

I would love to introduce to you the Jans Family from Woonona, NSW (near Wollongong).

Mum, Carley 37 and Dad, Chris 39, sons Zachary 14 and Ryley 13, daughter Holly 7, twins Hayden and Jake (both deceased) and the adorable little Sophia 7 months. Sophia is a very happy and inquisitive baby who is part of a beautiful and loving family. Carley is a Registered Nurse, currently lecturing nursing at University of Wollongong and a former NSW Ambulance Paramedic. Chris is a Firefighter with Fire and Rescue NSW and a Registered Nurse who is also a former NSW Ambulance Paramedic. Both have dedicated their working careers to help others in their time of need.



In August 2014, the Jans' celebrated the birth of the beautiful Sophia Rose. Sophia was born with a very rare limb deficiency called Fibula Hemimelia affecting her right leg and Tallipe (club foot) to her left foot, which is currently being successfully treated. Fibula Hemimelia is the malformation or absence of the fibula bone with a shortened tibia bone and can also include deformities to the ankle, foot and thigh. There are varying degrees of severity of this condition. In Sophia's case she has no fibula and her ankle, foot and thigh are also malformed. In Australia the only treatment that has been recommended for Sophia is amputation of her leg, leading to a life prosthetics and the complications that are associated with this, such as pressure sores to the stump, back pain and then there are the body image challenges that Sophia would face as an amputee. Even after amputation the ongoing costs of prosthetic limbs for Sophia will be a financial burden on the family, especially while Sophia is growing as a new prosthesis may be required every 6 months.



However, Carley and Christian through researching more about Fibula Hemimelia, have found out that Sophia's leg can be saved. [Dr. Paley, from the Paley Advanced Limb Lengthening Institute in Florida, USA](#) specialises in limb reconstruction and can save Sophia's leg. Carley and Christian have already been in consultation with Dr. Paley and Sophia is a candidate for this treatment which will also include rectifying the deformities to Sophia's ankle and foot with the Superankle procedure which is not available in Australia. This treatment will allow Sophia to walk normally and live an active life with her own leg. But this is at the estimated cost of \$255 000 as the treatment is ongoing while Sophia is growing and there is no Australian Government assistance available.



As a family, the Jans' have been through more than their fair share of life-altering events. Christian's mother tragically died, at the hands of her husband, his father. After this, Carley and Christian became the carers for Christian's younger brothers to ensure that they all stayed together as a family. Then in 2009 Carley and Christian suffered the terrible and unexpected loss of their twins, Jake and Hayden, due to complications caused by Carley contracting Parvovirus during her pregnancy. Carley and Christian were then given the heartbreaking news that any further pregnancy's would be nearly impossible. Carley told the doctor that her family was not yet to be complete and they tried for a further 4 years to fall pregnant.

In July 2013, 3 weeks after moving into their new family home, the Jans family experienced another tragedy, a house fire. Fortunately all the family members were able to evacuate with no one being injured even though the fire was only metres away from Holly's bedroom where she was asleep and Christian had to run back into the house to retrieve Hayden and Jake's ashes. This house fire took most of their belongings.

The Jans family has since had to battle with their Insurance Company, which has included involving their local member of parliament and seeking legal advice, but finally a resolution with the Insurance Company has been reached, a year and a half later. The end result is the Jans are now paying rent (insurance covered 1 year rent) and mortgage payments during this time and have had to extend their mortgage to get the home and contents completely replaced. Unfortunately Carley has also had to return to work early from maternity leave in order to help keep up the mortgage and rent payments. Their new family home has also been modified for Sophia's recovery which now includes a heated pool as hydrotherapy will be important in little Sophia's recovery from her pending the surgery.

The reconstructive work to their family home only commenced in Jan 2015 and the Jans' are hoping to be in their family home by June. Carley and Christian have made the heartbreaking decision that should they not make their fundraising goal that the house, once completed, will be sold with all equity going to fund Sophia's surgery.



Although Sophia is a healthy baby, her limb disabilities are just another unlucky sequence of unfortunate events that this family has had to deal with together. But they are a strong family and will do whatever it takes to the best for Sophia and to give her every chance of keeping her leg. Sophia is a beautiful girl who deserves a chance to have full use of both her legs, especially when there is treatment available overseas.



The Jans family are a very proud and giving family, who are prepared to fight and give everything to Sophia to ensure that the best possible outcome for an able bodied life has been attempted. Both Carley and Christian find it difficult not to try everything medically possible to save her leg.

Friends of the family are rallying together to organise some fundraising events such as a trivia night and selling chocolates, but fear that this may not be enough.

I am asking on behalf of the family to share their story to help Sophia's fund page to save her leg and ultimately save their family home which has been designed to also aid Sophia's recovery.