



Health
NSW Organ & Tissue
Donation Service

Incorporating:
NSW Bone Bank
Lions NSW Eye Bank
Australian Ocular Biobank



NSW Tissue Bank Newsletter

August 2022



Welcome to the August 2022 edition of the NSW Tissue Bank Newsletter

DONATELIFE WEEK 2022 RECAP!

The national awareness week for organ and tissue donation was held from 24th until the 31st of July 2022 and saw the long awaited return of in person events! The 'Great Registration Race' campaign aimed at gaining 100,000 new registrations on the Australian Organ Donor Registry and to kick off, enhance or reinforce discussions about organ and tissue donation in the community.

Activities took place around the state to celebrate DonateLife Week and raise awareness for donation. In South Western Sydney, the Lions Clubs of Parramatta, Canterbury-Bankstown and Wakeley Fairfield joined forces to host a DonateLife BBQ at Campbelltown Hospital. The event was also supported by liver recipient, Wayne Aiken who is competing in the iconic [Shitbox](#) Rally as Team DonateLife to raise funds for cancer research and bring awareness to organ and tissue donation.



Pictured above: Staff enjoying the BBQ hosted by the Lions and the DonateLife Rally car sponsored by liver recipient Wayne.



The NSW Tissue Bank incorporating the Lions NSW Eye Bank, NSW Bone Bank and Australian Ocular Biobank, acknowledges the outstanding generosity and long term support of the Lions NSW-ACT Save Sight Foundation.

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Cycle for Life, a social cycle and walking event, took place at Kingscliff in Northern NSW. The event saw eager participants tackle the long distance road cycle at either 50 or 100km, while the more social cyclers and walkers enjoyed a relaxed 5km short course through the picturesque countryside to promote the many benefits that community discussion can deliver to organ and tissue donation, by improving local awareness and making discussions about donation approachable and common place.

Pictured below from left to right: participants from the 5km walk, cyclists completing the 50km with his dog and a photo of the starting line.



Donateline staff hosted an array of events across the network. Donation Specialist Nurses hosted morning teas for critical care staff to say thank you for their compassion, support and dedication to families who embark on the donation journey. Staff from the broader hospital network were also invited to join these celebrations to start the conversation about organ donation with their colleagues, family and friends. We also thanked the Executive, Media & Communications teams for their support of the 'Great Registration Race'.

The Sydney Children's Hospital Network alongside the Leaping Livers Team participated in an awareness walk at Narrabeen Lagoon on Sunday the 24th of July. The event raised funds for the Paediatric Liver Transplant Unit of the Children's Hospital, Westmead and continued the theme of raising awareness of the importance of registering as an organ and tissue donor.

Pictured below from left to right: JHH staff enjoying their morning tea, Leaping Livers Thank You and NSLHD donation nurses in their scrubs.



We also had over 100 Cafes across NSW participate in our #RegisterInTwoSips campaign, delivering QR codes for the Australian Organ Donor Registry with each delicious beverage all week long, linking thousands of people with the to assist with our Great Registration Race goals. We had representation across every LHD in the state!

These events were accompanied with a large media campaign which featured TV advertisements and interviews. We also encouraged the public to join the Donateline Week campaign online by sharing our social media titles and selfies holding up a 'one' to signify how long it takes to sign up to be an organ and tissue donor.



AUSTRALIA AND NEW ZEALAND HOSTS THE WORLD EYE BANK SYMPOSIUM.

The 2022 World Eye Banking Symposium (WEBS) was hosted by the Global Alliance of Eye Bank Association (GAEBA) founding Partner, the Eye Bank Association of Australia and New Zealand (EBAANZ). EBAANZ is a not-for-profit organisation, and the peak body for eye donation and transplantation services across the Trans-Tasman. It is dedicated to helping restore sight, providing national and international leadership and standards for eye banking, advocating for the eye banking sector and facilitating the sharing of information and expertise amongst EBAANZ members.



The WEBS aims to re-set collective global goals and improve equitable access to services. Furthermore, the symposium aims to improve methods of treating and preventing ocular conditions as well as enhancing donation pathways. The conference was held virtually on the 21st and 22nd of July and featured 12 abstract sessions covering topics ranging from research and development, practice standards and quality assurance and donor consent to individual eye bank historical milestones.

