



THYROID FLYER

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Newsletter of Thyroid Australia Ltd

Volume 8 No 1 April 2007

Medication update

Editorial

By *Christopher McDermott*

Welcome to our first Thyroid flyer issue for 2007. The feature of this issue is medication.

The main article has been written by Professor Jim Stockigt who has had a long association with and interest in Thyroid Australia.

His article is about the inaccuracies of sources of information on thyroid medications. Conflicting "scientific" information (continued page 7)

Call for Volunteers

Do you live in/near Mount Waverley? Are you able to donate a few hours of your time? Thyroid Australia (TA) is a not-for-profit organisation which was founded on the passion to provide leading edge information for people with a thyroid condition. Thyroid Australia was founded by volunteers and is still run by volunteers and receives NO Government funding

We are currently looking for people who can spare a few hours on a regular or even casual basis to assist Brenda, our office manager, @ Thyroid Australia's Mount Waverley office with light administration tasks. No experience is necessary, just a keenness to assist!!!

Please contact Brenda:

Phone: (03) 9888 2588

Fax: (03) 9561 4798

E-Mail: support@thyroid.org.au

Thank you in advance!!!

Inaccurate, out-of-date pharmaceutical product information for thyroid-related medications:

Consumers beware!

By *Jim R Stockigt, MD, FRACP, FRCPA*

Abbreviations

TGA: Therapeutic Goods Administration

MIMS: Monthly Index of Medical Specialities (Annual)

PI: Product Information

CMI: Consumer Medicine Information

Introduction

In a recent review in the Medical Journal of Australia (MJA) January 15, 2007

(http://www.mja.com.au/public/issues/186_02_150107/contents_150107.html),

I have drawn attention to inaccurate, out-of-date product information (PI) on thyroid-related medications in standard reference sources that pharmacists and some medical practitioners use as a basis for patient information. The texts in question are Monthly Index of Medical Specialities (MIMS) Annual 2006, MIMS On-line and the Australian Prescription Products Guide. It is my aim here to place practical points in perspective, so that those who use thyroid medications will know whether or not they need to be concerned. It is also important to consider the reasons for the current unsatisfactory situation and how that might be fixed up. We should all be concerned if the health of even one or two percent of the 200,000 or so Australians who use thyroid medications were impaired as a result of flawed, out-of-date pharmaceutical PI.

Importance of thyroid-related drug information

In countries such as Australia about 5% of the population have a thyroid disorder; about a quarter of this number needs to take medication, either to correct deficiency, or to control thyroid hormone excess. In 2005, over 700,000 Pharmaceutical Benefits prescriptions were filled in Australia for thyroxine, with about 80,000 scripts for the antithyroid drugs carbimazole or propylthiouracil. Those who take thyroid-related medications need reliable information to help them achieve self-confidence and self-sufficiency with their treatment, especially as long term follow-up usually extends beyond contact with any one medical adviser. Reliable information about medications is crucial to allow people to make an informed choice between various treatment alternatives, for example in thyrotoxicosis. Further, people need to have confidence in information that they get from health professionals so that they are not misled by the overflow of electronic disinformation on thyroid-related products. Consumers should be able to assume that information from health professionals will be reliable, which in turn depends on the quality of the sources that these professionals use.

**Annual Melbourne Meeting
Camberwell Civic Centre 29th July 2007**

Put this date in your diary now!

A special event not to be missed with leading speaker.

Who is affected?

Fortunately, those taking continuing thyroxine replacement need have no cause for concern, provided that they have come to terms with our unusual, uniquely Australian directions for storage of thyroxine.

(http://www.mja.com.au/public/issues/182_12_200605/letters_2006051.html). The most important issues relate to starting treatment, to adjusting antithyroid drug dosage, to treatment before during and after pregnancy and to the potential for misuse of triiodothyronine, the most active form of thyroid hormone.

