

Still talking

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

www.cancerconnections.com.au

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 223

The Laryngectomee Association of NSW[©]

SEPTEMBER 2011

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OFFICE BEARERS 2011

PRESIDENT: Brian Gardner, 4 Merelyn Road, BELROSE, 2085. 02 9452 2858

VICE PRESIDENT (1): Russell Green, 17/765 Princes Hwy, BLAKEHURST, 2221. 02 9547 3669

VICE PRESIDENT (2): Peter McGregor, 21/39 Cook Rd, CENTENNIAL PARK, 2021. 0419 421 324

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

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SPEECH AIDS COORDINATOR: John Chaloner, PO Box 31, SUMMER HILL, 2130. 02 9560 2852

EDITOR: A.T.Krasnodebski, PO Box 232, BONDI, 2026. 02 9130 2560. Email - antoni.krasnodebski@deewr.gov.au

WHO TO CONTACT

BLOM SINGER SUPPLIES: David Smith, 27 Bellevue Pde, NORTH CURL CURL, 2099. 02 9939 1539 Ask for David personally.

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

SHOWER SHIELDS, STOMA COVER MATERIAL AND 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 of NSW, 153 Dowling Street, WOOLLOOMOOLOO, 2011 (PO Box 572, Kings Cross, 1340) Phone 02 9334 1900 Fax 02 9357 2676. Or contact Social Worker at the hospital you will be attending.

WEBSITES

ASSOCIATION WEB PAGE: www.stilltalking.org

INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES: www.theial.com/ial

WEB WHISPERS: www.webwhispers.org

NEXT MEETING

Wednesday 21 September, 2011
at the Sydney Mechanics Institute
280 Pitt Street, SYDNEY. 11 am.

The meeting will be followed by light refreshments.

Laryngectomees, Friends, Families,
Professionals all WELCOME.

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MONTHLY MEETINGS

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

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

NEWCASTLE: 3rd Tues. Monthly Mayfield Bowling Club, Ingall St, Mayfield. Contact John Lovett 02 4954 8308

NORTHERN RIVERS: 4 times annually at rotating venues. Contact Speech Pathology Lismore Base Hospital 02 6620 2157

ALBURY: Meets alternate months from Feb. Contact Norma Teasdale 02 6021 1749

CANBERRA: Wed 24/8/11 - 10:30, Wed 7/12/11 - 10:30 Canberra Hospital 02 6244 2230.

SOUTHERN DISTRICTS: Last Wed of month 11am. Thomas Rachael Moore Education Centre, Liverpool Hospital. Contact Pres. George Petkovic 0432 077 095

MID NORTH COAST: Port Macquarie Community Health Centre. Last Wednesday of March, June, Sept, & 1st Wed Dec. Contact David McClymont - President 02 6559 8383

CENTRAL COAST: Meet at Central Coast Leagues Club. Contact Speech Pathology Department (Gosford Hospital) 02 4320 3634 or Bill Byfield 0402 045 048.

COFFS/CLARENCE: Coffs Harbour Health Campus, Shearwater Lodge. Meets 4 times annually. Contact Melissa Parish (SP) 02 6656 7606

MINUTES

MINUTES OF MONTHLY MEETING HELD 17th AUGUST 2011 – Laryngectomee Association of NSW at SMSA, 280 Pitt Street, SYDNEY at 11am

PRESENT: Brian Gardner, Russell Green, Ruth Gray, John Czadrik, Peter Tierney, Bruce Hodges, Bob Nash, Antoni Krasnodebski, John Pyle, Victor Stumbles, John Chaloner, Peter McGregor, Lorraine Beltrami. Non Lary: Carol Gardner, Glenda Tierney, Pat Dawson, Charm Nash, Patricia Lamont. **GUESTS:** Jessica Payne, Jim McMullen.

APOLOGIES: Arthur & Jennifer Hirshowitz, Nelia Knight of Granville.