This year's WEBS had a slightly larger focus on Australian and New Zealand Global Alliance members thanks their hosting duties, with the NSW Tissue Bank being featured many times throughout the event. Pierre Georges, Coordination Team Leader presented the abstract *'Is there a ceiling for donor consent? A comparison of consent rates from 2005 to 2015 at the NSW Tissue Bank'* and Dr Chris Hodge delivered a session called the *'Family and general practitioner recall: assessing the knowledge of prior ocular conditions in donor eyes'*. Andrew Muthurajah, a master's student spoke about the impact of cataract surgery on donor cornea suitability. The NSW Organ & Tissue Donation Service's General Manager Danielle Fisher also featured to chair the session *'Goals, Frameworks and Governments'*, which outlined the range of global frameworks, initiatives and goals that are necessary to help build local, national and global services and foster collaboration. The strong Australian presence was continued by Lucinda Barry, CEO of DonateLife Australia who shared insight into the national program's collaboration with each jurisdiction and the Australian Government.



Our very own Tissue Donor Coordinator extraordinaire Pierre Georges was unwittingly nominated for the inaugural GAEBA award which is designed to celebrate the achievements and contributions of members of the international eye banking community. While not taking out the award on this occasion, the NSW OTDS recognises the historic and ongoing contribution of Pierre to the NSW Tissue Bank and to both Lions NSW Eye Bank and EBAANZ. Pierre has worked tirelessly over the past 22 years to improve outcomes for the tissue donation sector and has been key figure involved with setting the foundation for EBANNZ as we currently know it. For the Lions NSW Eye Bank, Pierre has readily and generously shared and leveraged his experience to help shape our teams and the broader organisation. It was our pleasure to go through the process of nomination for Pierre and reflect on his historic accomplishments and the value we have yet to tap !!

Pictured left: Pierre Georges.

HAVING RECEIVED A CORNEAL TRANSPLANT AT FIVE YEARS OLD, SIENNA REFLECTS ON HER “LUCKY” GIFT.

Sienna Shah has undergone 13 surgeries in as many years of her life, including a corneal transplant, to help with her rare condition, Goldenhar Syndrome. Now in Year 7 and thriving, Sienna alongside her mother, Alison reflect on her journey.

Born prematurely in 2008, Sienna and her twin Isabella came close to dying. Alison recalls the difficult time for the Shah family, “We almost lost them and Sienna was a bit touch and go for a while so above everything we are just so grateful”. Adding to the challenging situation Alison and her partner Greg were informed at their five month ultrasound that one of their babies had cleft, however when the twins were born it was evident that Sienna was struggling with something more. Sienna was born with “a big tumour coming from her right eye”, “little tags on her ears”, “without a thyroid and her face was misshaped”, Alison remembers.

Following on from her subsequent Goldenhar Syndrome diagnosis, Sienna had the delicate surgery to remove the tumour and have a corneal transplant when she was just five years old. The Shah family knew from an early age that Sienna would need a transplant as “the part of her brain responsible for the vision never developed”, Alison explains. Whilst the surgery restored some of Sienna’s vision, she is still legally blind in that eye. “It was more for cosmetic purposes because the tumour bulged right out of her eye, she couldn’t close it or anything” Alison elaborates.

Sienna doesn’t recall having the transplant but understands and appreciates the difference it made to her life. “It meant I could get at least a little bit of vision,” she said. “I feel pretty lucky to have this gift”. The effects of this gift are also felt by the extended Shah family, labelling the experience as “really humbling”. Every year the family write to the corneal donor’s mother to provide updates on how Sienna is travelling to forever “let her know what an amazing gift (they) gave to us.”



Pictured Above : Sienna Shah as a baby.



Pictured Above : Sienna Shah post corneal transplant surgery.



Pictured Above : Sienna Shah aged 13.

WORLD TRANSPLANT GAMES COMING TO PERTH IN 2023!

Western Australia's Capital is set to host the 24th edition of the World Transplant Games from the 15th to the 21st of April in 2023.



First held 1978 in Portsmouth, UK, the Games have grown to become the largest organ and tissue sporting event in the world, welcoming transplant recipients, their families, donor families, living donors and supporters to an inclusive and competitive arena to sport their stuff!!

Earlier in the year the Federal Minister for Sport, Richard Colbeck announced that the games would receive additional funding to ensure the successful delivery of the seven-day program which consists of both high exertion and low impact sports as well as social and cultural events. "The games are another major sporting event in our green and gold decade and we look forward to welcoming up to 2,000 transplant athletes as well as family, supporters and crew from 60 countries." Minister Colbeck said.

Transplant Australia CEO Chris Thomas echoed Minister Colbeck's comments saying "the games provide a unique opportunity to cast a spotlight on the lives of those saved by the gift of life", adding that "the support will enable us to leverage the games to promote organ and tissue donation."

