

# The New Voice

*Newsletter of the*

Laryngectomee Association of Victoria Inc. (A0022313R)

*Dedicated to the rehabilitation of laryngectomees and those with similar vocal disorders.*

Patrons: Mr. S. Kleid. MB; BS; FRACS.

Mr. J. Kennedy. FRACS; FACS; M.S.(Iowa). DABO.

Affiliate: International Association of Laryngectomees. (IAL)

Accredited Support Group: Cancer Council of Victoria.

Founded 1954

May 2018

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**Committee : Ms Jennifer Goon Mr. Alf Glover**

**Mr. Geoff Keith**

**Subscription : Fifteen dollars a year, payable January.**

**Note: Receipts will only be issued if requested, and a stamped self addressed envelope would be appreciated.**

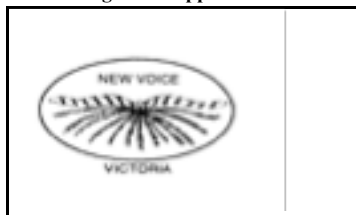
**Loan of Speech Aids : A loan instrument is available for members while awaiting for provision under A&EP or when a member has to return instrument to a supplier for repair.**

**Mr. John Fardell Mob: 043 206 4807**

**Mr. Lorraine Lancaster 5143 3307**



Laryngectomee Association of Victoria  
Acknowledges the support of Victorian Government



**All correspondence:**

**Laryngectomee Association of Victoria**

**14 Hoddle St Sale Vic 3850**

17 HOUGH ST SALEM VIC 3088.  
(03) 5143 3307 Mob: 0488 022 385  
inquiries@LaryAssocVic.org

Following items available by post or at meetings.

Stoma Covers:

White, Navy, Black and Maroon stocked  
Single (1 bib on a neck band) \$5.00 + p/p

Double (2 bibs on a neck band) made to order only.

Shower Collar: (vinyl bib type) \$12.00 + p/p  
Shower Shield: (molded pvc 'nose') \$30.00 +p/p

Stoma Patch Kits: (foam + double-sided tape)  
Make-Your-Own \$30.00 +p/p\*\*\*  
Double sided tape: \$12.00 +p/p\*\*\*

Ready Made Patch: 30 pack \$34.00 +p/p

Battery rechargeable Ni-Mh:  
Suit 'Servox' 'Romet' \$25.00 +p/p

Postage and packing please allow \$10.00 minimum on each order.

#### SPOUSE'S SUPPORT

Ring if you need a sympathetic ear.  
Mrs. Robyn Stark, (03) 9808 9264

#### MEETINGS:

Normally held on the **THIRD SUNDAY** of each month Support Group at 11.30am.  
Followed by a light lunch and a General Meeting  
(no meeting December / January).  
Venue: 383 Toorak Rd. South Yarra.  
(Melway 2M-B6) Tram Rout 8, Stop 33. Met Station is on this route, or a stroll of four or so blocks along Toorak Rd will find us.

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**Next Meeting 20th May 2018**

**Starting 11.30am**

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#### WELCOME

Lorraine welcomed the members in attendance at our April meeting, it was lovely to see those in attendance. He commented that he had battled his way through the wind up from Gippsland in his 4 wheel drive as he says it sits on the road better. We had two new faces, a new laryngectomee Graeme and his wife Min from Ocean Grove. Lorraine then explained to our newcomers that the first part of our meeting was run like an open forum in order to encourage people to talk about what they may be going through following their surgery and recovery, their problems and concerns their successes that worked for them. Any topics that are subsequently arise will generally be a guide for content of future newsletters where relevant.

It was also nice to see Lorraine Lancaster back still recovering from her recent illness. As well Michael McQuade, and Valma and Bill Crump and all the other members who attended.