THE PRESIDENT opened the meeting and welcomed Jessica Payne – Community Network Co-ordinator Central and Southern Sydney/ Cancer Council NSW and Jim McMullen – Managing Director PDP Audio Alerts Pty Ltd and our members. It was requested that the Minutes of the meeting of 20th July 2011 as presented in the August 2011 Newsletter be accepted as read. There were no matters arising therefrom.

Resolved. Bruce Hodges/Russell Green.

SECRETARY/TREASURER REPORT

CORRESPONDENCE: Newsletter “The New Voice” from Laryngectomee Assoc. of Vic. Inc., with addendum “LATE VALE” regarding the death of their esteemed President, Bob Young on 4th August 2011. Our condolences and sympathy to his family, friends and our Victorian counterparts losing “one of their best”.

Email from Erica Casey with an August update re her study, in which a number of our members participated by filling out and returning questionnaires – “113 distributed and 87 returned, 67 from NSW alone – a fantastic figure given I only needed 30 from each state to make my study viable.” Erica is in the process of analysing all the info – “an exciting process to have results now to look at.” “Please pass my thanks onto all of your members, without their support, none of this would be possible.”

Emails and parcel of preliminary samples from Bert Siviero, a recent member from Swansea, who has been making a very fine job of sewing stoma covers – he is perfecting his technique (and asked for a critical appraisal). We will see if he would like to publicise his email and/or address to make individual orders/colours etc – you might like to purchase your own choice of material and specifications and send to him. It is not possible for the Association to handle everyone’s individual choices of colour, size etc that we get requested. Some of Bert’s samples were distributed at the meeting.

FINANCIAL REPORT: (Carol Gardner) from 21st July 2011 to 17th August 2011

ADELAIDE BANK		EXPENDITURE	
Opening Balance	9499		Nil
Income/Interest	34		
TOTAL	9533	TOTAL	Nil

BALANCE AS AT 17/8/11 = \$9533
 IOOF (PSI) as at 18/7/11 = \$ 27893 – Later obtained (as at 18/8/11) = \$27882
 COMMONWEALTH BANK Term Deposit = \$415,000 @ 6.2% maturing 4/1/2012

COMMONWEALTH BANK		EXPENDITURE	
Opening Balance	4340	Catering	25
Sales	623	Phone/Internet	86
Members’ Subs	65	Printing	297
Donations	40	Postage	477
		Pat. Supplies	1156
		Rent	33
		Bank Fee (US Draft)	30
TOTAL	5068	TOTAL	2107

BALANCE AS AT 17/7/11 = \$2961

Email sent to IOOF re “Adviser Fees” being charged to the PSI investment (in addition to Administration Fees) when the funds are “frozen” and NO advice has been sought or given by the present nominated Financial Adviser. We have requested that the Financial Adviser be removed. Our email was acknowledged but no answer received as at today. To be followed up and enquiry to be made about why these funds are still frozen and/or when can the Association expect to receive them.

John Chaloner was nominated to take the late Noel Gildea’s position on the Financial Committee (of 4) to make any future decisions regarding the Association’s funds. John is already authorised (with any 1 other authorised) to sign any financial transactions on behalf of the Association. The nomination was accepted by John and a majority vote.

A deposit of \$200 has been made for the same venue as last year for the Christmas Party. An amount of \$800 has been made available to Mrs Pat Dawson for progressive purchases of good value raffle prizes for the function. A further \$200 was approved for later liquor purchases to be included.

Resolved. Peter McGregor/Ruth Gray.

WELFARE REPORT: (Carol Gardner)

NEW MEMBERS

Mark O’NEIL of Mascot,
 George THOMAS of Laurieton,
 Arthur HIRSHOWITZ of Rose Bay,
 Michael COLEMAN of Dubbo,
 Daniel BRYANT of Bathurst.

VALE

Mrs Elaine JACKSON of Belmore. Elaine was a long time member and will be missed by all who had met and knew her – especially the professionals and administration personnel of the Speech Pathology Department of St Vincents Hospital, who always received some marvelous handmade knitted or crocheted gifts at their annual Christmas Party at Paddington R.S.L. Club at Woollahra, which Elaine and husband Dick always attended. Our sincere

MINUTES CONTINUED . . .

condolences have been sent to Dick, family and friends .

