THE NAME GAME

There hasn’t been a very enthusiastic response to the call for suggestions to finding a new name for your Newsletter. It looks as though any of the names nominated below which receives more than one vote, ought to be the title for this Newsletter and also our eventual internet presence.

The suggested title of “Let’s Talk”, that was mentioned in the editorial last month, is not on the list below because there is already a newsletter of that name in the United States.

Here then are the choices for you to make:

“STILL TALKING”

“The Echo”

“Talk About It”

“Speakeasy”

“The Lost Chord”

There you have it. Choose one of the above and write in, either to the Secretary or Editor, with the name that you would like to see as the masthead for the Newsletter and wait for next month’s edition.

A.T. Krasnodebski

WHO TO CONTACT

FOR BLOM-SINGER SUPPLIES - David Smith, 27 Bellevue Pde, North Curl Curl 02-9950-1539

FOR SPEECH AIDS, BATTERIES PARTS AND ADVICE ON REPAIRS - John Chaloner, 111 Station Street, Petersham 02-9560-2852

REPAIRS - John Chaloner, 111 Station Street, Petersham 02-9560-2852

FOR STOMA COVERS, SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS - Lilah Welton, 23 Baker Street, KENSINGTON 02-9663-2550

FOR ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME - Cancer Council of NSW 153 Dowing Street, WOOLLOOMOOO, PO Box 572, Phone 02-9334-1900. Fax: 02-9357-2676
MINUTES


THE PRESIDENT Brian Gardner in the chair opened the meeting at 11.05 a.m. on a beautiful autumnal day. Minutes from the April meeting as distributed in the Newsletter were accepted on the motion of John Gifford, seconded by P Halliburton. There was no business arising out of these minutes.

SECRETARY/TREASURER'S REPORT - John Nicholson was absent, visiting family, and his report was read by Lilah Walton.

SECRETARY’S ABSENCE

Because the opportunity has presented itself and I am free of doctors appointments for a couple of weeks we have taken the time to visit one son in Wagga and one daughter in Payneville. This means we miss our second meeting in many years - sorry but we don’t get chances like this very often.

MEMBERSHIP

Two more Newsletters have been returned marked ‘Return to Sender’ so am not sure if they have moved. The members concerned are Mr Ian Wall of Warrawong and Mr J Cubby of Dubbo, so if anyone knows their new address would they please advise me accordingly. Only one new member this month and that is Mr C Smith, Speech Pathologist of Manning Base Hospital, Taree. We extend a cordial welcome to Mr Smith.

ACTION ON SMOKING & HEALTH (ASH)

Tony Krasnodebski attended the recent gathering in Sydney so I’ll leave it to him to report on the exercise. (See page 6 for story)

I omitted to report that Ken Isherwood of Cremorne has advised me that his wife Barbara - one of our members - passed away peacefully at Greenwich Hospital on the night of the 11th April. Ken asked that we thank Dave Smith and John Chaloner for their support. We certainly extend our sincere condolences to Ken, his family and friends.

DONATIONS

Our thanks, again, to Jo Nowland for another financial donation to our Association. You are a very kind lady Jo.

Moved by Lilah Walton, seconded by Bruce Darlington.

WELFARE OFFICER’S REPORT - On Wednesday 26th April Anne Jones from the Cancer Council rang me to arrange for as many larrys as possible to assist her with a project connected with tobacco companies and smoking dangers. Anne was hoping for the larrys to attempt to sing a song. I spent a lot of time ringing around but was only able to get two larrys (Sid Lowe & Tony Krasnodebski) to participate, for which I thank them, they will give you details. TV Channel 9 or 2 were supposed to show it but I watched both band it wasn’t shown, although Anne Jones was on TV on the Saturday and I believe it was to do with getting larrys to talk to school children. As most of you know, I don’t think there is a school in Sydney that over the years I haven’t contacted requesting this. If my memory is correct, Alan Dawson did a talk at Blacktown The Only School.

On 5th June Julie, the Speech Therapist, has asked John Chaloner (DSP8), Sid Lowe (Blm/Singer) and Bruce Darlington (Senvox) to speak to surrounding district nursing and medical staff re requirements of larrys after operation. They can give reports later.

John Chaloner and his wife Clarissa at the request of an upset mother, via me, to speak to their young schoolgirl daughter re smoking. John Chaloner feels that in future these types of visit be given by trained counsellors. I feel actually seeing a larry is more frightening than being told about the operation. What do the Newsletter readers think?

Another ‘use by date’ has arrived on 11/4/00 for one active member. Another position to be filled??? Have been busy these past few months answering queries from larrys/partners, I sometimes frighten myself with the knowledge I have. If I wasn’t so modest I could write on for weeks. I really like hearing from people and finding out how they are coping and if I can help them.

John Nicholson and wife are taking a few weeks to unwind now that their district show is over. John rang me on Sunday and while we were experiencing sunny weather they were having cold rainy weather, let’s hope it improves as they move on. I was sorrowful in learning of the death of Barbara Isherwood. Barbara has been a hospital visitor for years and will be missed. To her husband Ken and family our heartfelt sympathy.

Two new members for this month and both, would you believe, have been larrys for ten years. Welcome Kevin Maher of Cabramatta West and David Lamont of Lane Cove. Sid Lowe has not been well. Trust everything is okay Sid. To anybody else not feeling well we send our best wishes for a speedy recovery. Lilah Walton

Moved by Jo Nowland, seconded by Pat Halliburton.

As John Chaloner was not present there was no Speech Aids Co-ordinator’s Report.

GENERAL BUSINESS - John Chaloner contacted Lilah Walton regarding the purchasing of supplies from the Association, in particular those made by members of Veterans Affairs. The way that the transaction should work is that payment is made in full to the Association and then accounts/receipts are forwarded to Veterans Affairs, who will then reimburse the purchaser.

There was much discussion over many topics, mainly members exchanging experiences. The meeting closed at 12.05 p.m. and was followed by a light luncheon in the church hall.
MINUTES CONTINUED . . .

WESTERN DISTRICTS NEWS - May 2000. At the May meeting the annual raffle was drawn. The prizewinners were:

First ($100 Gift Voucher) - Ron Mobbs, Eastwood Bowling Club.

Second ($50 Gift Voucher) - Peg Fazackerley, Dundas.

Third ($25 Gift Voucher) - H. Harvey, Eastwood Bowling Club.

Instead of the normal monthly meeting a bus trip has been arranged for the second Tuesday in June. The bus will leave the Parramatta Masonic Club at 9.00 a.m. for Richmond - Wisemans Ferry - Saint Albans.

A bus has been arranged for the October barbeque at Budgewoi but as no bus is available for the September meeting with Illawarra at Woronora a group of cars has been organised.

The Committee wishes to thank everyone who bought tickets in what was a very successful raffle for Western Districts. P. Halliburton.

LAUGHING GAS HELPS SMOKERS QUIT

Scientists have found that laughing gas could have the potential to help smokers quit, the Associated Press reported May 17.

In a study conducted by psychiatrist Dr Carlo Bayrakdarian of the Weill Cornell Medical College at New York Presbyterian Hospital, seven smokers went through a single session of breathing nitrous oxide. After breathing the laughing gas, five of the smokers quit for at least three days, while four remained tobacco-free when checked a month later.

How laughing gas works in helping smokers quit is still a puzzle to doctors, however. “That’s the million dollar question,” said Bayrakdarian.

Researchers got the idea for the study after reading about a South African doctor who was using laughing gas to prevent alcohol withdrawal. Bayrakdarian hopes to conduct another study, which would involve more smokers and a control group given a placebo.

This Article is Published by Join Together:
http://www.jointogether.org

LETTERS TO THE EDITOR

Dear Sir,

I am a speech pathologist from the Northern Illawarra Rehabilitation Aged and Extended Care (RAEC) Speech Pathology Service. Recently our department gratefully and excitedly received a donation of 3 new artificial larynges from the Illawarra Branch of the Laryngectomee Association. We anticipate that new laryngectomees undergoing speech therapy at Wollongong Hospital will be able to trial the devices to assist them in making choices about which method/methods of communication best suit/s their needs. Additionally, laryngectomees in the Illawarra community will be able to borrow the devices while their own devices are being repaired.

Would you be able to include this information in the next edition of the NSW Newsletter. We would just like to acknowledge their kind donation.

Thank you very much.

Ellie Annesley

Ellie also asked the question:
“What methods of stoma protection have you found to work best to cover the stoma when exercising (eg walking, bike riding etc) in windy or cold weather?”

(People have reported that stoma covers tend to get sucked into the stoma or foam covers tend to hamper breathing during exercise)

If you have any insights or suggestions please advise the editor, contact details front cover, or Ellie Annesley herself on 02 4222 5441.
COVER-UP


In addition to the aesthetic consideration and the possibility of offending some people’s sensitivities, the main thrust of the piece was pointing out the benefits that flow from wearing them.

Stoma covers perform some functions that used to be carried out by the nose and mouth, such as filtering airborne dirt, bacteria and other harmful particles. They help in retaining a little moisture from the lungs that would otherwise be dissipated. They hold a little warm air to mix with the incoming cold air.

The main reason given for not wearing a stoma cover was that it interfered with the intake of air. In fact, some resistance to breathing is beneficial to pulmonary (lung) function, which is why Heat/Moisture Exchange (HME) filters are recommended.

Apparently, not wearing a stoma cover can increase your susceptibility to respiratory ailments such as pneumonia; cause you to cough more; increase mucus production which in an extreme case could give rise to a life threatening mucous plug; increase bleeding with the potential for infection; more crusty, with the potential of a blockage in the airflow; reduce pulmonary function with the lessened air resistance.

If you are one of the non-stoma cover wearers, they give a four step plan to get you into the habit of wearing one.

i) Begin with an open weave cover such as a lightweight, lint-free crocheted one.

ii) Wear it when you’re not engaged in any physical activity, including talking.

iii) Gradually lengthen the time you wear it.

iv) When comfortable with that one, go to a tighter weave cover, or a foam one.

SKIVVIES

Instead of wearing stoma covers and scarves, in the winter a skivvy or polo neck shirt doubles as a stoma cover and shirt. In the summer, just shorten the sleeves by cutting them off and hemming them about 6 inches or 20 centimetres from the shoulder seam. This will turn your skivvy into a short sleeved t-shirt with no need to wear a stoma cover. The "Solutions" brand from K Mart (about $10 or so) is good as the neck stretches comfortably.

POEM

Written by Regina Acred for her husband Peter, from CLAN.

NEW LARYNGECTOMEE

You hear him here, you hear him there
You hear him simply everywhere
But, suddenly, it's different.
The voice that often wanted breath
At small things gone away
Has met so premature a death
Each curse is now a sigh.

A sigh to mourn each trilling word
That cannot simply be uttered
A sigh to mourn each loving word
That now with care is muttered.

We take the gift of spoken words
So thoughtlessly for granted
But, when it's gone, it surely hurts:
We know how much we want it.

The way ahead will take some time
But, even now, it's clear
That we CAN understand your mime
And, ultimately hear.

We hear the words you mouth and write
And know each one that matters
We CAN converse and can avoid
The silence that just shatters.

Like you, I know there lies ahead
Those times of great frustration
When lack of real spontaneous speech
Will stretch imagination.

Will stretch our patience too.
Perhaps patience it will teach.
Patience never was for you
But now it's within reach.

You would not choose this trade-off
But that is what it is:
Your voice for patience may not seem
Your own idea of bliss.

But blessed are we because we have
YOU still here to be.
How could we want to ask for more:
You're Viable, you see!

That's all you wanted, or at least,
It's what you said before.
Now persevere and keep it up,
Embrace life all the more.

NEXT MEETING

The next meeting for the Laryngectomee Association of NSW will be held on Wednesday, 21st June, at the Uniting Church Hall, Carrington Avenue, Strathfield, at 11 am.

There is parking on site and it is also a short walk from the Railway Station.

The meeting will be followed by a light luncheon.

Laryngectomees, Friends, Families, Professionals all WELCOME.
CHEMOTHERAPY DEVELOPMENTS

There are a couple of things happening on the chemotherapy front. Researchers in the US and Canada have discovered that sustained low-dose chemotherapy and drugs, called 'metronomic dosing', seems to be proving more successful than the accepted standard method.

Two studies, one by a Dr Kerbel and another by a Dr Folkman, have been published and discussed at the annual American Association of Cancer Research conference held in San Francisco in April.

Both studies demonstrate that chemotherapy not only destroys cancer cells but also the tiny capillaries that deliver blood to the tumour and without blood, the tumour can't grow. With a normal course of chemotherapy patients need a rest period of around three weeks between treatments so they can recover a little from the toxic side effects. During this rest period, the capillaries taking blood to the tumour have time to repair themselves so a lot of the damage to the tumour can be reversed. Two steps forward, one step back.

However, in experimental mice, low-dose chemotherapy had a killing effect on their tumours and in conjunction with an anti-angiogenic drug that blocks new blood vessel growth the success rate was greatly improved and without the side effects such as hair loss, nausea, loss of bone marrow etc.

Within a year or two definitive results should be in, although, at present there are sceptics and dissenters who say that there is no clinical evidence at all as it is based only on experiments in animals and that nobody knows the long term effects of these drugs.

Looking on the bright side, if this treatment regime proves effective, cancer will become a chronic disease rather than the death sentence that it can be now.

A negative aspect of chemotherapy has been brought to light by D.Q. Haney of Associated Press. He said that cancer patients often complain of woolly-headedness during treatment and are reassured that the problem will go away.

A study at Dartmouth Medical School shows that people receiving standard chemotherapy scored badly in intelligence tests an average of ten years after their treatment. In the study 71 patients who were cancer free after getting chemotherapy for breast cancer or lymphoma were compared against 58 people who had been treated with radiation or surgery only. A psychologist, T.A. Ahles, presented the results to the American Cancer Society saying that this was one of the first formal studies of the problem, although the results were unlikely to surprise many cancer patients.

