

Eyelight

March 2024

Preservative in glaucoma drops

Your Glaucoma
Awareness Month

Doing more for you

GLAU@MA NZ
TO SAVE SIGHT



Lucas and his Mum Sonia feature in a video to create awareness of congenital glaucoma thanks to you

It all happens thanks to you

I'm thrilled to welcome you to your first Eyelights of 2024.

A fresh year brings new opportunities. In this edition you'll meet two new members of the Glaucoma NZ team. They'll be supporting you to live well with glaucoma and encourage an early diagnosis in others.

See how you can celebrate Glaucoma Awareness Month with us. Have conversations about eye health tests, share your knowledge and, if you're able to, please donate.

You may remember NZ research we shared in our March 2023 newsletter that compared the effects of Benzalkonium chloride (BAK)-preserved glaucoma drops on inflammasome activation.

The research highlights the concerning impact of the preservative Benzalkonium chloride (BAK) on your ocular health and

the lack of funding for preservative-free glaucoma drops available in NZ. With your support we hope to change this.

Thanks to your wonderful response to our November appeal, we have produced a video to create awareness of congenital glaucoma. It will be released later this Awareness Month.

With the incredible foundation you've enabled us to build over the past 21 years, alongside the practice of our shared values, we are confident that Glaucoma NZ can continue to grow and meet the needs of our community. Thank you for your incredible support.

Warm regards,

Pippa



Wendy Nowell-Usticke: Dad's glaucoma journey

Wendy keeps a close eye on her Dad, Jasper (87).

He has a long history with glaucoma and has had a tough run. But the future is looking bright with support from people like you.

“I only took a lot more interest in Dad's eyes probably two years ago because of the extraordinary pain he always seemed to be in...The condition of his eyes was just deteriorating so much. And he was in pain. It was just like all scratchy, massive dry eye, pain.”

Jasper lives in the Hawkes Bay. He has travelled to Auckland, the Waikato and Wellington to manage his glaucoma. He's lost one eye because of serious complications. The last thing Jasper and his family needed was the hardship that followed.

“Part of the problem with Dad was the drops, because every drop he was on to reduce the pressure damaged the cornea of his eye, which then meant it really hurt him to open and close [his eye]. And it damaged the surface of his eye so much that they thought that he had this immunosuppressant condition.

We have been lucky to have an eye



specialist who has been relentless in investigating this further to provide further options.” Wendy's Dad went to every other specialist that he could. There was rheumatology and dermatology to name a couple. He took new drops. He endured one biopsy that was inconclusive. And he went to Wellington to see a colleague of his eye specialist for more advice.

The preservative in the drops was really damaging his eye. His eye was in dire need of relief and time to heal. So, it was decided that it was best to switch from drops to an oral pill.

Speaking about the pill, Wendy said “it's incredible at getting the pressure down, but as a result of that, Dad was rendered an incredibly old and helpless man. He was unsteady on his feet. He would sleep all day. Some days he struggled to dress himself. This becomes another problem because what if he falls over?”

Wendy mentioned the toll it has taken on family gatherings. Last year they intended to celebrate her parent's 60th wedding anniversary, but her Dad was in too much pain.

“He had his birthday last September...he stoically sat there for as long as he could, then he had to go to sleep. The poor bugger, this drug was just awful...his life has just been diminished to zero.”

Fast-forward to February 2024. After even more investigation, treatments, two

Wendy and Jasper's story cont...

operations (after finally getting a conclusive biopsy to rule out the immunosuppressant condition), his pressures had reduced sufficiently to no longer need an oral pill.

“He can walk...every day, he's got a little bit more of his vision back...he's in the best place he has been for a long time... Now we're back on the problem with the eye drops.”

One of Wendy's sisters is sourcing a preservative-free glaucoma drop for their Dad in the United States. He is still suffering from dry eye and soreness from the only option (preservative version) available in New Zealand.

“I just don't understand why, why? If preservative damages the eye so much, why don't we just make the preservative-free ones available?”

How much more is preservative-free over preservative? That's the million-dollar question. If they [Pharmac] want to save money, how much money would have been spent on my father that could have been saved if he'd been using

Glaucoma is an extremely complex disease to diagnose and treat. Everybody's experience will be different. Report any new symptoms to your eye specialist, or doctor, such as redness, irritation, itching, tearing, or decreased vision. Symptoms may be related to the disease, side effects, or complications of medication or surgery.

Your responses - impact of preservatives

“To answer your question re the preservatives in the eye drops - constant stinging, irritated eyes the majority of the time, very red eyes, looks as if I've been crying, dry eyes, especially on waking”
- Jenny

“My eyes are bloodshot, red, itchy and irritated all the time. I would give a great deal to have preservative-free eye drops. I do not understand why this is so difficult...NZ must be the only country in the world where we do not have the option. I would gladly pay the difference in price but preservative-free drops are not even available” - Anne

“My eyes went very red and were extremely itchy and quite sore. I went into our local pharmacy and the pharmacist suggested that it was the preservative in that particular drug...and ever since I have been on drops that do not contain that preservative and am fine” - Victoria

preservative-free drops?

