JUNE 2022 ISSUE 23

RETINA AUSTRALIA QUARTERLY

IN THIS ISSUE

CONTENTS

In this issue

Chairman's Report

A word from Leighton

Welcome to this winter edition of Retina Australia Quarterly for 2022. Although our respective communities are still being impacted by the coronavirus (COVID-19) pandemic, the Board and staff of Retina Australia have achieved some significant milestones during recent months.

One of the positive outcomes of living with COVID-19 has been our increased proficiency in the use of video technology with meetings being held online and actions taken more instantaneously. As a result:

- Work has commenced on the rejuvenation of the website, and it is anticipated that this will be completed by October 2022
- Sally has been collaborating with the company, Vega, to transfer the current Retina Australia data across to the new database. Email subscribers will receive renewal notices via email in the next few weeks, while print subscribers will renew with a form in the usual way this year
- A new “branding video” has been recorded and is currently being produced in readiness for uploading to the new website, for use across all social media outlets, and for any other presentations as deemed appropriate
- Board members have established the new committee and task force structure as outlined in my report in the previous newsletter and commenced their respective tasks
- The first webinar for the year has successfully taken place with Professor Alex Hewitt from the University of Tasmania and Associate Professor Fred Chen from the Lions Eye Institute, Perth, providing details of their research

- Planning has taken place for fundraising activities, and events where members can raise awareness of inherited retinal disease in the community, and
- Staff are currently working from the office in Ross House, or offsite, depending on their tasks, however they can always be reached on Tuesdays and Thursdays between the hours of 9:30am and 3pm.

Thank you to all members and friends who participated in the recent “Do it in the Dark” campaign, which raised funds for Retina Australia’s research appeal. From all reports, everyone who contributed had good fun whilst developing an awareness of inherited retinal disease through endeavouring to manage tasks with the aid of our “tunnel vision specs”. If you were unable to participate this year, please consider joining next year in March or April as it is planned for “Do it in the Dark” to be held annually.

Preparations are well under way for our matched “Giving Day” to be held on Tuesday 21 June 2022. The purpose of the Giving Day is to create a high-level awareness of inherited retinal disease in the community and to receive the majority of Retina Australia’s fundraising revenue for the fiscal year. Last year we raised more than $78,000 for our research fund on this day and we are hopeful that, with your support, and donations from across the Australian community, we can increase this amount in 2022.

It is pleasing to report that for more than ten years, many Retina Australia members and their families, across Australia, have given freely of their time to assist in various research projects. Such contributions have included: donating blood or saliva samples, completing surveys, having their eyes examined or photographed, or in being interviewed about various aspects of the effect of inherited retinal disease. As a consequence of this well-known participation, Australian researchers continue to approach Retina Australia with news of their research and requests for help. Currently there are at least three projects where researchers have called for assistance, and I thank all of you who responded and are actively involved. I know that the researchers are extremely indebted with the assistance you provide to their work.

I am sure that with the increasing interest in research into inherited retinal diseases globally, and with the planning for many clinical trials to be undertaken in Australia, there will be opportunities for more people to assist with these

studies. We will continue to keep you informed through this newsletter or by separate communication when assistance is requested.

In the March newsletter, I called for help from members or friends interested in assisting with the work of our Board committees or task forces. We have had a number of people volunteer already, however if you would like to contribute your expertise and ideas in this way, please contact me through the office. There is much work to be done to continue to build Retina Australia into a national organisation representing all those affected by inherited retinal disease across the country.

Thank you for your continued membership and support,

Leighton Boyd
Chairman
Retina Australia

For the second consecutive year, supporters across the country took part in our fundraising & awareness campaign, Do it in the Dark.

The concept of Do it in the Dark is simple – gather your family, friends, or co-workers and do an everyday activity like you normally would, while wearing custom-made glasses which simulate tunnel vision.

Participants held a variety of innovative, creative events throughout March & April including an Easter themed bake off, movie night, card games, Pilates class, morning and afternoon teas, and a painting session.

Over $6,000 was raised throughout the campaign – an incredible effort from our community which will support medical research projects.

Why not consider hosting your own event in 2023?