VALE Noel GILDEA of Dulwich Hill, following late emergency hospital admission with pneumonia. Noel had been a member since 2005, a regular at our meetings and always willing to offer any assistance/support to new laryngectomees when he was visiting RPA . Brian Gardner, Bruce Hodges and John Pyle attended the funeral service . Noel's sister, Pam Whelan, was appreciative of the support and comradeship he had enjoyed from being a member of the Association and handed in some useful items for distribution to others needing them. A letter of thanks and sympathy for Noel's family and friends has been sent to Pam.

George PETKOVIC has replaced long standing Southern Districts President, Richard PATMAN. Congratulations, Richard on a job well done for many years and thanks to George for stepping up to the position. The Association cannot function successfully without willing volunteers.

Congratulations and Best Wishes to one of our favourite Speech Pathologists, Candice Baxter, at Liverpool Hospital, to be married mid August. We hope the sun shines for you both on the day and in the future!

SPEECH AIDS CO-ORDINATOR'S REPORT - John Chaloner

The latest delivery of Varta batteries (for the Servox & Romet speech aids) that I received has decreased slightly in cost. The batteries are assembled in Sydney but the cells are made in Germany so probably something to do with the high Aussie dollar.

So the price to members is now \$20.10 each (\$1 less).

Postage and packaging costs have recently increased to \$6.00 per dispatch, but your Association continues to absorb this cost, and continues to not pass on the GST - so the price to you is the net cost to us.

I've learnt that RemediX in Melbourne are still the Australian agents for the Griffin TruTone and SolaTone electrolarynxes (though the Griffin website doesn't list their agents).

The details for RemediX are -

Contact - John Dale

Phone - (03) 9822-9124

Address - P.O.Box 2019, Camberwell West, VIC 3124

Email - info@remedix.com.au

They do repairs, and have loan aids available. One of our members who is trialling a TruTone is quite happy with it.

GENERAL BUSINESS:

Pat DAWSON has again agreed to make the arrangements for the annual Christmas Party. The date/time booked is Saturday 3rd December 2011 at 12.00 noon. A form with details will appear next or following month for acceptances/attendance. Invitations will be sent to our health professionals and sponsors. It is requested that, if anyone accepts and then finds out (for whatever reason) before the occasion they cannot attend, they notify Pat or the Association because once final numbers are submitted about a week before for catering purposes, the meals have to be paid for.

An interesting and informative presentation was then given by Jessica Payne about Cancer Council NSW's work/support in the community, information, free literature and resources available from them.

We were advised that our Branches can apply for a Cancer Council NSW grant annually – needs based – applications available in April each year. Those present enjoyed the talk and the sample goods kindly donated. Contact details – phone, email, website (with various links) supplied. See later report.

A magazine "LIFE CIRCLE" (available at newsagents for \$8) was also recommended.

Letter of thanks and appreciation to be sent to Cancer Council NSW and to Jessica for her participation. We will be taking up the offer of having more Community Guest Speakers on various specific subjects when they can be arranged at future meetings.

Another presentation/demonstration followed by Jim McMullen on a PDP (PRESS DON'T PANIC) "small, highly visible, audio medical ID which can communicate vital information in an emergency – at the press of a button." Contact details made available. Jim advised that a small percentage of any resulting sales to our members would be donated to the Association.

One of our members has already purchased one (about \$69), and had a message recorded by a family member, to take overseas while he is currently not able to communicate.

The meeting closed at 12.45pm and lunch (many thanks, Peter and Clare McGregor for the delicious sandwiches, helping out while our trusty helpers, Pat and Barry Bunker, are away) and more talk followed.

NEXT MEETING – 11.00am - 21st September 2011 at SMSA, 280 Pitt Street, SYDNEY.

"I once had a rose named after me and I was very flattered. But I was not pleased when I read the description in the catalogue: 'no good in a bed, but fine up against a wall.'"