We kicked off the morning session with Mike George who advised us what further progress has been achieved since our last meeting in March for his campaign on behalf of our laryngectomees towards obtaining funding from the Victorian State Government for HME's and other Laryngectomee Consumable Items. Mike said there has been massive progress. He has obtained the number of laryngectomy operations performed in Victorian

Hospitals last year, breaking them down into individual hospitals. Since the last meeting a number of politicians both current and past have come on board with their support, including writing letters. Speech Pathologist Louise Malcolm wrote a magnificent letter, and a meeting with the Opposition Party. Mike said they are finally starting to understand what laryngectomees are about and why it is so important we get Government funding support. Mike said Government funding to our NSW counterparts (the same that we want from our Victorian Government) is now in its sixth year.

Mike said the benefits of HME's needs to be continually emphasized including the massive savings to the Government Health System both in length of stays following laryngectomy for HME users and non HME users, (Hospitalizations are longer and more costly for non users than HME users) and more importantly to emphasize the benefits health wise to laryngectomees such as improved quality of life. (Laryngectomees using HME's get fewer chest infections than non-HME users). Mike said final numbers will be given to the Government on Monday.

Mike is encouraging laryngectomees to continue writing to their local MP, and he said be persistent don't take no for an answer. He then informed us that this Laryngectomy issue will be raised in the Victorian Government in May 2018.

Mike emphasized that each and every one of us has a responsibility to let people know about what a laryngectomy is and what a life changing experience it is. Laryngectomy operations are still being done and it has been evidenced that HME's have a benefit health wise for laryngectomees. They do cost money however Mike said that you wake up in the morning feeling a lot better when you are wearing one, As previously mentioned Larys using HME's get fewer chest infections than non HME users, hospitalizations are longer and are more costly for non-users than HME users. (Non-user on average is hospitalized 8.98 days longer than a HME user).

Mike emailed us a brief summary of the history of the campaign on the 27<sup>th</sup> April. (see below)

\*I started this campaign in November with an ex premier of Victoria.

\*Neil Mitchell – 3 AW championed and publicized the Laryngectomy HME funding issue on his radio program in February.

\*Jill Hennessy - MP Health Minister was then involved in this issue directly.

\*Surgeon Ben Dixon, Speech Therapist Louise Malcolm and Assoc Prof Adam Vogel - Melbourne University added their professional medical supporting written evidence to the Health Minister.

\*Other influential people made direct written contact to the funding cause.

The outcome and end goal was always that we Larys in Victoria received the formal written advice from Jill Hennessy MP Health Minister that the Victorian Government will fully fund the HMEs and associated consumables from 1<sup>st</sup> July 2018.

Finally Mike said at least now the newer Larys and future Larys in Victoria will benefit and have a healthier life as a result of this funding.

We have a wonderful surprise (see end of this edition of our newsletter for the announcement) for all laryngectomees.

### **NEW MEMBERS AND VISITORS**

Again we welcomed Graeme and Min from Ocean Grove. It was lovely to have you attend our meeting, and we hope that you will come again.

## **NEW REGISTRATIONS**

New registration this month was Samuel Britton of Reservoir. Welcome Samuel to our association, we hope to see you, your family or friends in attendance at our future meetings.

## **VALE**

We acknowledged the passing of the following members, Franco Manzocchi of Vermont, David Graham of Morwell, Karole Hurst of Essendon West, and Ken Cullen of Kerang. Condolences to all their families and friends from our association.

## **LARYNGECTOMEE BIRTHDAYS**

Congratulations to Michael McQuade on his 73<sup>rd</sup> birthday on April 9<sup>th</sup>.

## **LUNCHEON**

Thank you ladies for another lovely luncheon and to those who prepared and cleaned up afterwards, thank you also.

Lorraine then introduced the afternoon portion of the meeting. He said that he did enjoyed the chatting going on following lunch as it indicated that everyone was enjoying the socialization part of our meeting, communicating with each other which is what our meetings aim to encourage amongst our laryngectomees and carers.

Lorraine then officially welcomed our new laryngectomee Graeme Due and his wife Min from Ocean Grove, its good you made the effort to come. Lorraine commented that there was a lot of wisdom mixed up with the chatter in this part of the meeting. He emphasized to our new members not to be frightened to ask questions. You may not always get an answer straight away, and it may not be a professional medical text book response either. In fact laryngectomees through their own personal experiences have sometimes found quite simple ways of fixing problems using plain commonsense. Lorraine said we are not mind readers unless you speak up and tell us about an issue you may be facing we can't offer you help, so again, please don't be frighten to speak up.

