

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

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.

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**Do the people close
to you know your
donation decision?**



Transplant

I've had insulin dependent diabetes for 25 years. Throughout that time I developed many complications including neuropathy, blindness and then renal failure.

I have been on dialysis for over a year and this was a life changing time. I found it difficult to attend work, drive and maintain a home. I felt worse coming off dialysis than I did going on—but I battled along.

Then that unexpected and wonderful phone call came to say 'yes I have my organs'—so off I went to Sydney. It was a frantic roller coaster morning that I will never ever forget.

I have been blessed by an angel, for I can now lead a happy, healthy and long life.

It has been 10 weeks since my kidney and pancreas transplant and I feel fantastic. I also believe that being positive goes a long way and that this attitude helped my recovery.

Thank you is not a powerful enough word to use, for the selfless act of kindness by the donor family. I am forever in their debt and believe that their loved one continues to live on—in me.

Lynda



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



A gift from a stranger

I would like to tell you about a gift I received. It was from someone I don't know and may never know, yet it is the most generous gift one can receive—the gift of life.

My name is Kyla. I was born with a serious and rare liver disease called biliary atresia. This meant that my body was unable to remove bile from my system as the ducts that carry bile from my liver to my gallbladder were completely blocked.

At five weeks old I had an operation called a 'Kasai procedure' to create new ducts aimed at removing the bile. At first we thought the Kasai procedure worked, but unfortunately when I was 10 weeks old my condition began to deteriorate. I was constantly getting infections, extremely lethargic and not able to eat. My skin became very yellow to the point where I looked green—even my tears were yellow. The doctors said my only chance at survival was a liver transplant.

I was placed on the transplant waiting list as a high priority as I was already in chronic liver failure. Then, when I was four and a half

months old, the call we had been anxiously waiting for arrived. We were told that there was a family who despite their grief and loss, agreed to donate their loved one's organs, one of which was given to me.

Because of this exceptional, selfless act this donor family saved my life, as well as several other people in the same situation as me. Without their gift it is highly unlikely that I would be here today to share my story, and I am eternally grateful to this special family for giving me the chance of life.

As a transplant recipient I know firsthand how important organ donation is. I also know how important it is to increase our organ and tissue donation rate, as currently we don't have nearly enough donors for those waiting for transplants. So please consider becoming an organ donor—your one decision can change a person's life forever. My donor family's decision changed mine, and I can't thank them enough.

Kyla



Kyla at four months and today at four years

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



A breath of fresh air

From as young as I can remember, I had been preparing for this day. It was always known to me, that it would come around at some point in my life. The only thing I wasn't prepared for was that I would have to face this path at the age of 18.

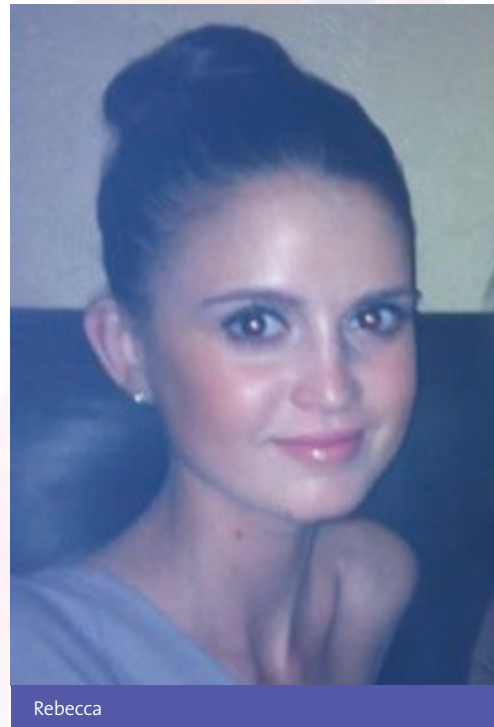
I was told that I had a maximum of two years to live. I was born with the chronic and debilitating lung disease, cystic fibrosis. By definition, cystic fibrosis affects mostly your lungs, pancreas, liver, intestines, sinuses and sex organs.