Clinical study testing a treatment for RP

An exciting development in vision research is the discovery of synthetic molecules that can respond to light in a similar manner to the naturally occurring pigments. These molecules are called photoswitches. In animal models of RP, these photoswitches were able to restore vision and electrical function in blind mice. The chemicals are injected into the eye and are taken up by remaining healthy cells in the retina called retinal ganglion cells. The retinal ganglion cells are now able to respond to light and send visual information to the brain.

Professor Robert Casson and his team at the Royal Adelaide Hospital are working with Kiora Pharmaceuticals in conducting the world first human trial of this technology with the aim being to evaluate the safety and effectiveness of intravitreal injections (injection into the eye) of KIO-301 as a potential treatment for RP.

The team will be recruiting 2 groups of participants, patients with severe RP and patients with less severe RP. Patients will need to attend the study site for a screening visit, then five additional study visits over 28 days in period 1 followed by a gap of at least 28 days then, an additional five trial visits over 28 days in period 2.

All study visits will happen in Adelaide, with some support available for attendance.

The study is expected to commence in approximately July 2022.

If you or someone you know would like to be involved, please contact Mel Willoughby on (08) 70742257 or at Melanie.willoughby@sa.gov.au

Research Update from Our Grant Recipients

Webinar held on Thursday 26th May

Our first webinar for 2022 was a Research update from two of our currently funded researchers, Professor Alex Hewitt from the University of Tasmania and Associate Professor Fred Chen from the Lions Eye Institute in Perth, with over 60 people registering for the event, our best audience yet.

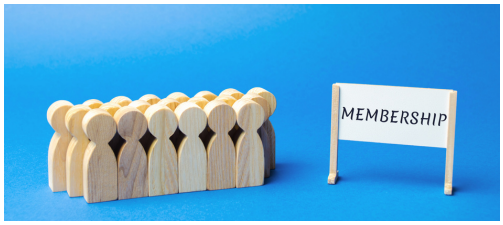
Professor Hewitt discussed the latest developments and current state of gene therapy, including barriers to future success. His talk provided a fantastic overview of a very complex area of study in an easily understood and engaging format.

Associate Professor Chen discussed the work that his team are currently doing in the search for disease causing mutations in families with dominant RP pedigrees. He provided a detailed explanation of the different kinds of inheritance patterns and how these can influence the occurrence of RP in families. He also updated us on the exciting progress being made in the long clinical trials process for VP-001 in the treatment of RP11.

A recording was made of this session. If you would like to view it, follow this link: https://youtu.be/utG3YkC1BcI

Membership Renewals Due 2022/2023

It is time to renew your annual membership with Retina Australia. While you can receive our newsletter for free, funds we receive from memberships help us to provide the information and services to our members, like this recent webinar. Email subscribers can expect to receive a renewal email in the next few weeks which will allow you to make your payment conveniently online. If you would prefer to use a paper renewal form, please contact the office. Associate Membership is $30, and Full Membership, which includes voting rights at the AGM as well as eligibility to stand for Board positions, is $50. Please consider this extra way to support our organisation.



Usher Syndrome Pre-Conference Workshop

Wednesday 29th June

The 11th National Deaf-Blind Conference is to be held from 30th June - 1st July, 2022, in Fremantle. Prior to this event, a pre-conference session is being held to focus specifically on the stories and experiences of those living and working with Usher syndrome. The five presenters are:

Dr Tina Lamey, Senior Scientist and Research Fellow, Sir Charles Gairdiner Hospital, Perth

Dr Lamey will provide a brief gene therapy overview before giving an update on the current pre-clinical and clinical Usher syndrome gene therapies taking place in collaboration with the Australian Inherited Retinal Disease Registry & DNA Bank, Sir Charles Gairdner Hospital and the University of Western Australia.

Fleur O'Hare, Senior Research Manager, Centre for Eye Research, Melbourne

Ms O'Hare will present an update on the Nacuity Pharmaceuticals research trial currently being conducted in Australia for patients with Usher syndrome. The world-first trial involves examining the safety and efficacy of an antioxidant, N-acetylcysteine-amide (NACA), in slowing the progression of retinitis pigmentosa. It is thought that NACA may protect retinal cells from oxidative stress and this will result in a slower decline in vision.