Ahles said that patients told him they were relieved that scientists were finally taking seriously the complaint they had made for years and many of them still had trouble remembering and concentrating. Maybe the low-dose treatment strategy mentioned earlier has arrived at just the right time.
BAT AGM PROTEST

On April 28th, British American Tobacco Australia held their Annual General Meeting in the ballroom of the Nikko Hotel in Sydney under the chairmanship of Nick Greiner.

There was a small protest group in attendance at the Nikko Hotel comprising Associate Professor Simon Chapman, Anne Jones of ASH Australia, Sid Lowe, Tony Krasnodebski and Mr Butts. It was quite a polite affair with some pamphlets entitled “Diary of Denial”, detailing the attitude of Big Tobacco in Australia, being handed out to the few shareholders turning up for their meeting.

Sid and Tony ‘sang’ a satirical version of “Smoke Gets in Your Eyes” for the benefit of reporters outside the main entrance to the hotel. It was obvious that they needed more practice.

LARYNX TRANSPLANT

A 21 year old volunteer fireman, Tim Heidler, had an accident on a motorbike when he ran into a steel cable at 65 kilometres per hour and severely damaged his trachea and oesophagus and crushing his larynx.

Twenty years later he undertook a larynx transplant operation at The Cleveland Clinic with a donor larynx from a 41-year-old man who’d died from a brain aneurysm. His damaged larynx was removed and the donor larynx fitted and connected into place in the first laryngeal transplant.

Two years on, the operation has proved an unbridled success with Tim speaking in a normal voice with almost perfect pitch, beyond all expectation of his surgeon Dr Marshall Strome.

Dr Strome is optimistic for the future possibilities of this type of surgery and anticipates that the next patient will be someone 5 to 10 years down the track from a larynx resection. The hold up is cost, US$110,000 for this operation, which is not covered by insurance.

Dr Strome says that he has plenty of patients eager to undergo the operation but 2 years later, the money just isn’t there.

HUMOUR

A young boy asked his mother, ‘Mummy, why do all fairy tales begin with “Once upon a time”?’

‘Not all of them do,’ his mother replied, ‘The ones your father tells start with, “Sorry I’m late dear, I was held up at the office”.’

If your wife was yelling at the front door to be let in and the dog is at the back door barking to be let in. Who would you let in first?

The dog. He would stop barking once you let him in.

L. Walton

As the foreman of the Irish jury said, “We find the man who stole the car not guilty”
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<tr>
<th>Time</th>
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<tr>
<td>9.00 - 9.30am</td>
<td>Registration Tea/Coffee</td>
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<td>9.30 - 10.00am</td>
<td>Historical Perspective/Developments</td>
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<td>Patient Selection Criteria</td>
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<td>10.45 - 11.30am</td>
<td>Tracheo-Oesophageal Puncture; Constrictor Surgery</td>
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<td>11.30 - 12.15pm</td>
<td>Laryngectomy and Primary TEP</td>
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<td>1.30 - 2.30pm</td>
<td>Voice Prosthesis; Tracheostoma Valves: Fitting and Management</td>
<td>Eric Blom</td>
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<td>4.00 - 4.30pm</td>
<td>Patient Demonstration: Tracheostoma Valves</td>
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<td>4.30 - 5.15pm</td>
<td>Problems and Resolutions</td>
<td>Eric Blom, Tony Cheesman, Ron Hamaker, Alison Perry</td>
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Introduction

This Conference course - one day only - offers an unique opportunity for Australian clinicians to hear/sec/interact with three international experts in the field of Surgical Voice Restoration after total laryngectomy who are visiting Australia in 1997.

The Workshop to be presented in the Council Chamber, John Scott Meeting House, La Trobe University, Melbourne, is a mix of videotape demonstration, discussion and ‘live’ patient demonstration as well as offering an opportunity for discussion of common problems and resolutions. The morning will be in lecture format with the afternoon offering a ‘master class’ involving Dr. Eric Blom PhD demonstrating and problem-solving with live patients in Melbourne.

The Blom-Singer Procedure is a surgical/prosthetic form of speech restoration after total laryngectomy surgery and this course offers teaching on all aspects of the surgery and prosthetic management, whether undertaken as primary (i.e., at the time of initial larynx removal) or as secondary (delayed until after laryngectomy) voice restoration.

Specifically, we will teach:

- selection criteria;
- assessment methods;
- surgical technique(s);
- prosthesis fitting and patient management; and
- problem-solving and ‘trouble shooting’

Keynote Speakers

Dr. Eric Blom PhD is a USA Speech Pathologist and inventor of the ‘Blom-Singer procedure’. His centre in Indianapolis, USA, is world-renowned for speech rehabilitation and he has over 20 years’ experience in the field of laryngectomy and speech rehabilitation.

Dr. Blom has published widely and taught world-wide, sharing his experience and wide knowledge base with clinicians in Europe, North America and Japan. This is his first visit to Australia and the only workshop he will be undertaking.

Dr. Ron Hamaker MD is a widely known USA Head & Neck surgeon who has extensive experience of laryngectomy surgery as well as more major surgery in the area of Head & Neck cancer treatment(s). His contribution to developing surgical principles and aspects of laryngectomy has been profound.

He has established, with Dr. Blom in Indianapolis, the International Centre for Surgical Voice Restoration and has published and taught extensively in this field.

Mr. Tony Cheesman FRCS is Consultant Head & Neck Surgeon at Royal National Throat, Nose and Ear Hospital and at Charing Cross Hospital, London, UK, which has one of the largest Head & Neck Oncology practices in the UK.

As well as being widely known for skull-base surgery, Mr Cheesman has been significant in developing surgical aspects of the Blom-Singer Procedure and has taught extensively across Europe, Australia and UK.

Registration Information

Registration Fees
(registration includes lunch and refreshments).
Speech Pathologists and
Junior Medical Staff $120.00
Consultants $170.00
Students $70.00

Payment Details
Payment (in-full) is required together with the Registration form. Registration must be received no later than Friday, 31 January 1997.

Cancellations
No cancellation fee will apply if cancellation occurs outside of 48 hours of the commencement of the Conference.

Further information

Conference Content, please contact:
Professor Alison Perry
Chair, Clinical Communication Sciences
School of Human Communication Sciences
Tel.: (03) 9479-1940; Fax.: (03) 9479-1874
E-mail: A.Perry@latrobe.edu.au

Registration and Venues, please contact:
Mrs Denise Atkinson
Secretary to Head
School of Human Communication Sciences
Tel.: (03) 9479-1939; Fax.: (03) 9479-1874
E-mail: D.Atkinson@latrobe.edu.au
A.T. Krasnodebski,
P.O. Box 232,
Bondi, N.S.W. 2026

24th January 1997.

Dear,

I am writing to let you know that Eric Blom of Blom-Singer fame will be in Australia at the end of February at the school of human communication sciences of Latrobe University.

I got in contact with a Professor Alison Perry with a view to attending the conference to see what Dr. Blom and his crew had to say for themselves in the way of any possible improvements in the lives of users of voice prostheses, especially of course, Blom-Singer users like me. However, Professor Perry said that the conference was for workers in the industry and that I wasn't welcome to attend.

I would like you to get in touch with our Victorian affiliated association and ask them a couple of things for me. Firstly I'd like a report of what transpires at the conference, I know I can find out for myself but I think a report in our newsletter would be useful for all of us. Secondly you could ask them where the organisers of the conference are going to get their laryngectomees that are supposed to appear as examples in the patient demonstrations, would it be through the association?

Anyway, I enclose a copy of the blurb on the conference for your information and I hope to see something in the newsletter about it in March or April.

Yours sincerely,

A.T. Krasnodebski
Hi Tony,

Received your letter today. I contacted Peter Grodin, the Vic. President, and he said he knew about the seminar. No request has been made for Harry to go to the Seminar demonstrations at this time. Peter said they usually are requested when they need them. He will use his contacts to try and obtain a report on the Seminar for us, and will let me know what he knows. I will keep you up to date as info comes to me and Ann will be included in the newsletter when complete. Seminars that college registration fees usually are about $20 minus $10 non medical, non engineering or whatever are not invited, as a rule, (may be why that outsiders could know more than them!) Any way thanks for your letter and I hope to see you in the coming year.

Regard

John Stein
Dear Mr Lancaster,

I am writing this letter to you after reading a report in the Queensland laryngectomee newsletter that said you attended the Melbourne Conference that featured Dr Eric Blom.

I would have liked to have attended that conference myself and made some calls to the School of Human Communication Sciences in particular to the office of Professor Alison Perry but was given short shrift. They told me that laryngectomees were not welcome and that the conference was strictly for medical personnel and medical students, so I gave up on the idea even though their program indicated that they would be used as guinea pigs to be subjects of two demonstrations at least. It seemed a little hypocritical.

Now I am given to wondering in what capacity you attended that conference, ie you one of the demonstration patients who was permitted to be part of the proceedings under sufferance, or did you have an unencumbered seat for the conference?

The medical fraternity on the whole seem to be a cabalistic group held in low regard by the community and on Ms Perry and her associates’ performance I can understand why. Since my laryngectomy in 1992 any useful information or advice has generally come from other laryngectomees and, occasionally, a particular speech therapist. Is this the underlying reason why I was prevented from attending their conference, that an informed laryngectomee is more likely to be able to show up the ignorance of most doctors in matters concerning our condition? We have all heard the horror stories such as the anaesthetist who put surgical tape over a stoma before an operation, was that an in joke around the coffee urn at morning and afternoon tea?

Please drop me a line with an explanation of why you were allowed to attend the conference and why I was not. I look forward to your early reply.

Yours sincerely,

Antoni T Krasnodebski 30/6/97
A T Krasnodebski  
PO Box 232  
Bondi NSW 2026

Dear Antoni,  
Your letter of 30/6/97 was received on 18 July.

My initial response was to answer in a like style of your own, as I thought your letter was insulting and in very poor taste. Those couple of replies that I started have been consigned to the rubbish bin and I will try again.

I attended as a guest of Professor Perry and was very pleased to be able to once again assist in advancing the knowledge and needs of laryngectomees using tracheosophageal speech. Having been associated with Professor Perry's tutorials on tracheosophageal speech for speech pathology students at LaTrobe University for the past two years and with her predecessor Doctor Jennie Oats before that. LaTrobe is the only university that offers speech courses here in Victoria, and I welcome every opportunity to expose future speech pathologists to working with a laryngectomee.

I attended to enable a tracheosophageal speaker to be interview by media and as a standby patient for procedure demonstration by Doctor Blom. Three other laryngectomees from clinics in the Melbourne area volunteering to have specific procedures demonstrated sizing and fitting of Blom-singer prophesies and trachea-stoma valves. They having been selected for the requirements of the procedures being demonstrated.

It was a speech rehabilitation conference with the emphasis being on the surgical procedures required to enable good outcomes for developing tracheosophageal voice when combined with Blom-singer prosthesis. For surgeons to discuss the surgical procedures being used in the US and UK. and how speech pathologist can use the Blom-singer products for voice restoration.

Copies of papers published by the speakers and a Blom-singer procedure video have been made available by a sponsor Monarch Medical, and I believe made available to each state laryngectomee association.

At all times myself and the other laryngectomees where made most welcome.

Sincerely  
Lorraine Lancaster  
RMB 4645 Sth. Gippsland Hwy. Darriman Vic. 3851
Dear Pat,

Here's the two letters that I promised you, written back in 1997 before I got myself a computer. No need to comment on them really. I guess I might have smart-arsed him a little bit in my letter but my main gripe was against the medical people who ran the conference in question. However, the way he jumps up and defends the medicos against a fellow laryngectomee leaves me suspicious of the kind of guy we might be dealing with there.

Still, not to worry, it's all in good fun and it's good to have an idea of where someone stands in case you have the misfortune to run into him somewhere down the track.

Take care,

Tony

See also 2 letters in January.
WHAT'S IN A NAME?

There have been a couple of suggestions that "Newsletter" isn't really the best title for our monthly newsletter, that it should have an individual title of its own. This seems an opportune time to put this suggestion to the membership, especially if we could be putting a website on the internet. The website and newsletter titles should be linked.

Here are a few examples of names that are currently in use: "Laro Link" is the Queensland newsletter. "CLAN" is the UK one, the initials of National Association of Laryngectomy Clubs backwards. "Web Whispers" is a great name used by the main US website. "Headlines" a US newsletter, good name if only a tenuous connection.

Put on those thinking caps and send in suggestions for a name for your newsletter, with a view to naming our internet presence as well. Next month we will print the suggestions and ask readers to vote for their preferred choice. Two suggestions so far are "Echo" and "Let's Talk".

A.T. Krasnodebski

WHO TO CONTACT

FOR BLOOM-SINGER SUPPLIES - David Smith, 27 Bellevue Pde, North Curl Curl 2099.
Phone 02-9939-1539

FOR SPEECH AIDS, BATTERIES PARTS AND ADVICE ON REPAIRS - John Chaloner, 111 Station Street, Petersham 2049 Phone 02-9650-2852
REPAIRS - John Chaloner, 111 Station Street, Petersham 2049 Phone 02-9650-2852
FOR STOMA COVERS, SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS - Lilah Walton, 23 Baker Street, KENSINGTON 2033, Phone 02-9663-2550
FOR ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME - Cancer Council of NSW 153 Dookie Street, WOOLLOOMOOGO, PO Box 572, Phone 02-9634-1906, Fax: 02-9637-2876
MINUTES


APOLOGIES - L Walton, W Byrne, J Chalonier, M Silver, J Bluett.

THE PRESIDENT - Brian Gardner opened the meeting and asked if anyone wished to move that the minutes of the March meeting be accepted. This was moved by Pat Halliburton and seconded by Mary Halliburton. There was no business arising from the March minutes.

SECRETARY/TREASURER'S REPORT - John Nicholson gave a rundown on the finances of the Association then detailed his report.