Australia has previously hosted the World Transplant Games twice, in Sydney in 1997 and the Gold Coast in 2009. To find out more about the games, [click here](#).



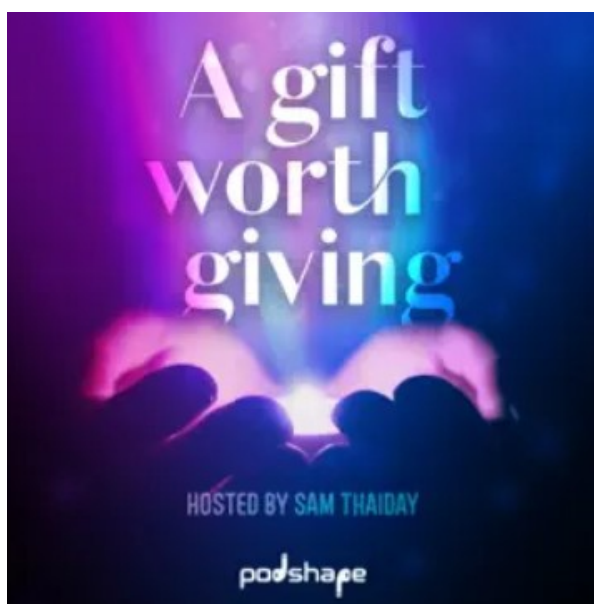
Pictured left: NSW DonateLife Volunteer & liver transplant recipient Mary Burton at the World Transplant 2022 in San Diego. She took home two gold medals in track and field!

'A GIFT WORTH GIVING' WITH NRL STAR SAM THAIDAY.

A part of the 2022 DonateLife Week Campaign, Sam Thaiday explores organ and tissue donation through a new podcast called 'A gift worth giving'. The 6-part series explores stories of hope and heartache from both donor families and recipients and delves into importance of discussing donation with your loved ones.

Sam said the podcast opened his eyes to the importance of registering as a donor. "Across my career I've had a lot of deep and meaningful conversations with my friends, teammates and family but the one conversation I haven't had is the one that really is important," he said. "It's the conversation that could literally save a life – it is the conversation around organ donation."

[Click here to listen to the podcast.](#)



AUSTRALIAN AND NEW ZEALAND PAIRED KIDNEY EXCHANGE PROGRAM BACK UP AND RUNNING AFTER TWO YEARS COVID HIATUS!

Forced to temporarily shut due to the COVID-19 border closures, the Australian and New Zealand paired kidney exchange program has returned to pairing waitlisted patients across the country and sea with live donors.

Clinical director of the exchange, Associate Professor Peter Hughes is excited to see this “powerful” program back up and running as “lots of (participants in the program) who otherwise would not get a transplant get one and do really well”. The program is designed to match willing kidney donors who are incompatible with their intended recipient with other incompatible pairs to facilitate a donation swap, with some exchanges involving multiple donor-recipient duos.



Pictured above: Shannon Moss and Dr Wines prior to the exchange swap.

The exchange program began in Australia 2010 and expanded in 2019 to include New Zealand to increase the pool of potential donors. Prior the trans-Tasman exchange hiatus, the program completed 39 transplants which included four chain donors and saw eight kidneys flown overseas.



Pictured above: Shannon Moss and Dr Wines after the transplant.

Royal North Shore Hospital Urologist, Dr Michael Wines works on about 50 kidney transplants a year but his connection to kidneys extends further than his work as he previously joined the exchange to help out his neighbour, Shannon Moss. Shannon had been diagnosed with polycystic kidney disease which saw fluid-filled cysts grow in her kidneys, causing them to decline and in her case eventually fail. Ms Moss reflects on her life before she received her transplant, “I had a young family. I was a very active 45-year-old and the thought of being on dialysis for the rest of my life was terrifying. I was going three days a week. It restricted my life, it’s not easy to travel, I was tired and sick”.

“Shannon was crying to my wife that she didn’t think she would be able to attend her daughters’ weddings,” Dr Wines said. Heeding the call for help, the urologist and his wife, Nina embarked on the rigours process to find out if they were suitable donation candidates. Dr Wines was approved as a donor but was unfortunately not a match for Ms Moss, so they joined the exchange program. After several months waiting and a few COVID related setbacks, Shannon received her transplant via a series of interstate chain donations.

Despite being extremely thankful for her new lease on life, Ms Moss stresses the importance of deceased organ donors urging Australians to [register via Donatelife](#).