Peter Cracknell, Vision Technology Specialist at Quantum Reading Learning Vision

Mr Cracknell is passionate about supporting those living with vision impairment with practical solutions to communication. He will provide a fun and interactive introduction to early braille learning for both adults and children with Usher syndrome.

Bronwyn Doak, parent from Western Australia

Ms Doak was devastated when her two young boys were diagnosed with Usher syndrome. She will present the highs and lows of living with the genetic condition and how her family have overcome the barriers the condition presents. After investigating the clinical treatments available for her boys, she was disheartened to learn Western Australia lacked some of the specialist research equipment available in other states in Australia.

She has since raised significant funds to ensure Western Australia is at the forefront of leading research into supporting those with Usher syndrome.

Daniel Talko, individual living with Usher Syndrome
As a young man, Dan Talko was diagnosed with Usher Syndrome, a rare degenerative disease which effects the hearing & sight. Remarkably, coming to grips with sight loss gave him an innate desire to see it all. It encouraged internal reflection & personal growth ensued. The moments of humiliation & struggle were essentially freeing. It presented the opportunity to live a full & meaningful life which Dan has embraced. He is now in pursuit of having a positive impact on others through coaching & in more recent times stand-up comedy.

Workshop participants can attend in person, online, or at the Melbourne Hub at Ross House, 247- 251 Flinders Lane, Melbourne. For more information about this session and the main conference, visit:
https://event.icebergevents.com.au/db-2022/usher-syndrome-pre-conference

Annual Giving Day 2022

We are excited to announce our second Matched Giving Day to be held on Tuesday 21st June. As with last year, all your donations on the day, or leading up to it, will be doubled by our generous matching donors.

Those who receive hard copy newsletters will have already received donation forms that they can complete - all donations received on or before Tuesday 21st June will be matched.

Keep an eye out for more information about this exciting event.

Cell fusion 'awakens' regenerative potential of human retina

Hybrid cells could be a potential therapeutic strategy to treat retinal damage and visual impairment

Date: March 15, 2022
Source: Centre for Genomic Regulation

Fusing human retinal cells with adult stem cells could be a potential therapeutic strategy to treat retinal damage and visual impairment, according to the findings of a new study published in the journal eBioMedicine. The hybrid cells act by awakening the regenerative potential of human retinal tissue, previously only thought to be the preserve of cold-blood vertebrates.

Cell fusion events -- the combination of two different cells into one single entity -- are known to be a possible mechanism contributing to tissue regeneration. Though rare in humans, the phenomenon has been consistently detected in the liver, brain, and gastrointestinal tract.

A team led by ICREA Research Professor Pia Cosma at the Centre for Genomic Regulation (CRG) in Barcelona and funded by Fundació "la Caixa" has now found that cell fusion events also take place in the human retina.

The researchers tested whether cell fusion events could differentiate into cells that turn into neurons, which would show potential for tissue regeneration. The team fused Müller glia, cells that play a secondary but important role in maintaining the structure and function of the retina, with adult stem cells derived from human adipose tissue or bone marrow.

"We were able to carry out cell fusion in vitro, creating hybrid cells. Importantly, the process was more efficient in the presence of a chemical signal transmitted from the retina in response to damage, resulting in rates of hybridisation increasing twofold. This gave us an important clue for the role of cell fusion in the retina," says Sergi Bonilla, postdoctoral researcher at the CRG at the time of publication and first author of the study.

The hybrid cells were injected into a growing retinal organoid, a model that closely resembles the function of the human retina. The researchers found that the hybrid cells successfully engrafted into the tissue and differentiated into cells that closely resemble ganglion cells, a type of neuron essential for vision.

"Our findings are important because they show that the Müller Glia in the human retina have the potential to regenerate neurons," says Pia Cosma. "Salamanders and fish can repair damage caused to the retina thanks to their Müller glia, which differentiate into neurons that rescue or replace damaged neurons. Mammalian Müller glia have lost this regenerative capacity, which means retinal damage or degradation can lead to visual impairment for life. Our findings bring us one step closer to recovering this ability."