CF causes your mucus to be thick and sticky. The mucus clogs the lungs, causing breathing problems and making it easy for bacteria to grow. Difficulty breathing is the most serious symptom and results from frequent lung infections that are treated with, though not cured by, antibiotics and other medications. By my definition, it does all of that and so much more.

I received a call that changed my life. I received a double lung transplant that night and have been living my life to the absolute fullest since.

I am so thankful and so grateful to my donor family for giving me such a precious gift, the gift of life. Because after 19 years, I was finally able to take a breath of fresh air. And I've never felt better.

Rebecca



Rebecca

Do you know the
donation decision
of your loved ones?



Our pair of hearts

Our daughters Jayne, then nine, and Nicole, 11, received heart transplants within months of each other. Nicole had been diagnosed with dilated cardiomyopathy and had been on treatment ever since. But Jayne became ill very suddenly and was air lifted to the hospital. We were told that she too had dilated cardiomyopathy and needed an urgent heart transplant but her recovery was slow and she needed intense rehabilitation for many weeks. We moved the whole family from Tasmania and set up 'home' in Brunswick, where our other three daughters attended school.

After three months Jayne was allowed home to Brunswick. Unfortunately, Nicole's health then deteriorated and she had a ventricular assist device fitted while she waited for a heart transplant. About six months after Jayne's operation, Nicole received her new heart and

was discharged from hospital within a week. We finally returned home, forever grateful for the wonderful care we received at the Royal Children's Hospital.

Both Jayne and Nicole now have a normal life, like any other teenagers. They have to take regular medication, but they make the most of every day. Nicole hopes to become either a hairdresser or cook and Jayne is attending high school. They have participated in three Australian Transplant Games (2006, 2008 and 2010) and the World Transplant Games on the Gold Coast in 2009, where Nicole won a silver medal in swimming.

If it wasn't for some remarkable people who decided to donate their loved one's organs, we would have lost both our daughters. Our whole family feels that we are so very lucky and we are extremely grateful for those special gifts.



Jayne and Nicole.

**Donors and recipients
vary in age from
infants to the elderly.**



Christopher

Hello, my name is Christopher and I am 11 years old.

I was born eight weeks early and was diagnosed with kidney failure which had other health issues attached. I am also intellectually impaired.

I needed oxygen for the first three years of my life and had to be tube fed for the first five years.

I was lucky enough to receive a kidney transplant at the age of five and for the first time could eat and drink without being tube fed.

My life is a lot better now. Not so many visits to the hospital and my transplanted kidney is doing great.

I am the youngest of eight children. I have five sisters and two brothers and they along with mum look after me very well.

My dad died when I was five and didn't see me get my transplant but I'm sure he is watching over me from heaven.

I like to play on the computer and watch movies. I also like to run around and kick my soccer ball.

I go to school and am in mainstream schooling attached to the special education unit.

I love all my teachers and I have lots of friends at school who I like to play and talk with.

When I grow up I would like to work with animals as I love them all.

Steve Irwin was my hero and I was sad when he died.

I went to camp for the first time last year with Kidney Health Australia and I am looking forward to going again this year and having some fun with other kids who have a disability like me.

Thanks to everyone who supports me and my family.

Christopher



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



Our kidney transplant

My brother, Phil had suffered ill health for five years due to kidney disease. From the first seminar I attended with Phil and our family, I had no hesitation in putting myself forward for possible kidney donation. This would hopefully eliminate dialysis.

I cannot say the entire testing process was smooth. My immediate family and I endured an emotional rollercoaster. Certainly there were the 'up' moments where I was so pleased to be part of something that will enable a family member to live a long and happy life. Then there were the down times when I was left waiting for results of tests, days where I was off work, my children were dragged around hospitals and told that due to radiation they had to wait in rooms where I could not even see them, and the parking fines outside Fremantle hospital!

These few times left me vulnerable and questioning myself. What am I doing here—I'm not sick. This is all by choice! At the end of testing it was a good result for me and an even better result for my brother!

