

# Sight + Sound

**NEWS | AUTUMN 2022** 



The Steeds family, Shelby, Jasper, Luke, David, Oliver and Donna

### Hereditary eye condition doesn't stop father-son duo

The Steeds are an extraordinary family.

Donna and David have four children, Jasper (17), Shelby (15) and twin 10-year-old boys Oliver and Luke.

They enjoy family time together, staying active, playing a range of different sports with football and cricket holding a special place in their hearts. During the pandemic they have navigated home-schooling like every other family. However, unlike other families, the Steeds are regulars at the Eye and Ear. David has been legally blind for the majority of his life, with eldest son Jasper experiencing the same diagnosis. Little Luke also has vision impairment along with Down syndrome and an autoimmune disorder.

None of this stops this tight-knit family unit from achieving great things, all while supporting genetic research.

David has both optic atrophy, a condition that affects the optic nerve, and nystagmus, a condition that causes involuntary eye movement. First-born son Jasper was diagnosed with the same condition at the age of nine. When Donna and David began their family, they did not know what type of optic atrophy David had, which would have helped them understand whether it could be passed on to their children.

During this time, David visited our Genetics Clinic where Dr David Mackey and Dr Jonathan (Jon) Ruddle determined that David had a 50/50 chance of passing his optic atrophy onto his children. We spoke with mum Donna to learn more about this Eye and Ear family.

"We have a really great relationship with the hospital, Jon is a part of our critical care team for all the children and sees both Luke and Jasper regularly," said Donna.

After multiple tests, the genetics team identified the genetic anomaly that causes David's optic atrophy.

"Late 2019, we learned about the gene sequence and then began testing the children. During this time it was discovered that, as suspected, David had passed the gene onto Jasper," Donna explained.

Now, Jasper also visits the genetics team at the Eye and Ear regularly and Dr Jonathan Ruddle is his primary Ophthalmologist.

"It's a combination of having the information and the comfort of knowing what to expect in the future. As more stem cell research is being conducted around the world, if we know a certain study is working on that particular gene sequence it gives us hope for the future," Donna continued.

Continued on page 3



CEO Welcome

Welcome to the Autumn edition of Sight+Sound, our first newsletter for 2022. This year marks an exciting period as we embark on the final stages of our hospital redevelopment. We also hope to welcome back our volunteers later this year and celebrate Volunteers Week in May, pending COVID-19 health advice.

Recently, we celebrated World Hearing Day featuring many patient stories, in particular, cochlear patient, Laurie, who has experienced life-changing outcomes. You can read Laurie's full story later in the newsletter.

At the end of 2021, we launched our new website, which was developed with a focus on accessibility, simple navigation and essential information for patients. I encourage you to take a look at <a href="https://www.eyeandear.org.au">www.eyeandear.org.au</a> and let us know if you have any feedback via our online feedback form.

I hope you enjoyed reading Erika's story featured in our recent appeal letter. I look forward to updating you on how much money was raised and the impact of these funds.

In this edition of Sight+Sound we meet the Steeds family who have been on a remarkable journey with our genetics clinic.

We also feature:

- Monthly donor, Kim, who shares the story of her late mother
- Our new perioperative suite opening, and
- A snapshot of our Annual Review publication available on our website

Thank you and I hope you enjoy this edition.

Best wishes, Brendon Gardner

Bardine

A focus on innovation and research

# Annual Review out now!



We are pleased to present The Royal Victorian Eye and Ear Hospital's Annual Review—Innovate. As a world leader in eye, ear, nose and throat services, we are proud to tell the stories of the cutting-edge research, teaching, and clinical care that takes place throughout the Eye and Ear, and, in conjunction with our partners such as Centre for Eye Research Australia (CERA) and the University of Melbourne.

The Annual Review is an opportunity to share with you some of our stories through profiling a selection of staff, patients and research.

Some of the publication highlights include:

- Smartphones monitoring glaucoma at home
- Second-generation bionic eye trial improves navigation at home
- Better outcomes for Aboriginal and Torres Strait Islander children with otitis media
- 3D printed anatomical orbital model for anaesthesia and ophthalmology trainees
- FED trial reduces the need for a corneal transplant
- And much more!

You can read the full Annual Review and our other publications on our refreshed website at www.eyeandear.org.au



#### Continued from cover...

As Jasper's sight declined, he had to give up sighted AFL and cricket, as it became too dangerous for him to play. However, with his dad as a role model, who has been playing blind cricket and AFL most of his life, Jasper started playing blind cricket and, impressively, has worked his way to be part of the Victorian state team.

"It was a massive achievement for him and around the same time the AFL community team were working on diversity in the sport and set up a blind football league. Jasper jumped at the opportunity to be a part of it," Donna said.

In his first year of Victorian Blind Football League (VBFL), Jasper was the leading goal kicker for his team and won Best and Fairest for the entire league. Next on the horizon for Jasper is blind cycling and running, where he aims to normalise his blindness while socialising with his peers.

The tenacity, positivity and sheer joy of this family is truly inspirational and the Steeds are a well-loved part of the Eye and Ear community.

## New perioperative suite

As we progress through 2022, it is timely to reflect on the year that was 2021, in particular the hospital redevelopment progress. Our most significant step made in 2021 was the launch of our new Perioperative Suite in September. The suite combines Surgical Admissions, Recovery, Operating Theatre Suite, Day Surgery Facility and Sterile Processing Services.

The launch of this space involved moving our Day Surgery service and Sterile Processing Services from its temporary home at Eye and Ear on the Park back to our main hospital campus. We asked some of our Perioperative Team to reflect on their experience in the new space so far and what it means for patients.