DONATIONS
The Association's members sincerely thank the following people and organisations for their generous donations to our Association:
Mr B Yates, Frenchs Forest
Amcliffe Uniting Church Friendship Centre
Mrs J Nowland, Padstow Heights
Mr J Ryan, Woy Woy
Mrs A Szanyi, Londonderry
Mrs M McIntyre, Penrith
Mrs L Walton, Kensington
Mrs L Stein, Northbridge
Mr J Costigan, Doonside
Mr A Draper, Eulalong
Mr L Shaw, Tuncurry
Mr K Holstein, Gloucester

MEMBERSHIP
On behalf of our committee, I welcome the following new members and we hope they will enjoy their membership and make use of the facilities we have to offer:
Mr G Pitisci, Kirrawee
Mr GJ Duncan, Barraba
Mr L Krivans, Highfields
Mrs JL York, Singleton

ACTION ON SMOKING & HEALTH (ASH)
Anne Jones of ASH has sent me a video entitled 'The Awful Truth - The Laryngectomee Choir' to peruse and comment as she may seek assistance from some of our members at a forthcoming gathering in Sydney. Unfortunately our video player went bust so I am handing it over to our President for his comments. Further information will be forthcoming shortly.

CORRESPONDENCE
1 Mr TM Shapter, Hallidays Point. Advising of change of meeting dates for the Mid North Coast Group.
4 Uniting Church Strathfield. Property Users Agreement.
5 National Relay Service. Advertising material.
6 Western Districts Branch. Advising names of widows of past members who wished to become honorary members.
7 Mr Ken Shultz, Manly. Seeking Centrelink information.
8 Commissioner of Taxation. ABN information.
9 Waters Edge function venue. Advertising.
10 Speech Pathology, Australia. Invitation to attend their planned Silent March during Speech Pathology Week in July 2000.
11 Mrs L Dunbabin, Seaforth. Thank you to Lilah Walton for assistance she provided for her mother.
13 Information Australia. Advertising 'Who's Who' and other publications.
14 Centrelink. Community magazine.
15 Newsletters from other Laryngectomee Associations in other States and overseas.
16 Pamphlet 'Emergency Resuscitation for Laryngectomees' put out by the National Association of Laryngectomee Clubs of UK and reprinted by Laryngectomee Association of Victoria.
17 From members with subscriptions, donations, changes of address, payment of accounts etc.

John also related an uplifting story about a young laryngectomee from the Windsor area named Brian Appleby who has managed to go back to playing grade hockey again. Also the fact that there were no reported deaths of any of our members during the past month. Acceptance moved B Darlington, seconded B Dun.

WELFARE OFFICER'S REPORT - In the mail I received a brochure from Australian Communication Exchange about a service called Speech to Speech Relay (SSR) for people with speech impairment. I shall bring all the information to the May meeting but feel that laryngectomees don't require this service but I thought we might ask them (ACE), to speak at a meeting and explain their service in detail.

Bill Byrne's query regarding tablets taken from the free list. Veterans' Affairs told me that your doctor has to ring Veterans' Affairs Pharmaceutical Section on 1800 552 580 and request that tablets be made available. Let me know how you get on, any Vet. People.

Also had another brochure sent regarding an intra-oral voice prosthesis for laryngectomees. Rang a speechie about it and I have sent to the U.S.A. for more information, so more about that later.

As far as I know there haven't been any calls about the two positions that shall be vacant in February 2001 that Tony asked about in our last Newsletter. Out there, there must be somebody under the age of 72 that is able to take on a Secretary or Welfare position. Remember, these positions don't have to be laryngectomees, only the President must be a lary.

I have two lots of 'goodies' sent to me from deceased members' families, for which I thank you. They will be put to good use, in fact some already have.
MINUTES CONTINUED...

With the help of good old Des I have sent patient packs to John Hunter Hospital, Newcastle and John Chaloner. We are still without electricity but by the time this Newsletter is out we will be to the interior paint/papering stage and after that ELECTRICITY, and I vow we will never have a candlelight dinner again.

Norman wishes me to thank all who rang enquiring after his health. (Of course, the home nursing had a lot to do with his recovery).

Bill Byrnes had a fall and injured his kneecap and was, when I last heard, in Auburn Hospital. We all send our best wishes Bill and to any other members who aren’t 101 percent. We send our best wishes.

Keep smiling, Lilah.

SPEECH AIDS CO-ORDINATOR’S REPORT - A fairly quiet month with only a couple of aids lent out. A donation of a Servox and some batteries received from the family of a late member.

The good news is that the cost of the Varta and Eveready batteries we sell for the Servox & Cooper Rand aids should drop post July 2000. We are awaiting advice in June from our supplier.

It was mentioned in the last newsletter that the anti-reflux medication Losec is now off the "free list" - i.e. not covered by the Pharmaceutical Benefits Scheme. My wife and I both used Losec but now we’re on Acimax which is on the PBS. The ingredients are the same, it looks the same, the packaging is the same and it’s made by the same company who also make Losec. No - I don’t understand the health system either but as laryngectomees we’re probably bemused already by our experiences. If you take Losec ask your doctor about Acimax.

The other day a lady asked me about overseas air travel with a laryngectomee - would an 8 hour flight present a problem. I could only relate my experience. In '95 we went to Europe and the return flight was London-Bangkok-Sydney - 2 sectors, each of 11 hours. The air-conditioning on an aircraft is very drying so my wife bought a spray bottle of Evian water. We used this to spray our faces at regular intervals (it dries in moments) and I also sprayed my stoma cover. I still coughed a little more than usual (as you do if your lungs get dry) and I had some crustings around my stoma but it really wasn’t a problem. Apart from that there were no problems that I wouldn’t have had on the ground. It can be quite cold on a flight so if you have circulation problems take some gloves & a scarf and wear warm socks - but don’t take your shoes off. It may be very comfy but your feet will swell and when you put your shoes on for landing it’s agony. If you don’t need oxygen at home you shouldn’t need it on the flight either. However, if you think you may need oxygen, notify the airline in plenty of time. In writing, so they can have the different mask available on your flight - although I think the major airlines carry them as standard and I think the normal mask would be quite adequate anyway. That’s it for the traveller’s tales - enjoy your trip!

GENERAL BUSINESS - Bruce Darlington said that St George Hospital needed a speaker and that he would organise something with Lilah.

Tony and Brian attended a meeting/seminar about the establishment of a Health Consumers’ Network organised by the NSW State Department of Health. The idea sounded promising but it turned out to be a propaganda exercise by Health personnel who left immediately after delivering their spiel. A report or summary of the days proceedings were to have been sent to participants but have never been received. A subsequent report in the newspaper claimed that the figures quoted by the Department were fudged. It could be the case of a good idea in the wrong hands.

Mary Halliburton initiated a short discussion on the state of play regarding the class action against Big Tobacco, presently the claimants are having to pursue their cases individually with Slater & Gordon appealing to the High Court against that decision.

Mary then asked whether the Association could approach Telecom about using a laryngectomee with an alaryngeal voice in one of their advertisements to raise awareness of laryngectomees. Brian Gardner said he would follow up that idea with Telecom.

The next meeting will be on 17th May, 2000.

Meeting closed 11.50 a.m., followed by delicious snacks.

WESTERN DISTRICTS NEWS - April 2000. On 7th March we had a barbecue with the Illawarra group at Woronora Dam and it was very well attended, by approximately 35 people. The day was enjoyed by all who attended and it was agreed that another barbecue be held in September.

The raffle tickets must be returned before the meeting on 9th May as the raffle will be drawn on that day.

As an alternative to our normal meeting in June, because of increased bookings at the Club, the bus has been booked for the second Tuesday in June for an outing to Windsor, Wisemans Ferry and St Albans. A 9 a.m. start from Parramatta Masonic Club is the arrangement.

Unfortunately the company has advised that the bus will be off the road during August to October and therefore other arrangements will need to be made for the barbeques with the Illawarra and Hunter Districts groups.

After the April meeting some 14 members enjoyed lunch and a concert in the Club auditorium.

NORTHERN RIVERS BRANCH - The Northern Rivers Branch held their luncheon meeting at "Ho Ho" restaurant on the 1st of March with nine people in attendance. We welcomed our new speech pathologist to Saint Vincent’s Hospital, Rachel Payne. It was a sad loss to lose Jocelyn Kidd who has been a staunch supporter of our group for the last three to four years.

There has been a few changes to Lismore Health Services. All the laryngectomees patients have been transferred to the Lismore Base Hospital under the care of Karen Wylie, but Karen and Rachel will still be working together, so there shouldn’t be any problems.

Karen Wylie presented us with a "Nu Voice" servox on behalf of the Lismore Base Women's Auxiliary which was greatly appreciated and will be kept as a spare for our members.

It was with sad regret that we lost another one of our members, Frank Dodd. Who passed away on the 6th of February.
WHO DOESN'T REALLY CARE ABOUT CANCER DEATHS?

It appears that the optimistic report in the April Newsletter could be ill-founded. The World Health Organisation approach does not give the impression that they are following an Anti-Tobacco strategy. For a start, Derek Yach, Program Manager for the Tobacco Free Initiative, has recently been given further responsibilities as Executive Director of The Noncommunicable Diseases and Social Change and Mental Health combined cluster.

Now that hearings are underway, tobacco companies and farmers have been invited to submit testimony. Mr Yach has said that the tobacco industry will be interested in rebuilding their crumpled image and that he would be surprised if they weren't interested in sharing information and resisting their use of underhanded lobbying. We cannot hold out much hope of an effective treaty if proceedings are in the charge of a person demonstrating such gullibility as Mr Yach.

Anti-smoking groups are already up in arms because the United States, United Kingdom and Japan, where Philip Morris, British American Tobacco and Japan Tobacco have their headquarters, are taking a fairly weak position on the FCTC. Yet, the US is taking a tough position at home. The US delegation has further shown its colours by calling for a Framework Convention that excludes the most 'controversial' elements, which would limit the effectiveness of preventing the spread of tobacco addiction around the world.

Oronto Douglas of Nigeria said that the tobacco companies are moving shop due to agitation in their home countries and they want third world countries to pay for their total disregard for human rights. Mary Assunta from the Consumer Association of Penang stated the opinion that tobacco corporations shouldn't be allowed to do in foreign countries what they are prohibited from doing at home.

A report, together with the draft Convention, will go to the WHO Assembly in May. If endorsed by the Assembly, the draft Convention text will be referred to a Negotiation Group which is not expected to start work formally until the end of October.

FLU VACCINATION

Now is the time to talk to your Doctor about flu vaccine. It is strongly recommended for those over 65 and is available free of charge to pensioners. The best time to be vaccinated is in autumn.

For most people influenza is a moderately severe illness but the dangers of flu are the complications. The most common complication after flu is pneumonia (infection in the lungs). It can also worsen heart conditions, asthma, chronic bronchitis, diabetes and kidney disease by making a weak body work harder. People with lasting health problems such as these, people over 65 years of age, and anyone undergoing treatment that may suppress their immune system are advised to have flu vaccine.

VAPORISERS

If you haven't already got one, it may be a good idea to buy a vapouriser (about $30 from your chemist) for use during winter. Regular use of a vapouriser will help stop your stoma from drying out. A vapouriser can also be borrowed from Lilah Walton, her contact number is on the front page of this Newsletter.

If you don't want to use a vapouriser, you can use steam. Just boil some water, put it into a warmed up dish or bowl, cover your head and the bowl with a towel and inhale the steam.

Regular use of radiators or heaters in winter can dry the air, and your stoma and skin. To counteract this dryness, simply keep a bowl of water in the room where you use your heater. This will help to replace moisture in the air.

In America a company named Kaz has come up with a portable humidifier that is ultrasonic rather than steam or evaporative and will work off 110 or 220 current, so it can be used all over the world. Apparently, it can use any standard plastic bottle which means you don't have to carry the water with you on a trip but buy it at your destination. It will probably run to around $100 when it arrives in Australia but could prove very useful.

NEXT MEETING

The next meeting for the Laryngectomy Association of NSW will be held on Wednesday, 17th May, at the Uniting Church Hall, Carrington Avenue, Strathfield, at 11 am.

There is parking on site and it is also a short walk from the Railway Station.

The meeting will be followed by a light luncheon.

Laryngectomees, Friends, Families, Professionals all WELCOME.
ARE CIGARS SAFER?...........READ ON

Cigar aficionados tend to rave about their preferred smoke. They treat their cigars the same way wine buffs do with their favourite tipple; humidifiers, special cutters and other smoking paraphernalia, they write poems and songs about them.

Rudyard Kipling wrote:
"Open the old cigar-box - let me consider anew -
Old friends, and who is Maggie that I should abandon you?
A million surplus Maggies are willing to bear the yoke;
And a woman is only a woman, but a good cigar is a Smoke."

However, it has been confirmed that cigars are not the mild mannered less harmful relatives of cigarettes that has been claimed. Cigar smoking increases your risk of cancer of the mouth, throat and lung, heart disease and chronic obstructive pulmonary disease.

Cigar smokers have about twice the risk of cancer of the mouth, throat and lung plus one and a half times the risk of getting any smoking related cancer as a non-smoker. Drinking alcohol increases susceptibility to mouth and throat cancers for cigar smokers.

David Satcher, the US Surgeon General suggested that measures used against cigarette smoking such as heavier taxes, health warning labels, public education and law enforcement be employed against cigars also. He said that all tobacco, including tobacco in cigars, is hazardous not only to those who use it, but also to society.

Apparently cigar smoking is increasing in popularity, especially among yuppies but also women and teenagers. The increase in cigar smoking is fueled by a perception that cigars are safer than cigarettes. This is a complete myth as cigar smoke contains the same toxic and carcinogenic chemicals as cigarette smoke. In fact, the main intake of smoke from a cigar has heavier concentrations of chemicals than that from a cigarette.