The authors caution that much work remains to be done before the development of any potential treatments. One of the next steps is understanding why hybrid cells -- with four complete sets of chromosomes -- don't result in chromosomal instability and cancer development. The authors of the study believe the retina may have a mechanism regulating chromosome segregation similar to the liver, which contains tetraploid cells that act as a genetic reservoir, undergoing mitosis in response to stress and injury.

The study was led by the Centre for Genomic Regulation in collaboration with the Institute for Bioengineering of Catalonia (IBEC) and the Barraquer Ophthalmology Center. The work is mainly funded by the CaixaResearch Health Research Call from Fundació "la Caixa" awarded to Pia Cosma (CRG), Nuria Montserrat (IBEC) and Justin Christopher D'Antin (Barrraquer). It is also funded by the European Union's FET-Open EcaBox project, Velux Stiftung, the Spanish Ministry of Science and Innovation and the Catalan Agency for Management of University and Research (AGAUR).

Salamanders can repair damage to their retinas thanks to their Muller glia cells.

Researchers stimulate blind retinas using focused ultrasound technology

The number of Americans with visual impairment or blindness is expected to jump to more than 8 million by the year 2050, according to research lead by the USC Gayle and Edward Roski Eye Institute conducted back in 2016. With the youngest baby boomers reaching 65 years old by 2029, age-related eye diseases and conditions are expected to swell during what's being called the "silver tsunami".

According to medical experts, it's safe to say many of those cases will be caused by retinal degenerative diseases, the progressive degeneration of the light-sensitive photoreceptors in your retina.

Based on these estimates, there is an unmet need for new technologies that treat vision loss due to diseases of photoreceptor degeneration. While there are no successful non-invasive therapeutics currently available for the treatment of vision loss, researchers at USC have come up with a new idea to address this growing problem.

Currently, ophthalmologists use electronic technology to directly stimulate retinal neurons by implanting electrode devices inside the eye, a technique that requires expensive and invasive surgery.

The research team in the USC Viterbi School of Engineering's Department of Biomedical Engineering is exploring a non-surgical solution that could restore sight by using another of the five senses - sound.

Ultrasound Technology

"This is innovative technology," said Qifa Zhou, professor of biomedical engineering and ophthalmology at USC. "Right now, we are doing animal studies trying to use ultrasound stimulation to replace electric stimulation."
The research group is led by Zhou, and Mark S. Humayun, professor of ophthalmology and biomedical engineering at USC, and one of the inventors of Argus II—the world's first artificial retina.

"The technology is advantageous since no surgery is required and no device will be implanted inside the body," said Gengxi Lu, a Ph.D. student in Zhou's lab. "A wearable ultrasound device will generate ultrasound waves to stimulate the retina".

How It Works

To test this ultrasound approach, in pre-clinical studies the team at USC stimulated a blind rat's eyes using high-frequency ultrasound waves that are inaudible to humans.

The technology used in this research is comparable to the ultrasound probe used for baby imaging that sends and receives sound waves through a pregnant woman's stomach.

In this case, for retinal stimulation the research group created a small ultrasound device that can be directed at a specific region of the eye to send sound waves to the retina, which is located in the back of the eye.
Using these high-frequency sounds that can be manipulated and focused on a specific area of the eye; the study demonstrated that when the ultrasound waves are projected as a pattern —for example, the letter 'C'—the rat's brain was able to pick up a similar pattern.

Unlike in humans, researchers are unable to get direct answers about the rat's visual experiences during the ultrasound stimulation. To answer these questions of what exactly the rat was able to visualize from the ultrasound waves, the team measured visual activity directly from the rat's visual brain area known as the visual cortex by attaching a multi-electrode array.

Based on the visual activities recorded from the brain, researchers found the rat was able to perceive visualizations comparable to the ultrasound stimulation pattern projected to the eye. This work was just published in BME Frontiers.

The Future

The research is currently funded by a four-year, $2.3 million grant from the National Eye Institute (NEI). The team recently applied for another NEI translational grant to take their studies to the next level.

Current studies are conducted mostly using rodent models. However, the team plans to test this approach using non-human primate models prior to conducting human clinical trials.

The team at USC stimulated a blind rat's eyes using high-frequency ultrasound waves that are inaudible to humans.