Yes, the surgery was painful and at times I thought I was never going to recover, but as promised by surgeons, I will be running again at six weeks post op! At the time I thought they were stretching the truth and this would never be possible, but six weeks to the day, I went with my dog for a run and felt fabulous.

I could not have put myself forward for possible donation if it were not for my wonderful husband, who supported me through the entire process—a sounding board for the emotional times, and then taking the household reigns! To him, I am forever grateful!

Phil is well and in good health. His young family are enjoying happy times with their old dad back again, the one who doesn't tire and has energy to play cricket, soccer, pool swims and lawn mowing without needing a rest. Something they had missed for many years.

To those considering live kidney donations, do it! Your physical life won't change, emotionally and spiritually you may, but you will change the life of someone close to you for the better. And that is the greatest gift!

Josie



Phil and hospital staff

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



Jessica

My name is Jessica and I'm 18 years old. I didn't think I'd ever be able to say that, because since the age of 13 I'd been getting progressively worse with cystic fibrosis. I was just a child and facing the daunting reality that I could die, without yet having lived. I was devastated. I felt I had so much to give, but my body was physically stopping me from giving it. I was getting more and more sick, weak and debilitated. I couldn't walk, talk, or even breathe without help.

But after years of being sick, missing out and then so close to death, I received a double lung transplant. It's a new chance of life that I've been committed to making the most of. I graduated from Year 12, finished a college course with HDs, am doing a law/journalism double degree and French at university, met my journalism hero Ray Martin, had a makeover with my mum on television, won 16 medals in the Australian Transplant Games, and met the inspiring, amazing Prime Minister Julia Gillard.

But it's little things that the average person takes for granted that I am also grateful for. Being able to do everyday things without it being a tiring and painful effort and not being constantly dependant on others.

I have my life back now and the difference has been incredible. All the dreams and aspirations I once had, became possible again. Everything now is a new opportunity to seize.

I wouldn't have got through this ordeal without my family, but it would have been impossible without a donor. I treat this extraordinary gift of life with the highest respect and appreciation. I encourage all Australians to donate their organs to save lives—it could be the most amazing thing you could ever do for someone else.

Jessica
Member of Transplant Australia



Do you know the
donation decision
of your loved ones?



An act of undying love

Nothing could have prepared us for the most shocking, tragic news of our life. Our beautiful, loving, compassionate, priceless Mamma and Nonna Angelina suffered a massive cerebral haemorrhage and there was no hope of survival. Although we were (and are still) in a state of acute grief it wasn't a difficult decision for my brother and I to have Ma's wish of being an organ donor fulfilled.

You see, Angelina (Ma) died as she lived—generously! Her giving, selfless spirit and the fact that she always put others first—never having a bad word to say about anybody—made her love everyone. And everybody loved her. Ma would have given you her last piece of bread even if it meant she'd have to go hungry, so it came as no surprise to her family and friends when they learned of her ultimate gift of life.

The proud adoring Nonna (Italian for grandmother) of five grand-daughters, Ma lived for them. Her love of cooking, gardening and entertaining reflected her love for humanity and nature. The words we heard most from her lips were, 'Love one another!'. Ma was always helping people and asked me to sign her up as an organ donor as soon as I told her of my decision. As this was the ultimate way of helping people, she knew it would bring happiness, hope and a better quality of life to recipients and their families.

So Ma's wish was fulfilled and three people's lives were transformed with her 'pristine' liver and kidneys. The letters we've received from grateful recipients truly honour Angelina's memory. She's not only our hero, but many people's.

Please, please consider organ donation. Discuss it with your family. It won't bring your loved one back but it's a wonderful feeling knowing that her donation gave a new chance at life to others. God knows, we won't need our organs up there!

Tonia



Angelina and her grand-daughters

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



Gift of life a miracle

My father, Vincenzo, celebrates two birthdays. One the date he was born. The other is the day he received a life-saving liver transplant.

Thanks to the generosity of an organ donor, Dad received the greatest of gifts in the nick of time.

He had spent the previous week in a coma; his failing liver had shut down and was unable to filter his blood. His fight for life had become a race against time.

He had been on the transplant waiting list for almost three years, but finally, with death knocking at the door, a saviour family stepped in to give Dad another chance.