We are still waiting to be advised who our new representative is from Atos Medical Australia, following the resignation of our existing representative, Andy Tusa. Atos Medical Australia is a relatively new standalone company here in Australia. They now have their own representatives here which you can place orders with, rather than having to go online and order from overseas. They also have a new website. The address details and product range from Atos Medical Australia can be found on the back page of our New Voice newsletter along with details of the other suppliers of goods and services for laryngectomees.

## **APOLOGIES**

Gwen Sedgman, Maureen and Keith Abbott, Wilma and Vincent Minogue, Barbara and David Caldwell, Harry Hudson, Val and Stewart Walker and Dot Pockett.

## **SICK LIST**

Dot Pockett, Val Walker and Agostino Olivetti. Sending all of you our very best wishes to all of you.

## **PREVIOUS MINUTES**

Moved by Geoff Keith. Seconded by Josephine Gwynne.

## **BUSINESS ARISING**

**Nil.**

## **SCHOOL VISITS**

Both school co-ordinators have been having trouble trying to get schools on board for our school visitation program. They commented that it seems like a lost cause because they

are losing contact with previous contact points at the schools due to the fact that everyone is on a short contract, one minute they are there and the next time they may have moved on to another school. This makes it very hard to do follow up work because of this situation. There is no school school's reports for either co-ordinator this month.

## **CORRESPONDENCE**

### **DHHS**

Email 21/3 containing QDC End of Quarter 63 Data for Laryngectomee Association of Victoria Inc.

Email 27/3 containing FAC Newsletter.

Email 27/3 containing final reminder about CIMS IT registration and on boarding.

Emails 20/3 advising timeframe to go to nominate for 2018 Victorian Disability Awards, and emails 29/3 and 4/4 advising number of days to closure of Victorian Disability Awards 2018

Email 9/4 in regard to a Standards and Regulation update.

Email 10/4 in regard to DHHS Positive Practice Framework April 2018.

### **Miscellaneous**

Email 18/3 from member Mike George containing details of Link for his WIN News Laryngectomy segment and 3AW Neil Mitchell Interview segment. He wanted to encourage Laro's to view and share link as will generate more awareness of being a laryngectomee and challenges through this life saving procedure that we face.

Email 18/3 containing details of Laryngectomee Association of NSW contact website.

Email 18/3 from Bobbi Lehman-Horn containing template for Lary funding email campaign and email 19/3 raising the importance of our Association raising awareness of laryngeal cancer on a local, state, and national level.

Email 23/3 from VMIA requesting feedback on their 2018 calendar which has been sent to us.

Email 24/3 from member Gerard Pelicier containing details of what he has sent to politicians in regard to funding for purchase of Laryngectomee consumables.

Email 3/4 from VMIA containing the Training and Development Newsletter.

Correspondence moved by Valma Crump. Seconded by Lorraine Lancaster.

## **TREASURER'S REPORT**

Receipts \$12749.30

Expenditure \$13973.34

Banking Credits \$34329.31

Outstanding Invoices \$4106.00

Total Credits \$38435.31

Stock Value as at 31<sup>st</sup> March 2018 \$1457.48.

Total Debits \$268.10.

Moved by Lorraine Lancaster. Seconded by Jennifer Goon.

## **GENERAL BUSINESS**

In regard to the New Laryngectomee Bag Presentation Pack Project initiated by Lorraine, we have put 50 odd bags in circulation via the hospital system in the past two and half years. We are trying to make these bags available to all new laryngectomees to help them.

A comment was made by one of our members Bill Crump in regard to the purchasing and using of HME's that more people would use them if they could afford it. Graeme our new laryngectomee received a trial pack which was given to him at the time of the operation by the hospital concerned to be trialed for a short period of time. As mentioned previously some hospitals are getting funding for them while others are not. Some laryngectommes are paying for them themselves while others are going without, thus the announcement at the end of our newsletter will be pleasing to all.

