

DonateLife  
BOOK OF  
LIFE

A collection of life-saving and life-changing stories from people touched by **organ and tissue donation.**







Her Excellency Ms Quentin Bryce AC  
Governor-General of the Commonwealth of Australia

*Foreword to the DonateLife Book of Life*

by Her Excellency Ms Quentin Bryce, AC  
Governor-General of the Commonwealth of Australia

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As the inaugural DonateLife Ambassador, I have been privileged to observe the impressive leadership of the DonateLife team and agency network in managing organ and tissue donations throughout the country, and in educating Australians about the issues that are central to our decisions to give life.

Inspired by the work of these outstanding professionals, the *DonateLife Book of Life* is a heartfelt appeal to all Australians urging us to find out the facts about organ and tissue donation, to make well informed decisions, and to discuss those decisions with the people close to us.

Here is a collection of stories from brave and thoughtful Australians whose lives have been touched and transformed by a donor's life-affirming decision. These honest and grateful accounts pay tribute to the generosity of lives tragically and abruptly ended: the ultimate act of giving life to another as one's own life passes.

The *DonateLife Book of Life* starts its journey around Australia in DonateLife Week, Sunday 20 to Sunday 27 February 2011, a campaign led by the Australian Government's Organ and Tissue Authority to raise donation awareness among Australians and to increase our donation rates.

It is my hope in 2011 that, as these stories are shared across the nation, many more of us will be moved to think, talk and act on a decision that can help bring life and healing to thousands of Australian lives.

This is a decision for all of us and each of us. We share life and we share a capacity to give life. Our personal experiences of living and giving are most powerfully told through our stories. This book is our carriage and our conduit for ensuring that our decisions bring the greatest good to the greatest number in the Australian community.

We are forever indebted to those Australians who have chosen to give life. They have made their mark in the most profound ways and the *DonateLife Book of Life* bears their courageous stamp.

May these pages travel far and deep across our generous land.

6 February

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2011

**On average, people on  
transplant lists wait between  
6 months and 4 years.**



# Your powerful gift

**A** week before my 24th birthday, I was diagnosed with kidney failure. This was a real shock to me and all of a sudden I knew my life was going to change forever. After thinking about all the information that was presented, I decided to take full responsibility and ownership of this condition.

I made a promise to myself, 'to create the best life possible'. I continued to work full-time as a tradesman and never gave up. I spent eight years on nocturnal dialysis at home. Setting up the machine to needling my fistula and switching off the machine in the morning, I was my own nurse.

I received a kidney. It was a complicated procedure, and I spent six weeks in hospital fighting to keep this gift. I never gave up,

and the doctors and nurses were amazing and so supportive.

A few years ago I decided to try snowboarding and with some reservations, the sport has now taken over my life.

I recently came back from my first trip overseas where I went snowboarding in Japan to celebrate the fourth anniversary of my transplant. With this second chance I have been able to reflect my life. It was a very emotional and amazing experience.

Thank you for the opportunity to experience this beautiful life.

Jason



**Around 1600 people  
are on official transplant  
waiting lists at any one time**



# She lived her life to the fullest and wished to give something back

**M**elody worked as a Photo-media Assistant Curator at the National Gallery of Australia and was on the threshold of a promising career when her life was tragically cut short. She had always lived life to the full and had a passionate interest in art history which was her honours thesis. She was also a practitioner in the fields of pottery, music, writing mixed media, jewellery making and artistic photography

David and Robyn's daughter died as a result of a motor vehicle accident near Boorowa NSW as she was returning home to Cowra.

The wishes of Melody were followed once we were informed of her registration to be an organ donor. Melody wished to give back to other people in their time of need and her gift of life was able to save the lives of three people.

David felt the overwhelming need to do something to both honour his daughter and start conversations about organ donor awareness. Melody's gift inspired his motorcycle bike ride which he hopes will inform the public of important issues relating to organ and tissue transplantation in Australia.

The Organ Donation Awareness Ride (ODAR) has travelled about 5000km through New South Wales, Victoria and the Australian Capital Territory.

As I rode through cities, country centres and small rural townships, sometimes alone, sometimes with others, I felt it was important to stop as often as possible to talk to people about organ donation and its implications from the point of view of a father who has had that experience. To me it was vital to impress on the people I met about the importance of ensuring their families understand their decision and respect their wish to be organ donors should they be placed in the position I was.