--Eleanor Roosevelt

CANCER COUNCIL SERVICES

At our August meeting we were fortunate to have a Cancer Council presentation by their representative Jessica Payne who enlightened us of all the research, patient support and information, cancer prevention and screening, advocacy and work within the community, provided by the Cancer Council. All of this is funded via fundraising events and donations etc, no funding comes from the Government, except on the occasion where they may co-fund a specific research project.

The central point of contact between the Cancer Council and the general public is via their Cancer Council Helpline number - **13 11 20**. They receive about 20,000 calls a year to access their team of oncology health professionals and receive information, support and literature covering over 2,800 cancer related services. Their vast team of volunteers, who complete a comprehensive training program, provide one-to-one support by phone before, during and after treatment. Telephone support groups of 3 - 7 participants are available for those isolated by their cancer or situation and are run by trained facilitators, again referred through **13 11 20**.

Post cancer services include a 2.5 hour program for cancer survivors, their carers, family and friends which are facilitated by volunteer cancer survivors state-wide, providing strategies, tips, activities and resources which people may find helpful to live their life well subsequent to their cancer treatment. There is also a free one day program for people who have finished cancer treatment and plan to return to work or are working through their treatment. Another program is for a person caring for someone and juggling work. There is even a program for a manager, employer or colleague who would like to understand more about cancer in the workplace. Further information on **13 11 20**.

A valuable service for those connected to the internet is provided at www.cancerconnections.com.au. Forums, groups, blogs etc are ideal for people living in an isolated location, those who would like to remain anonymous or anyone suffering a cancer that has affected their speech and of course anyone looking for peer group support.

The Cancer Council also provides practical support to cancer sufferers and the high cost of cancer treatment. In addition to providing a small, means tested grant the Cancer Council provides assistance towards transport to your cancer treatment and also helps in obtaining accommodation during your treatment. Home help may be provided should your treatment be debilitating. For all of these services **13 11 20** will be your first point of contact.

Free, means tested, legal assistance is also available for people affected with cancer towards areas of law including wills, powers of attorney, superannuation, insurance, credit and debt, employment and guardianship of children. Again, initial contact **13 11 20**.

Cancer Council Information Centres are dedicated spaces in hospitals and treatment centres hosting a full range of printed information and with access to online information. The Centres provide a friendly, comfortable place to sit quietly, no appointment is needed, and all resources are free. Trained volunteers guide patients and carers to relevant information and support.

As you can see, Jess spent a lot of time with us giving an informative talk and answering many members' personal questions. All the more reason, if you are able, to join our monthly meetings in the city, if you are able.

PRESS DON'T PANIC

At the August meeting we were given a presentation by Jim McMullen for a new device developed by his associate in Scotland called "Press Don't Panic". It is a small, highly visible, audio device that can communicate vital information in an emergency at the press of a button.

George Stewart, a UK laryngectomee for 21 years, said in the CLAN newsletter that he has an SOS badge on a chain and also a leaflet in his pocket indicating that he is a neck breather. George feels this new device would be invaluable to laryngectomees in an emergency. It's very compact and light and can be attached to your clothing - shirt, blouse, top, jacket, handbag or, if desired, on a neckchain or ribbon.

You record your message. My wife, Nancy, recorded the following for me. "George is a neck breather. Do NOT throw water over his head or neck. If he has stopped breathing, expose his head or neck. Keep his head straight and chin up. Keep neck opening clear with clean cloth. Do NOT use tissues. Give him neck to mouth breathing after he starts to breathe again. Use oxygen to neck opening only. Thank you."

There is a two minute recording time to record any relevant message. In an emergency, the green cross on the front can be pressed and the message plays loud and clear.

For more details contact Jim McMullen on

Mobile - 0419 445 067

Email - jimmc38@bigpond.net.au

The price of the Press Don't Panic device will be \$68.50 including GST.

What On Earth Happened To My Thyroid Gland?

First, the thyroid gland is shaped like a butterfly and lies in a position adjacent to the larynx and trachea. There are two lobes, one on each side of the larynx and trachea. These lateral lobes are connected by a narrow isthmus, which crosses the trachea just below the larynx.