"Right now, we are using a transducer placed in front of the rat's eyeball to send the ultrasound signals to the retina, but our final goal is to create a wireless lens transducer" said Dr. Zhou.

While the team is currently analyzing the capabilities of ultrasound technology for vision study, their future goal is to generate sharper images and install the ultrasound transducer on a wearable contact lens for next generation.

There is also a pending patent for this novel ultrasound technology that hopes to change the way visual impairment is treated years down the road.
Similar to how shapes and bright spots appear when you gently push on your eyeball with your eyes closed; researchers realized that applying pressure to the eye can activate neurons and send signals to the brain.

Unlike a normal eye that is activated by light, the blind eyes were stimulated by mechanical pressures generated by ultrasound waves in this study.
"The neurons present in the retina of the eye possess mechanically sensitive channels that respond to mechanical stimulation," Lu explained. "These neurons are activated when we use ultrasound to generate mechanical pressure."

Stem cell-derived retinal patch is shown to survive two years post-implantation

Date: March 16, 2022

Source: University of California - Santa Barbara

A retinal stem cell patch developed through a collaboration of researchers at UC Santa Barbara, University of Southern California and California Institute of Technology continues to make progress in its bid to secure approval from the Food and Drug Administration. The latest milestone? Results finding that after two years, not only can the implant survive, but also it does not elicit clinically detectable inflammation or signs of immune rejection, even without long-term immunosuppression.

"What really makes us excited is that there is some strong evidence to show that the cells are still there two years after implantation and they're still functional," said Mohamed Faynus, a graduate student researcher in the lab of stem cell biologist Dennis O. Clegg, and a co-author on a paper published in the journal Stem Cell Reports. "This is pretty important, because if the goal is to treat blindness, we want to make sure that the retinal pigment epithelium cells that we put in there are still doing the job they're supposed to."

A treatment in development since 2013, the California Project to Cure Blindness -- Retinal Pigment Epithelium 1 (CPCB-RPE1) patch consists of a monolayer of human stem cell-derived RPE cells cultured on an ultrathin membrane of biologically inert parylene. The goal for this patch is to replace deteriorating cells in the retinas of those who have age-related macular degeneration, one of the leading causes of blindness worldwide for people over 50. The condition affects the macula -- the part of the retina responsible for central vision. People with AMD experience distortions and loss of vision when looking straight ahead.

The researchers have made strides with the patch since its inception, guiding it through clinical trials for use with the dry form of AMD. If the implant works, the new cells should take up the functions of the old ones, and slow down or prevent further deterioration. In the best-case scenario, they could restore some lost vision.

The first sets of trials concentrated on establishing the safety of the patch and collecting any data on its effectiveness. The group, in a one-year follow-up published last year in the journal Translational Vision Science & Technology, concluded the outpatient procedure they were developing to implant the patch could be performed routinely and that the patch was well-tolerated in individuals with advanced dry AMD. Early results were promising: Of the 15 patients in the initial cohort, four demonstrated improved vision in the treated eye, while five experienced a stabilization of their vision. Visual acuity continued to decline in the remaining six, and the researchers are working to understand why.