The problematic information

The key points of difference between the directions given in PI-based texts and the practice of specialists, who keep in touch with endocrine literature, are as follows:

1. Thyroxine treatment does not always have to commence at no more than 50 microgram daily, (although that is an important precaution in the hypothyroid elderly who may have coronary heart disease). There is absolutely no reason why a healthy younger person, who has a near-total thyroidectomy for goitre, thyrotoxicosis, or cancer, should experience months of unnecessary partial thyroid deficiency, until they eventually get appropriate replacement.
2. High dosage of antithyroid drug should not be continued until the patient is euthyroid. Progressive dose reductions should be considered on the basis of serial testing every 3-4 weeks (T4 and T3!!). Failure to do this can result in serious over-treatment; abrupt cessation of medication then leads to recurrence, a sequence seen too frequently in specialist practice.
3. For pregnant women who require thyroxine replacement, the advice to increase the dosage of thyroxine on the basis of testing each trimester, will result in increased dosage too late to be optimal for the developing foetal brain. Increased dosage can be reliably and safely anticipated.
4. Breast-feeding is safe and should not be ruled out in women taking standard doses of antithyroid drugs. (The directive that prohibits this over 10 years out of date.)
5. The suggestion that high-dose iodine should be used instead of antithyroid drug in the management of thyrotoxicosis in late pregnancy is unsafe and totally without support.
6. There is no basis for the assertion that triiodothyronine is useful in "hypometabolic conditions other than hypothyroidism"; no such T3-responsive conditions have been shown to exist. This pseudo-indication endorses a potentially dangerous misuse of thyroid hormone.

Sources of Pharmaceutical Drug Product Information (PI)

Pharmaceutical PI is generally supplied by the manufacturer or sponsor of a medication and then reviewed and sanctioned by the Canberra-based TGA. For new or recently introduced medications this is a rigorous process, but for long-established medications updating has fallen behind. Review of sequential MIMS annuals indicates that there have been no substantive changes to the entries for antithyroid drugs since 1985. The entry for thyroxine (Oroxine) was last revised in 1990 and advice that dosage of thyroxine should be increased in pregnancy was added in 2004. Storage instructions for thyroxine

were modified in 2006.

While it is true that no new thyroid medications have been introduced in recent years, new and important information on how these agents are best used is missing from PI.

It is perhaps a disadvantage that each of the four thyroid medications has a non-competitive monopoly market in Australia. If these markets were competitive, there might be commercial incentive to keep PI up-to-date. In the current situation, efforts to improve thyroid product information depend on how effectively the TGA interacts with the sponsors of each product.

Sponsors do have an obligation to keep PI accurate and up-to-date, but under current arrangements, each sponsor has to pay an application fee to the TGA, seeking approval to revise PI. Thus, there are both monopoly-inertia and financial disincentives to revise these texts. The TGA does not usually initiate revision of PI, except where questions of safety arise.

The deficiencies listed above clearly include significant safety issues. Thus, we have reached a point where something may need to be initiated by the TGA, without waiting for pharmaceutical sponsors' applications for revision of PI.

The link between PI and Consumer Medicine Information (CMI)

As the public is urged to take increasing responsibility for personal health, the development of accurate, understandable CMI becomes an important health priority. The TGA has commissioned a consultancy to facilitate the development and upgrading of this material.

(<http://www.tga.gov.au/consult/2005/accesspmi.pdf>).

Under current arrangements there appears to be an unbreakable link between CMI and PI, apparently regarded as the "gold standard" or benchmark for CMI. Apparently, there is no perception of any need to go further than PI in seeking reliable information or best-practice guidelines. Thus, CMI can be no better than PI. In my view, that is by far the most compelling reason why PI, particularly for the thyroid products, must be improved. (While health professionals should be able to distinguish between reliable and flawed sources of information, consumers cannot be expected to make that choice). Patient support groups, however well intentioned or well informed, might eventually find it difficult to disseminate information that differs from officially sanctioned CMI, regardless of its flaws.

Where to from here?

As one might expect, the recent review

(http://www.mja.com.au/public/issues/186_02_150107/content_s_150107.html, pp 76-9.) has produced no early response from either the TGA or the sponsors of the medications in question, although the bureaucratic difficulties of achieving change have again been emphasized.

(http://www.mja.com.au/public/issues/186_02_150107/content_s_150107.html, pp 51-2).

It is an unfortunate paradox that the TGA, the key organization that could take the initiative in improving drug product information, is in a sense "behind the eight ball". It is political history that its resources come from fees paid by the pharmaceutical industry. Would any organization voluntarily bite the hand that feeds it?

