



Heartbroken parents Viktor and Kristina Petraskova who lost their daughter to rare disease CHARGE Syndrome are now fundraising to help research this devastating disease.

Nth Beaches

Freshwater baby girl sparks major Westmead hospital event

Kathryn Welling, News Corp Australia Network
June 24, 2016 3:13pm

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Tiny Ela Petraskova only lived 56 days but her life has inspired a major Westmead Hospital appeal to buy lifesaving equipment to save babies like her.

The Freshwater baby was born premature last August at the hospital with a serious heart defect. She was operated on at just two days old.

It was then discovered she had CHARGE syndrome which is a complex condition affecting

her eyes, airways, ears as well as her heart.



📷 Ela Petraskova who died less than two months old.

Parents Viktor and Kristina Petraskova were heartbroken but thankful for the care their child received at the Paediatric Intensive Care Unit at Children’s Hospital at Westmead.

“She was on breathing support all her life,” Kristina said. “Ela’s heart valve couldn’t be fixed, it needed to be replaced. Her brain wasn’t developed well and couldn’t process what she was seeing. She would probably never learn to walk or speak.

“The PICU team organised for us and our parents to meet all the specialists involved in Ela’s care. Ela’s situation was summarised and after this meeting we knew we will have to let Ela go.”

Baby Ela died on October 26 last year.

In gratitude to the hospital, and to maintain a legacy for their daughter, Viktor and Kristina offered to raise money for a special \$15,000 surgical lamp needed by the intensive care unit.

The couple are organising a fundraising dinner and live music night in August, called Ela’s Night of Angels. The fundraiser night is in the same week as Ela’s first birthday.

The couple also intends to take part in a hospital fun run and raise awareness of the rare genetic disorder that affects one baby in 10,000.

“We know Ela’s life had meaning,” Viktor said.

“It has not only made us and our relationship stronger than ever but Ela opened our eyes to new worlds.

“She has inspired us to carry her legacy forward through helping others and keep her memory alive in this way.”

Ela’s Night of Angels is on Saturday August 27 at Valentine’s Function Centre, Brookvale at 7pm.

Tickets are \$99 each and include a three-course dinner and live music.

For more information, visit the website www.lovefromela.org/