They don't know what their decision has meant to him and his family. The transplant has allowed him to lead a normal life.

He tends to his garden and shares its fruits with the family. He savours the love of his grandchildren. He's been overseas to catch up with the brothers and sisters he thought he'd never see again.

To this day, our happiness is tinged with sadness as we try to comprehend the pain the donor family suffered when making their decision. I hope my father's recovery offers some comfort. He prays every night for the donor and their family who came into his life at the right time.

Sixteen years on, and almost to the day, I walked those same corridors where I had been with my dad years earlier.

This time, I watched my sister-in-law Christine being wheeled into the theatre where doctors would retrieve her organs.

Christine had collapsed at her home two days earlier after suffering a brain haemorrhage. She was a registered organ donor and her children Christopher and Kylie wanted her wish to be fulfilled.

The decision eloquently summed her up. Christine was a people's person. She was generous to the point where she preferred to go without, lest a relative or friend was in need.

So Christine wouldn't have thought twice about giving others a second chance at life. Her choice saved the lives of three people and gave sight to two others. Most of us think we'll never need the organs of another person to survive. Some of us don't want to donate our organs.

But put yourself in my dad's shoes. If not for organ donation, they'd be the shoes of a dead man.

Sandro



Vincenzo and Christine

Courtesy: Leader Community Newspapers, Melbourne

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



Life is a gift

My name is Kate and I am a transplant recipient. Four years ago I received a double lung transplant which changed my life forever. That's why I want to tell you a little bit about my story and how it affected my life and the people around me.

Twenty-nine years ago I was born with a genetically inherited disease—cystic fibrosis. Having cystic fibrosis caused my lungs to deteriorate from an early age.

My health deteriorated to the point where the doctor told me I had less than two years to live, and would require a double lung transplant to survive. A year later I was placed on the transplant waiting list. Not knowing whether I would survive long enough to receive a double set of lungs was the scariest time of my life. Throughout that year my health continued to get worse, where I was spending more time in hospital than out. When I was not in hospital I was house bound and spent most of my day connected to oxygen. This I found extremely difficult as I have always attempted to maintain a relatively normal and active life.

My twin sister returned home from overseas to help care for me, as I reached a stage where I needed someone with me 24 hours a day. Most people don't know that on the night I received the call that they had a donor match, was the 19th anniversary of my father's death. I believe he was letting me know that he was up there looking for a pristine set of lungs just for me.

I woke up from the surgery and felt like I had been hit by a bus. It was all made better when I saw my family around me. It was the first day of the rest of my life. I will forever thank my donor and their family for giving myself and my family a life-changing second chance.

I have always believed that organ donation is all about turning something tragic into something positive.

I am so passionate about organ donation because I am living proof that miracles can happen.

Kate



Kate

**Do the people close
to you know your
donation decision?**



Bluey's story

We are an organ donor family. When 16, I signed up as a potential kidney donor (the only transplant available then). Subsequently I have been a blood donor.

Most of my family have signed up including my brother Ian (but called Eggy and then Bluey in his later years). Bluey was a hard worker with a strong interest in Australian history and literature, a great sense of humour and was a keen metal detector. He was devoted to his wife and family and well before his death became a non-drinker. He never smoked or took illegal drugs.

Bluey retired at age 55 and spent a lot of his time on Melbourne's beaches searching for hidden 'treasures'. He was very successful at it.

Bluey was attacked and suffered severe brain injury. He had not provoked the attack. Seven weeks later he died while in rehab. Those seven weeks were a roller coaster of ups and downs as he moved from high dependency to ICU and back to the high dependency unit before being sent off for rehabilitation. He had a brain injury but it was important for the family to see that his sense of humour and personality remained intact.

When he died, I knew that he wished to be an organ donor and alerted the ICU staff to this fact. He donated his liver, spleen, pancreas, skin, bone, and his kidneys. Ironically the cornea bank was full and they could not take his corneas.