Melody

**Each year around  
1,700 corneal transplants  
are performed to give  
the gift of sight.**





# Life is an amazing journey

**A**t the age of 39, I was diagnosed with end stage renal failure. Three months later I was on dialysis. It was an unexpected shock that changed my life completely. It affected my whole family. I had to resign from my job. It was no longer easy to pack up and go on holidays or be there for my children during special events at school. Even with a supportive group of friends and family, just getting them to school and back was a challenge. It was a problematic, stressful life and I felt quite unwell and tired most of the time.

Then, three years later, I received the most amazing gift of all, a pre-loved kidney. The transplant absolutely transformed my life. The wonderful thoughtfulness of an organ donor gave me a second chance to live a healthy fulfilling life.

Most importantly I have been able to be there for my family and have fully enjoyed watching my children grow up. I now have the energy to dance like a teenager at live gigs and play in the waves of our beautiful beaches.

My transplant has given me the opportunity to meet some interesting people. When they ask me what life means to me, my answer is simple. I am so blessed to be alive and life is an amazing adventure. Every day is precious and like many transplant recipients, I live life in the moment. I will always be incredibly grateful for the most generous gift any human being could give, a part of them that lives on to give another person a chance for a happy, healthy life.



Katrina

**The most important thing  
that helps a family's decision  
is their knowing the donation  
decision of their loved ones.**



# Mum

As a baby, there would have been endless sleepless nights for you.  
As a toddler, I would have kept you on your feet.  
As a teenager, no doubt I gave you many headaches.  
I thought you were too strict and over protective, I wanted to run away.  
The day I got diagnosed with my illness, the only place I wanted to run to...was into your arms.  
You were there with me, every step of the way.  
Every treatment, every procedure, you were there holding my hand.  
There were many days where I wanted to give up but you were there to inspire me.  
Days I felt I was drowning in despair, you threw me a life line.

Mum, you gave me life 38yrs ago.  
You gave me life twice when you donated me your kidney.  
It is because of your gift of life to me, I was able to give life to my two sons.

No amount of words can describe the love and gratitude I have for you, but know this  
Mum – I am the woman that I am today because of you.

Irene  
Member of Transplant Australia



Irene and her mum

**Any day is a good day  
to talk about organ  
and tissue donation.**



# Andrea's story

**W**hen I was just a young girl, I was diagnosed with a rare type of diabetes that made me severely obese. Last year a tragic accident occurred and I was called into the hospital. I was immediately taken into surgery where I received a pancreas. The surgery went well and I am just thankful that I received an organ.

I was so grateful that I have turned my life around. This young person's family, in a time of tragedy, saw the opportunity to give life to

someone else. A tear comes to my eye as I write this. It was the best news of my life and now I have successfully changed my life.

Now I am living the life I had always wanted—with my husband, Mitch.

I have encouraged many of my close friends to donate and I have encouraged my whole family to register as donors.

Andrea



**Australia is a world  
leader for successful  
transplant outcomes.**



# A Gift of Love

## Dedicated to my donor and their family

I see my wife, my daughter, my son  
The light that brings the new day on  
These precious things from God above  
For those are but the Gifts of Love.

These precious things we hold so dear  
Accepted so year after year  
Are but on loan from God above  
Though everlasting, the Gift of Love.

When our time on earth has come  
Happily we'll return back home  
With God's approval from above  
That we have shared a Gift of Love.

We share your grief, your loss, your pain  
But know the love and pride you gain  
His love inspired from God above  
With compassion given, his Gift of Love.

For those of us who share that gift  
Remember ere our thoughts to lift  
To family and their loved above  
With heartfelt thanks for their Gift of Love.

Mal



Expressions of my and my family's love and everlasting thanks

**Discover the facts**  
**Decide about becoming**  
**an organ and tissue donor and**  
**Discuss your decision with**  
**the people close to you.**





# Australians please become organ donors

**I am a passionate advocate of organ and tissue donation and know the benefits of donation first hand.**

I was working a couple of jobs and life was good. Then it came out of the blue. One day I was struck down by pancreatitis.

I was in Intensive Care for four days and in hospital for three months. I had to give up work.

I followed my doctor's advice and things settled for a while. Then I got worse and was told I needed a kidney transplant. I went on the transplant waiting list and on dialysis for three years.

