

## **Baz is taking the Gentamicin road!**

Baz wrote a letter to his bike group CLBG letting them know where he is at and what he plans to do. Baz will keep us updated as to how he is progressing after the 23rd. Let's hope that this will get Baz back on his bike! Thanks for sharing Baz!

"Hi CLBG , fellow bike riders , and family ,

I have been asked to provide a report on my visit today, to a ENT Specialist doctor.

It was to confirm my hope of being given a gentamicin injection, into my ear, to "kill off" my balance nerve to my brain. Sounds heavy doesn't it?

The doctor, ENT, was delightful. She quizzed me of my health history. She examined my ears and studied my hearing report. Only then did she agree that I did have Meniere's Disease, that I was diagnosed with 25 years ago.

Then she swung onto treatment, how it works, what are the short term affects, and the long term affects. She is confident in her ability to make me "normal" again. Diane was suitably impressed with her detailed explanations. She answered all my questions. The ENT was recommended to me by ENT Victoria, as a gentamicin specialist. She was very professional.

It has come down to my last resort action, to attempt to stop my full body attacks, that have left me completely uncontrolled ...spinning world, no balance, no ability to stand, no strength, vomiting, headaches, can't ride my bike, cannot leave home without my carer and I can't drive. On my good days, I spend only half a day on the bed.

Have you noticed I haven't been out riding with you? Boy, do I miss that!

So to go and get a gentamicin injection into my ear, to "kill off" the nerves, sounds dramatic and should be viewed as questionable. While reports I have read have been positive, and it's been around for at least 30 years, it does not get promoted much. So it is viewed with reservation.

So I have searched and searched. I've read study reports. I have been well informed. I have communicated with known patients who have had this treatment. I have asked them over and over of treatment and results, to firm up my view. Diane has been very cautious, but she's over it. She doesn't want us to continue in this manner. We cancelled Christmas, the Maryborough trip, my brothers, and other village activities.

Fortunately, Diane was able to enjoy a lower level 80th birthday celebration with our beautiful family, as well as our special friends. My osteo and nurse daughters have also been very cautious. But then they haven't seen me in full blown attacks and that would change their view. I have been consulting regularly with a Professor, who I have great respect of his opinion.

Having done my homework, and been living a life I do not want for 5 months. I am to be booked in for treatment on May 23rd, at Epworth, Box Hill. If it works, and the doc says it will , I will be back on my bike late June.....maybe ?

Thanks to you all for caring.

"I loves ya all" . (Jeff Fenech)." Baz

30 Jun 2023

### **Baz decided to take the Gentamicin road!**

I had decided that I would contact you after my treatment, to let you know how I am progressing. Because I am most grateful to you especially, and your organisation. I'm not sure you know that I live in Melbourne, and while I was a member of the Melbourne Support group 25 years ago, they do not have an easy web site now. Your web site is very clear and helpful. So I wondered if Melbourne ENTs performed the gentamicin treatment. So I contacted ENT Victoria and they directed me to Dr Sherryl Wagstaff, who is absolutely professional, pleasant, and a super communicator.

She treated me at Epworth Box Hill on May 23rd. It was 10 days later that my balance was upset. Prior to that I was thinking that it was not going to work, (because I am impatient!). I had a follow up appointment With Dr. Wagstaff on June 8th and she directed me to the Dizzy Centre, for assessment and an exercise program.

All of this is a new, unknown experience. Because the injection does not seem to be heavily promoted, at least to my knowledge, or here in Melbourne. And it is only, through you, that it was opened up to me. I pestered you for information and you are supportive...thank you so much! The "Kate" video is so positive...she looks in the camera and says, "Go and get the injection!" She filled me with confidence.

So after the injection I am surprised that my balance has been quite good. I did not know what to expect. I do not really enjoy my vestibular exercises of head twisting. But I am walking regularly each day, with several sideways dance movements. I practice with my bike, by getting on, then riding a short distance, then getting off. Then do it again, and again. And I know I'm not ready to leave home too far yet and join my mates. I am able to do my usual chores...clean the AC filter, help a mate build a wall (up and down the ladder made me suffer), wash the car, etc . So I am progressing well.

The most beautiful thing is that when I wake up each morning, I don't feel dizzy, and I'm gaining confidence that I am not going to fall down from a drop attack. I am now even able to plan ahead each week. My guitar does not sound quite as good as it did, but I am determined to manage. And I am not a burden on my beautiful wife, who really has had to suffer during my recent long period of constant attacks. She had to pick me up regularly.

I am reading the "Dear Meniere's" book. I'm recognizing much of the distress in the letters, often with a tear in my eye. Anne, I recognize in your writing, your anger. I had plenty of that too. Your picture is sad also. Thank you so much for the help you have given me. You are a special person. I am so appreciative, that I seem to be sane again.

Baz