EUREKA "ARTIFICIAL LARYNX" PROJECT

The Rijksuniversiteit in Groningen, Holland is developing a totally implantable artificial larynx prosthesis. The artificial larynx will sit on top of the trachea and an interface that will firmly fix the artificial larynx to the trachea is being developed. The artificial larynx will be connected to the interface by magnets. If the artificial larynx fails then the patient will be able to push it free for removal.

On top of the artificial larynx are the valves. Like a natural larynx, the artificial one will be covered by an epiglottis to stop food and drink from going down the wrong way when swallowing. They will use the patient’s muscles that are involved in swallowing to control the epiglottis and if that is unsuccessful they will develop a mechanical epiglottis, driven by pressure or inertia. The artificial epiglottis is to be made from materials that are resistant to candida and other fungal infections.

Here is where it gets even more complicated. There will be another valve mechanism that makes it possible to choose between breathing and speaking. To speak, a firm outflow of air, as in the Blom-Singer hands-free valve, will be produced to close a valve. The air will be forced through artificial vocal chords which will have an adjustable pitch, enabling an individual voice for each patient. During coughing, the valve and valve housing will release.

This is not solely a Dutch project as medical and technical input has been received from research institutes in Italy, Germany and the Czech Republic. The situation for laryngectomees is not at all static and our future prospects look very bright in the not too distant future.

This Newsletter printed by:

BREAKOUT
Design & Print,
19 Buckland Street, Broadway
Phone (02) 9281 5100
STATEs TAKE ON TOBACCO COYS

The first collective lawsuit against the tobacco industry is being filed by 2,000 people with cancer of the larynx. Reuters

OH, WHAT A COST!

This poem is from the ANAMEMO newsletter.

From Join Together - http://www.jointogether.org

ON THE SHORES OF THE

LEGAL ADVICE FOR WOMEN

Your Association has received a questionnaire and brochure from the Women's Legal Resource Centre, based in Lismore. They provide FREE legal advice to women in particular women with a disability, Aboriginal and Torres Strait Islander, non-English speaking women and women from a working party to consider options for taking joint action against tobacco companies. Although the solicitor was not a participant in any active patient is available to assist the working party, the Federal Government did not intend being against tobacco companies. The Federal Government was not at the meeting. The laws will be filed on May 31 to coincide with an international anti-smoking day. Nine groups representing smokers and ex-smokers are filing the lawsuit. Two law offices leading the effort hope an additional 3,000 victims join the suit.

A hard lesson learned, and my voice was lost.

My payment for sins of my terrible addiction.

I was diagnosed with cancer, and broke down in tears

A round vicious circle, for thirty nine years.

I felt so guilty, and so full of shame

With only myself to carry the blame.

The cancer to battle, was my conviction

I'd sneak and I'd lie, and steal for a smoke.

And suck down the cigarettes until I was broke

So my stealing and thievery, became my trend

I'd smoke and I'd hide, and smoke where I hid.

No money for cigarettes, and no allowance to spend.

When I was a child, and just a little kid

The lawsuit will be filed on May 31 to coincide with an international anti-smoking day. Nine groups representing smokers and ex-smokers are filing the lawsuit. Two law offices leading the effort hope an additional 3,000 victims join the suit.

This follows the success of US States in forcing big tobacco to pay $250 billion over 25 years. Evidence shows an estimated 675,000 Australians have died from smoking-related diseases in the past 25 years and health care costing billions of dollars a year.

 Accord to the Spanish Health Ministry, an estimated 40,000 people live in Spain die each year from the effects of smoking.
POSITIONS VACANT

It seems that this could be a crisis year for your Association. At the end of this year John Nicholson will cease to be our Secretary, a position that he has filled ever since I have been a member and doing too good a job of it maybe, in that it seems to have scared off anyone else who might have considered taking it on.

If you think you can perform this function for the Association, why not give John a call to find out all the details of what the position entails and how you could manage to take it over next year.

The same problem applies to the Welfare Officer role. Lilah Walton had wanted to retire this year but reluctantly continued for one last year. Lilah has suggested that anyone who may consider taking over the Welfare Officer position might like to ease themselves into it by working with her for a couple of months or so, thereby establishing contacts with essential people and organisations.

This may seem early days yet but time certainly flies and it will be next year before we know it. So anyone reading this Newsletter, (remember you don’t have to be a laryngectomee to serve on the committee), who has the time and/or inclination to fill one of these roles, please speak up sooner rather than later.

A.T. Krasnodebski

WHO TO CONTACT

FOR BLIND/ SINGER SUPPLIES - David Smith, 27 Bellevue Pde, North Curl Curl 2099 Phone 02-9939-1539
FOR SPEECH AIDS, BATTERIES PARTS AND ADVICE ON REPAIRS - John Chaloner, 111 Station Street, Petersham 2049 Phone 02-9560-2852
FOR STOMA COVERS, SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS - Lilah Walton, 23 Baker Street, KENSINGTON 2033 Phone 02-9669-2550
FOR ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME - Cancer Council of NSW 153 Dowling Street, WOOLLOOMOOO, PO Box 572, Phone 02-9334-1900, Fax: 02-9337-2676
MINUTES OF THE MARCH OF NSW, HELD IN THE
UNITING MEETING OF THE LARYNGECTOMEES
ASSOCIATION CHURCH HALL, STRATHFIELD ON
WEDNESDAY 15TH MARCH 2000.

PRESENT - P Hallburton, N Bluett, J Knight,
A Krasnodebskii, A Szanyi, P Rodgers, J Gifford,
W Byrne, R Green, B Darlington, B Gardner, J Nowland,
L Walton, M Hallburton, J Bluett, Helene, M Silver,
C Gardner, F Green, B Dun.

APOLOGIES - Des and John Nicholson

THE VICE PRESIDENT Bill Byrne opened the meeting as
the President was held up by a serious traffic accident.
Brian arrived shortly after the meeting began and
assumed the chair on a very humid and damp day. He
made welcome two new members, Russ and Faith Green
of Collaroy.

Minutes of the last meeting held in February 2000 were
accepted on the motion of Lilah Walton, and seconded
by Jo Nowland.

SECRETARY/TREASURER’S REPORT - was read by
Lilah Walton in the absence of John Nicholson:
I have an appointment with a vascular surgeon today
(legs giving me trouble) so will have to miss my first
meeting. Hopefully I’ll be back for the April meeting.

PUBLIC LIABILITY INSURANCE
I have arranged for our brokers to have included in our
Public Liability insurance cover all the branches of our
Association so they need not take out their own cover
from now on. The cover is for existing branches and
“any other Branch declared from time to time”. Our poli-
cy is with CGU Insurance Ltd. and the Policy No. is
10M7613584 - the cover is $5,000,000 and it expires on

MEMBERSHIP
On behalf of the committee may I welcome the following
new members and extend to them an open invitation to
attend one of our or our branch meetings:
Mr Aisake Nawaikula, Merrylands. (Aisake is from Fiji and
he will be returning to Fiji towards the end of April)
Mr Russell Green, Collaroy.

The Newsletter addressed to Mr Clint Paull of 41 Karloo
Road, Umina was returned “unknown at this address” so
if anyone knows of Mr Paull’s new address would they
please let me know.

NEWSLETTER
I would like to congratulate Tony Krasnodebskii on his
first Newsletter. I thought was well presented and that
it contained the sort of information that would interest
laryngectomees and their spouses. Tony, thank you for
taking on the job of Editor.

SHOWER SHIELDS
The shower shields we ordered from the USA in early
December 1999 never arrived so the suppliers, Med
Mart, have advised they have sent to us air mail, a repeat
of the original consignment and they should arrive by the
time this Newsletter is printed.

CORRESPONDENCE
1 Mr Jack Darby, Glendon. Payment for material.
2 Centre for Grief Education. Future meetings.
4 Elizabeth Galvine, Speech Pathologist, Tamworth
Seeking information on laryngectomees.
5 Mrs Mary McIntyre, Penrith. Payment for stoma
covers and thank you letter.
6 IDEAS. Information on Disability, Equipment and
Access Services - Advertising literature.
7 Centrelink. Pamphlets.
8 University of NSW. Advertising Executive
Presentations at a fee of $2785 for 3 day course.
9 Medmart, USA. Fax advising they are forwarding,
air mail, a replacement consignment of shower
shields. Replacing original missing consignment.
10 Anti Discrimination Board. Newsletter.
11 Commonwealth Ombudsman. Advertising their roles.
12 Cancer Council of NSW. Seeking donations.
15 Mrs Jo Nowland. Donation of $25.
16 Newsletters from inner and inter state associations.

Moved by Pat Hallburton, seconded by Brian Gardner

WELFARE OFFICER’S REPORT
Because of our house repairs (Due to hail damage last
April) I am still passing sewing orders to Des
Nicholson.

I wrote to Alison Marshall (Secretary of Tasmanian
Laryngectomee Association) regarding a lady from
Hobart who was operated on in Sydney. Alison’s reply
was a repeat of our problems in that nobody wants to
stand for office bearer. The Tasmanian state membership
is only 22.

Have been receiving, and because of my great knowledge
and modesty, answering many varied questions. For
example, John Nicholson had a birthday on March 13th.
We all wish him and Alan Dawson, who has a birthday in
April, many happy returns.

Keep your stoma covered as days are so changeable
and we don’t want anybody sick. Phone still working if
you want assistance. - Lilah.

Moved by Bruce Darlington, seconded by Noel Bluett
Due to the absence of John Chaloner there was no
Speech Aids Co-ordinator’s Report.

GENERAL BUSINESS - A letter has been received from
Illawarra District saying that they are aware they were not
an affiliated branch and therefore were not covered by our
insurance.

Bill Byrne brought to our attention the fact that some
tablets are now off the free list, including Losec, used for
reflux. A possible solution being that some drugs are now
being manufactured by a different drug company and
therefore now known by another name. Lilah will contact
the Repatriation Department and check.

A new Health Consumers’ Network, funded by NSW
Health, will hold a meeting in Sydney on Monday 27th
March to determine the future directions of consumer
participation. There should be a report on the meeting in
next month’s Newsletter.
MINUTES CONTINUED...

The President moved that our news editor have the go ahead to go on the internet and later establish our own website, initial cost to be $174.00.

Apparently there was an enthusiastic turnout at the Western Suburbs and Illawarra Branches picnic at Woronora Dam.

A suggestion was made that we might change the name of the Newsletter to something that would stand out and be noticed, particularly on the internet, next month’s Newsletter will be asking for suggestions for a new name.

Next meeting will be 19th April, 2000.

Meeting closed 12.10 p.m., followed by a light lunch.

LETTERS TO THE EDITOR

I have received a letter from Alan Dawson, ex-President of the Association, who writes in praise of the efforts that Des Nicholson has made and continues to make on behalf of our Association. I am sure the whole membership endorses the sentiments that are reproduced here in full:

Dear Tony,

Would you please print the following thanks to Des Nicholson in the next Newsletter.

On behalf of all members I would like to thank Des Nicholson for all the work she has done for laryngectomees. Not only has she been our Editor since the death of Alan Dear but has helped Lilah Walton and even filled in, with the help of husband John, during Lilah’s problems in the last twelve months.

Sincere thanks Des for a job well done. As you have indicated you would help out when possible in the future we also say thank you for that thought. Wishing you health and happiness for the future.

Yours sincerely,

Alan Dawson

ELECTROLARYNX USERS

A TIP FROM HEADLINES

When you are going to be doing work that might get your hands messy, such as working on a car, gardening, chopping onions or kneading dough, slip the electrolarynx into a very thin plastic sandwich bag or wrap it in Gladwrap.

You can pick it up with greasy or oniony hands and talk just as you usually do. Just throw away the bag when you are finished.

CENTRELINK LEAFLETS

John Nicholson advises that he has received the latest Pensioner Concession Card and Health Care Card leaflets. These are comprehensive guides to concessions available from Centrelink in NSW in the year 2000.

If you would like a copy of these leaflets contact John and he will be able to send them to you.
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Meeting closed 12.10 p.m., followed by a light lunch.

LETTERS TO THE EDITOR

I have received a letter from Alan Dawson, ex-President of the Association, who writes in praise of the efforts that Des Nicholson has made and continues to make on behalf of our Association. I am sure the whole membership endorses the sentiments that are reproduced here in full:

Dear Tony,

Would you please print the following thanks to Des Nicholson in the next Newsletter.

On behalf of all members I would like to thank Des Nicholson for all the work she has done for laryngectomees. Not only has she been our Editor since the death of Alan Dear but has helped Lilah Walton and even filled in, with the help of husband John, during Lilah’s problems in the last twelve months.

Sincere thanks Des for a job well done. As you have indicated you would help out when possible in the future we also say thank you for that thought. Wishing you health and happiness for the future.

Yours sincerely,

Alan Dawson

ELECTROLARYNX USERS

A TIP FROM HEADLINES

When you are going to be doing work that might get your hands messy, such as working on a car, gardening, chopping onions or kneading dough, slip the electrolarynx into a very thin plastic sandwich bag or wrap it in Gladwrap.

You can pick it up with greasy or oniony hands and talk just as you usually do. Just throw away the bag when you are finished.

CENTRELINK LEAFLETS

John Nicholson advises that he has received the latest Pensioner Concession Card and Health Care Card leaflets. These are comprehensive guides to concessions available from Centrelink in NSW in the year 2000.

If you would like a copy of these leaflets, contact John and he will be able to send them to you.
WHO Wants to Reduce Cancer

Last October in Geneva, the World Health Organization hosted negotiations for a Framework Convention on Tobacco Control (FCTC). This is the first time that WHO has used its constitutional mandate in creating an international convention.

The FCTC will bind Member States to clamp down on the global spread of tobacco products. However, it is a complicated process forming an international treaty on tobacco as it raises economic and political issues, as well as health issues, which many countries will have difficulties in coming to grips with. It is hoped that the FCTC will be finalised by May 2003.