Then one day I got the call—and someone's kind generosity changed my life. I received a new kidney.

I am no longer tied to a hospital or home for dialysis and I no longer feel so tired and sick—there were days when I just couldn't do anything. I had my transplant at St George Hospital.

I encourage all Australians to become organ and tissue donors as one day it could be someone in your family who needs a transplant.

I now speak to community groups through a foundation that I set up called the Gift of Life Foundation to further the cause of organ and tissue donation for transplantation.

I am involved in working with sporting clubs and I organise a celebrity golf day each year.

Phil



Phil

**On average, people on  
transplant lists wait between  
6 months and 4 years.**



# A chance for better sight

**A** few years ago I was told I needed a corneal transplant, and was placed on the waiting list. I had no idea how long the wait would be, but hoped it would not be too long, as my husband was already registered as being legally blind. I saw the surgeon again six months later, and was told it shouldn't be too long to wait.

Two weeks later, I had the call to attend the hospital for surgery, and the operation went well. It is impossible to stress how grateful we both are for the gift of a cornea, and the surgeon tells me the graft is looking good. I'm told the sight in that eye will continue to improve for about two years.

Many thanks once again to the donor and family who made my transplant possible.

Miriam



**One organ and tissue donor  
can save or enhance the  
lives of 10 or more people.**



## Our Linda – our sister

**L**inda or 'Lou' as we called her was one of a family of seven brothers and sisters. She was also a wife and mother of two. Lou died suddenly when she was 42 years young.

She was someone who was fiercely protective of her family and friends. She was always there to give a helping hand, and even in death she was able to help by donating her heart, lungs, kidneys, liver and corneas. There are people alive today because she had let her family know her wishes, and we as a family honoured her wishes. It was simply part of her personality to give.

They say The Lord works in mysterious ways. In the hours before her sudden death she talked to all her sisters and even had a cuppa and a scotch finger biscuit, laughing and having a good time planning her trip to the races on Melbourne Cup day.

Linda would have been sorry to have missed knowing her beautiful grandchildren, seeing them running carefree on her beloved Nudgee Beach.

The world was a better place for her being part of it. She will always have a place in our hearts—love you Lou.

Barbara



**Around 1600 people  
are on official transplant  
waiting lists at any one time**



# Donation is a valuable conversation to have with your loved one

**D**ale was a proud Jaywon and Torres Strait Islander man, who I was lucky to call my life partner. He was looking forward to the birth of his first granddaughter when he died suddenly at the age of just 38.

Dale collapsed at work surrounded by his colleagues who frantically tried to save his life. And I would like to take a moment to pass on to those colleagues that the paramedics that attended to him have told me that they were incredibly impressed with their efforts – I know they did everything they could.

Dale was rushed to the Intensive Care Unit, where again the doctors and nurses did everything they could. Despite this, very quickly I was faced with one of the hardest decisions of my life – whether to donate Dale’s organs and tissue.

The decision was relatively easy for me. And that was because prior to Dale’s death, we had had many conversations about his wishes to be an organ and tissue donor. Indeed the first of these was on our very first date, where we talked literally about life, death, the universe and everything. Throughout the next 14.5 years, each time we would have those discussions, they were always relaxed and informal conversations – we both cared about what may happen in each other’s futures.

Having had those conversations, when the time came, the decisions I had to make were so much easier as I knew Dale’s wishes.

As a result, Dale was able to give sight to two people through the donation of his corneas. As well as making a difference to the lives of these recipients, his lasting legacy has made an enormous difference to the healing of the family as, even in his death, Dale was able to give the gift of sight.

I urge you all to please have the discussion with your family, your partner or your significant other as I did.

Kathy



Kathy

**Any day is a good day  
to talk about organ  
and tissue donation.**





## John

**M**y husband was very ill though I had no idea how ill! As we saw doctors and specialists the seriousness became more obvious. He had cirrhosis of the liver and needed a new organ. I believe that his 'bloody mindedness' helped him to get through this difficult time. Apart from the ascites, loss of weight, peritonitis, tiredness and multiple visits to doctors and hospital, in hindsight, we now realise just how fortunate he was to get a transplant after only five months of being on the waiting list.

We got the 'magic call' at 10.30pm for the surgery to take place first thing in the morning. Although the operation itself was a great success there were some complications with several infections but this was a small price to pay for the chance of a new life.

