

COVID-19 Virus

Implications for blepharospasm patients

Since this virus issue has become a worldwide pandemic we have become increasingly concerned that those of us living with BEB may be impacted by the increasingly strict rules and regulations. Hopefully, the doctor that you go to every three months or so will continue to offer you treatment be it under stricter protective conditions.

However, we are hearing new stories everyday about appointments being delayed or even cancelled for various reasons and we know that once we get beyond that regular treatment period the impact on our lives becomes more and more urgent by the day.

There seems to be a view that BEB is a non urgent, elective treatment that can be postponed till after this crisis is over. Nobody can predict how long this will be but the experts are saying many months. If we don't get that all important treatment, functional blindness is what many of us face with the impact that will have on our lives and those around us.

What should we be doing about it?

1. Firstly we suggest you telephone your regular doctor and check that the appointment you have is still valid. If so they will tell you what extra precautions they are taking.
2. If not, and you can't manage till this thing is all over, then you will need to find an alternative doctor to treat you.
3. Ask your regular doctor if they can refer you to any other doctor they know who can offer you treatment.
4. If so you will need a new referral and your patient records. Your regular doctor would normally provide these to the new doctor.
5. Should this become an issue you do have the legal right to ask your doctor for your own patient records.

Click on the attached link for the federal government guidelines on how to go about this.

<https://www.oaic.gov.au/privacy/guidance-and-advice/guide-to-health-privacy/chapter-4-giving-access-to-health-information/>

What are we doing about it?

1. Currently we are putting all our efforts into finding those alternatives and will be updating this notice as we find them. Keep checking the website.
2. We will also list any of our regular doctors who have closed their practices for the duration and are definitely not offering treatment to their patients. The sooner you know, the sooner you have to start shopping around for an alternative.
3. We are lobbying both government and the clinical profession to recognise that BEB is not something that can be just deferred for an indefinite period without a major impact on our lives. **It is not optional, it is urgent and should be defined as such.**
4. Stressing to all who will listen that whilst COVID-19 is very serious and life threatening, treatment for BEB does not take up a hospital bed, can be done in half an hour in a regular consulting room.
5. As yet we haven't sought any media coverage but are keeping that option open should we consider it productive in achieving our aims.

In Summary

Throughout the 20 years or more since this support group was started we have faced the challenge of raising the profile of BEB in the medical profession. Many years in the wilderness has been the norm just to get the diagnosis and start treatment. Once treatment has started we have celebrated that life can return to some normality with just the nuisance of having to have treatment every three months or so.

Now we are faced with the new challenge of treatment being withdrawn or deferred so we have more obstacles to overcome. This is our top priority.

May we extend our best wishes to all those sufferers throughout Australia and ask that you keep us informed of how you are managing, what steps you are taking and how it's working out. Your feedback helps us all.

It is alleged that there is old Chinese curse "May you live in interesting times" We certainly do!

Best Wishes

A handwritten signature in black ink, appearing to read 'John Yeudall', with a stylized, cursive script.

John Yeudall
Chairman
For and on behalf of the Board of Directors
Blepharospasm Australia Inc