Lorraine personally thinks they are a good idea, and has been using them for a long period of time (since as far back as the year 2000). Lorraine said recently in an email "I still think that this device is the 'Rolls Royce'" and was using Hands Free when I attended IAL Voice Institute Vancouver (2001) and Atlanta (2002). In 2001 this device was not

available in USA.

Lorraine reminded us that our association incurs running costs including room rental, import costs for items purchase from overseas to on sell to our members, newsletter production and postage costs which we are required to cover through the revenue we receive from sale of items through our lary shop, annual subs from those who pay them (30% to 40% actually do pay their subs), as well as a grant from DHHS (approx \$300per month to provide a newsletter to all known Laryngectomees in Victoria. Lorraine and now daughter Lorraine are responsible for the astute running side of our financial costs and they both have done a wonderful job as is reflected in our current favorable financial position. Thank you to both of you for this from the association. This healthy financial position is one of the main factors that may help to ensure that our association doesn't go broke like those of our counterparts in Tasmania, Queensland (disappointing when QLD group folded as most support came from local bowling club), and South Australia.

The NSW and Victorian Associations are the only two support groups left out of all the states now. We don't have annual meetings to put our thoughts and needs to the Government anymore through the Cancer Council of Australia as once was the case. Seminars held by them were over a period of a week and alternated between different capital cities. These have ceased being sponsored Cancer Council of Australia.

The last big project was the Laryngectomy Education Resource Package. It consisted of a document that was made up of three volumes/sections. It involved consultation and participation from Speech Paths, Physios, Surgeons, Nurses, Social Workers, Psychologists, dietitians, and three members of our association. The working party was made up of health professionals from Monash, Peter Mac, The Alfred, and The Austin. Lorraine saw a draft of it however there was only one section devoted to laryngectomees and their needs.

There are still a number of laryngectomy operations being preformed as he still is getting requests over the telephone and via email for 3 or 4 stoma covers. This is not always reflected at our meetings as it is not always convenient for people to come along to our meetings but they are still using our facilities.

Lorraine advised members that there are still bits and pieces of medical equipment donated from families or friends of deceased estates of laryngectomees who have passed away. These are available to any members of the association who would like them free of charge. Items include saline, capsules, and nebulizers in working order amongst other items. Please contact Lorraine by email or telephone if you are interested in them, same thing goes for electrolarynx. Lorraine has a large number of old machines which he is happy to hand out. He will service them. Let him know what you need as they are always handy to have a backup as accidents can happen to your TEP.

### **CORRECTION**

Below is a correction to a comment made in our newsletter last month in regard to HME's funding in Tasmania. It was reported that Tasmania was also supplying these items until the surgeon in charge at that hospital went on Long Service Leave and it was just stopped. It was pointed out by Kristin Fulton Senior Speech Pathologist, Oncology that this was not correct (see below email to our President Lorraine Lancaster).

Hi Lorraine,

Further to our discussion this morning regarding incorrect information about HME in Tasmania in your last newsletter, please find below brief information on HME in Tasmania.

Tasmania Speech Pathology successfully implemented subsidization for HME equipment around 6 years ago. Since then, people eligible for concession receive most HME equipment at greatly subsidized rates. We also have non concession people accessing and enjoying the benefits of HME who order equipment through speech pathology.

Consequently, HME is well embedded in the Laryngectomy community with many users very happy with the products. For further information or enquiries please contact:

[Kristin.fulton@ths.tas.gov.au](mailto:Kristin.fulton@ths.tas.gov.au);

Thank you for correcting the information Lorry. Please let me know if there is anything we can do to support implementing subsidization of this valuable, life altering equipment in your state.

Best wishes, Kristin Fulton Senior Speech Pathologist, Oncology Tel: +61 03 61668434

Again we wish to apologize for this error made in last month's edition of the New Voice Newsletter.