We are grateful that me and my other sister are around to help him, as that would be another cost to the system but the drops and additional medications can be complicated so I feel for anyone doing it alone, my other sister who is a nurse has helped navigate the system when I couldn't.

For me, it's multiple hours off work... I can't guarantee how many appointments Dad's going to need to go to during the week. Will he be able to see tomorrow? Will he be able to walk tomorrow? Because of the constant result of not having options for preservative-free.

All those years of pain, discomfort and destruction of his eye could have been prevented. All that misery and suffering could have been prevented”.

Things don't stop there for Wendy and her family. Other families could be in the same situation. You can help.

Glaucoma NZ is supporting a clinical trial that can help people like Wendy and her Dad Jasper, but it needs funding. Please consider donating towards it. Every little bit helps.

New staff doing more for you

Glaucoma NZ has grown its small team, determined to increase its impact for members like you.

Sandy McGregor is your new Fundraising Manager. Her extensive fundraising experience will impress you. She has used it to raise vital funds for Hospice over 18-plus years.

“It’s my job to develop fundraising programmes. I’m going to make supporting Glaucoma NZ as easy as possible for members and the public. This is very, very important because our charity receives no funding from the government whatsoever.”



Sandy knows that your support allows Glaucoma NZ to provide sight saving services. If you want to help secure funding or donate, contact Sandy on 021 808 909 or by emailing her at sandy.mcgregor@auckland.ac.nz.

Jenna Tuuta is your new Supporter Care Manager. She is taking the duties of

Administrator Karon Farmer, who retired last November. Her role also includes promotion and communications.

“It’s disturbing to know that, as we speak, people are needlessly losing their sight. What’s worse is that they don’t know it’s happening - that’s something I want to change. I also want New Zealanders who have glaucoma to know that they’re not alone. Resources and support are here - I have to make them aware of it.”



This means Jenna will work to make your voice heard and to tell your stories. You can contact her on 020 404 35577 or at jenna.tuuta@auckland.ac.nz.

Sandy and Jenna are Glaucoma NZ’s commitment to continual improvement. They’re here for you. And to increase the charitable trust’s impact. So you, and all New Zealanders, can keep moving to eliminate blindness from glaucoma.

Join in and say ‘Thank You’ to funders

Sincere gratitude goes to the following Trusts & Foundations. Alongside you, they have funded patient support, glaucoma awareness and education in the community.

Trillian Trust • The Trust Community Foundation • Blue Sky Community Trust
COGS (Community Organisation Grant Scheme) • Ara Lodge • Maurice
Paykel Community Trust • Grassroots Central Trust • Thomas George
McCarthy Trust • One Foundation • Page Trust • Pub Charity

You can support people affected by glaucoma with your family, work or community trust. Contact Glaucoma NZ on 0800 452 826.



Dr Sam Kain:

Preservatives a double-edged sword



The most common reason to use medicated eyedrops on a long term basis around the world is Glaucoma. Glaucoma is the name we give to a group of eye conditions that affect the optic nerve and pose a significant, long term risk to vision.

The most common treatment for glaucoma is medication in the form of eyedrops. These eyedrops have transformed the way we care for people with glaucoma and made complete blindness from glaucoma a rarity in modern times.

For decades now preservatives have been added to these medications in order to prevent bacterial contamination and extend the shelf life of the formulations. This in turn has made them safer and more convenient to use which has benefitted millions of people around the world.

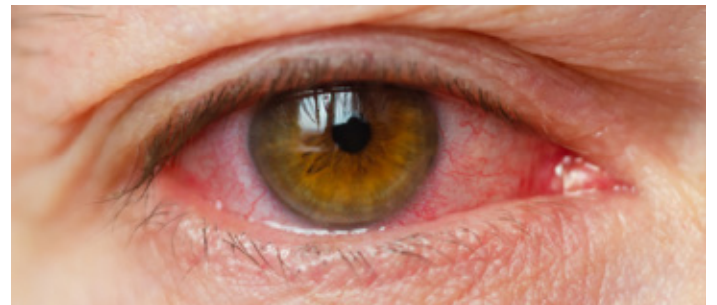
As is often the case though these preservatives can be a mixed blessing and in recent years more interest has focussed on the problems they can cause for some people.

There are several different preservatives that are used but the most common and the best studied is benzalkonium chloride (BAK). BAK is a very effective antiseptic and has been used in eyedrops for many years.

Pilocarpine was the first effective glaucoma drop and has been used for

around 100 years. The addition of BAK not only improved the shelf life of these early drops but also may have helped the medication to be absorbed better.