Australia, a tobacco producer itself, strongly supports the development of the FCTC in whatever form it takes as it will be useful in supporting countries in their domestic tobacco control agendas.

Let’s hope that having the WHO on board in the fight against tobacco usage and in reducing the incidence of smoking related cancers, the day will not be too far off when the hold of Big Tobacco is loosened and the number of smokers and the consumption of cigarettes starts to go down rather than continually rising.

Shower Shield Repair

Do you have a Medmart Shower Shield that has come to the end of it’s usefulness because the velcro is no longer holding while you take your shower?

If the stoma guard is still in good condition then rather than buy a new Shower Shield, consider replacing the velcro.

Buy a length of 20mm wide velcro from a sewing shop or department store. Carefully unpick the old velcro from the Shower Shield. Cut lengths of new velcro to match the discarded pieces. Stick the new velcro in place on the Shower Shield and hand sew through the holes left from the previous cotton.

There, you have a new Shower Shield, or as good as new.

NEXT MEETING

The next meeting for the Laryngectomy Association of NSW will be held on Wednesday, 19th April, at the Uniting Church Hall, Carrington Avenue, Strathfield, at 11 am.

There is parking on site and it is also a short walk from the Railway Station.

The meeting will be followed by a light luncheon.

Laryngectomees, Friends, Families, Professionals all WELCOME.

CLASS ACTION

On March 13th, the Full Bench of the Federal Court threw out the class action against Big Tobacco that is being conducted by Slater and Gordon on behalf of six people suffering from lung cancer.

The court has determined that a class action is not appropriate in cases such as this. Henceforth Slater and Gordon will pursue the claims on an individual basis for the four surviving claimants, pending an appeal to the High Court.

Two claimants, Mr Michael Nixon and Mr Gregory Durkin, died last year after having given evidence for the class action.

Their claim is that they continued smoking because the companies marketed cigarettes as a fashionable and pleasant thing to do, meanwhile denying that there was any evidence to prove that nicotine was addictive.

The claimants were ordered to pay costs.

VALE

With deep regret we have to report that one of our members has passed away.

MHR Scullion of Kensington

We extend our sincere condolences to his family and friends.
WHO Wants to Reduce Cancer

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Their claim is that they continued smoking because the companies marketed cigarettes as a fashionable and pleasant thing to do, meanwhile denying that there was any evidence to prove that nicotine was addictive.

The claimants were ordered to pay costs.

VALE

It is with sadness that I have to report that one of our members has passed away: Mr R Scabhill of Kensington. We extend our sincere condolences to his family and friends.
Tobacco Wars

A man by the name of Banzaf told of how TV advertising rules meant that if the tobacco industry were allowed to make promotional and lifestyle ads then equal time had to be allowed to groups to advertise the opposite message. Eventually TV advertising for cigarettes was outlawed, yet the incidence of cigarette consumption continued to rise.

A person who was making an impact on the tobacco companies was the Health Secretary in the Jimmy Carter administration, a man named Califano. He was making such an impact on the tobacco industry that they brought pressure to bear on Jimmy Carter's re-election campaign and the fact that Jimmy Carter was from the southern, tobacco growing and cigarette manufacturing States meant that Califano was promptly dropped from the Carter team.

An interesting aside was covered in week two of the series. The makers of Chesterfield cigarettes, Ligget & Myers, were involved in a secret project looking for a cancer free cigarette. Apparently they discovered that the addition of the metal palladium to the manufacture of cigarettes resulted in fewer cancers in mice. In amongst all the other additives in cigarette tobacco a little palladium would hardly be noticed.

Anyway, they were all set to test market the new cancer free cigarette under the name of Epic when the other tobacco companies got wind of it. The upshot being that the whole project was cancelled because if Ligget & Myers were to produce a safe cigarette then that would be an admission that other cigarettes were not safe. Nothing more was heard of Epic.

The program attempted to demonstrate that Big Tobacco was recruiting young thirteen and fourteen year olds to become smokers to replace the older ones that were dying from smoking related disease. In early 1980 R J Reynolds' Winston Man - Dave Geritz used his macho image to encourage young boys to smoke. Joe Camel was also very successful in raising the consumption levels among children from 1% being Camel smokers up to 13%.

Marlboro researchers working for Phillip Morris discovered that nicotine addiction was a biological process and observed that rats were mimicking people in their manner of acquiring their regular nicotine fixes through the day. A researcher on this project was summoned before the Phillip Morris president and told to withdraw the results of his research from publication. He was ordered to destroy the evidence of his findings but managed to keep some documents.

A US Surgeon General, C Everett Koop stated that nicotine was just as addictive as cocaine or heroin.

There was a short interview with a laryngectomee named Debi Austin who was still smoking cigarettes through her stoma to satisfy her nicotine craving.

It would seem that the tide has turned in the war against the tobacco companies. Merrell Williams stole documents from Brown and Williamson, a subsidiary of BAT at the same time that the Chief Executive Officers of Big Tobacco were perjuring themselves before Congress by saying that they didn't believe that nicotine was addictive. Dr Barrett was pursuing a vendetta against Big Tobacco and joined forces with Dickie Scruggs. Michael Moore in Mississippi took on the case of suing Big Tobacco for the cost of health care for smoking victims using Jeffrey Wigand, subject of the film "The Insider", as a witness. Big Tobacco sued the University of California library for the return of stolen documents but lost and that information has now been posted on the internet. A group of States in the US have received a payout of $206 Billion for healthcare over a period of years and an ex-air hostess named Norma Brook sued over getting cancer through passive smoking in her work. She received a payout of $300,000,000 yet Big Tobacco refused to officially accept responsibility.

Some American States are taking things more seriously than others. For example Florida has formed smokers courts and children under the age of eighteen can be fined or face community service if caught smoking. California has smoking police who raid bars and have powers to fine people $75 if caught smoking in a public place. Britain on the other hand seems to be falling behind as a recent survey indicates that 1 in 3 fifteen year old girls smoke regularly. Big Tobacco is now diverting it's attention from the developed countries and is targeting young smokers in third world countries.
RECIPE FOR SOYA LOAF
INGREDIENTS:
1 HEAPED CUP OF SOY BEAN FLOUR
1 CUP BREADCRUMBS
1 TIN TOMATO SOUP ( OR HALF SOUP & HALF MILK OR WATER )
2 EGGS
1 FINELY CHOPPED ONION
3 TABLESPOONS OIL
1 TABLESPOON SOY SAUCE
HALF TEASPOON SALT
MIX EVERYTHING TOGETHER AND BEAT WITH AN EGG-BEATER UNTIL SMOOTH.
POUR INTO AN OILED DISH AND BAKE IN A HOT OVEN FOR ONE HOUR. GRATED
CHEESE AND/OR SLICED TOMATO CAN BE USED FOR A DECORATIVE TOPPING.

And finishing on a light hearted note . . . .

When God made man she was only practising!
A husband, proving to his wife that women talk more
than men, showed her a study which indicated that
men use on the average only 15,000 words a day,
whereas women use 30,000 words a day.
She thought about this for a while and then told her
husband that women use twice as many words as
men because they have to
repeat everything they say.
Looking stunned, he said
"What?"
Light travels faster than
sound . . . . This is why
some people appear
bright until you hear
them speak.
To be upset over what you
don't have - is to waste
what you do have!
The most difficult secret for
a man to keep is his opin-
on of himself.

COOKING OILS
When choosing an oil for
cooking, olive and canola oils
are recommended. Their high
ratio of monounsaturated fat
seems to have a beneficial effect
on cholesterol levels in your
blood, slightly lowering the 'bad'
(LDL) cholesterol, and slightly
raising the 'good' (HDL).
Canola is mostly monounsatu-
rated fat (62%), with the rest
being polyunsaturated. Olive
oil is higher in monounsaturated
fat (72%) but has 17% saturated fat.
Each oil has it's own benefits.
Some people love the flavour of
olive oil and never use anything
else. Many nutritionists claim
that the range of antioxidants
it contains may be just as
important as the type of fat.
Canola oil, meanwhile, has the
added benefit of containing
linolenic acid. When you eat
foods with linolenic acid, your
liver converts a little of it into
'EPA' and 'DHA'. These are fatty
acids found in fish oil that help
prevent blood clotting, and cut
the risk of heart attacks.
This information was extracted from
Health Yourself Newsletter.

In olden days sacrifices
were made at the altar -
a practice which is still
continued!
Gossiping on the phone
with your girlfriends for ten
minutes will firm up the jaw
and chin and is far better
than plastic surgery
- Dr Jane Curtin

Never be afraid to try
something new:
Remember . . . . Amateurs
built the ark. Professionals
built the Titanic!
MONTHLY MEETINGS:

#SYDNEY: Third Wednesday 11am at Uniting Church Hall, Carrington Ave, STRATHFIELD.

#HUNTER VALLEY: Third Tuesday, at Mayfield Bowling Club, Ingall St, Mayfield.

#PARRAMATTA: Second Tuesday, 11.00am at Masonic Club, 183 George St, Parramatta.

#ILLAWARRA: Third Wednesday, 2.30pm at Warilla Medical Centre, Belfast St, Warilla.

#NORTHERN RIVERS: 4 times per year, rotating venue, Contact J Kidd, PO Box 572, Lismore.

#MID NORTH COAST: First Tuesday, 1.30pm at Staff Centre, Manning Base Hospital, Tarcoo.

#DUBBO: Lourdes Hospital First Friday, 10.30am, Conference Room.

#ALBURY: Ph. 02-6323 2011, extn. 323.

#CANBERRA: First Thurs, 11am, Level 1, Bldg 3, Canberra Hosp.

#SOUTHERN DISTRICTS: 4th Wed. 5.00pm, Thomas Rachel Moore Education Centre, Liverpool Hosp. Ph. 02-9607 6708.

OFFICE BEARERS 1999

President: Brian Gardner, 4 Marellyn Rd, BELROSE, 2085. Ph. 92-9462 2858
Vice Presidents: Bill Byrne, 422 Guildford Rd, GUILDFORD. John Chaloner
(see below)
Secretary/Treasurer: John Nicholson, MBE, PO Box 58, RICHMOND, 2753. Ph. 62-4678 9111
Minute Secretary: Mrs Margaret Silver, 69 Spencer Rd, KILLARA, 2071.
02-9488 4490
Speech Aids Co-ordinator: John Chaloner, 111 Station St. PETERSHAM 2049.
02-9560 2852
Welfare Officer: Mrs Lilah Walton, O.A.M., 22 Baker St, KENSINGTON, 2033.
02-9603 2650
Editor: Tony Krasnodebski
moving house.
Committee: Bruce Darlington, 5 Alexander St, ARNCLIFFE, 2200. 02-9560 2650.
Pat Halliburton, 94 Caren Drive, CARLINGFORD, 2118. 02-9571 8690.
Marilyn Ploeges, 7 Tyran C1, BLUFF POINT, 2262.

A FRESH START FOR THE NEW MILLENNIUM

Hello everyone. I have taken on the job of editing our newsletter. I hope to be able to continue as seamlessly as Des Nicholson managed when she took over the editorship upon the untimely death of Alan Dear.

I have been a laryngectomee now since May 1992 and a member of the Association since July of the same year. During this time I have gained a lot of help and support from the members of the Association and the monthly Newsletter.

I don’t expect that it will be too far in the future before the Laryngectomee Association goes online with a website of our own with links to other Associations and sites that could prove beneficial to members and I hope to at least start that process. In the meantime I will endeavour to bring you news of any innovations that may benefit Laryngectomees. Provide news of the Association and branches. Act as an information exchange for members and their families.

At the same time I hope that introducing my own style to the Newsletter will meet with your approval. Feel free to write to me with any criticisms or suggestions care of my address or the secretary’s address.

A.T. Krasnodebski

WHO TO CONTACT

FOR BLOM-SINGER SUPPLIES - David Smith, 27 Bellevue Pde, North Curl Curl 2099.
Phone 92-9560-1500

FOR SPEECH AIDS, BATTERIES PARTS AND ADVICE ON REPAIRS - John Chaloner, 111 Station Street, Petersham 2049
Phone: 92-9560-2852

REPAIRS - John Chaloner, 111 Station Street, Petersham 2049
Phone: 92-9560-2852

FOR STOMA COVERS, SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS - Lila Walton, 23 Baker St, KENSINGTON 2033.
Phone: 92-9603-2550

FOR ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME - Cancer Council of NSW 153 Dowling Street, WOOLLONGOO, PO Box 572, Phone 92-9334-1900.
Fax: 92-9357-2876
MINUTES OF THE 43rd ANNUAL GENERAL MEETING OF THE LARYNGECTOMEES ASSOCIATION OF NSW, HELD IN THE UNITING CHURCH HALL, STRATHFIELD ON WEDNESDAY 16TH FEBRUARY 2000


APOLOGIES - were received from P. Rodgers and E. Lindsay.

THE PRESIDENT Brian Gardner in the Chair welcomed members on a lovely summers day and opened the meeting at 11 a.m.

MINUTES of the 1999 Annual General Meeting as distributed in the Newsletter in March 1999 were accepted on the motion of Lilah Walton and seconded by Pat Halliburton.

BUSINESS ARISING - There was no business arising out of these minutes.

SPEECH AIDS CO-ORDINATOR'S REPORT
During 1999 your Association supplied 30 batteries, being 24 Varita and 6 Eveready, to our members at a reduced price. Also provided, a loan speech aid on 30 occasions, being 13 Servox, 12 Nu-VOIs and 5 Cooper Rand. Moved by Lilah Walton, seconded by Brian Gardner.

ELECTION OF OFFICERS - As there was only one nomination for each position there was no need for a ballot and all committee members were elected unopposed. The names of the 2000 committee are recorded on the front page of this Newsletter. Further to discussion last October it was agreed that part of the membership fees be allocated to the local Branch to which a member belongs. Renewals will be paid to the parent body as normal with 25% being passed on to the local Branch nominated. Moved by Des Nicholson, seconded by Bruce Darlington.

