PO Box 742, Wollongong, NSW 2520

Media Release
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Local School Helps Raise Awareness for Students Living with Rare Diseases

More than two million Australians live with a rare disease, and each year, the Immune Deficiencies Foundation Australia (IDFA) calls on communities to come together, spread awareness, and engage in conversations about rare diseases such as immunodeficiencies.

This year, a local school, California Gully Primary School, is working to raise awareness of rare diseases.

School Principal, Andrew Frawley, highlighted the significance of the initiative, stating: "Rare Disease Day (28 February) is an important opportunity to educate our students about the challenges many families in our community face. Through the colouring competition and fundraising, our students not only expressed their creativity but also gained a deeper understanding of rare diseases and the importance of inclusion and empathy."

Six-year-old Ebony Derby started having health issues at just 3 months of age, including chronic ear, fungal and skin infections; respiratory aspiration and eczema. After multiple hospital admissions, Ebony was diagnosed at the end of March 2022 with Autosomal Dominant Hyper IgE Syndrome Stat3 Immunodeficiency – a condition that affects 1 in a million people.

“Raising awareness of immunodeficiencies is deeply important to our school community. By sharing Ebony's story, we aim to ensure she feels seen, supported, and not alone,” Andrew added.

Ebony’s treatment includes daily antifungal and prophylactic antibiotics as well as regular immunoglobulin infusions. This has significantly improved her quality of life, allowing her to live in less pain and regularly attend school. For Ebony’s parents, it has provided a sense of security knowing that their daughter is more protected against life-threatening infections.

California Gully Primary School embraced Rare Disease Day by taking part in IDFA’s Colour a Zebra Competition, with the winner being selected from the school, receiving a family zoo pass. The competition not only encouraged creativity but also helped students learn about rare diseases and the challenges faced by those living with them.

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As part of the collaboration, the school held a casual clothes day and raised funds for IDFA, giving back to those impacted by immunodeficiencies.

On Rare Disease Day, the Immune Deficiency Foundation launched a children's book 'What Does Brave Feel Like?, featuring two child characters navigating their treatment for their immunodeficiencies. One of the main characters is Ebony, based on the school student attending California Gully Primary School.

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 greater awareness and support.

"Ebony's story is a powerful reminder of why we must continue advocating for individuals with rare diseases," says Dews. "No one should feel alone on their journey, and together we can make a difference."

With 72% of rare diseases being genetic and nearly 1 in 5 cancers classified as rare, this day serves as a crucial opportunity to start conversations about the challenges of diagnosis, treatment, and daily life for those affected.

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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.

About California Gully Primary School

California Gully Primary School is situated in Staley Street, California Gully, and geographically located between Bendigo and Eaglehawk. The school was opened in 1883 and is known as 'Bell Topper Hill'. Their motto is 'Small School - Big Results'.

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.