

# Still talking

Dedicated to the welfare of Laryngectomees and those with similar vocal disorders

ALL CORRESPONDENCE: The Secretary, The Laryngectomee Association of NSW, PO Box 380, BELROSE, NSW, 2085 Fax & Phone 02 9451 7926, Email: lansw@bigpond.com

No. 244

The Laryngectomee Association of NSW

AUGUST 2013

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## OFFICE BEARERS 2013

**PRESIDENT:** Brian Gardner, 41/2 Dawes Rd, BELROSE, 2085 02 9452 2858

**VICE PRESIDENT 1 :** Peter McGregor, 21/39 Cook Rd, CENTENNIAL PARK, 2021 0419 421 324

**VICE PRESIDENT 2 :** Greg Joss, 61 Morrice Street, LANE COVE, 2066. (02) 9427 0509.

**TREASURER/WELFARE OFFICER:** Carol Gardner, PO Box 380, BELROSE, 2085 Fax & Phone—02 9451 7926, Email - lansw@bigpond.com

**ASST WELFARE OFFICER & Hospital Packs:** Bruce Hodges, 31 Clack Rd, CHESTER HILL, 2162—0404 400 842

**SPEECH AIDS COORD:** John Chaloner, PO Box 31, SUMMER HILL, 2130 - 02 9560 2852

**EDITOR:** A.T.Krasnodebski, Box 232, BONDI, 2026— antoni.krasnodebski@deewr.gov.au

## WHO TO CONTACT

**SPEECH AIDS, BATTERIES, ADVICE ON REPAIRS:** John Chaloner, PO Box 31, SUMMER HILL, 2130—02 9560 2852

**SHOWER SHIELD, STOMA COVER MATERIAL & WELFARE MATTERS:** Carol Gardner, PO Box 380, BELROSE, 2085—Fax/Phone 02 9451 7926

**ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME:** Cancer Council NSW, 153 Dowling St, WOOLLOOMOOLOO, 2011 (PO Box 572, Kings Cross, 1340) Phone 02 9334 1900, Fax 02 9357 2676. Or contact Social Worker at hospital you will be attending.

## WEBSITES

**ASSOCIATION WEB PAGE:** [www.stilltalking.org](http://www.stilltalking.org)

**INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES:** [www.theial.com/ial/](http://www.theial.com/ial/)

**WEB WHISPERS:** [www.webwhispers.org](http://www.webwhispers.org)

## NEXT MEETING

Wednesday 21 August, 2013 at the Sydney Mechanics Institute, 280 Pitt Street, SYDNEY at 11 am.

The meeting will be followed by light refreshments.

Laryngectomees, Friends, Families, Professionals all WELCOME.

## Sponsors of "Still talking"

[www.mainmed.com.au](http://www.mainmed.com.au)

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**& Servona Electrolarynx**



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MEDICAL**

## MONTHLY MEETINGS

**NSW Association:** 3rd Wednesday of month Sydney Mechanics Institute, 280 Pitt St, SYDNEY, 2000 at 11 am.

**NEW ENGLAND:** Meets 2pm 1st Wed. Dec. Conference Room, Rehab Unit, Tamworth Base Hosp. 02 6767 8369

**NEWCASTLE:** 3rd Tue, Monthly Mayfield Bowling Club, Ingall St, MAYFIELD. John Lovett 02 4954 8308

**NORTHERN RIVERS:** No regular meeting. Contact Speech Pathology, Lismore Base Hospital. 02 6620 2157

**ALBURY:** Meet alternate months from February. Contact Norma Teasdale 02 6021 1749

**CANBERRA:** Wed 29/5/13 10:30-12 noon, Wed 4/12/13 11am—12:30 Canberra Hospital 02 6244 2230

**SOUTHERN DISTRICTS:** Last Wed of month 10am. Thomas Rachel Moore Edu Ctre, Liverpool Hosp. Contact Hei Lan Byun 0477 330 719 or Luci Dall'Armi 0439 813 807

**MID NORTH COAST:** Port Macquarie Community Health. Last Wed Jun, Sept & 1st Wed Dec. Contact David McClymont—President 02 6559 8383

**CENTRAL COAST:** Meet 3rd Fri of month. The Hive, ERINA FAIR—10am-12noon. Kate Hudson 02 4320 2587, Cancer Council 4336 4500 or Bill Byfield 0402 045 048.