Copies of the AGM will be sent to the Branch secretaries. There being no further business the President closed the Annual General Meeting.

SPEECH AIDS CO-ORDINATOR'S REPORT
The last couple of months have been quiet for battery and speech aids supplies, but not for hospital visits. Our thanks go to the family of our late member John Thompson, from Amciffe, for the donation of his speech aid and equipment.

SECRETARY/TREASURER'S REPORT
MEMBERSHIP
Although most members have paid their subscription for this year there are still a few that have not sent their sub. for 2000. It would be pleasing to receive these outstanding subs. as soon as possible.

On behalf of the committee may I welcome the following new members and hope that they will be able to come to our meetings or the meetings of one of the branches:

Ms Kristen Farrell, Speech Pathologist, Canowindra.
Ms Louise Williams, Speech Pathologist, Lourdes Hosp. Dubbo.
Mr Clive Paull, Umina.
Ms Angela Firth, Speech Pathologist, Rehab. Centre, Bathurst.
Mrs V. Caruana, Miranda.
Ms S. Haerse, Bulga.
Mr Steve Rosser, Kelso.
Mr John Garisyn, Belrose.
Mr Alfred Draper, Eulalong.
Mr R.J. Adair, Bathurst.
Mr Ken Shultz, Manly.

Newsletters sent to the following members have been returned endorsed ' not at this address ' so if anyone knows their present address would they please let me know:

Mr Arthur Garland of Greenacre.
Mr Ray Ditterick of East Botany.
Mr W.D. Evans of Burwood.

GOVERNMENT REGULATION
To comply with the requirements of the Department of Fair Trading I would like to move - " That all office bearers of the Association be authorised to sign on behalf of the Association those forms required by the Department of Fair Trading and the Chief Secretary's Department."

DONATIONS
Several members have forwarded donations and we thank them for their generosity. A list of those donors will be in the next Newsletter.

CORRESPONDENCE
1 Mr Pat Halliburton. Explaining he cannot accept nomination as Treasurer.
2 Mrs Elizabeth Lindsay. Expressing thanks for messages of sympathy received concerning death of her husband, Allan.
3 Mrs Jo Nowland. Donations.
4 Directory of Australian Associations. Seeking update on our Association.
5 Mr E.E. Martin of Belmont North. Seeking info on stoma covers.
6 Illawarra Laryngectomee Assoc. Christmas greetings.
7 St Vincents Hospital. Seeking copy of ' Smooth as Silk ' booklet.
MINUTES

8 Mr Eric Smith of Chatswood. Sub. and Christmas greetings.
9 Charities Bulletin.
10 Mr E.E. Martin of Belmont North. Payment for batteries and Christmas greetings.
11 Mr John Chaloner. Report on loan of voice aid to Mr Keith Holstein.
14 Mr Bill Pattison of Hamilton. Seeking replacement membership card.
16 Mr John Chaloner. Stocktake for 1999.
17 Mr L.P. McIntyre of Penrith. Stoma cover details.
18 Ms S. Haerse of Bulga. Seeking stoma covers.
19 Mr John Ryan of Villawood. Seeking stoma covers.
20 Arncliffe Uniting Church Friendship Centre. Donation of $70.
22 Mr Chris Bowman of Glendale. Advising of death of Mr D.R. McDonald.
23 Mr Don Vowles of Ermington. Donation.
24 Mr K. Weinert of Pelican. Payment for supplies.
25 Mr P.H. Lloyd of Parramatta. Payment for supplies.
26 Mr John Gifford of Seaforth. Sub. and Christmas greetings.
27 J & M Clyne of Bellevue Hill. Sub. and Donation and Christmas greetings.
28 Mr R. Adair of Darling Point. Seeking stoma covers.
29 Margaret Lydon of Salt Ash. Payment for material.
30 Mr P. Brooks of Miranda. Seeking shower shields and wishing all a merry Christmas.
31 Newsletters from overseas and other states.

WELFARE OFFICERS REPORT
Trust you all had a happy Christmas and New Year. I was fortunate/unfortunate to break my right arm, and for the first time in 51 years I didn't cook Christmas dinner. I was amazed at the amount of people (while I had my arm in plaster) who opened doors for me and helped me up and down steps. I have decided that in future when we are going to something and there will be a crowd, I will put my arm in a sling.

I spoke to an ex-president a few weeks ago and asked why he doesn't attend Laryngectomee Association meetings. He told me he didn't like how it was being run but he wouldn't elaborate. Isn't this what the meetings are all about? If you don't like something or know how to improve something.....SPEAK UP.

Julie August rang me to tell me that Doug has been in hospital and hasn't been 100%, but was slowly improving. We all send our best wishes to you Doug and hope to see you soon. You were missed at the Christmas party and Jean Case's girls send their regards.

Michael Jordan and staff from Pacific Medical delivered to me a beautiful basket of Christmas goodies. Because it was after our party I took it to Western Districts' party and Stan Morley allowed me to sell tickets and we went halves in the proceeds. Thanks Pacific Medical.

I also had a phone call from Marisa Toscano of the NSW Cancer Council, wanting to know if I had any Laryngectomee books in different languages as they are now including information on Laryngectomees. I am not sure of the exact details, but Marisa is coming to one of our meetings. I have posted my books to her.

Have sent hospital packs to R.N.S., R.P.A., Bruce Darlington and John Chaloner.

I wish to thank Des Nicholson for doing so much of my work. I really did appreciate it Des.

I wrote to Jack Darby (who makes our yearly raffle) to find out his products and prices so anybody wishing to purchase anything can deal directly with Jack.

Hope everyone is bursting with good health......Lilah Walton.

Moved by Brian Gardner, seconded by Margaret Silver.

GOVERNMENT REGULATIONS - To comply with the requirements of the Department of Fair Trading, Secretary John Nicholson moved "That all office bearers of the Association be authorised to sign on behalf of the Association those forms required by the Department of Fair Trading and the Chief Secretary's Department". Seconded by Lilah Walton.

GENERAL BUSINESS - Information regarding Identity Bracelets called Medic Alerts is available. Contact Welfare Officer for further details.

Following the article in the December 1999 Newsletter regarding the training of Ambulance Officers in dealing with Laryngectomee patients, there is now a monthly course available. More information will later be available. This is good news.

It was moved that the September 2000 meeting be cancelled as the Olympics will be on at that time. All were in favour.

President Brian Gardner has indicated that he will be attending some country meetings and anyone interested is welcome to join him. For further details contact Brian Gardner.

Bill Byfield has indicated that he is available for hospital visiting on the Central Coast where he already visits other Cancer patients. Margaret Patterson has organised a new course for hospital visitors at Royal North Shore Hospital commencing 28th February over four Mondays.

Keep in mind Tuesday, 7th March. Western Districts and Illawarra Branches are holding a picnic at Woronora Dam.

Next meeting is on Wednesday 15th March, 2000.

Meeting closed at 12.10 p.m. when refreshments were served.

She said - "Say another word and I'll go home to my mother!" He said - "Taxi!"

-Norm Walton
INTERNET SITES

Looking on the internet the other day I came across a very informative site for all diseases and ailments. In particular, I was impressed with their treatment on the subject of Larynx Cancer.

The article gave very detailed yet easy to understand answers to the following questions:

What is the larynx? What is cancer? What causes cancer of the larynx? What are symptoms of cancer of the larynx? How is cancer of the larynx diagnosed? What are treatment options for cancer of the larynx? What are the side effects of treatment for cancer of the larynx? What is involved in rehabilitation after surgery for cancer of the larynx? What happens after treatment for cancer of the larynx? What support is available for patients with cancer of the larynx? What resources are available to patients with cancer of the larynx and their families?

As you can see the topic is given a very comprehensive coverage and even though most references are sourced in the US I found it very interesting and highly informative.

You can find this information at http://www.medicinenet.com/, search laryngeal cancer, and then click laryngeal cancer in Diseases and Conditions.

Other good sites for laryngectomy are:
http://www.larynxlink.com/, which has newsletters from US associations and support groups.
http://www.webwhispers.org/, this site is managed by "Dutch" Helms who has been the initial source of most of the good information regarding laryngectomees that I have found on the Internet.
http://www.ashaust.org.au, the web site for the Cancer Council's Action on Smoking and Health.

At some future date I anticipate that our Association will have a web presence with one-click links to sites such as those listed above.
ABC TV ran a documentary over three weeks, from Thursday 20th January to 3rd February in a regular timeslot called The Big Picture. Tobacco Wars is a BBC program even though the bulk of the content is American. It looked at the history of smoking, the rise and consolidation of the major tobacco companies, their efforts in maintaining their grip on such a lucrative industry and avoiding responsibility of the health and social problems that smoking has caused.

A person by the name of Buck Dukes started the rot by being the first manufacturer of ready made cigarettes and it was the World Wars I and II that turned us into a world of smokers as the troops on all sides were given a ration of tobacco or cigarettes. Apparently it helped control their nerves before going over the top. After the wars most of the men continued the habit they had picked up on the battlefield. So lung cancer sprang from being a rare disease around the turn of the century to become a very common disease by the 1930's when surviving soldiers of WWI began to succumb to it.

In the 1950's, tobacco companies were denying that smoking cigarettes caused cancer even though documents that are now coming to light have confirmed otherwise. To counter the growing public concern the companies introduced filtered cigarettes as being a healthy way to smoke. The tobacco companies were concerned that not enough women were contributing to their profits and embarked on an advertising campaign to demonstrate that smoking was a healthy habit when using cigarettes as a substitute for sweets and there by losing weight. Janet Sachman was known as the Lucky Strike girl. She wasn't a smoker when she secured the job but the tobacco company persuaded her to light up for the cameras, she became a regular smoker and is now a laryngectomee.

In 1957 the British government confirmed that there was a proven connection between smoking and cancer. Research by the tobacco industry had also arrived at the same conclusion but that information was suppressed and the results denied. In 1962 British-American Tobacco suppressed evidence that their researchers had found that nicotine was addictive. In Britain, at Harrogate, the Tobacco Research Council was able to prove the link between tobacco tar and cancer but the US tobacco industry was unimpressed and brought pressure to bear on the British. The results of the research were published but not long afterwards Harrogate was closed.

The US tobacco giants have a history of suppressing and distorting evidence proving or indicating the deleterious effects of cigarette smoking, yet throw millions of dollars at research that might show that some other agent causes cancer. There are numerous examples of tobacco companies intimidating, bribing and coercing scientists and researchers. One such occasion occurred in 1974 when a Professor Homburger was about to publish the results of research undertaken at the CTR tobacco institute. Tobacco company representatives approached him to try to get him to drop the word cancer from the report of his findings. After presenting his paper he went to a hotel where he was due to conduct a press conference and found nobody there. The tobacco lobby had somehow managed to call his press conference off . . . .

To be continued in next month's Newsletter.
MOVIE REVIEW

THE INSIDER ...starring: Al Pacino, Russell Crowe, Christopher Plummer.

The basic plot for the film is that a leading scientist employed by the tobacco company Brown and Williamson is sacked for questioning the ethics of continuing use of an additive that had been proved to be dangerous. He is contacted by a producer from the TV show "60 Minutes" on an unrelated matter and subsequently becomes embroiled in whistleblowing on Big Tobacco.

This is a true story, embroiled a little for the sake of the film, which shows what a lying, double dealing, unscrupulous bunch of criminals run Big Tobacco.

I won't divulge too much of the story here, even though most of it is on the public record, but recommend that you see it at the cinema if you can. Alternatively, make a note and get it out when it's released on video.

Michael Moore - The Awful Truth

On SBS TV at 8.00pm on Tuesday 18th January there was an episode of the regular program of The Awful Truth. Michael Moore, the star of the program, has created a TV show in which he attempts to take on Corporate America in a mainly humorous fashion. I think that it was the third episode that I'm referring to here and it would have been recorded shortly before Christmas.

Michael Moore had gathered a small group of five or six laryngectomees together, dressed them in santa suits and went to sing Christmas Carols in the foyers of Phillip Morris, RJ Reynolds and the office of lawyers who had defended the cigarette companies. The Carolers were mostly men but there were one or two women in the group, one or two servox users but most had prostheses. Two of them claimed to have been only passive smokers who were married to heavy smokers and one man was married for 47 years to a smoker who died of lung cancer.

They also went and sang outside the home of a Chief Executive Officer of a cigarette company where they decorated a christmas tree with cigarette packets and made quite an effective wreath using single cigarettes.
NOTICE OF ANNUAL GENERAL MEETING

THURSDAY 17-FEB-2000

The Annual General Meeting of the Laryngectomee Assocn. of Qld Inc. will be held at the Qld Cancer Fund Headquarters, William Rudder House 553 Gregory Terrace Fortitude Valley. (Parking available under building)

10 a.m. Tea, Coffee and Chat time
10.30 Meeting Commences. Welcome by President.
Apologies. Minutes previous AGM. Treasurer’s Report.

11.15am GUEST SPEAKER: CAROL THOMPSON

Carol is a community Consultant (Speech Impairment) for the Australian Communication Exchange (ACE) which has recently expanded the National Relay Service to include 2 new services to help people who experience difficulty with telephone services. As problems with telephones are commonly reported by our members – ranging from annoying to tragic in consequences- this should be a talk to interest everyone.

Come and join us for the first meeting of the Millennium.
(Please bring a plate to share if you like to bake.)
Welcome to our first issue in the Year 2000, and congratulations to all of us who overcame many obstacles to survive to see in the new century!