Just six weeks after the transplant he was back in for major bowel surgery to correct the peritonitis that occurred as one of the complications. Two major operations in six weeks, but thank goodness he was strong enough to get through both of them.

We have sent 'thank you' cards to the donor family every year (these are sent via the Liver Transplant Unit) but my husband and I thank them every day for their very difficult and wonderful decision to make their family member a donor. Their 'tragedy' became our 'miracle'.

My husband will celebrate seven wonderful years of extra life thanks to them! The only way he feels he can acknowledge this wonderful donation is by keeping as fit and healthy as he can; cycling several kilometres a day, eating as healthily as possible and living life to the full. He really does deserve to be well and he works hard to keep fit. I am so lucky to still have him here with me and my heart breaks for the donor family whose situation is so, so different. Our thanks will never be enough.

Sandra



John

**Organ and tissue donation  
for transplantation is based  
on the concept of altruism.**



# A new liver, a new life

**I**t all started when I was born and diagnosed with Alpha 1 antitrypsin deficiency—a rare liver disease. When I was three months old I had to have an operation so the doctors could find out more. After this, other than regular medication and doctor's appointments, I wasn't really affected by this disease until I was 12.

Towards the end of grade six, I was always sick with stomach aches, migraines and I never had energy. My stomach was filling up with more fluid each day as my liver was not able to do its job. This resulted in me having to quit sport and my skin and eyes turned yellow from jaundice. I was eating nonstop and never feeling full. I was just skin and bone and had no muscle tone. I wasn't able to attend high school normally like all my friends because I was always tired, sick or had to go home. After a while I had to stop going to school altogether.

I was put on the transplant waiting list and was told that it could be up to two years before I got a liver. Although it was making me really sick, I always tried my hardest not to give up all the things I love. The day before my transplant I went to football training and played with my team mates.

We got a phone call saying that they had my new liver only two months after going on the list.

After just six weeks in hospital I was sent home feeling the best I had ever felt in my life. My energy and fitness started coming back and I could start playing basketball and football again. My new liver is the best present I have ever been given.

Will



Will



**Organ and tissue donation  
for transplantation is based  
on the concept of altruism.**



# The life I waited for

**I had been ill since birth and treated for asthma when, at the age of 17, I suffered a stroke and was admitted to hospital for tests. The stroke turned out to be a blessing in disguise as doctors found that I was not asthmatic but had been born with a hole in the heart which had led to hypertension in my lungs.**

When I was told I needed a heart and double lung transplant, I was thankful that there was a solution to the blue tinge to my skin, being unable to breathe or walk far. I saw my transplant as the solution I had waited my whole life for.

I was 26 years old when I underwent the operation. My donor had died, however their incredible gift of life saved not only me but others as well and all of us are aware of how this selfless act had prevented our deaths.

Following transplant I realised how ill I had been as I'd never known any different. For the first time in my life my feet were pink and

finally I was able to walk up a hill. Then I found that jogging on the spot warmed me up rather than turning me blue and giddy. Who knew!

I have been incredibly fortunate to have had the last 17 years, where I can participate in the Transplant Games, make new friends, get married, have a career and basically do all the things I would never have been able to do.

And all because someone I never met was kind enough to make it all possible.

**Roxanne**



Cycling at the 2010 Transplant Games, Canberra

**Any day is a good day  
to talk about organ  
and tissue donation.**



# A life too short

**J**ason was nearly 19 years of age when he died. He was accidentally killed while attending an automotive spare parts traineeship.

Being the eldest of four children (two brothers and one sister), Jason was a very loving, caring and loyal son and brother with his family always coming first. Life was lived to the fullest, always in a hurry as though time was running out. He loved V8 cars, motorbikes and loud music along with his mates.

At 15 years he commenced work as a salesperson with an electrical store. Having the 'gift of the gab' he made many sales. Being an avid reader, Jason loved company and telling stories.

When Jason acquired his driver's licence at the age of 17 he proudly announced 'I'm an organ donor just like mum and dad'. His aunty commented that she couldn't be one. His response was 'When you're dead you're dead. If you can help somebody else you do'.

When Jason was pronounced 'brain dead' the doctors noted 'Organ Donor' ticked on his licence. As parents, never in our wildest dreams did we ever think we would be in this position. Jason's words echoed in our ears there was no other alternative but to fulfil his wish and give our consent.