As a first step, it is important that the medical issues outlined in the review and summarized here, be evaluated and, if found valid, endorsed by key professional bodies such as the Endo-

crine Society of Australia and the Royal Australasian College of Physicians. The National Prescribing Service, a body dedicated to "Quality Use of Medicines" publishes the government-subsidized showcase journal, Australian Prescriber, but that journal has so far declined the opportunity to take up the specific issues that limit the effectiveness and accuracy of thyroid-related PI. If inertia persists, it will become appropriate for active consumer groups to become involved. They might have a strong case for change in current PI procedures, based on safety issues, the immutable link to CMI and the right to verifiable information. Media involvement and political initiatives may eventually become important.

While those involved with Australian pharmaceutical PI, for example the TGA, Medicines Australia and the National Prescribing Service, are nominally at arms length from one another, one gets the impression that they tend to hold hands, or even link arms, if challenged. If nothing is done to improve the current state of pharmaceutical PI on thyroid-related medications, the 200,000 or so Australians who use these products cannot have confidence in advice that they are given by pharmacists and by medical practitioners who rely on PI-based sources such as MIMS.

Continuation of the current debacle is really unnecessary. By comparison with drug categories such as the anti-rheumatic or cholesterol-lowering agents, where commercially-sensitive, complex conflicting trial data need to be evaluated, the PI issues for thyroid-related agents are crystal clear. Information on these agents could be very easily improved, simply by getting expert advice to bring the material into line with current consensus literature in endocrinology, and by loosening up the cumbersome procedures for updating PI. To me, the current deplorable state of pharmaceutical PI in my field of specialty seems uncharacteristic of a society that values high standards of medical care.

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Product information past perfect

By John S Dowden

(http://www.mja.com.au/public/issues/186_02_150107/content_s_150107.html, pp 51-2).

Does drug product information need a use-by date?

Do not rely on the Australian approved product information for up-to-date advice about drug therapy. This seems to be the main message of Stockigt's review of entities (http://www.mja.com.au/public/issues/186_02_150107/sto10229_fm.html) for thyroid disease in prescribing references, which are based on the product information supplied for each drug. In some cases the information was so out of date, its recommendations were potentially harmful.¹

While these findings will not surprise everyone,² many health professionals will be disturbed to know that they cannot completely trust the product information approved by the Therapeutic Goods Administration (TGA). It is often the source that people turn to when seeking detailed drug information. As the product information also underpins consumer medicines information and sets the boundaries for advertising, flaws could have far-reaching consequences.

The Therapeutic Goods Act 1989 (Cwlth) has little to say about product information other than it relates to "the safe and effective use of the goods, including information regarding the usefulness and limitations of the goods". Details about what should be in the document are contained in the Australian regulatory guidelines for prescription medicines.³ These guidelines do not state that the product information should be kept up to date.

When a sponsor company applies to have a new drug registered in Australia, it supplies a draft of the product information. This is scrutinised by the TGA and the Australian Drug Evaluation Committee to check that the information reflects the evidence supporting the drug's safety and efficacy. Although the sponsor can make safety-related notifications, the product information cannot be changed after registration without the TGA's approval.

At the time of registration, the accuracy of the product information is at its zenith; however, it may soon be outdated. With the pressure to approve drugs quickly, new information is likely to emerge after the product is marketed. Some drugs seem to be approved mainly on the results of phase II trials. Their product information will therefore need updating when the results of phase III trials become available. Adverse effects may only emerge after marketing. A review in the United States of 548 new drugs found that more than 10% later acquired a "black-box" warning about serious adverse effects or were withdrawn.⁴

While major safety concerns are likely to trigger an update of the product information, less prominent problems may be overlooked. In Australia, the sponsor is responsible for keeping the information up to date. How seriously this responsibility is taken is unclear. Updating product information, particularly about old and possibly less profitable products, and disseminating the changes may not be a top corporate priority.