Unfortunately, BAK is also a cause of eye irritation in some people. It can cause redness, soreness and in some people can incite an allergic response resulting in swelling and watering of their eyes and inflammation of their skin. As well as these effects on the surface of the eye there is also evidence that there may also be effects on some tissues inside the eye which in some people may work against the beneficial effects of the medication itself.



Laboratory studies have confirmed that at least some types of cells from deep inside the eye respond to exposure to BAK by activation of inflammation pathways. If other types of cells are also affected, particularly cells in the pressure regulating trabecular meshwork part of the eye, then there may be an overall negative effect on pressure control. This may be one of the reasons why sometimes drops which have been working well for years seem to stop working. In medicine this is known as tachyphylaxis and is a commonly encountered problem when managing glaucoma.

There are a number of well-established treatment pathways when someone appears to be affected by the preservative in their eyedrops. The first

step may be to try a different drop with a different type of preservative. Another option is to try a preservative-free drop.

There are a number of drops on the market which do not have preservatives although these may be more expensive. In general, they are packaged in single dose vials to avoid contamination.

If drops can no longer be used, then laser surgery or incisional surgery become the most common treatment options.

In summary, preservatives in glaucoma eye drops can be a double-edged sword.

While they protect against contamination, they can sometimes have adverse effects which begin to limit the therapeutic benefits of the medication itself. Ophthalmologists must therefore tailor treatment regimens to individual patients, balancing efficacy and ocular safety.

Dr Sam Kain is a GNZ Trustee and Consultant Ophthalmologist with a special interest in glaucoma, cataract surgery and oculoplastics.



Dr Hannah Kersten: Preservative-free glaucoma eye drops; some are available but not funded

According to the NZ Formulary, there are currently three preservative-free glaucoma preparations available in New Zealand:

- Bimatoprost preservative-free
- Ganfort preservative-free
- Timolol 0.25% and 0.5% preservative-free *Section 29 - able to be prescribed by medical professionals only (ie. not optometrists)

Unfortunately, none of them are funded. The preserved versions of bimatoprost and timolol are funded, but Ganfort (which is a combination of bimatoprost and timolol) is not funded, even in the preserved form.

Long term treatment with preserved eye drops, in a chronic condition such as glaucoma, can lead to inflammation of the eyelids and ocular surface, resulting in blepharitis and dry eye.

Patients with blepharitis and dry eye often require other treatments, which can add to a sometimes already burdensome treatment load, impacting patient quality of life. This in turn can affect patient adherence to prescribed treatment regimens and can increase the likelihood of permanent vision loss from glaucoma.

Anecdotally, a number of patients come to us, having researched online, requesting preservative-free eye drops and we then have to explain to them that they are unfortunately not funded in New Zealand, despite being widely available elsewhere.

Dr Hannah Kersten is a GNZ Trustee and therapeutic optometrist with a particular interest in glaucoma and neuro-ophthalmic disorders.



Your research update

We're excited to let you know that the lab research from your March 2023 Eyelights newsletter "Research so good it makes your eyes water!" was completed.

Findings suggest that BAK in the BAK-preserved antiglaucoma eyedrops induces the inflammasome pathway and may introduce inflammatory effects at subclinical doses. The BAK-free eyedrops describe a more protective impact in comparison.

Despite the growing body of evidence suggesting the adverse effects of BAK, there is a paucity of well-designed clinical trials specifically addressing the inflammatory consequences of BAK exposure in the context of glaucoma medication use.

A new study aims to bridge this gap by conducting a case-control clinical trial,

focusing on the comparison of inflammatory markers in patients using BAK-containing glaucoma medications and their preservative-free counterparts.

This research holds significant implications for eye care policy in New Zealand. The evidence generated from this study will provide a robust foundation for Glaucoma NZ to approach Pharmac, advocating for the funding of preservative-free glaucoma drops. This has the potential to improve the accessibility of safer alternatives for glaucoma patients and contribute to long-term ocular health outcomes.

Donate now to support this vital clinical trial so kiwis have affordable and fair access to preservative-free glaucoma drops. Visit www.glaucoma.org.nz.

Three things you can do this Glaucoma Awareness Month

1. Encourage your friends, siblings, and colleagues age 40+ to head to their local optometrist for an eye health test.

If they say, "oh, I can see fine", then you must reply with, "Glaucoma is known as the sneak thief of sight because it often has no symptoms before diagnosis".

If you or family members have glaucoma, then add, "You are at a significantly greater risk of developing glaucoma because it's in our family".

2. Share your knowledge about the preservative Benzalkonium chloride (BAK) and its impact on your quality of life and eye health.

3. Donate now to support a vital clinical trial so kiwis have affordable and fair access to preservative-free glaucoma drops.



Glaucoma NZ is a registered charitable trust (No. CC21421) that receives no government funding. Education resources and support programmes are free thanks to the generosity of Glaucoma NZ members. Donations of \$5 and over are tax deductible.