**COFFS/CLARENCE:** Coffs Harbour Health Campus, Shearwater Lodge, Meet 9th April then every 2 months on 2nd Tues. Contact Melissa Parish—02 6656 7606

# MINUTES

## MINUTES OF MONTHLY MEETING HELD 17<sup>th</sup> JULY 2013 – LARYNGECTOMEE ASSOCIATION OF NSW INC at SMSA, 280 PITT STREET, SYDNEY at 11am

**PRESENT:** Brian Gardner, Bruce Hodges, Bob Mount, Bob Nash, Peter McGregor, Greg Joss, Peter Tierney, Les Byrnes, Barry Bunker, John Czadrik, Ray Chappelow, Tim Atlee-Bowra, Antoni Krasnodebski, Carol Gardner, Pat Bunker, Andrew Smithg, Vicky Smith, Charm Nash, Virginia Atlee-Bowra, Glenda Tierney, Patricia Lamont, Jane Toohey.

**APOLOGIES:** Ruth Gray, John Chaloner

**THE PRESIDENT** (with a little assistance from his “sidekick”) opened the meeting and welcomed our invited guest speaker, Ms Jane Toohey (RN – Clinical Sales Specialist – ENT from LMA PacMed). It was requested that the Minutes of the previous meeting held 19<sup>th</sup> June 2013 as presented in the July 2013 Newsletter be accepted as read. There was no business arising therefrom.

Resolved Bob Nash/Ray Chappelow.

**CORRESPONDENCE:** Letter dated 26<sup>th</sup> June 2013 from Speech Pathologist, Elise Hamilton-Foster, Westmead Hospital thanking the Association for the donation and delivery of three magnetic whiteboards for the use of new laryngectomee patients while in hospital. They will be labelled and kept as property in the Speech Pathology Department. ( THANKS to Bruce Hodges (Assistant Welfare Officer) for purchase and delivery of these and others similar to our other operating hospitals.)

Letter from Ruth Gray informing “ its too bl...y freezing for her to come to the city – staying out of germs and hate freezing! She hopes Brian is drinking warm beer or sitting on a heater? Will see us when it’s warmer”. (Attached 2 “Mr Rudd” cartoons enjoyed by either team players).

Newsletters (June & July 2013 “The New Voice” from L.A. of Victoria Inc.

**SECRETARY/TREASURER’S REPORT:** (Carol Gardner) 20/6/2013 to 17/7/2013)

ADELAIDE BANK		EXPENDITURE	
Opening Balance	22585		Nil
Interest	<u>41</u>		<u>    </u>
TOTAL	22626	TOTAL	Nil

BALANCE AS AT 17/7/2013 = \$22626

COMMONWEALTH BANK		EXPENDITURE	
Opening Balance	2261	Catering	30
Sales	247	Phone & Internet	128
Members’ Subs	30	Printing	99
Donations	5	Postage	157
Sponsorship Donation (Main Medical)	<u>2000</u>	Rent (June)	36
		Patients’ Supplies	<u>570</u>
TOTAL	4543	TOTAL	1020

BALANCE AS AT 17/7/2013 = \$3523

IOOF (PSI) as at 12/7/2013 = \$3684. For any astute readers “Dramatic” drop of \$454 (\$3654 to \$3200) from 15/5/13 to

19/6/2013 (reported July Newsletter) was queried twice before recorded, but latest balance obtained back to “normal”.

COMMONWEALTH BANK TERM DEPOSIT = \$425,000 @ 4.45% maturing 4/12/2013.

Amounts towards Christmas Party booking and raffle purchases to be discussed in General Business and at August meeting. Resolved: Ray Chappelow/Peter Tierney.