"It's great having everyone together on one site, giving us the ability to share staffing resources, and more easily support and receive support from the other clinical areas co-located on the same floor and within the same building," said Nurse Unit Manager, Chris.

Both staff and patients are already benefitting from the streamlined service the new Perioperative Suite provides. "Successful surgery and health care in general depend on effective teamwork. It is of particular importance that teamwork is well functioning in order to achieve quality treatment and patient safety. Having a new workspace where three areas have been combined under the one area, allows for better cvommunication, streamlined processes, easier navigation for patients and ultimately a better work environment for all," explained Perioperative Services Manager, Sharryn.

As part of the redevelopment, consumers were consulted and patient feedback was considered at various points of construction. Now in full operation, the space continues to be evaluated for improvement opportunities, with the patient at the centre of all decision making.

"The space allows for a much better patient experience. Patients now have their surgery in a bright new facility, in an open friendly place with all the services from registration to discharge provided on one floor,"











The team and facilities in the new Perioperative Suite



## **Lasting legacy**

A donor profile

Eye and Ear patient Thi Rang grew up in Saigon during the Vietnam war, and as an only child, longed to have a big family of her own one day. Thi Rang's dream became a reality with her and her husband having six children; five girls and one boy. Moving to Australia in 1991, Thi Rang lived a full and happy life.

Thi Rang's second eldest daughter Kim, later became her primary carer and would accompany her to all her medical appointments, including those at the Eye and Ear, where she was treated for cataracts.

Fortunate for the care they received, both Thi Rang and Kim became regular monthly donors, and over the years they have donated over \$18,000 combined to the Eye and Ear, with a particular interest in supporting research. Kim would even donate a portion of her carers allowance to the hospital in gratitude.

"The Eye and Ear was always very good at communicating with us especially as my mother did not speak English," Kim explained.

Sadly, in January 2022, aged 90, Thi Rang passed away.

"She was a very strong and wonderful woman with a good heart. She was always smiling. She loved her family, and was very down to earth," Kim explained.

Kim misses her mum, but is grateful for the time they had together, and attributes her long and happy life to the Australian public health care system, explaining that access to healthcare is very different in Vietnam.

"I talk to my mum every day, I know she is still here watching over me and my family," said Kim.

"I want to take this opportunity to thank the Eye and Ear and the public health care system for the wonderful care provided to my mother. This is why we have donated so much, we are so grateful for all the public health workers and want to give back," said Kim.

If you would like more information on becoming a monthly donor please call our Fundraising Team on **1800 808 137** or visit our website:

https://eyeandear.org.au/support-the-eye-and-ear/join-our-monthly-giving-program/



### **World Hearing Day**

Laurie is one of our cochlear implant patients. Laurie spent decades struggling with hearing loss before seeking cochlear implant surgery. World Hearing Day is celebrated each year on March 3 to build awareness of hearing impairments and the deaf community. Without the Eye and Ear, Laurie would still be living in a life of impacted by hearing difficulties.

"I first noticed I was having problems with hearing loss at the age of 17. From there it started progressing very fast, and by the time I was 22, it was very bad," said Laurie.

Laurie began using hearing aids, relying on lip reading in his every day interactions, and increasingly lost independence in his day-today life. While out with his family, Laurie found himself relying on his six-year-old daughter when completing simple tasks such as food shopping.

"My wife would ask me to go out and buy some bread or milk and I would be petrified. I couldn't hear, and I couldn't communicate with people in that environment. My six-year-old daughter would have to help me," Laurie explained.

After years of specialist appointments and cochlear implant recommendations, Laurie met with Ear, Nose, and Throat Surgeon, Professor Stephen O'Leary who examined his tests and explained the cochlear implant process in a way that made Laurie feel at ease with his decision. Almost 15 years on from his initial hearing loss, Laurie received his first cochlear implant at age 35.

"Stephen told me the way it was. I felt comfortable with him and felt it was the right time. I was sick of the life that I was living and constantly relying on other people" said Laurie.

Alongside Professor O'Leary, audiologist Cordelia Khoo supported Laurie at every stage of his Eye and Ear journey, helping him to overcome his initial concerns.

The support that I have had from Cordelia and Stephen has been amazing. They reassured me that it would all go well. I really couldn't have done it without them!"

Now seven years on from his initial right ear cochlear implant, Laurie has seen significant benefits, with dramatic improvement in his hearing, day-to-day experiences and otosclerosis. His eldest daughter is now all



How the cochlear implant changed Laurie's life

grown up, and is turning 18 this year. The family also welcomed their second daughter during this time.

"You wouldn't know the guy I used to be. I'm so lucky that I can now do those tasks so many people take for granted," explained Laurie.

Laurie can listen to his favourite music, watch his favourite TV shows, engage completely with loved ones, and finally bought the motorbike it was once too dangerous for him to ride. Laurie has seen the life-changing benefits of cochlear implant surgery thanks to his trust in Professor O'Leary and Cordelia Khoo here at the Eye and Ear.

The redevelopment of the Cochlear Implant Clinic, planned over coming years, will allow more patients access to this life-changing surgery.

Disclaimer The Royal Victorian Eye and Ear Hospital respects your privacy and does not disclose details to third parties. All information is treated in confidence. If you do not wish to receive further mailings, please phone 1800 808 137.

Sight+Sound is published bi-annually. ©The Royal Victorian Eye and Ear Hospital. April 2022.

ABN 81 863 814 677 Phone: 1800 808 137 Email: fundraising@eyeandear.org.au