Contact Us

Please contact the NSW Tissue Bank on 02 9382 7855 if you have any questions.

NSW TISSUE BANK UPDATES

TGA INSPECTION -

Earlier this year the NSW Tissue Bank underwent a TGA inspection. Inspections take place to ensure acceptable standards of quality, safety and efficacy are in place which comply with the code of Good Manufacturing Practice. During the periodic audits, Inspectors review the Quality Management System, manufacturing areas and personnel involved in the manufacture of therapeutic goods. If an inspector identifies areas of non-compliance these are called deficiencies. Sites are required to provide corrective and preventative action plans for all critical and major deficiencies and return a response detailing the corrections and addressing any further minor deficiencies.

Compared with previous audits, we fared well, with 13 deficiencies observed, 7 major and 6 minor, for which we have developed a sensible and achievable plan in response. The previous Therapeutic Good Orders (TGOs) were sunsetted 30 September 2021 and we are in the processes of registering the variations required to our processes by virtue of the introduction of new TGOs and should be finalizing our submissions later this month (August).

BIENCO UPDATE -

As the MRFF Research Programs continues, the NSW Organ & Tissue Donation Service reflects on the progress of the research within the last three months.

BIENCO's Phase 2 application for a further five years' funding was officially submitted 14 June 2022. The application was laden with the team's collective expertise and learnings, projecting a roadmap of the activities, methods and partnerships required to transform the suite of bioengineered tissue products from concept to reality. The ongoing research plan has been the Consortium's focus for the better part of this year and Program Lead Professor Gerard Sutton reflects that "BIENCO is a great example of synergistic collaboration with a little serendipity thrown in for good measure."

The Phase 2 application comprising of a Research Plan, Commercialisation Plan and 2 sets of appendices has undergone an independent peer review and a due diligence review by subject matter experts. The consortium will be given a right of response to any scientific issues and due diligence findings when BIENCO group presents the plan to the Frontiers MRFF Selection Panel at the end of August. The group of 4 presenters have been working hard preparing for this important event, finessing their slide deck, rehearsing their narrative, participating in mock interviews and attending a NIDA Corporate workshop on interview techniques. This is the last surge to the finish line and one final opportunity to hone BIENCO's competitive edge. The outcome of the Phase 2 application will be known sometime in November 2022 and we are both proud and confident of our contribution to this tremendous collaboration. Good Luck BIENCO!!!!



This project received grant funding from the Australian Government

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STAFF UPDATE -

The Quality Manager position has been made a permanent full time role and is to undergo competitive recruitment. This role is responsible for the day-to-day administration of the Quality Management System (QMS) and to ensure that the NSW TB complies with the regulatory requirements of the Therapeutic Goods Administration (TGA) including Code of Good Manufacturing Practice and Therapeutic Goods Orders.

Shortly the Tissue Bank will also be welcoming four people into the Production and Procurement Team on the re-graded position as P&P Scientists. This position has a broad range of responsibilities that occur across our value chain from the point of retrieval (procurement) of deceased donor tissue or receipt, through the tissue specific manufacturing pathways to our logistics and distribution channels. After a particularly hard 6 months of operating at less than half of the substantive team establishment, cross skilling in all lab functions and being introduced to working from home, we are thrilled to know that the team under the relatively new management of Alexandra Viglianti is soon to return to its full strength of numbers.

VALE PHILIP BOWER

The NSW Tissue Bank extends our deepest sympathies and support to the family and friends of Philip (Phil) Bower as we reflect on his amazing contribution to the tissue donation sector.

Phil was a prominent and influential Director, Chairperson and member of Lions NSW/ACT Savesight Foundation, and Board Member of the Sydney Eye Hospital Foundation Board of Management. Phil's support and guidance has extended through the amalgamation of traditional services into the current multi-tissue model of the NSW Tissue Bank and he has been a constant, dependable and pioneering influence since our official opening on the 27th June 2013. His inspiring passion will remain with us. At the NSW Tissue Bank we will continue innovating and developing our way to a sustainable future to honor Phil's rich legacy.

He will be sorely missed.



Pictured above: Mr Phillip Bower

UPCOMING EVENTS

Jersey Day— Friday 2nd of September. Visit jerseyday.com.au for more information.

Saffron Day— Friday 22nd of October. Visit saffronday.org for more information.

Service of Remembrance—Saturday 19th of November held at the Wesley Centre, Pitt Street, Sydney, commencing at 2:00pm.