**WELFARE REPORT:** (Carol Gardner)

NEW MEMBER:

George SMITH of Batehaven

VALE:

Janet ROBERTSON of Goulburn,  
Garth JONES of Normanhurst (lovely old gentleman, who always came to the Christmas Party up till last year).

Pat Dawson has been having a bad run of health problems this past year with some further hospital treatment coming up shortly. We all send our best wishes to a tireless worker (not only for our Association). PAT, enjoy the BED REST part of things!!

**GENERAL BUSINESS:**

Jane Toohey gave an informative presentation regarding LMA PacMed’s products and services, emphasising the benefits to members of using HME (Heat/Moisture Exchange) devices and advising that members can “trial” these by requesting their Speech Pathologists to obtain a “trial pack” for them from LMA PacMed. Jane stressed sometimes the benefits of the devices (long term) come after a short period of adjustment, which varies for individuals. The cost can be subsidised by EnableNSW for those that qualify (means tested) for that system. Jane was happy to answer questions from those present and has offered to source another guest speaker Speech Pathologist for one of our future meetings – date to be advised. Jane was thanked for her personable and helpful talk and visual demonstration.

Carol Gardner requested some help with the Christmas Party arrangements. The function will be on the 7<sup>th</sup> December at the same venue (Ryde-Eastwood Leagues’ Club) as the last few preceding years. Ray Chappelow put his hand up to assist and Peter McGregor is “Chief of Staff” organising some shopping duties for some of our faithful members. We thought it was only “girls” who loved to shop but Ray wants to show his prowess in that field also. At the August meeting the volunteers will get together so as not to duplicate items.

Peter McGregor requested that it would be beneficial to invite Dr Julia Maclean and/or Professor Ian Cook along to update the members on the research project, towards which the Association made a donation. A letter will be dispatched for this purpose.

The meeting closed at 12.45pm. Light lunch/tea/coffee (and delicious cake brought along by our guest) were enjoyed.

**NEXT MEETING** will be on 21<sup>st</sup> August-see front page. (We may be in the Norman Selfe Room -Level 3).

# PRICE GOUGING BY AUSTRALIAN MEDICAL SUPPLIERS

extracted from a [stilltalking.org](http://stilltalking.org) website article by Greg Joss

**A**n Australian resident wishing to purchase significantly priced medical items, can readily access a wealth of promotional material on the internet from manufacturers around the globe. When it comes to actually making a purchase, some websites are not so open. International medical manufacturers will most often refer the purchaser to local suppliers or agents.

The Information Technology (IT) industry recently drew considerable adverse publicity when it was found that this practice was used to foster differential pricing based on country of purchase. One result was the House of Representatives Committee's Inquiry into IT Pricing.

The ABC TV program 'The Checkout' asked why Australians pay more for music and movies on iTunes compared to Americans. CHOICE magazine is also constantly monitoring the discrepancy between what Australians pay for items as opposed to purchasers in other countries. Visit the 'Still talking' website to follow the links to see all the supporting evidence of these practices. The 'price gouge' confronting the Australian resident purchaser of computer software pales into insignificance in comparison to that hidden from the Australian resident purchaser of medical supplies. The price differences with computer software that attracted so much attention were a mere 50 to 75% whereas the **price in Australia** for the commonly used brands of speech aid for a laryngectomee range from **2 to 3½ times the RETAIL price in the US!** Similar discrepancies apply to most other medical items from the specialist Australian medical suppliers.

## **For example an Electrolarynx speech aid for a laryngectomee.**

An Australian resident laryngectomee wanting to purchase a speech aid may be attracted by a report from a support group such as THE VOICE - June, 2012 or on social media such as Facebook: Lauder Enterprises Inc. He has ready access to advertising of, say, the Blom-Singer Electrolarynx, but when it comes to purchase, the primary supplier site in the US: InHealth Technologies greets them with "Price: U.S. Members Only\*". The site is geoblocked – see the CHOICE article on 'circumventing geoblocks'.

If he were to access the site as a US resident, he would be invited to 'register'. After 'approval' of his registration, he would see the same but with a price of US\$199. Australians are referred to the local Australian agent: Main Medical; when it comes to a price enquiry or purchase they are in turn referred to customer service at Clifford Hallam Healthcare. The local price A\$650, 3½ times the US price!, is obtained by email.