The TGA also has to set priorities. It has limited resources but many areas of regulatory responsibility, including complemen-

tary medicines. While the TGA was once government-funded, it now has to recover all its costs in fees and charges. Having the regulator funded by fees from the industry it regulates may have disadvantages. Industry probably prefers to pay the TGA to register new drugs, than to dust off the product information of old drugs. To manage within its resources the TGA has adopted a "risk management approach" to regulation.⁵ Activities with a low risk of adverse outcomes receive less scrutiny. This is why complementary medicines are not evaluated before they are listed in the Australian Register of Therapeutic Goods. Similarly, the TGA's risk analysis may not identify the product information of old drugs as a high risk.

Many old drugs only have brief product information. This may not have been updated for years and it can be difficult to know its currency. The date of approval at the end of the document reflects the most recent change. However, this change may have been a minor variation rather than a rigorous review. Perhaps there is a need for a "use-by date". Drugs have an expiry date, so why not extend the concept to product information? This would require a date to be set for a comprehensive check of the product information. Such reviews would be more frequent early in the product's life to ensure emerging data were included. For older products the reviews could be less frequent, but at least there would be a mechanism for checking that the information was not obsolete. This could be an opportunity for specialist societies to assist the TGA with updating.

Regularly reviewing product information would require greater resources for the TGA. As the TGA can charge for changes to the product information, the mechanism exists to recover the additional costs. (Changes to the product information involving the evaluation of data currently cost about \$4000.)

Although an agreement between the TGA and industry to keep product information up to date seems sensible, there are likely to be commercial objections. The TGA's philosophy is to regulate while "freeing industry from any unnecessary regulatory burden". Most corporations aim to cut costs, so it is possible that a company may withdraw an old drug rather than be forced to review the product information and then pay to have it approved.

In 2005, the TGA circulated a discussion paper on improving access to information about prescription medicines.⁶ This contained several suggestions for greater use of electronic methods to make up-to-date product information easily available. The outcome of this discussion is currently unknown. Would a recommendation to update the product information regularly be accepted in a business environment focused on new products, cost containment and reduced regulation?

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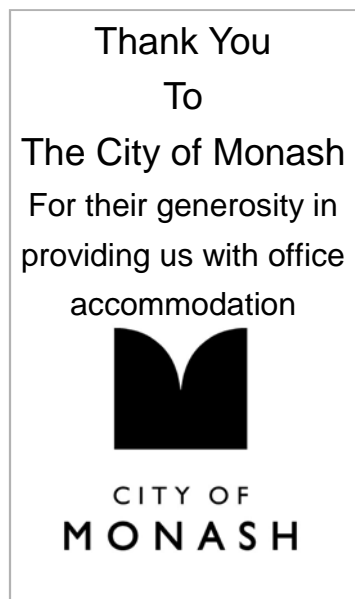
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What are your thoughts regarding the two articles on thyroid medication?

We are keen to receive your feedback.

What experience have you had regarding the prescribing of your thyroid medication? Did you receive a CMI with your thyroid medication? Did your doctor make any comments to you regarding the currency of the information on your CMI? Did he/she make any comments to you regarding the PI that accompanied your thyroid medication?

Please send your feedback to us via email, mail or phone.

Mail: 333 Waverley Rd. Mount Waverley VIC 3149

Phone: (03) 9888 2588 FAX (03) 9561 4798

E-Mail: support@thyroid.org.au

Please note, we will keep your details confidential

Home Medicines Reviews Helping to manage medicines at home

These days the use of medicines is an integral part of maintaining our health, not only for people with thyroid disorders but also for those in the general community as a whole. It is not uncommon for people to be on five, ten or even fifteen different medicines daily, depending on their medical conditions. Particularly as people age, the number of medications that they take naturally tends to increase.

One of the unfortunate consequences of multiple medication use is that problems can often arise. In fact the statistics show that there are approximately 140000 hospital admissions each year that are the direct result of medication mismanagement, and furthermore, up to 69% of these are avoidable.

As a result, a service exists that is designed to help people understand and use their medication better. It is called a Home Medicines Review, and in the 5yrs since the program began over 115,000 reviews have been conducted nationally.

A Home Medicines Review is a Medicare-funded service to consumers living at home in the community to assist in the quality use of medicines. Residents of an aged-care home have access to a similar program, although there are some procedural differences.

In collaboration with the general practitioner (GP), a pharmacist will visit a patient at home in order to review the use of their medication. This process must be initiated by the patient's GP, and following the home visit the pharmacist will write a report to the doctor outlining any findings and possibly offering some suggestions or recommendations on drug use.