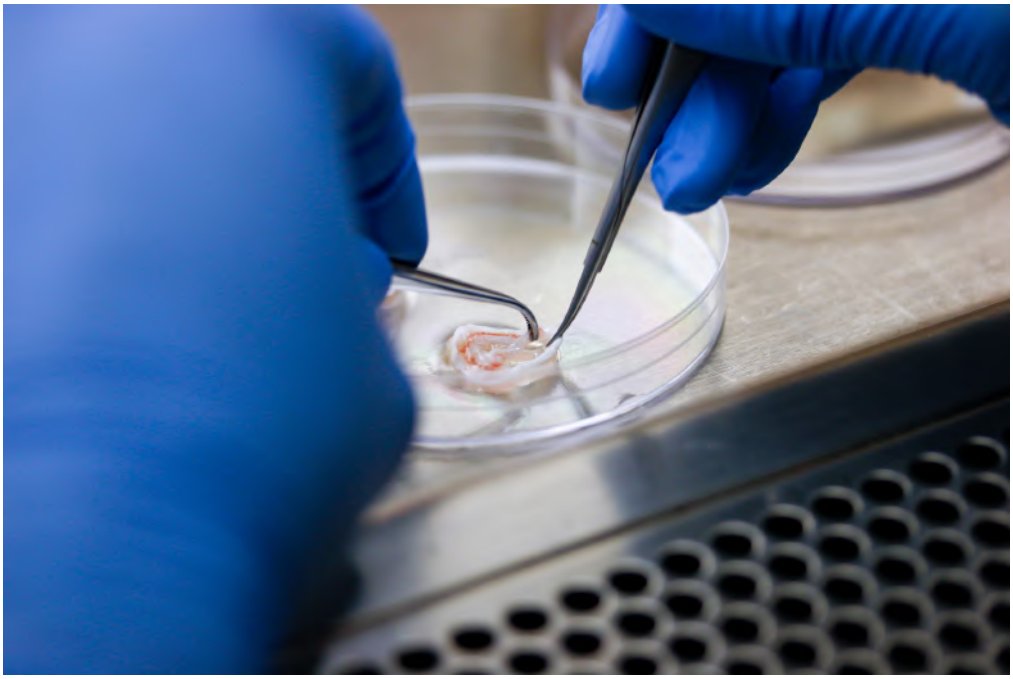
Having implanted the patches in live volunteers, however, the researchers no longer had a direct means for assessing the patches' function and any changes in the longer term.

"It's a lot more difficult and complicated to do that a clinical trial setting," Faynus said. "But we can figure things out by proxy if something is working. So for example, if a patient's vision was getting worse and is now getting better, that's worth noting."

But the team had other questions that couldn't necessarily be answered by proxy. Had the cells maintained their identity and thus, their function? Was the patch still in place and were the donor cells surviving? Were there any signs of immune rejection, a common and serious concern for any patient receiving an implant? If they could answer these questions, they would not only be able to take next steps with the patch, they would gain significant knowledge in general for the field of regenerative medicine.

Thanks to the generosity of one patient in the trials, the group would get their chance to find out. Named "Subject 125," she passed away at the age of 84 from pneumonia two years after receiving the implant, donating her eyes -- and a rare opportunity for the team to check the progress of their patch.

"We are very grateful to the brave patients who volunteered in our clinical trial," said Clegg, who holds the Wilcox Family Chair in Biomedicine. "Without them, we could not advance the science into what could be an effective therapy for millions of people."



A Key Test

To address their questions, the team had to first identify the cells in the general area of the patch.

"Now that we had these sections of tissue, how do we demonstrate that the cells on the membrane were RPE cells?" Faynus said. "That was one of our key questions." Beyond that, they had to identify whether the cells were from the donor or the recipient, and whether they were functional.

Through a careful process of staining and immunoreactivity testing, the team determined that the cells were in fact RPE donor cells, confirming that the cells on the patch hadn't migrated and that the cells were oriented in the optimal, polarized position -- a sign that they had maintained a healthy, functional form, according to Faynus.

"The whole point of us implanting the cells was for them to perform the many functions that RPE cells do," Faynus said. One of those functions in particular is the breakdown of debris and the recycling of vital cellular material.

"Every day you open your eyes, and light gets inside the eye, which triggers a whole cascade of events," Faynus explained. "One of these being the shedding of photoreceptor outer segments." Without the constant recycling of this material conducted by the RPE cells, he continued, it is thought that proteins and lipids accumulate, forming deposits called drusen, a hallmark of AMD.

In addition, the team found that after two years, the presence of the patch hadn't triggered other conditions associated with implantation, such as the aggressive formation of new blood vessels or scar tissue that could cause a detachment of the retina. Importantly, they also found no clinical sign of the inflammation that can indicate an immune response to the foreign cells even after the patient was taken off immunosuppressants two months post-implantation.

"This is the first study of its kind and it indicates that the implanted RPE cells can survive and function, even in what could be a toxic environment of a diseased eye," Clegg said.

Having passed the initial phase of trials, the team is now gearing up to begin Phase 2, which more specifically assesses the effectiveness of the patch. They have also made improvements to the shelf life of the patch, a technological advance they document in the journal Nature. In it, they describe a cryopreservation process that simplifies storage and transport of the cultured cells.

