodeficiencies to raise awareness and support
- Spreading the word on social media with #RareDiseaseDay

Together, we can create a vibrant and supportive community for those navigating rare diseases.
For more details on IDFA's Colour a Zebra Competition, Austin's journey, and ways to get involved, visit our website: Rare Disease Day - IDFA.

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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 28th (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/