

Bandaged Bear Day™

Friday 26th March 2010

Zali Venables

2 years old

At 18 months old Zali Venables was diagnosed with Langerhans Cell Histiocytosis - a severe disorder of the immune system treated with chemotherapy. Children in the first two years of life only have a 20% survival rate.

What did this mean for Zali? Histiocyte cells usually travel with white cells. Normally these Histiocytes are responsible for cleaning up waste, but in Zali's case there were too many and they simply worked in reverse. The disease fed on all of Zali's immunoglobins and blood, storing itself in her major organs and attacking them. This was very rare. Doctors had not seen this happen in the major organs in 10 years.

Zali began treatment with one dose of chemotherapy once a week for six weeks. This was not effective. There was no choice but to introduce a new type of intensive treatment requiring the dose to be increased to two types of chemotherapy, once a day, for five days – enough to make any healthy adult feel unwell. Intensive chemotherapy would be associated with side effects, but the treatment would be vital for Zali's survival.

Exactly 24 hours after the new treatment began Zali was rushed to the Paediatric Intensive Care Unit (PICU), where she would spend the next four months. She was intubated and ventilated to help her breathe, and suffered major organ failure eight times. The list of side effects grew, as did the amount of catheters, tubes and medications.

What seemed like the end came when Zali was faced with calcification in her heart, lungs, and other parts of her body, a rare complication of extreme illness that caused her entire body to weaken. With chemotherapy still key, a number of different specialist teams worked on Zali as she grew weak. The chemotherapy was having a delayed effect, Zali just needed to live long enough to experience it.



Her family had not yet lost hope when they were offered a first of its kind option. It was a medication called Pamidronate, more typically used for children with osteoporosis. This would be the first time that this treatment was used for this type of calcification. There was no certainty that the Pamidronate would work - Zali could very well continue to weaken, or she might improve.

Zali was given the medication which allowed all her organs to hold their own again. One hundred and five days after her first admission to PICU Zali was back in a normal ward, eating 4 icky poles a day, blowing bubbles, and enjoying hugs with her family. Chemotherapy continued and soon became the reason Zali was able to celebrate her second birthday with a completely inactive condition.

“They say it takes a village to raise a child – it took 15 groups of experts to save Zali’s life. She only had a small percentage of survival, and in PICU it was even smaller. Without their extraordinary skills we would have had a funeral for our child by now,” said Lisa, Zali’s mum.

Against all odds Zali is now in complete remission. She is no longer an inpatient, but she still visits the Hospital regularly for check-ups once a fortnight, and physiotherapy and occupational therapy four times a week. They will continue to do this for the next six months.

“The Hospital gives unconditionally. The doctors and nurses have worked on Zali as if she was one of their own. They have revived her several times, they have cried with us, and ultimately made her well enough to be the centre of our family again. I hope donations to the hospital are as generous as they have been to us.”

Zali is a happy, bubbly and brave little girl. As mum describes:

“She is very cute, soft hearted and gentle. She copies everything her siblings do. She loves a laugh and eating with the family. She is a forceful sharer and insists on family being together.”

Hopes for the future... What Lisa hopes Zali will be when she grows up

“I want Zali to have the opportunity to be a mother when she grows up so she can fully understand how much we love her.

I want her to be unafraid to say yes and believe in herself enough to know she is worthy of any opportunity.

I want her to be free and controlled only by herself.

I want her to be compassionate and loving.

I want her to have peace in her heart.”



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