

Web: www.ausee.org Email: admin@ausee.org

## - FOR IMMEDIATE RELEASE -

## My dad... my hero... my button buddy

Most boys look up to their dads as hero's and four and half year old Zephyr Anderson is no different. Zephyr's dad Clay would stop at nothing for his son and he even got a tattoo of his son's feeding tube so they could become button buddies!

Zephyr has had a feeding tube from 6 weeks of age, first he had a nasogastric tube (NG) for 10 months, then he had a button inserted in his stomach at 11 months of age. Living with FPIES (Food Protein-Induced Enterocolitis Syndrome) and suspected EoE (eosinophilic oesophagitis), Zephyr is now only able to eat 19 'safe Foods' and his nutrition is supported by his elemental formula feeds which occur 4 times and day and overnight as well.

Last week Zephyr started prep and he was excited to be able to share with his class mates what having a feeding tube meant for him. It's taken a lot of preparation to get him ready for school but it paid off with him enjoying his first week.

A few years ago Zephyr's mum, Kate started the Facebook group **AU Tubie Support** to bring together all Australians who need a little bit of help and support in caring for someone with a feeding tube. AU Tubie Support is now partnering with Australian charity, ausEE Inc. to promote Australia's **Feeding Tube Awareness Week** to be celebrated nationally **7–13 February 2016.** Together they hope to raise awareness for those living with feeding tubes and the day to day challenges they face.

Kate says 'Life with a tubie was overwhelming at first, I found it hard trying to get tube feeding specific help and reach other parents, so I came up with AU Tubie Support and we are growing, learning and supporting each other.'

a charity dedicated to improving lives affected by eosinophilic disorders

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'Living with a tubie has changed our life and perspective. We take each day as it comes, from infected

sites, to buttons and tubes being pulled out and put back in, to Zephyr swimming at the beach and

skating. We live by the ruling he can do anything until he reaches his own limits.'

There are many reasons why children or adults may require feeding tubes. ausEE's president, Sarah

Gray's 12 year old daughter Bella has EoE and had a feeding tube inserted in her stomach when she was

7 years old due to the complexity of her food allergies and chronic illness. Up until last year she spent

every night for four years attached to a pump to feed her almost all of the nutrients she needed to

survive. A keen cheerleader, last year she opted to start drinking the formula instead so she could live

her dream and this is proving harder than having the tube itself. She's already had her feeding tube

removed so now she's at risk of needing a nasogastric tube and this is something she's desperately

trying to avoid.

Sarah says 'We want to raise awareness for those with feeding tubes as there is a lot of misconceptions

about them and for those who are personally affected, it's easy to feel isolated... we want to give these

people a voice'.

Those living with feeding tubes who are looking for support can join AU Tubie Support on Facebook at

https://www.facebook.com/groups/Autubies or visit www.ausee.org for more information.

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Page 2 of 2