### **RAFFLE**

Raffle takings total was \$50.00. Thank you for all who brought tickets and prizes. Thank you to Jenny for running the raffle and to Valma for folding the tickets, you did a great job with added humor. The winners of this month's raffle were Valma Books and Wine, Josephine Maltezers and Books, Marilyn Book, Lorraine Book, Michael Honey, Geoff Honey (just a note the honey was kindly donated by Gerrard and Glenda Pelicier from their own Bee Hives, and I heard that it was delicious, thank you both), Min, Books, Alf Wine and Puzzle, Lorraine Book.

### **GREAT NEWS THE ANNOUNCEMENT OF FUNDING APPROVAL FOR HME'S AND OTHER LARYNGECTOMEE CONSUMABLES BY THE VICTORIAN STATE GOVERNMENT.**

#### **Following is an email received from Matt Harris**

Country Manager Australia and New Zealand M. +61 (0) 455 999 648T. +61 (0) 1800 286 728

Unit 1204, 100 Walker Street, NORTH SYDNEY, NSW, 2060

<http://www.atosmedical.com.au/>

The campaign has been successful with the Victorian State Government announcing today that they will fund HME's and consumables for laryngectomees from 1<sup>st</sup> July 2018. This will be similar to the scheme already available in NSW that has been in existence for over 5 years. The aim is to now replicate this success in every remaining State and Territory in Australia that is not currently reimbursed, so please reach out if anyone you know can be of assistance or you want to lend your support.

#### **Announcement on 3AW this morning:**

<https://www.3aw.com.au/government-to-fund-support-for-victorian-laryngectomy-patients/>

A huge thanks to the tireless efforts of everyone involved but a special mention to the dedicated voices of Mike, Barb, Bobbi, Darron and Faye.....to name just a few. You have raised the profile of people living with a Laryngectomy and the life changing challenges they face on a daily basis. Today's announcement will have such a positive impact on this community, their families and carers. It was of course a concerted team effort that brought about this outcome with a number of your clinicians and local politicians getting involved, so thank you all.

The job is however not done. Now to make sure ALL Australians have access to this same level of funding.

Regards Matt Harris.

Also following is the letter received from Hon Jill Hennessy MP Minister for Health and Minister for Ambulance Services in regard to the Announcement regarding the approval of the funding of HME's and other Laryngectomee Consumable Items.

We personally would like to thank you Mike for your amazing efforts in helping to bring this outcome to fruition, and to all who participated in any way. **"THANK YOU"** the result is magnificent.

We would also like to acknowledge Bobbi Lehman-Horn for her contribution to the campaign for Victorian Government funding of HME's and other consumable items. (It has been especially hard on Bobbi who has had to abandon her TEP due to damage caused through radiation to the area. She has had trouble to get it to close up and there is no guarantee it will work again. She is now relying on keyboard and magic slate to communicate).

A handy hint most laryngectomees would find it difficult to be heard in a room where there is a lot of noise going on for example people chatting at a restaurant (even non laryngectomee people may also find this hard) where equipment is operating both household and industrial, or just general noise and it may be handy to resort to these items (keyboard and magic slate) if necessary, so always carry them with you.

Lorraine then closed the meeting for April.

We hope to see you all at our next meeting to be held on the 20<sup>th</sup> May. Cheerio Robyn.

**\*\*ATOS Medical Australia. Unit 1204, 100 Walker St, Nth Sydney NSW 2060.**

**Phone : 1800 286 728    Email: [info.au@atosmedical.com](mailto:info.au@atosmedical.com)**

**ATOS: Provox Vega Voice Prosthesis, HMEs and Base plates, Provox FREEHANDS, brushes, tubes and buttons and all accessories. KAPITEX: Laryngofoam, Buchanan Covers and many accessories.                    NU VOIS: Nu Vois III Electrolarynx**

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**\*\* Axion Biomedical. (Alan Beal) 59 Haley St. WONDAL, QLD 4606.    Phone: 1300 650 272                    Email: [axionmedical@bigpond.com](mailto:axionmedical@bigpond.com)  
Electro larynx service and repairs. Please ring first, a simple adjustment may be the answer.**

**\*\* Laryngectomee Association of Victoria (03) 5143 3307 . Please leave a message.  
Rechargeable battery to suit 'Servox' and 'Romet' , stoma covers and foam products.**

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Issue: May 2018
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