A competing supplier LMA Pac Med Aus will quote A\$1159 (by email) for a Nu-Vois III electrolarynx; more than twice the price of US\$561 for the same item in the US. Neither Australian agent makes prices available on their websites; prices are only available on application. Both are sole Australian agents for their devices. This practice of hidden differential pricing would appear to be with the assistance of the US suppliers who hide their prices from international viewers.

The experience of members of the Laryngectomee Association of NSW (LANSW) is that this practice of inflated pricing is not restricted to any particular class of supplies but applies to the broad range of items including disposable foam stoma covers, silicone laryngectomy tubes, voices prostheses etc priced from a few dollars to hundreds of dollars. These items are generally listed in Australia at twice the price of the US.

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## Purchase medical supplies from the US online.

Some of us have sufficient personal contacts to allow us to import from the US for ourselves even from those US companies that only sell within the US. In order to demonstrate to LANSW members how they too can, quite legally, order lary supplies directly from US suppliers and to test an Australian commercial business which performs this service for the public, the author ordered a BLOM-SINGER ELECTROLARYNX from InHealth via 'Price USA' (an Australian purchasing agent company based in Bendigo Vic) on 12th June. It was delivered to my home 3 weeks later on 4th July. It was billed as US\$158.89 + agent's fee US\$49.47, ie US\$208.36 purchase price. Delivery by UPS was US\$54.95 and delivery protection US\$4.98. The money was paid with a bank transfer via a Commonwealth Bank for a deposit of \$174.03 followed later by a payment of \$119.82 making a total of A\$293.85. This is well under 45% of the price charged by the Australian supplier Main Medical despite the unnecessarily expensive delivery option chosen and despite the A\$ conversion at 91.8c rather than 105c. The delivery charge would have covered additional or multiple items (the electrolarynx boxed weight is 220g, 0.5lb). A variety of payment methods mean that perceived complexities of internet payments by credit card, PayPal etc can be avoided.

Some US suppliers are happy to sell directly to Aus customers e.g. *medexsupply.com* (including laryngectomy tubes) and *medmartstomashield.com* (stoma shields). The price differences more than pay agents' fees and shipping costs even for less expensive items like a packet of 30 ready-made foam stoma covers.

*Michael Schaffler, of Main Medical, had responded to an unpublished draft version by email and by addressing the June LANSW meeting. He had promised a written summary which was not yet to hand at the time of going to press.*

## UK LARYNGECTOME WEBSITE

**Well the pommies have taken their time in getting a website up and running, but now that they have it is certainly a humdinger. It could easily be missed as it is located at <http://www.laryngectomy.org.uk/>, not using the word laryngectomee, however it is well worth your time and effort as it is packed with valuable information and links.**

The Publications section is particularly useful for Speechies as well as for laryngectomees, relatives and carers. All pamphlets are downloadable and will be regularly reviewed, making the site worth a regular visit if only for these. The YouTube links are great as they plonk you on pages with loads of laryngectomee related links.

The site is of course UK-centric, but at least half the pages are relevant to aussie laryngectomees. Back issues of CLAN, their quarterly newsletter, with personal stories, anecdotes and tips, medical information etc. often a source of material for "Still talking".

So I encourage all of you to visit the website and check out any pages of interest.

## THE ROYAL BABE

By Len A. Hynds

Welcome my young prince, to the human race,  
your sweet innocence plain to see.  
Lifes long journey, starts at this gentle pace,  
as you begin your own family tree.

Each day you will see, and slowly learn,  
to recognise those around you.  
See their warmth and love, as each in turn,  
with their eyes, show their feelings true.

Every step of the way, they will guard you,  
as the precious babe that you are.  
Every step of the way, they will guide you,  
those near and those afar.

And so young prince, you will slowly grow,  
learning so many wondrous things.  
Of astronauts and eskimos,  
of cabbages and kings.

But babe you will always remember,  
your mother and fathers love.  
Something you will always cherish,  
and why sent from god above.