In doing a laryngectomy, we try to save as much of the gland as possible. Usually, we can save both of the lateral lobes, which means you are left with essentially all of your thyroid tissue. However, sometimes it is necessary to resect half, or even all, of the

thyroid in order to adequately remove the cancer. When we remove the larynx, we dissect the portion of the thyroid that we are going to save off of the larynx and trachea and leave it lying in the neck on either side of the esophagus. This means that your thyroid gland is actually in two halves, one on each side of the esophagus and slightly above your stoma.

The problem with thyroid function can come in several scenarios. The first one is obvious with the need to remove all of the thyroid tissue. You will be on thyroid replacement medication before you leave the hospital.

(By the way, you will also be on calcium and vitamin D replacement before your discharge as well.) The other two scenarios are more subtle. The first involves leaving some thyroid tissue but compromising the blood supply in doing the laryngectomy. What happens is the thyroid slowly gives up the ship and dies.

The last and probably the most common thing to happen is radiation therapy. The radiation causes the small blood vessels in the gland to slowly stop up so you end up with a small scarred gland with poor blood supply and inadequate function.

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Does everyone who has radiation to the neck need to be on thyroid replacement medicine? The answer is ?No?. If you are having the symptoms of becoming fatigued easily, low energy level, weight gain, etc., and if you have had radiation, then you should have your thyroid hormone levels checked with a simple blood test. Replacement medicine can then be given on the basis of those results.

Glenn E. Peters, M.D. , F.A.C.S.

Director, Division of Otolaryngology - Head and Neck Surgery
University of Alabama at Birmingham, USA

humour

EVER WONDER...

...why the sun lightens our hair, but darkens our skin?

...why women can't put on mascara with their mouth closed?

...why you don't ever see the headline "Psychic Wins Lottery"?

...why "abbreviated" is such a long word?

...why doctors call what they do "practice"?

...why you have to click on "Start" to stop Windows ?

...why lemon juice is made with artificial flavor, while dishwashing liquid is made with real lemons?

...why the man who invests all your money is called a broker?

...why there isn't mouse-flavored cat food?

...who tastes dog food when it has a "new & improved" flavor?

...why Noah didn't swat those two mosquitoes?

...why they sterilize the needle for lethal injections?

...why they don't make the

whole plane out of the material used for the indestructible black box?

...why sheep don't shrink when it rains?

...why they are called apartments when they are all stuck together?

...why they call the airport "the terminal" if flying is so safe?

A truck driver was driving along on the freeway. A sign came up that read "low bridge ahead." Before he knew it the bridge is right ahead of him and he got stuck under the bridge. Cars were backed up for miles. Finally, a police car came up. The cop got out of his car and walked around to the truck driver, put his hands on his hips and said, "Got stuck, huh?" The truck driver said, "No, I was delivering this bridge and ran out of fuel."

It was that time, during the Sunday morning service, for the children's sermon. All the children were invited to come forward. One little girl was wearing a particularly pretty dress and, as she sat down, the

pastor leaned over and said, "That is a very pretty dress. Is it your Easter Dress?" The little girl replied, directly into the pastor's clip-on microphone, "Yes, and my Mum says it's a bitch to iron."

"If I sold my house and my car, had a big garage sale and gave all my money to the church, would that get me into Heaven?" I asked the children in my Sunday School class. "NO!" the children all answered. "If I cleaned the church every day, mowed the yard, and kept everything neat and tidy, would that get me into Heaven?" Again, the answer was, "NO!" "Well, then, if I was kind to animals and gave candy to all the children, and loved my wife, would that get me into Heaven?" I asked them again. Again, they all answered, "NO!" "Well, I continued, "then how can I get into Heaven?"

A five-year-old boy shouted out, "YOU GOTTA BE DEAD!"

"There is no pleasure in having nothing to do; the fun is in having lots to do and not doing it." --Mary Wilson Little

"Camping is nature's way of promoting the motel business." --Dave Barry

How do you know when it's time to tune your bagpipes?