"Cryopreservation of the therapy significantly extends the product's shelf-life and allows us to ship the implant on demand all over the world, thus making it more accessible to patients across the globe," said Britney Pennington, a research scientist in the Clegg Lab, and lead author of the Nature paper.
Looking to the future, the Clegg Lab and colleagues are exploring combining multiple cell types on the patch.

"AMD progresses through several stages," Faynus explained. "When the RPE cells degenerate, the photoreceptors and varying other retinal cells that are supported by the RPE quickly follow suit. To treat patients at varying stages of the disease, we need to consider the remaining cell types. If we can create composite implants that support many of the impacted cells, we can hopefully rescue a patient's vision despite the severity of the disease."

3D printing shaping learning for blind and low vision students

More than 1,000 blind or low vision public school students in NSW are benefiting from access to 3D models, which can be created at their school with a 3D printer.

The NSW Department of Education has developed a growing library of files for printing more than 70 3D resources, aligned to the curriculum and opening a world of learning possibilities for students who are blind or have low vision. Minister for Education and Early Learning, Sarah Mitchell said that these learning resources, including tactile globes and components of the brain, are world leading examples of inclusive education.

“This is incredible and innovative work by our inclusion specialists. 3D prints of human anatomy are making learning biology easier for students with a vision impairment who would traditionally have used simpler raised line diagrams to help build understanding in the course,” Ms Mitchell said. “3D prints of different components of the brain show the complexity of how the pieces fit together and also inside the skull.

“We’ve also found that the models are loved by and are enhancing engagement with learning for all students, not only those who are blind or have low vision,” Ms Mitchell said.

Along with developing innovative curriculum materials for students who are blind and vision impaired, the Department has also commissioned a variety of research into best practice for inclusive education.

A hands on geography lesson

“We are also releasing a series of externally researched reports to continue strengthening our approach to inclusive education and improving learning outcomes for students with disability,” Ms Mitchell said.

The result of two and half years of research and development, schools can print the new 3D materials on their own 3D printer or borrow one from the Department’s central store.
To access the inclusive education research reports visit the Department of Education website:

https://education.nsw.gov.au/teaching-and-learning/disability-learning-and-support/our-disability-strategy/initiatives

Ebony is blind and has four kids under four: 'My disability does not define me'

Source: 9Honey Parenting - honey.nine.com.au
Date: March, 2022
By: Heidi Kraus

Looking after four kids under four, including a set set of eight-month-old twins, would be a daunting task for any parent.

Ebony Uamaki, however, appears to take it all in her stride. The remarkable 28-year-old Brisbane mum is also blind, but that has never, ever stood in her way.

"Unfortunately, a lot of people have questioned my ability to be a parent because I'm blind," she tells 9Honey Parenting. "But honestly, my eyesight hasn't hindered my ability to parent. Children require patience and resilience and that has nothing to do with not being able to see."

The mum-of-four has retinitis pigmentosa (RP) and has progressively lost her sight since birth. At the moment, she only has one per cent sight in her left eye and is completely blind in her right. Diagnosed with the genetic disorder at age two, when she had less than five per cent vision, now she can only make out shadows and day/night perception.

"There have been so many times where I have lost a big chunk of eyesight so

I've had to readapt and do things differently," she explains. "That's not easy. You go through a grieving process. And I think because of that adversity, I've had to learn from an early age that if I want to be happy and feel good about my life I have to shift my perspective."

And despite a barrage of negative comments and doubts from family, friends and even a medical practitioner, questioning her ability to parent, 28-year-old Ebony is embracing motherhood.

"When I first fell pregnant, the family doctor I saw actually encouraged termination," Ebony explains. "She thought I wouldn't be able to cope or that I would pass my genetic eye condition on to my children."

According to Ebony, who is mum to Arorangi, 4, Tavake, 2 and twins Manaia and Koia, one of the biggest challenges of becoming a parent was other people's perceptions and opinions that she wouldn't be able to cope.

"I've even had people say to me, 'Being blind would be the worst thing imaginable'," she reveals to 9Honey Parenting. "That's really offensive. Those things really affected me. There is this perception out there, and I think it stands for disabled parents general in general, that we aren't capable."