Having a pharmacist visit you at home can provide a wonderful opportunity for you to show them exactly how you are taking your medication, have any questions answered and raise any points that may not have been previously mentioned to either your doctor or pharmacist.

There are many reasons for considering a Home Medicines Review, such as any:

- Confusion about medicines including the use of generics
- Adverse effects experienced, or possible drug interactions
- Recent discharge from hospital or changes to your drug regime

Although there are some guidelines for who is entitled to have an HMR, generally most people will qualify although this is entirely at the GP's discretion. However, it is important to note that requests for an HMR may come from a patient or their spouse, family member, carer, or other health professional.

There are four steps involved in the Home Medicines Review process. Firstly, your GP must initiate the service by generating a Referral form that is directed to your community pharmacy of choice.

Your pharmacist will then organise the home visit. Note that the pharmacist who conducts this service needs to be accredited to do this, so if your community pharmacist is not accredited they may enlist the services of an independent consultant pharmacist.

The pharmacist will always ring to make an appointment and will ask you to have all your medicines out on the table beforehand, including non-prescription items, vitamins and any other complementary medicines you may be using. You will then have around 30-60min to discuss any issues about your medications and their use, with the opportunity to ask all those questions you have had on your mind. Following this visit, the pharmacist will then write a report for your doctor.

Finally, you will then have a second consultation with your GP who will go over the pharmacist's report with you and discuss any issues that have been raised. Together with you, the doctor will document a Management Plan based on the report, offer you a copy and also forward one to your pharmacist.

A Home Medicines Review is designed to help you get the most from your medication by involving you, your GP and your pharmacist and there is usually no charge to the consumer. If you would like to arrange a Home Medicines Review or would like any further information, please contact your GP or community pharmacist.

Author details: Alan Freedman is a pharmacist and the State Facilitator for the Home Medicines Review program at the Pharmacy Guild of Australia (Vic).

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Are you familiar with the consumer medicine information (CMI) for your thyroid medication?

By Cornelia Cefai BSc Hons MBA

Consumer medicine information (CMI) leaflets accompany all prescription medication sold in Australia including the two most common prescription thyroid medications in Australia, Oroxine™ (Thyroxine) by Sigma Pharmaceuticals and Neomercazole (Carbimazole) by Roche Pharmaceuticals. The information included in a CMI reflects the information contained in the product information (PI), but written in plain English for easier reading for the general public.

The pharmaceutical industry is one of the most highly regulated industries in Australia. This is a good thing for the consumer, as it ensures medicines are assessed rigorously prior to release for use in patients.

In Australia, the regulatory guidelines state that the PI (upon which the CMI is based) is a document that contains information sufficient to ensure safe and effective use of the medicine. It is to represent the scientific, objective account of the medicine's usefulness and limitations as shown by the data supporting the application for registration to Therapeutics Goods Administration (TGA).

It is important to remember that medicine and the knowledge around it is an evolving and forever changing area. Information is being constantly re-assessed. This is a good thing, as ultimately we should reach a point where we should know almost everything regarding each medical situation and the medicines used. However, how much of this new information is incorporated into the PI varies dependant on many factors. Some of this new information is required by TGA to be inserted, but some is not.

Therefore, at any given point in time a PI may not contain everything that is known about that medication. Also, clinical practice is often able to adopt new evidence sooner than it can be adopted into the PI. This will certainly result in situations as described by Prof. Jim Stockigt and supported by John Dowden.

Maybe an ideal scenario is to have one document that provides everything that is known regarding that medication "real-time", but then how well can this be regulated? Maybe a supplementary document can provide this extra information with a clause highlighting that this has not been assessed as rigorously as the PI? In some ways consensus documents attempt to fill this latter role. Overall, "how" an ideal scenario can be achieved will certainly be a challenge for all involved.

So what do we as a patient do in the meantime? Do we still read our CMI? The least we can do is be aware of the information that the CMI for our thyroid medication contains, plus make a full note of all of Jim Stockigt's recommended additions.