We are very proud of his decision. It is of great comfort that he saved four people's lives, two being imminent deaths. His life was not in vain!

The Service of Thanksgiving is a wonderful event which we have attended every year since Jason's death. The Closing Song 'What a Wonderful World' always brings tears to our eyes.

We have shared in something very special over the years, thanks to Jason and all the other organ donors. May They All Rest in Peace.

Jill and Keith



Jason became a donor at age 18

**Australia is a world  
leader for successful  
transplant outcomes.**





# Finally I can breathe

**M**y name is Laurn and I was given the gift of life.

I had cystic fibrosis with probably the worst infection in the lungs you could have. I went on the transplant waiting list and waited six months before I got the call.

When I woke up in ICU two days later I couldn't believe the difference. I could breathe without gasping. I was in hospital for two weeks. During that time I was walking around the hospital, riding the exercise bikes, things I hadn't done in I don't know how long.

It's been nearly nine years now and I have never had any rejection or problems with my lungs in any way. I've gone on to learn and work in the career I've always wanted but was never able to do before.

I think of my donor and their family often. To be able to make the decision to donate at such a time of loss must be so hard. I lost my brother to cystic fibrosis two and a half years before my transplant while he was waiting for his call.

Organ donors are the real heroes in our society, not sports stars. They aren't saving peoples lives and giving them a second chance. The organ donors do that. They are heroes to every transplant recipient and their family. Without them we wouldn't be here. We can

never express our gratitude enough. Thank you just doesn't cut it. But we can live and move forward, we can take our second chance and run with it. The best thing we can do is live for ourselves and for our donor who is with us every step of the way.

To every donor and their family, a massive THANK YOU for giving us a second shot at life!

Laurn



Laurn

**40% of Australians  
do not know the donation  
wishes of their loved ones.**



# A transplant made me a better person

**The most important thing I have learned is that people who make the decision to donate organs are the kindest and most generous people. There are no words that can adequately express the gratitude felt by recipients and their families for this most generous gift.**

Living with chronic disease is no fun for anyone. Life becomes very restricted, you become dependant on others and you feel lousy most of the time. But this is how it is so you deal with it. You take each day as it comes and appreciate the good days and try to forget the bad ones.

To be told that you will be dependant upon a machine to keep you alive unless you receive a transplant is devastating. The thought that another family needs to lose someone they love and adore to enable you to live is just heartbreaking. Seems like a win-lose situation to me: my future good health vs their grief.

When I was told I would need a transplant, my aunt immediately volunteered to donate one of her kidneys. What a humbling experience. We were all aware of the risks involved and my concern was more for her future health than my own. It still amazes me that a person can be

so selfless that they are willing to give a piece of their body to another in order to save that person's life. What makes my life so important that she should do this for me? Quite simply – she loves me. She cares deeply for my family. She doesn't want to see my family suffer any longer. She is a hero.

Our transplant took place and what a difference it has made to my life. After the expected recovery period I was able to return to an active life: full time work, overseas travel, I even stayed awake all day and washed my own car. I felt the darkness of illness and depression lift from my world and I began to enjoy life once again. The feeling of freedom and independence is never sweeter once it is found after being lost.

My transplant experience has taught me some valuable lessons and made me a better person. Appreciate everyone in your life. Enjoy each moment. Don't stress over things you cannot change. Accept people for who they are. Be honest about your feelings. Accept help when you need it and give it to those who need it too. Enjoy life and be happy. I am.

**Karen**  
**Member of Transplant Australia**

**The majority of  
Australians support  
organ and tissue donation.**



# The valve that saved my baby's life

**M**y baby boy was born on Valentine's Day. He fell sick after three days and was rushed to hospital. He was diagnosed with Aortic Stenosis. He was unable to breathe on his own and they had to perform the Ross Procedure at five and a half weeks. This was to move his pulmonary valve to become the aortic valve and get a donor pulmonary valve.

It saved his life. He was able to breathe on his own again after six weeks. It was still a rocky journey after the operation but he is still with us today—and happy. He will need future surgery to replace the pulmonary valve with one that has been donated about every 10 years.