As it was a criminal matter, I was required to formally identify his body after organ donation. He looked the same. In Bluey's wallet I found three organ donor cards of various vintages. On one he had written 'Don't hurt me, I bruise easy'. This was an example of Bluey's keen sense of humour and I read it out at his funeral.

A few months later I received an anonymous letter from a recipient of one kidney expressing how Bluey's donation had changed her quality of life dramatically.

In the weeks, months and years after Bluey's donation, the fact that he did donate helped my family and myself immensely. I would recommend that everyone consider becoming an organ donor and sign up. It is about the best thing that you can do for fellow Aussies.

Geoff

**Do the people close
to you know your
donation decision?**



Kerry

Twenty-five years ago at the age of 23, I was diagnosed with the degenerative eye condition keratoconus.

As I sought to understand the implications of my diagnosis I learned that one day I may need to have corneal transplants to restore my vision.

More than 20 years later I suddenly lost the vision from my right eye. I had developed the rare complication of keratoconus—corneal hydrops. Slowly my eye healed and some vision was restored but I struggled with reading and distance vision. My eye was very light sensitive. I wore sunglasses even to put rubbish in the outside bin. Confidence in my vision and my ability to be involved with my family was reduced.

As a nurse I had dedicated myself to caring for and helping others. Now I was facing the prospect of losing my independence and being a burden to my family—it was devastating.

Making the decision to have a corneal transplant to improve my vision was difficult. Even being wheeled into theatre I still struggled. Should I just be grateful for the vision that I had and let sleeping dogs lie?

On the first day I inserted my new contact lens into my eye, I was simply stunned at how clear and perfect my vision was—before it became blurred with tears. I could not ever recall having vision like this.

I know my need was not life threatening, yet it was. It threatened the quality of my life and the essence of who I am.

My donor shall forever hold a special place in my heart. Every day when I wake, open my eyes and can see, I feel blessed to have received their gift.

The easiest letter I have ever written was to my donor family. The words just flowed and yet there were not the words to describe the overwhelming gratitude that my husband, my daughters and I feel for their decision. It does sadden me to know that it was the death of their loved one that enabled me to have improved vision.

Kerry



Kerry and her family

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



The heart of it all

I was only seven years old when my dad was in desperate need of a heart transplant. Through the excellent work of Dr Victor Chang and the heart transplant team, my dad's life was saved. He lived a further 11 years.

I am so grateful to the family whose own personal heartbreak at the loss of a family member was not in vain. They are truly selfless people who deserve so much. As a result of my dad's transplant, I regularly donate blood and have made my wishes clear to my family (along with the Australian Organ Donor Registry). I will never forget the years I was able to have with my dad and I am forever in debt to the family that made that heartbreaking decision.

Lynda



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



Memorial to Douglass

My husband Douglass was a generous man. He held dear his family, adoring his children, then grandchildren. He was generous with his time for others, be it family or friends.

When I was diagnosed with multiple sclerosis, Doug took it on with his usual energy and enthusiasm, deciding to bring his retirement forward so we could enjoy life as my future was uncertain. He kept me active and is the reason I am as mobile as I am today.

In retirement we did a lot of travel both overseas and across Australia in our caravan. We would come home every three months as he couldn't be away from his family any longer than that. He often used me and my 'granny fix' as an excuse to return.

Doug loved to exercise and one particular passion later in life was bike riding. He passed away after an unimaginable and unexplained pushbike accident. Doug had always wanted to donate his organs and three people benefited—two received a kidney each and one person received his lungs. He would be chuffed to know that his organs were good enough!

Of course our time in hospital following the accident was difficult. The most harrowing of our lives. But after we farewelled Doug from this earth and left the hospital, we shared an uplifting moment as Doug's organs were escorted away under flashing lights and plenty of speed. It was so apt – he loved going fast!

We received a 'thank-you' card from one of the kidney recipients. This was a wonderful

thing for them to do. It certainly helps in the grieving process to know that a little bit of Doug lives on.

If we had not known so clearly what Doug's wishes were regarding organ donation it could have been a difficult decision to make under the most stressful of circumstances. But we knew what he wanted, enabling us to provide consent confidently and without doubt.

Doug's niece and her husband put a beautiful plaque up at the site of the accident which says it all!

