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Sight + Sound

NEWS | WINTER 2020



Emil Chalhoub

Finding the bard in Bardet-Biedl Syndrome

Emil Chalhoub humbly describes himself as “a pretty normal guy.” Except he isn’t at all. He’s rather exceptional. This isn’t because he is just one in over 140,000 people diagnosed with Bardet-Biedl Syndrome. It’s his attitude and approach to living with this genetic condition that makes Emil stand out.

Emil has been diagnosed since the age of three. Bardet-Biedl Syndrome affects multiple parts of the body. A major feature is vision loss, often caused by retinitis pigmentosa, a worsening of peripheral vision and night vision sometimes described as “tunnel vision.” Emil has experienced vision loss since his teenage years. He is treated for this at the Eye and Ear where he receives regular check-ups to assess how his eyes are functioning and if there is any haemorrhaging.

This loss of vision hasn’t held him back. He details exactly how he manages in a world that, at least for him, appears to be getting smaller, through his blog “The Bardet, The Biedl and Me - Learning to live with Bardet-Biedl Syndrome.” His descriptions are practical and positive. “I dress myself by touch,” he says. “All my clothes are ordered and specifically placed in my wardrobe so it’s easy for me to know where they are.”

When he visits a new location, Emil has a Vision Australia representative to guide him through the first time, and then he memorises the route. He also uses visual aids to help him navigate his computer and phone.

Where some people might want to go into detail about the challenges Bardet-Biedl can present, Emil’s blog focuses on the positives. As he

describes: “I can’t count on my eyes to get me places, but ask any one of my 20 first cousins and they’ll tell you that I can get anywhere with my mouth ... One of the advantages of vision loss is that it enhances your other senses because, naturally, you have to rely on them more. I like to think that my ability to talk is my sixth sense.”

Even when confronting the years of depression he experienced as a teenager, he tries to outline the things that ultimately helped him pull through – faith and support from his family and community. “Talking to someone made the difference,” he said. “My brothers, my family in general.”

When the black dog reared its ugly head again in 2019 it was landing an accessible job in a call centre that pulled Emil through. “It really turned my life around” he said. “I can control my phone with a computer and it means I can take calls all day. My advice to others feeling the same way is to have a go, having a hobby or a social life can really enhance your life.”

When asked what drove him to write such an empowering version of the Bardet-Biedl Syndrome story he said: “Originally it was going to be a book but I thought a blog was an easier read,” he said.

He hoped that by sharing his story he could help anyone else dealing with vision loss feel that there’s still a rich life to be lived beyond diagnosis. “A diagnosis is not the end of the world,” he said. “You can still live a full life, work and go on holiday.”

You can read more about Emil’s remarkable journey at: emilchalhoub.wordpress.com



CEO Welcome

Due to the COVID-19 pandemic and the cancellation of our Autumn edition, it's a joy to be able to welcome you to the Winter issue of Sight+Sound. While

we have entered a wetter and cooler period, the challenges of the COVID-19 virus remains. We all know someone who has been impacted, or have our own experiences. You can read our response to COVID-19 on Page 4.

I have been extremely proud of our staff and volunteers at the Eye and Ear for their responses to the pandemic, and during the bushfire events that took place earlier this year. Many have

donated funds, their time, or their expert health advice to help others get through. It is in this spirit of togetherness we will emerge stronger from the challenges of 2020. If you have been affected by COVID-19 and need to reschedule your appointment, please call us.

I hope this issue gives you an update on what we have been up to since December which, at the very least, provides some happy distraction.

Brendon Gardner

Celebrating Excellence

In May last year (2019), a multidisciplinary team from the Eye and Ear and University of Melbourne arrived in Tonga to conduct screening of ears, nose and throat (ENT) and hearing tests for primary school-aged children.

ENT surgeons Professor Stephen O'Leary and Associate Professor Jean-Marc Gerard were joined by audiologists, volunteers and staff nurses from the Ministry of Health in Tonga. The trip was planned as part of Tongan ENT surgeon Dr Sepiuta Lopati's research, supported by the Royal Australian College of Surgeons, which has a specific interest in advancing the opportunities for surgeons from the Pacific.

In just two weeks, 491 children were screened in their schools and precise data collected on the condition of their ENT health and hearing. While there was a high incidence (40%) of ears impacted with wax, the majority of blocked ears were able to be treated during the visit. Only a small number of middle ear diseases were found with a few rare cases requiring advanced surgery.

