

- FOR IMMEDIATE RELEASE -

What we want you to know about life with a feeding tube

13 year old Bella Gray had a feeding tube inserted in her stomach at the age of 7. When she got the tube, little did she know that it would change her life forever. Nearly four years passed and every night she was attached to a pump to feed her overnight a special elemental formula that met 90% of her nutritional needs.

Bella says of her time with the feeding tube 'The only thing that was stopping me from taking it out was, the fact that it was the only thing keeping me alive.'

At the age of 11, she was getting fed at school every day at lunch time too and as she now had the energy and strength to participate in sports, had taken up Cheerleading. Training three times a week, she yearned to build on her skills and having a feeding tube was limiting her. So she made the difficult decision to go back to drinking the formula and try to increase her food intake. Bella has a complicated list of allergies and chronic conditions including being diagnosed with a rare disease, Eosinophilic Oesophagitis (EoE) at 18 months of age, so tube weaning was certainly not easy.

'It might sound odd to you but I was actually a bit upset that I had to take my feeding tube out.' says Bella. She doesn't regret any of her time spent with the feeding tube though and in Bella's words 'Without it, I wouldn't be me or be where I am today.'

5 and half year old Zephyr Anderson had a feeding tube from 6 weeks of age, firstly a nasogastric tube (NG) for 10 months, then he had a gastrostomy button inserted in his stomach at 11 months of age. Living with FPIES (Food Protein Induced Enterocolitis Syndrome) and suspected EoE, Zephyr has gone from eating 16 foods for the last 4 years to now, in the last year expanding his safe foods to over 30. His elemental formula has helped him along the way and without this; his safe foods may not have grown as fast.

Zephyr's mum Kate says 'With Zephyr's struggles over the last 5 years there have been delays with speech and his mental health so as a family we decided it would be best for Zephyr to repeat Prep again.'

This year will be different as Zephyr has the choice to try more foods and drink his formula orally and the plan is to have his button removed in the next 5 months. Kate says 'He is up for the challenge and is smashing it daily!' 'I don't know who is more nervous him or me, but I do know that Zephyr would not be where he is today without the help his button has given him.'

From NG tubes being sneezed out or pulled out to buttons popping (just as recent as Boxing Day 2016 for Zephyr) and Kate having to insert a new one herself, this is all just part of the life of an AU Tubie mum. 'I will surely miss it, but I'm thankful, Zephyr's button hasn't stopped him and it's shown our family a new perspective on life!' Kate says.

There are many reasons why children or adults may require feeding tubes. 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.

Each year ausEE Inc. partners with AU Tubie Support to promote Australia's Feeding Tube Awareness Week which will be celebrated nationally 5–11 February 2017. Together they hope to raise awareness for those living with feeding tubes and the day to day challenges they face.

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Media Contacts:

Sarah Gray
Founder, ausEE Inc.
admin@ausee.org
Ph. 1300 923 043