This is my last President’s Report for the time being as I will be standing down at our A.G.M. to make way for new people and new ideas, and hopefully there will be volunteers who have a bit more time on their hands than I have had the past few years. It will always be a cause of great regret in my life that my nomination and acceptance of the Presidency was followed by a dramatic alteration in the time I was able to give to laryngectomy matters. Each year I hoped circumstances would improve, but instead they got worse. Some people mistakenly believe I’m retired. I’m actually involved in the running of not one but two small businesses in tough economic times. In fact how I haven’t come down with another bout of cancer caused by stress astonds me. Last year I only continued because I thought we had a new Secretary at last, unfortunately Jeff O’Rourke (who undertook this position so it wasn’t vacant for ANOTHER year) ended up being employed most of the year which also involved travelling so, although this was great for Jeff, in fact, the Association has had no-one to be Secretary yet again. The follow-on effect from this was that finally in 1999 we did not have the required number of Executive Meetings because (a) I had to call and attend them during the day which has been very difficult (night meetings are not suited to other committee members who live a fair distance away and/or have difficulties travelling at night) and (b) since nobody else would volunteer to take the Minutes guess who ended up with this job too. I really hate doing a half-baked job and in 1999 there were so many daytime meetings of various organisations that the President should have attended to make sure we were being represented. With such a small pool of active workers it is difficult to even find “stand-ins” for an event.

I believe it is time to scrutinise ourselves.

Is the Association still relevant? Does everyone get a prosthesis and go about a normal life nowadays?(NO!) With the major hospitals running such excellent support groups, perhaps all we are needed for is to run a Seminar once a year, send out a Newsletter, maintain stocks of aids for loan or purchase by members and organise a couple of interesting social outings for members and their families and friends. Certainly our most important function has always been support for the new laryngectomye, but every organisation needs to review their goals and current method of functioning and what better year to lay new foundations for 2000 and onwards? Chemotherapy and Immunotherapy seem to be the hope of the future and should mean a reduction in the number of people losing their larynxes, but for many years there is still going to be a large number of people requiring electrolarynxes, batteries, prostheses, glue etc all of which can become very expensive if you are required to pay for it all yourself.

This brings me to an issue of great concern. There appears to be a dangerous complacency amongst the vast majority of our members caused, it would appear, by the fact that everything is free to them. There are a number of people who have paid for private health insurance all their lives so if anything really serious happened they could afford all the treatment they required. So along comes a Laryngectomy – and so does the bill to cover the “extras” like the tests that Public patients take for granted, the drugs, the bandages, the Speech Therapy, the voice aids and all the items that go with them. Many of these people lose their jobs when they lose their voice (surveys around the world have shown a drop in income is a frequent result of the operation) so being faced with the regular cost of a prosthesis, particularly if this is every few weeks rather than months, can be a crippling blow when it is least needed. It’s also ironic that people in this position often find they cannot afford the Servox that is given away to people in the Public system. This complacency may disappear in future years if everyone is required to pay at least some of the costs that Speech Therapy and ENT Depts now carry out of the goodness of their hearts. And what about the GST which is exempted on so many items as long as the doctor supplies them him/herself. Can you imagine the size of the shop your doctor will be required to have with his surgery so his patients will be able to purchase items GST free? These are the sort of issues where an independent body plays such a critical role. Unfortunately a lot of the people fighting this injustice are doing so by themselves. I know one couple in N.S.W. have approached Bronwyn Bishop on this matter but I don’t know if there was any result. I believe we as an Association need to let people know we care, so we can all work together for the common good. If you currently have an issue concerning laryngectomy you are writing to a politician or a health-insurance fund about- please send us the details and let our voice be added. If a problem can be solved for one person it can have far reaching effects. Our advice to people who cannot get any refunds through their Health Fund is not to accept the first refusal. Members have reported being refused several times before a sympathetic counterperson finds someway of providing a refund. Of course this is more than unsatisfactory to have to travel all over the countryside to obtain a benefit you believe is rightly yours. Although we are a relatively small group in the Government –Funding Scheme of things this aspect has not
been the positive factor we had hoped it would be (in comparison with fully funded colostomy patients). The National Association of Laryngeal Cancer has been writing to the Federal Government regarding funding for all Laryngectomees for over a decade and getting "political" replies. In fact, our information probably needs updating, as our facts and figures are several years old now.

We would like to hear from YOU if there are any issues you think we should be addressing.

The other ongoing issues for the Association (as well as each individual) are
1. Public Awareness of throat cancer and its symptoms This awareness applies to General Practitioners and Hospital Staff also. Early diagnosis should be everyone's goal.
2. Neck Breather education, particularly for the Emergency Services
3. Emergency switchboard operator awareness of people with speech problems, particularly to recognise the sound of the electrolarynx and not hang up thinking it's a hoax call.

These are ongoing issues and they always will be, because of staff turnover particularly in the emergency Services switchboard- but enough of serious reasons for an Assocen such as ours to exist!

Last year it was 30 years since the Lost Chord Club was founded for support and fellowship, for sharing ideas and information, for sharing experiences and laughing instead of feeling down.
In the past few years since we changed the name to Laryngectomee Association of Qld I have been made very aware of many people's disappointment with the new name. The Lost Chord name had a uniqueness, a sense of humour attached to it, and, had we realise the sense of loss so many people would feel I think the Newsletter might have been called Lost Chord Notes or something similar.

Anyway, 30 years is certainly cause for a celebration and I would like to think one of the most important events of this year would be an Anniversary Party, with as many of the old faces attending as possible.

A great job for the incoming committee to track down all the founders of our Assocen and our early members for a truly memorable reunion.

Last year it was 20 years since I joined up, and I still remember the first Meeting I attended at New Farm in the church hall. When we think about how attendance has dropped off over the years it's sobering!? to recall the amber liquid that added to the convivial atmosphere of those evenings. Now we don't drink and we don't go out at night -perhaps we need poker machines to attract a crowd? (No they're too noisy). As you would expect over 20 years I have met some wonderful and remarkable people amongst fellow laryngectomees and the people who care for them, and even if we don't see each other any more I regard all of them as life-long friends. I'd better not start reminiscing or I'll be here for another 20 yrs-I'll leave that to the 30th Party.

So I know out there amongst the readers are many people with all the talents required to make an important contribution to our Association. I know there's someone out there who's really good at writing letters and who would make a great Secretary for a Self-Help Group that's really going places in the new Millennium.
I know there's someone who can organise a couple of social outings, I know there are several people who would make great anti-smoking visitors to High Schools which can be a very rewarding experience for all concerned I can remember when there were enough people on the Committee for things to get done and everyone knew they weren't alone. If you would like to lend a hand in any capacity, or if you can think of someone who only needs a little encouragement to join in, please come along to the A.G.M. and be welcomed as never before!

My very sincere thanks to all those people around the State who have played a part in establishing support groups that function throughout Queensland. I include in this the people who attend meetings, because without the people who come along there is no meeting. Thankyou- to the Surgeons who really care about their patients, and to their receptionists who provide lifelines in times of stress, to Oncology staff in various departments, to the ENT Nurses, and Speech Pathologists who provide the care, support and information that gets most of us back in the mainstream of life eventually, and to the wonderful support most families and friends provide once they are over their own anxieties. Finally, thankyou for the honour of being President of an Association that has been an important part of my life, and I know will continue for many years to represent, very vocally, a group somewhat famous for its silence.

Thankyou again

Heather

__________________________________________________________________________

THIS NEWSLETTER WAS PRODUCED WITH THE ASSISTANCE OF THE QLD CANCER FUND
NOMINATION FORM  L.A.Q. EXECUTIVE YR 2000

I wish to nominate ____________________________________________
For the position of ___________________________________________

Proposed by: ___________________________________________ (Name)
________________________________________ (Signature)

Seconded by: _________________________________________ (Name)
_________________________________________ (Signature)

I hereby accept the nomination for the position of: _________________
Signed: ____________________________________________________

*******************************************************************************

Yes! It’s that time of the year again when membership fees are due, but they remain unchanged at $10 per individual. With the loss of our Fundraising Bowls Club Day at present we are relying totally on membership dues until someone with a fundraising flair takes up our cause. (Or keen Bowlers or sports people of any type take up Ken Crockatt’s idea of Clubs around the State having a Fundraiser on the same day).

LARYNGECTOMEE ASSOCN OF QLD MEMBERSHIP RENEWAL 1999-2000

NAME ...........................................................................................................

ADDRESS ...................................................................................................

...........................................................................................................P/ CODE

Enclosed please find cheque/ money order being for

Membership fee $10. Send to: The Treasurer
Donation
Other items ______

TOTAL ______

Please take this opportunity to let the Executive know your opinion. What do you believe it is most important for the Association to be involved in? - Or any other comment you would like to make.

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I know many people are concerned that they missed the Christmas Issue. I apologise to all those people who have contacted us because they thought their copy had gone astray. The only thing going astray is me. I simply was unable to find the time to do it. The week I had set aside to do the Newsletter disappeared when a member of staff became ill and my nights were taken up doing work that I would normally cover in the day. The problem was that it should have been the Seminar Report Issue and to do this properly (which I think is very important for all our country members) I have to watch the videos of the day, make notes from them, and turn it into a meaningful experience for our readers.

As you will see I have not been able to do it for this issue either, but will have to have a “catchup” edition. If there is anyone out there willing to do a couple of editions of Lavo-Link it would be more than appreciated. This is very obviously a year that I need to use to plan the rest of my life, and I certainly intend to be involved with the Laryngectomee Assocn for many years to come—it’s just that I need a little long-service leave now! Thankyou everyone for the contributions to LavoLink they are safe and will certainly be used in the near future.

Many thanks to the constant support of Norm, Graham, Murray & Bill who are there every issue to help print, fold, envelope, address and post the newsletters on their way. Graham’s son Jason has been extremely helpful in establishing a second mailing list so if I’m run over by a bus, the Association will still have a mailing list. This has been a constant source of anxiety for Norm the past few years.

In the meantime, happy reading and I hope to meet quite a few new members at our Annual General Meeting!

Your Scribe in Decline - Heather W.

QLD SUPPORT GROUPS

As most groups are just starting the year we are yet to hear from most areas with new contact people, meeting place, phone number and times. If you have a Support Group in your area and are not mentioned here please let us know so we can add you to the list.

P.A.H. Brisbane. Unfortunately just missed this one – first Thursday of the month and Maura Bock is the new Speech Pathologist.

ROYAL BRISBANE HOSP. Second Thursday 10th Feb 2pm –3pm in 7H South Conference Rm

Ann-Louise will be contact person this year. Kylie has a wonderful baby and we hope to have a photo for next issue. PLEASE NOTE Everyone welcome at these meetings. If you have been done at a Private Hospital (Wesley, St Andrews, Mater, Holy Spirit etc) you are very welcome to attend any of these Meetings.

ROCKHAMPTON Second Tuesday, every second month. Contact Wendy Thompson Ph 49274387.

REDCLIFFE Every 3rd Friday of the month. PH Speech Pathology Redcliffe Hospital Ph 3883 0883

Or Mrs Anne Miller on 3205 3278

GOLD COAST Friday 4th Feb (just missed) Contact Laraine Turville Ph 5539 4450

BUNDABERG Contact Stan Millar, 81 Argyle Garden Village, Twyford Street Bundaberg 4670

IPSWICH Just being organised. Ph Speech Pathology Ipswich General Hospital

CAIRNS & TOWNSVILLE -Unsure of details but check with Speech Pathology at local Hospital If your group is doing interesting things please let us know, as we all seek inspiration from other sources.
SIR NORMAN’S DESK

Greetings fellow Laros’ Happy and Health 2000!

People say I should have been a dog. Why???

In this our office one comes across many interesting facts, e.g.,

We are 30 years old, yes, and we still have original members still burning the candle. Congrats to those Laros’ and to the others mainly being Elisas Kronk, Stomaltherapist and our patron Dr Quayle.

Yes, our association was formed at the Royal Brisbane Hospital.

What a fantastic opportunity for us, one and all of you people, to go to your support meetings and be with fellow Laros’ and learn from experience of their problems. May be you could pass on suggestions to others problems and learn something in the future.

Think of it then you can say with pride: ‘I attended the first meeting this new century. A feather in your cap. I have offered the challenge. Will you accept?’

At home, well the board of control (yes, I know who is the boss) reckons the office should go to my shed, lounge and sleepout where I store information I get globally about other overseas clubs and save petrol money.

Recently I re-read about ‘somebody else’. Where are you? The stress is starting to tell as a couple of people run your club we need more help (come on Brisbanites).

One can count on one hand the people who run your association. Be it with latest developments and hair brain ideas, jokes (from u no who).

The curtain is falling so I wish you all good health and hope to meet some of your personally at the first meeting this millennium.

Norm Fredericks

A few words from Grahame.
Our Annual General Meeting will be held on 17th February so I hope to see all my old friends in attendance to give me moral support (as you all realise I am very shy when it comes to speaking in public). Ha Ha!!
Our books are still with the auditors but they assure me they will be ready in time for the meeting. You will be able to get an up to date on our financials. YOUR support is essential for the success of the Association. Hope to see you there for a chat over tea and coffee.
OUR SEMINAR DAY WAS VERY MUCH ENHANCED BY THE SUPPLIERS WHO SET UP DISPLAYS ON THE DAY, AND ALTHOUGH WE DON'T NORMALLY CARRY MUCH ADVERTISING WE ARE VERY PLEASED TO SPREAD THE WORD ABOUT THESE VERY HELPFUL PEOPLE.

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Representative Garry Trotman
Ph 0412 383 718
Customer Service Free Call 1800 656 059

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Monarch Medical, P O Box 1545, Stafford City  Qld 4053
Tel: 07 3352 6100  Fax: 07 3352 6211
Email: custservice@monarchmedical.com.au

AXION BIOMEDICAL

ALAN BEALE is the person to see at his shop
431 Logan Road, Stones Corner, Brisbane  Q 4120
Ph (07) 3394 8253  Alan has a wealth of
3287 3158  information about care of electrolarynxes
Fax (07) 3394 8223

Tube cleaning brushes can be bought singly rather than by box.
Current SERVOX price is $950. Including charger.
From "CLAN" the U.K. Newsletter

Congratulations to Whispering Smith for living such a full-on lifestyle with such swallowing problems!