Jean-Marc described this phenomenon as surprising compared to other communities of the Pacific islands and Aboriginal communities in Australia, as well as the limited access to ENT preventative care in the region.

He praised the school-based checks as a positive model for healthcare delivery that was culturally appropriate and successful at reaching large numbers of children. "We moved sites a lot," he said. "We covered three to five schools per day so



Jean-Marc meeting students at a local school where screenings took place.

it was very efficient. Everyone was very warm, very welcoming. I am quite tall, so I stood out a little bit for the kids."

He also felt the visits helped to outline priorities for ENT healthcare in Tonga. Rather than a focus on refined and complex surgical procedures, the trips demonstrated a need to support prevention and screening. "Equipment is a major barrier," he said. "Sometimes the conditions in the schools were very basic, so you could see how important mobile equipment would be."

The engagement of the Tongan Ministry of Education and Ministry of Health, school teachers and local nurses are crucial for the success of the mission, as is the guidance of Dr Lopati. It is hoped in future that funds can be raised for transportable equipment and advanced training of the local nursing staff to empower the community beyond the need for visiting professionals.

Philanthropy in our eyes

A word on bequests

We were fortunate just before Christmas to receive a generous bequest of over \$330,000. A bequest is a gift that is left to us in a Will often made by a generous patient. Bequests are a very important part of our fundraising activities as they are often large sums of money that allow us to benefit patients by purchasing equipment or provide services we would not otherwise be able to.

This bequest was left to us by a long term patient who had many treatments with us. We are putting this money towards specialised equipment on their behalf. This humble bequestor did not wish to be identified publicly, but we have included their donation in this newsletter to assure their loved ones that the person will live on through the opportunities, procedures and care that have been made possible by their generosity.

As we go about our busy days here in the hospital, we can sometimes forget that a kind word or gesture to a patient can have a huge and positive impact. It may even result in a bequest much later down the track – a bequest that goes on to enable the treatment or exceptional care of patients in need. And so the cycle of giving continues.

We are so grateful to our bequestors and their families for remembering us in this way. We are frequently humbled by their generosity. Often bequests are left to us by people who have given us modest donations during their lifetime, but are able to give much more when dividing their estate at the end of life. This is another way to help the hospital.

After providing for your family and loved ones, have you ever thought about how you could help the hospital community in a different way? A conversation about leaving a philanthropic bequest might be something to consider in end of life planning. It is an opportunity to make a big difference to our services and provide funding for services or research that public health budgets may find difficult to stretch to.

Bequests are a crucial source of fundraising for the Eye and Ear, but they rely heavily on the ability of our Fundraising team to form good relationships with our large and diverse patient community. They are also a difficult conversation to broach because they involve the sensitive topic of a life coming to an end - a life that has been cherished by those around them.

Saying goodbye is difficult. So we encourage all our patients to discuss leaving a bequest early. Just like you would discuss advanced funeral planning or your will. Our team is empathetic, patient and ready to guide you through the process.

If you would like to discuss leaving a bequest, please call Jacqui Church our Bequests Officer on 9929 8598 for a confidential discussion. She can also be contacted by email: Jacqui.Church@eyeandear.org.au
As always, we remain so grateful for your continued support.

Welcome our new recruits and graduates

The corridors were abuzz with enthusiastic smiles and carefully ironed shirts as our Junior Medical staff and Graduate Nurses began their first day of service on February 3. Among them, there will be future ENT specialists, Nurse Unit Managers, Ophthalmologists and more. The new recruits are the successful applicants after a thorough recruitment process which began in 2019.



Junior Medical Staff and Graduate Nurses

Our response to COVID-19

The COVID-19 pandemic has been a challenge for all health providers and the health of our patients, visitors and staff is our biggest priority. We are living in extraordinary times and COVID-19 has radically changed the way we live, work and function as a society.

Over the last several weeks, we have put in place a number of measures to keep our community safe while providing the highest level of care. We continue to work closely with the Department of Health and Human Services (DHHS) and taking all advised precautions against COVID-19.

Elective surgeries were halted in late March however we are pleased that we have again started performing some surgeries taking guidance from the DHHS.

The last few weeks have certainly changed our lives in a way that we could have never predicted only months ago. Every single person within our community has been impacted in one way or another and it is more important than ever that we express gratitude and kindness to each other. Small and somewhat insignificant acts of kindness can have a dramatic effect on the wellbeing of the recipient. You can read more about acts of kindness we've received on Page 6.