Linda



Day after surgery

**One organ and tissue donor  
can save or enhance the  
lives of 10 or more people.**



# A new beginning

**I had a double lung transplant. Six months previously, I had been sent home from school with a headache. Over the next couple of weeks I progressively became sicker until I was eventually diagnosed with mycoplasma pneumonia and was ventilated in ICU for a few weeks.**

My family, friends and I all thought we were incredibly lucky when I was able to be taken off the ventilator and moved back to the ward. Three months later I was still in hospital and requiring constant oxygen and a wheelchair. At this stage I was diagnosed with end-stage respiratory failure and bronchiolitis obliterans.

This is when the wonderful paediatric team came in to our life. I was accepted onto the transplant waiting list and then transferred to the Children's Hospital for three months while I waited for a donor.

The team had originally planned on a heart/lung or double lung transplant from a child, but when no suitable organs were available, they decided to use adult cut-down lungs. This proved to be a great success.

After six months living in hospital and using a wheelchair, I was able to walk out only ten days after receiving the transplant.

The first couple of days post-transplant were very long and hard, but once I got past these my recovery was a breeze. I stayed a further three months for rehabilitation and then my family and I returned home just in time for Christmas. I returned to full-time school and apart from a few overnight stays in hospital for minor infections, I have been extremely well ever since. We now live on the Central Coast in NSW and I enjoy life to the full!

I have competed in two transplant games, where I have won several medals and experienced great things. My family, friends and I are so grateful that the paediatric lung transplant team exists and know that we owe everything to them.

Imogen



Four years after my double lung transplant

**If you want to donate life,  
discuss it today, OK?**





# Steph's story

**M**y diagnosis of Cystic Fibrosis at age four didn't have too much of an impact on my everyday life. During my teens, hospitalisations for antibiotics were about once a year and I maintained 60% lung function into my early 30s. My husband Kevin knew about my Cystic Fibrosis from the get-go, having researched it when we began dating.

After a relatively healthy pregnancy (excluding a painful broken rib from coughing), our beautiful daughter Aurora Joy was born at 32 weeks. The next day I went into respiratory failure and was rushed to the ICU. I almost died. Aurora went home with her daddy, and I went home on oxygen a week later. My lung function was around 20%, I had lost over 15 kilos and I had to use a v-pap machine at night. Whilst I'd been in the ICU, a work up for transplantation had started.

Adjusting to the role of new mother, combined with the drastic decrease in my lung function, was extremely difficult. My gorgeous cat Moses, sensing my hopelessness, sat with me when I sat, and lay with me as I slept, despite the noise of the oxygen converter and v-pap machine. Desperately wanting to see my daughter grow up, I decided transplant had become my only option.

An interview was organised for me and I was listed and began my wait for a double lung transplant.

The phone rang with news of a possible donor match. I called my husband to come home from work. I kissed Aurora and my dad goodbye, possibly for the last time. My sister, Sophie, met

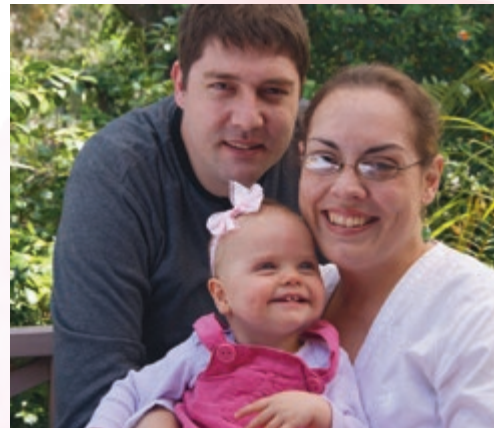
us at the hospital, but I couldn't get in contact with my mum. That was one of my saddest thoughts—that I might never speak to my beloved mum again.

Within 24 hours of our goodbyes I was awake and cleaning my teeth! Despite a few minor setbacks (swine flu and no voice) I felt so alive! After being in hospital a month, and suffering a more major setback (pulmonary embolism when my central line was removed), I was discharged.

I'm still 'learning' my new lungs, and getting used to my drugs. But the best thing of all is that I now have a future with my family.

I am so grateful to my donor. I can plan and dream. Kevin and I can now look forward to a long life together, watching Aurora grow up. Without my donor this wouldn't be possible.

Steph



Kevin, Aurora and Steph

**Ask and know your  
loved one's donation wishes**







**Australian Government**  
**Organ and Tissue Authority**



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**Alternative format**

The *DonateLife Book of Life* is available electronically on the Authority's website at [www.donatelife.gov.au](http://www.donatelife.gov.au)