An Early Millennium

A funny thing happened to me a few months ago. Laid in bed, I was debating whether to doze off again or rouse my ancient bones, when the fax machine on my bedside table sprang into life.

Now who was sending me a signal so early in the morning? I reached out, switched on the light and picked up the single sheet of paper. It was from Geneva, from the International Air Transport Association. Wow! For the best part of the year, I've had a running fight with the major airlines trying to get my bum on a seat to Australia. My Consultant Surgeon tells me that I'm "unique" in that I'm the only laryngectomee who uses a Maloney Bougie in order to keep my oesophagus open. My problem with the airlines is that the Maloney is filled with mercury, a substance they dislike. I think I was "unique" in that nobody knew what I was talking about.

I had reached the conclusion that all my enquiries were being answered by identical multi-lingual computer programmes which reacted to the word "mercury" with one word - "NO"!

Time for Poetry

Regina AcRed's husband, Peter, had a laryngectomy in July and she wrote a poem about it. Here is her foreword to it - followed by the poem itself.

"The original version of the following poem was written on the third day after my husband's laryngectomy in June this year. It just poured out as an expression of emotions like loss and grief mixed with thankfulness of still having my husband and determination of making the most of our new life. Peter recovered exceptionally well after his operation but is now undergoing radiotherapy with its side effects with which most, if not all of you, will be familiar. Meanwhile, with the proviso for ladies to read 'her' instead of 'him', I dedicate my poem to all laryngectomees, especially all new laryngectomees, and their families."

New Laryngectomee

You hear him here, you hear him there
You hear him simply everywhere
But, suddenly, it's different.

The voice that often wasted breath
At small things gone awry
Has met so premature a death
Each curse is now a sigh.

A sigh to mourn each trifling word
That cannot simply be uttered.
A sigh to mourn each loving word
That now with care is muttered.

We take the gift of spoken words
So thoughtlessly for granted.
But, when it's gone, it surely hurts.
We know how much we want it.

The way ahead will take some time
But, even now, it's clear
That we CAN understand your mime
And, ultimately, hear.

We hear the words you mouth and write
And know that each one matters.
We CAN converse and can avoid
The silence that just shatters.

Like you, I know there lie ahead
Those times of great frustration
When lack of real spontaneous speech
Will stretch imagination.

Will stretch our patience too.
Perhaps patience it will teach.
Patience never was for you.
But now it's within reach.

You would not choose this trade-off
But that is what it is.
Your voice for patience may not seem
Your own idea of bliss.

But bless'd we are because we have
YOU still here to be.
How could we want to ask for more:
You're VIVABLE, you see!

That's all you wanted, or at least,
It's what you said before.
Now persevere and keep it up.
Embrace life all the more.

Whispering Smith

Man To Man

Somehow that fax started off a chain reaction of phone calls, in what manner I know not, but at eleven a.m. I was speaking Man to Man with the British Airways manager who dealt with dangerous goods - his conclusion, "No problem, Mr Smith - book up with BA and let me know your flight details."

So, hopefully, on the evening of Wednesday November 10th, I shall "rotate" and head south with the birds to clear air, peace and quiet and the Snowy River.

When I raise my glass to the new Millennium (eleven hours ahead of England), I shall think of all the readers of Clan. "May the year 2000 bring us all Health and Happiness." Whatever bugs us individually, be it pain, loneliness or depression, be alleviated. May the research into our common disease continue apace and the Gene programme flourish. Peace and Love, Brothers and Sisters, Peace and Love.

Whispering Smith
Problems with PEGs

Doctor Peters, we know a PEG tube is often used for a throat cancer patient during healing or while having difficulty swallowing. We would like some insight into three problems.

1. If, over a period of years, a patient has repeated dilations, manages soft food occasionally but is on mostly a liquid diet, what are the choices to be able to eat again?

This concerns a chronic problem with difficulty swallowing despite repeated dilations. Let me give you my opinion about dilation. Basically, I don’t think it works. Let’s look at the problem. You have a round organ such as the oesophagus. Around this circular organ you have scar tissue. The most basic thing that scar tissue does is to contract. When you have contracture around a circular organ, you get narrowing or stricture. Now let’s look at what happens when you dilate something. What you do is forcefully break up the scar causing a new wound. This results in guess what? That’s right, more scar tissue. And what is scar going to do? Contract! Therefore you have set up a vicious circle of scar, contracture, more scar and more contracture. Hence no improvement. It is my feeling that, to truly improve the situation, you have to bring in new tissue that is not affected by this cycle.

2. When leakage occurs, is there a good way to stop it or a product to put on the skin to avoid excess irritation?

When leakage occurs around a PEG tube, it is always best to make sure that the tube is tight against the body wall. Make sure the bumper or balloon inside the stomach is working properly and the outer flange can be snugged up to the skin. Not too tight but just right. A single layer of gauze is usually enough to catch any drainage.

3. When you are eating easily and it is time to remove the PEG tube, are there complications involved in the healing after the removal of long time PEGs? If it doesn’t close up properly, where do you go from there?

Generally PEG tubes can be removed in the office and the wound will close on its own in 2 to 3 days. It is very rare for the fistula not to close but, if it doesn’t, it is a matter of a limited out-patient surgery to rectify the situation.

Dr Glenn E Peters MD
From Headlines on the internet

I’ve Used Both

I have had the opportunity of using two systems. During a trial of Neo Naze, my findings were that the baseplate was difficult to fit and that the filter units caused dryness and crustiness within the stoma area despite spraying within the trachea. In my opinion it was not really suitable for concave neck openings.

I currently use the Blom-Singer humidifier system which provides the necessary warmth and moisture enabling me to continue activities (cycling, badminton, keep fit) without the need for any additional bins. It does all that is claimed for other systems, is flexible within the muscles either side of the cavity, being quick to change (approx 2 minutes). I currently wear my filter for 24 hours before changing. Rarely do I now get blockages of mucus. Additionally, the system provides for a hand-free valve which is a boon for office work, social occasions and answering the telephone. These items are available in this country through Forth Medical Ltd and I hope their system will shortly be available on the NHS.

Cyril Seabrook
Chairman – “Second Chancers”

Sound of Music

Richard Roger – who partnered Lorenz Hart to produce 28 stage musicals and 8 film musicals such as “Oklahoma!”, “South Pacific”, “The King and I” and “The Sound of Music” – developed throat cancer and became a laryngectomee. He worked hard to achieve a good oesophageal voice and spoke publicly with it on several occasions. He died in 1979 leaving the world a wonderful gift – the sound of his music.

The Sound of Mucus
Poets corner

What is this life if, full of care,
We have no time to stand and stare?

No time to stand beneath the boughs
And stare as long as sheep or cows.

No time to see when woods we pass,
Where squirrels hide their nuts in grass.

No time to see, in broad daylight,
Streams full of stars like skies at night.

No time to turn at Beauty’s glance
And watch her feet, how they can dance.

No time to wait till her mouth can
Enrich that smile her eyes began.

A poor life this if, full of care,
We have no time to stand and stare.

W.H. Davies (1871-1940)

Life is to be lived,
But not squandered on excesses.

Others’ acceptance of you can reflect the
Way you have lived.

Peace is an environment where one can
Live to one’s potential,
While living in harmony with others.

Have you noticed that a spilled drink always flows in the
direction of the most expensive object.

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CHURCH HUMOUR
Counselling
Mr Casper Milquetoast and his unkept wife, Naggie
were in the Pastor’s office for marital counselling. After
listening for a few minutes, the Pastor got up from his
desk, walked around to where Naggie was sitting and
planted a big kiss on her astonished face. “See that she
gets two of these per week Casper” the Pastor
prescribed. (Pause) “Could I bring her in about 2.00pm
Tuesdays and Thursdays? Casper asked.

Life is mostly froth and bubble
But two things Stand like Stone
Kindness in another’s trouble,
And courage in your own.

George Corbett

The tree of life grows on the nutriments
of Love...

A bold person once said “try all things
Once” all doubts and fears defying.
But it takes an even bolder person,
To try and keep on trying...

Unknown

- It’s not only later than you think. It’s sooner
  than you suspect.
- It’s when you are faced with two parties and
  you choose the one that gets you home by nine
  o’clock.
- You work yourself to death to live better.
  kje

*********

If you ask enough people you can usually find one
who will advise you to do what you were going to
do anyway.

CONTRIBUTED BY JANICE BREEZE

I owe much I have nothing the rest I leave to the
poor. (Francisco Rabellius)
MONTHLY MEETINGS:
# N.S.W.: Third Wednesday, 11am at Uniting Church Hall, Carrington Ave, STRATHFIELD.
# HUNTER VALLEY: Third Tuesday, at Mayfield Bowling Club, Ingal St, Mayfield.
# PARRAMATTA: Second Tuesday, 11.00am at Masonic Club, 163 George St, Parramatta.
# ILLAWARRA: Third Wednesday, 2.30pm at Warilla Medical Centre, Belfast St, Warilla.
# NORTHERN RIVERS: 4 times per year, rotating venues, Contact J Kidd, PO box 572, Lismore. Phone 02-6623320.
# MID NORTH COAST: First Tuesday, 1.30pm at Staff Centre, Manning Base Hospital, Taree.
# DUBBO: Lourdes Hospital. First Friday, 10.30am Conference room.
# ALBURY: Ph 02-6323-2011, ext 323.
# CANBERRA: First Thurs, 11am, Level 1, Building 3, Canberra Hosp.
# SOUTHERN DISTRICTS: 4th Wed. 10.00am, Thomas Rachel Moore Education Centre Liverpool Hosp. - phone 02-9607-6708.

EDITORIAL -
As usual the February Newsletter is really just a reminder that the Laryngectomee Association year begins with the Annual General Meeting on February 16th. At that meeting all committee positions become vacant and the new committee to be in office until February 2001 is to be elected. The secretary tells me he as yet only five nominations for committee positions even though nominations close on February 1st. Do not forget you may nominate yourself for any position. Convention has it that the president is always a laryngectomee but other positions can be held by family or friends, so please come forward if YOU feel that YOU can help. Present members whose phone numbers are in the first column can answer any questions you may have.

NEXT MEETING
ANNUAL GENERAL MEETING
WEDNESDAY 16th FEBRUARY
11am
UNITING CHURCH HALL
CARRINGTON AVENUE, STRATHFIELD.
Parking on site, short walk to Strathfield railway station.
Laryngectomees, families, friends, professionals, ALL WELCOME.

LIGHT LUNCHEON SERVED AFTER THE MEETING

WHO TO CONTACT
FOR BLOM-SINGER SUPPLIES - David Smith, 27 Bellevue Pde, North Curl Curl. 2099 Phone 02-9939-1539
FOR SPEECH AIDS, BATTERIES PARTS AND ADVICE ON REPAIRS - John Chaloner, 111 Station Street, Petersham 2049 Phone 02-9560-2852
FOR STOMA COVERS, SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS - Lilah Walton, 23 Baker Street, KENSINGTON 2033, Phone 02-9663-2550
FOR ACCOMMODATION ASSISTANCE WHEN NEEDING OUT-PATIENT TREATMENT AWAY FROM HOME - Cancer Council of NSW phone 02-9334-1900. PO Box 572, KINGS CROSS.
As this is my last Newsletter I feel I should be able to say something wise and wonderful but I just can’t think of anything. I have enjoyed my time in the job but feel I am getting a bit stale and new blood, new ideas and a fresh outlook are called for. Tony Krasnodebski has volunteered to take it on and I am sure he will do it well as he has plenty of new ideas and much more computer know-how than I do. I certainly wish him well and just ask that you all support him with lots of contributions, Branch reports, handy hints etc etc. Thank you to all who have been so helpful to me over the last few years - I have learnt a lot and made many friends. I will continue in the Association and help wherever I can.

********* Lilah had a pretty traumatic year in 1999 but things seem to be on the up at the moment. She and Norman have both been unwell at times - they were in the middle of the hailstorm that hit the Eastern suburbs in April - Norman is waiting for surgery on a very painful hip - Lilah broke her arm towards the end of the year -- in fact they were both glad to see the end of 1999. But now slowly the house is getting repaired (new ceilings going in at the moment) and the end of that seems to be in sight (with binoculars) - Norman has a date for his operation - Lilah’s arm is out of plaster and she has declared herself ready to be contacted again re stoma covers, shower shields etc. As before mentioned she is willing to carry on as Welfare Officer until the Annual General Meeting in 2001 but would like to think there is someone willing to assist her this year with a view to taking on the position when she retires. THINK ABOUT IT.

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I mentioned in the December Newsletter a member who had contacted the Association about the purchase of a mobile phone and had been put in touch with the disability section of Telstra. Once again they turned up trumps and now have another very satisfied customer. Mr Les Warren of this section arranged for the staff at Gosford to help our member. Sue from Gosford sat our member outside with different phones and rang from her office in the building and graded each phone for clarity so that when the choice was made it was the best available to suit her voice (or, as she said lack of it)

Once again a very grateful Telstra customer. On behalf of all our members “Thank You Telstra for the wonderful service you extend to our members”

For your information the man to contact for these disability services is Mr Les Warren on 02-310-2022

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As you can see by all of the above the work of the LA has gone on during the Christmas, New Year break. The secretary tells me that a number of new members have joined the Association, welfare supplies have been ordered and satisfied; John Chaloner has been able to satisfy members with advice, batteries and loan of voice aids; hospital visits have been carried out to new laryngectomees etc etc.

Before Christmas we ordered a new supply of shower shields from the USA but these have not yet arrived so please make your old one ‘do’ for a few more weeks

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Remember - the Laryngectomee Association is a self help organization. Do your bit!!

RULE TO LIVE BY
The manner in which one endures what must be endured is more important than the thing that must be endured.

Dean Acheson.