Douglass—a giver in life and death.

Wendy



Douglass

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to talk about organ
and tissue donation.**



Gift to last a lifetime

I decided I could make a significant difference to my ailing brother's lifestyle.

I had done enough research and had the appropriate preliminary tests to know I was a suitable kidney donor.

I dropped by and told Barry I would like to give him a kidney. I suggested we should make some formal appointments and get things moving. He was quite shocked at my offer, but grateful.

Such is the miracle of life, Barry and I were a perfect match for transplant. The surgery uncomplicated, and the recovery powerful. In September this year we will celebrate 24 years sharing radiant health.

I maintain my advantage was being robustly healthy—as I am today. I remain healthy and ready for life's challenges.

Barry was diagnosed with diabetes at the tender age of 12 years. There was no history of diabetes in our family. Our dad was one of eight children and mum is one of 10. Barry has five children and seven grandchildren—amazingly, no diabetes.

Living a very full and active life, Barry grew to own his earth moving business, married and had children. His kidney failure put his active life on hold.

Dialysis made an immense difference with the chronic diabetic complexities which had left Barry so weak he was unable to walk across a room. The treatment could not sustain him indefinitely, hence my decision to help out with transplant.

He maintains good health apart from being sight impaired, carries a little weight and has ongoing diabetes issues.

With the use of his motorised mobility aid, he maintains his independence. With a supportive family he enjoys Steam Engine Rally's, dance classes (not quite ballroom) and his grandchildren's sporting activities. On the whole he is living a very full and active life.

Judith



Judith and Barry

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



Do not go gentle into that goodnight

Warren was my youngest brother and he was also a dear friend. Warren was also very close to my other brother Greg and the three of us grew up together bonded by blood and love—we were inseparable. As brothers three we would live, socialise, laugh and make mistakes together. Our lives were full, exciting, serious and wild.

Our mother Margo would display the wisdom of Job and more importantly employ the patience to watch an ice age thaw as we boys with carelessness and with impunity enjoyed our lives to the fullest. We three boys embraced life in a fashion that was seen and noted by many observers as impressive, tasting whatever delights life could serve up yet without a hint of selfishness or over indulgence.

Warren especially had a sense of humour that knew few bounds and his larrikin ways were the stuff of legend.

One morning, just three days prior to Warren's 26th birthday, tragedy struck and Warren was in an accident that involved a massive head injury. He was induced into a coma and kept alive by life support. Bravely, young Warren hung tough and occasionally brief signs of life would inspire hope but after an overwhelming three day bed side vigil and enormous effort from a team of doctors and nurses displaying a courage and strength few could imagine, all the best joint efforts in the world could not revive Warren from his deep coma.

Sadly on Warren's birthday a decision was made to turn off his life support. My youngest brother was 'officially' pronounced as deceased two days later. From that second on our lives were changed forever. A mother and father would lose a son far too prematurely and three brothers would be torn apart forever.

Warren was a fit and strong young man. While under immense distress, but sensitively and politely, we were asked about the delicate subject of organ donation.

Warren was generous and in keeping with his spirit and self-sacrificing attitude in life we wanted to preserve and continue a legacy to live on within others. It seemed not only the right and moral thing to do but it was in keeping with Warren's lust for life. We were convinced that Warren would have wanted, indeed he would have demanded, the brave choice be made that in death he would generate life in others. It's with immense sadness I write these words but it must be acknowledged that during an event so disastrous that incredibly happiness can be found.

I hope Warren's recipients have and are living prosperous and fulfilling lives and that my young brothers 'light of life' glows on and shines bright in others for eternity.

Stephen



A handsome man indeed

**Register your donation
decision on the Australian
Organ Donor Register
and make sure your
loved ones know your decision.**



Alison's story

I was nearly two when I was diagnosed with Type 1 Diabetes (Juvenile Diabetes). My parents were told this was a 'life sentence, with no cure'.

That news changed my whole family. Daily urine testing and injecting became the routine. As time went by and technology improved, blood testing with four injections a day was the routine. I grew up with a future filled with fear of amputations, blindness and continual illness—not like the other kids who were dreaming of fun, family and future.