In addition, Ebony found little to no support or literature for blind or visually impaired parents.

"When I was pregnant with my daughter, I remember posting on one particular parenting forum and asking if anyone was blind or visually impaired and if they had any tips. Not one person responded. This was a very active forum that had about 500,000 members. It just became very apparent for me that I had to work it out on my own."

So just how does Ebony do it?
"With my daughter, it was trial-and-error. I would research, listen to podcasts and go on forums and listen to how other women did things then adapt it to my own situation. With my son I had a better idea... then with the twins, it was a new ball game," she laughs.

The mum-of-four is completely confident with all four kids on her own at home, because she knows where everything is set up. "When I'm in my home, you can't even tell that I'm blind because I know my surroundings so well," she explains. "I can do everything a parent without a disability can do."

She can't, however, take all four kids to the park or go out in public alone, but that's something she was very much aware of before she had kids. Ebony also has a gorgeous guide dog, Hollie, and since the twins came along, a support worker for things she needs extra help with.

"It's been great to have her but at the same time I had to swallow a lot of pride, and be willing to have help and not feel like that help diminishes my ability to be my parent."

Growing up, Ebony struggled to accept her disability and she did encounter some bullying, but credits a lot of that to her own struggles.

"I didn't like to attach myself to my disability," she admits. "School was challenging, particularly as we moved around a lot. All kids just want to fit in, but I did not want to identify as being disabled or having a condition."

"I was taught Braille and to use a cane but I chose not to, because of my own hang-ups, so I just relied on whoever was around or would wing it."
"When I first met my husband at a mutual friend's 30th, I would often use alcohol as a disguise," she recalls. "And I waited to get to know him to tell him just how bad my eyesight was."

The inspiring mum-of-four says that having the ongoing support of her partner, along with leaving school at 16 and finding her passion in life, working as an intuitive reader, has really helped her accept her disability. She is about to go back to work full-time and the couple also plan to homeschool the children.

"I came from a big family and always wanted to be a mother... I just never ever doubted my ability to be a mum," she adds.

"Because I have gradually lost my sight, of course, there were times when I was petrified thinking 'how am I going to do this?' But when you are faced with those challenges, you just have to learn to adapt or be miserable.

"If anything, that's helped me be a better parent."

Hot off the Press

World Research Summary by Dr Catherine Civil

Here are a few more snippets for you which I have again tried to make readable. We have received less abstracts than usual, but there is still plenty to get excited about.

- Dilitiazem which has been used commonly as a heart medication for many years now seems as if it might benefit eyes too. It works by blocking calcium channels in cell membranes, and this could have an extra benefit of preventing some cell death in RP (Retinitis Pigmentosa). More research please....
- Vitamin A supplements seem to help some forms of RP, but worsen others for some reason.....If we can figure out which types of RP are helped, then vitamin A supplements could be useful. Meanwhile please remember that liver, sweet potato, carrots, and spinach and broccoli contain lots of vitamin A and are full of other nutritional magic too.....
- Blue light filtering lenses they now say “MAY delay the onset of AMD” (aged related macular degeneration). This feels like a bit of déjà vu to me.
- Optogenetics is relatively new but very exciting. It is a branch of research where light-sensitive proteins are inserted into cells that wouldn’t normally have them, to make new photoreceptor cells. The great thing about this is that this same technique should be able to treat many, many kinds of IRDs. There are already lots of stage I and stage II clinical trials going on, so hopefully we will see more on this soon. Watch this space!
- And in another new research direction, Samsara Vision in Italy have successfully implanted a miniature telescope into the eyes of three people with advanced AMD during their routine cataract surgery. This tiny, tiny telescope with ultra-precise micro-optics, enlarges the vision 2.7 x onto healthy patches of retina. A bit of training and practice is needed after surgery, but this looks like another great step forward. These subjects had AMD, but I don’t see why the process wouldn’t work for many other IRDs (Inherited Retinal Diseases).

That’s all for this edition folks.

Till next time. Stay well and don’t forget to keep your details up to date on the Australian IRD register. This will give you the best chance of being first in line for any up-coming treatment trials in Australia and around the world.

Get in Touch

Volunteers fighting blindness

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- Sally Turnbull, Administrative Officer
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