Volunteer Profile

The health of our volunteers is paramount, and as a precautionary measure all of our volunteers have taken a leave of absence during this difficult period. We are forever thankful for the ongoing support they provide to patients, and we are hopeful the team can soon return soon.

So what does new volunteer Ray Avery look forward to the most when he returns?

"I'm really looking forward to be able to help and talk to patients again! Being in isolation has helped me realise that I took socialising and having the opportunity to interact with patients for granted, and I wish to come back really soon."

It's easy to spot Ray, as he has a dazzling smile! But more than this, he is incredibly dedicated to serving others to the best of his ability.

Arriving from Singapore in 2019, Ray began his volunteering journey as a Volunteer Recruiter for the Australian Red Cross. Studying Biomedicine at the Australian Catholic University, he just wanted to serve. He took some time to observe at another health service, but found many volunteers there saw their role as a pathway to their future career. It didn't feel authentic. Then Ray found the Eye and Ear through our Saturday Lecture series. After learning more from our staff, he felt volunteering was a way to repay the favour.

It works because Ray wants to be a Cardiothoracic surgeon one day, so he is still exposed to an medical environment, but he's focused on being helpful not talking to the "right" people. Being helpful is where Ray shines. "I'd rather talk to one person and really help them thoroughly than divide my time between lots of people," he says.



Ray can often be found in our Emergency department.

This is something that can be difficult in a busy Emergency department, but Ray manages. Since joining the Eye and Ear he has already received multiple compliments for his dedicated and attentive service.

One patient in particular, had difficulty reading at Eye and Ear on the Park. Ray was new, but he sat down with the patient and explained some of the medical terms on her paperwork in simpler words. Two weeks later, she remembered him with a smile.

It's experiences like these that make volunteering worth it for Ray. Even though he admits to suffering from social anxiety. "If you're nervous, just go for it," he says. "I have social anxiety and I am anxious that I have a strange accent, but actually if you try and are genuine – people will just be grateful for what you did for them."

As one of his favourite Maya Angelou quotes attests: "People will forget what you said, people will forget what you did, but people will never forget how you made them feel."

Interested in volunteering? Please contact Betty Tellis on 03 9929 8658 or Betty.Tellis@eyeandear.org.au.



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Donate by phone 1800 808 137 or online at www.eyelandear.org.au

COVID-19 Donations to the Eye and Ear

These last few months have been very challenging for all hospitals as we all respond to the COVID-19 virus. At the Eye and Ear, we have adopted new ways of working and have needed a high level of Personal Protective Equipment (PPE) to keep our patients and healthcare staff safe.

During this difficult time, we've been extremely grateful to have received donations from many sources. We received a substantial donation from an incredibly generous anonymous donor who wished to assist our anaesthetists and surgeons who undertake very close work with patients. Their donation was for the purchase of Powered Air Purifying Respirators (PAPRs). These are used for high risk situations such as tracheal intubation for anaesthetists and some examinations or procedures that ENT surgeons and ED doctors perform.

A wonderful supporter of healthcare, Lin Lin donated PPE herself and arranged for the MedFamily Association and AuStar Group to jointly fund donations of equipment. These much needed supplies were adorned with children's drawings and gratitude messages for healthcare workers which provided a lot of joy to everyone who saw them. Ford Australia produced prototype face shields for the hospital and we also thank First State Super for the donation of the hand sanitiser which was in short supply.

On a lighter note, Bulla Dairy Foods and Superior Foods gave the Eye and Ear healthcare workers Choc Tops which were distributed throughout the hospital. It was a wonderful moment where staff felt valued by external organisations and it was marvellous to see all the smiles surrounded by chocolate ice cream moustaches.

A member of our staff, Nurse Unit Manager Chris Bitmatta was able to donate 200 3D printed frames for face shields, as her husband Paul and son Thomas designed and produced these devices which were greatly appreciated. An amazing effort where supporters are able to turn their skill and trade to assist our doctors and nurses.

One of our anaesthetists, Sarah Madden volunteers with Team Medical, an organisation who provides emergency medical care at motorsports events decided to get in touch with Erebus Motorsport. Erebus kindly donated face shields to Emergency Departments and Intensive Care Units of several hospitals which included the Eye and Ear.



Anaesthetist Sarah Madden and Anaesthetic nurse Ronald Kayiwa modelling the Erebus donated face shields



CEO Brendon Gardner trying on a Powered Air Purifying Respirator.