I was warned not to have children as this would accelerate the damage to my kidneys but I wasn't going to let my condition stop me. I now have two beautiful children.

As I got older, I was fast becoming very ill. High blood pressure, swelling limbs, unforgiving tiredness and vomiting—all while I was still working full time and bringing up my teenage kids and trying to fulfill their needs as a single parent.

At this time my son was in his decision-making years at school. My daughter was an angel, caring for me and accepting of the circumstances. My partner entered our life during this chaotic period of illness and teenagers needs. Then, when I was told that I needed a transplant to stay alive, he accepted this news without any hesitation of the journey ahead.

After having diabetes for most of my life, to hear that I needed a transplant for my kidney and pancreas I felt a mixture of emotions—shock, disbelief and excitement, but most of all anticipation of a future.

We got the call at 1.48 am. I knew it was my gain, but at someone else's loss. I shed the first of many tears for the donor. I think of my donor and their family as much as I think of my own family now.

My support from the first day until now has been my partner. The only way to describe him is 'my rock'. Every day I'm thankful for my family's support during my time of need and also the donor family's generous gift to me. If not for that generous decision by the family, my life would be a different story.

I can now look forward to spending many healthy years with 'my rock' and spending more time with my children. I am able to see grandchildren in my future which was something I was afraid to dream of before.

Alison



Alison and Dean

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



Just to be here...

I was born with reflux of both kidneys. I was always sick as a child, with infections, anaemia and high blood pressure.

When I was five years old I had corrective surgery in an attempt to fix this. Unfortunately the surgery was unsuccessful, and at the age of eleven, I became unwell. One kidney had died and needed to be removed, which meant surgery.

I fell pregnant at the age of 14 with my son. When the pregnancy was confirmed at three and a half months, I was sent straight to hospital for rest, right up until I gave birth.

My son was born one month early due to my remaining kidney beginning to fail.

I'll never forget my specialist saying 'You've really done it now', but despite this, my kidney continued to function and remained that way until I turned 22 and my kidney finally packed it in.

To cut a long story short I've had three kidney transplants in 20 years, all donated by members of my amazing family—my mum and two sisters. I come from a big family with eight brothers and sisters, two of which are indentified as perfect matches for donor kidneys.

Sometimes I think to myself I don't know why they did it. I guess I truly would do the same if someone in my family needed a kidney and I was able to help. I think it's just what you do for your family.

If you are as lucky as me (and I do consider myself lucky) when people say 'you poor thing', I say back to them 'I'm very fortunate to have had the extra opportunities the kidney transplants have given me in life'. I know a lot of people who aren't as lucky as I am.

My baby boy is now 27 years old and is married. He and his partner may even have a baby themselves next year. I'm still here due to the generous gifts of my family.

Julie



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



Barney's gift

My eldest son Barney was a typical boy, cheeky and headstrong, long and lean like his dad. He played soccer. He was into collecting Pokémon cards and playing Star Wars computer games. He was learning to surf and loved being in the water.

Barney was nine years and 22 days old when he died. He fell ill with Influenza A and suffered a febrile seizure whilst in the bath.

Barney was kept on life support for two days, before his organs began shutting down, and he was declared brain dead. Rob and I are registered organ donors. When we were asked if we would consider donating Barney's organs, Rob and I just looked at each other and said yes. That's exactly what Barney would want.

Barney's lungs, kidneys and liver saved the lives of four very ill people. Unfortunately there was no compatible recipient for his big strong beautiful heart, but it was donated to research, along with his corneas. All research conducted adding to the body of knowledge, to help save lives in the future.

I don't think you ever get over the death of a child. The pain becomes an ache that never leaves and it doesn't get any easier. You just somehow learn to live with it. We still have Sam, Barney's younger brother, to live for, and

we now have a new baby girl Lucy, to tell all our Barney stories to.

We pray for Barney's recipients every day and hope they might find the strength to write to us. In the meantime we thank God for the Gift of Barney and for Barney's Gift.

Lainie



Barney

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