First, if you have not previously seen a CMI for your particular prescription thyroid medication—ask for one! Ideally, your doctor or your pharmacist gave you the relevant CMI the first time you received your thyroid medication and read it through with you and discussed any possible drug interactions etc you may need to be aware of. If this is not the case, ask for a CMI

at your next visit to your doctor and/or pharmacist and ask them any questions you may have straight away.

Secondly, check with your pharmacist and/or doctor regularly if the CMI for your medicine has been updated. This information is updated regularly (but maybe not as often as could be deemed ideal, as noted by Jim Stockigt and John Dowden.)

With regards to how often you check for updates is up to you and maybe your doctor and/or your pharmacist can assist you here. The CMI has a "last updated by" date at the bottom so you will know if it is the same as your previous CMI. If you note this date is different, ask your pharmacist and/or doctor to determine what impact any changes may have on your particular situation.

Thirdly, how do you tackle the latest information that is not yet covered in the CMI, as alluded to in the articles? This is indeed a complex area. Many of us follow the golden rule — only we are ultimately responsible for our own health. So, this means we often try and become an expert on our own medical condition. Unfortunately, many of us do not have the medical or scientific background to tackle this appropriately. Many of us scour the internet for new information. But this is wrought with problems, particularly with the explosion of sites with dubious sources. Many of us read abstracts of medical literature. But this is also fraught with problems, as an abstract does not tell you about the scientific rigorousness of the study, the track record of the authors, plus other factors which may have skewed the results.

This is where Thyroid Australia may assist. Thyroid Australia prides itself in keeping abreast with the latest medical literature. Many of the excellent articles on Thyroid Australia's website and Thyroid Flyer are a result of the tireless work and excellent joint collaboration between the Volunteer members and Thyroid Australia's Medical Committee.

However, Thyroid Australia, just like the pharmaceutical industry, must accept the current PI that has been approved by the TGA. In the end, it is always important to ask your doctor any questions you may have, as they have the medical background to assess the relevance of any information pertaining to your individual situation.

Finally, remember you are an individual and no other person is exactly like you, so it is always important to review your medicine with your doctor and/or your pharmacist with this in mind. The *Home Medicines Review* service offered by Alan Freedman may also be of great benefit here.

Overall, good luck and good health and remember Thyroid Australia is here to assist where we can!

Author details: Cornelia Cefai is the incoming editor and new board member of Thyroid Australia (Vic). Cornelia works as a Medical Affairs Associate at a pharmaceutical company where part of her role is to review PI and CMI information prior to submission to TGA plus reviewing and critiquing the latest medical literature and the impact it may have on future updates to the relevant PI and CMI of her pharmaceutical product range.

Thyroxine & oestrogen

Adapted from a previous article

by Megan Stevens

An important issue in the treatment of hypothyroidism is knowing how to take thyroxine, as well as the effects other drugs may have on the absorption of thyroxine. It is important to note that other drugs may interfere with Oroxine™ - particularly drugs which contain oestrogen, such as oral contraceptives or hormone replacement therapy.

An article published by Arafah¹ in the well-regarded New England Journal of Medicine, suggests that “Women with hypothyroidism need an average of 45 percent more thyroxine during pregnancy to maintain euthyroidism”, and that “in women with hypothyroidism treated with thyroxine, oestrogen therapy may increase the need for thyroxine”. So if you are a woman on thyroxine and you are pregnant, taking the contraceptive pill, or taking hormone replacement therapy to diminish the symptoms of menopause, and you are feeling as if you are slipping into hypothyroidism again, please discuss this with your doctor as you may need to have your thyroxine dose increased.

References:

1. Baha M. Arafah, M.D., “Increased need for thyroxine in women with hypothyroidism during oestrogen therapy” NEJM Vol. 344, No. 23, June 7, 2001, 1743-1749

Author details: Megan Stevens is a co-founder of Thyroid Australia and now retired board member.

Editorial (cont from page 1)

-mation, used by medical practitioners, can be a serious problem. Depending on which information sources your doctor uses – you could be prescribed thyroid medications very differently with the potentially serious consequences. Information provided by the drug companies is regulated by the Therapeutic Goods Administration. This regulation may sometimes mean that the product information (PI) from the drug companies may be quite out of date and not reflect all of the latest research.

Professor Stockigt has already pointed out this problem in a related article published in the Medical Journal of Australia and is very concerned about raising awareness of this issue with both the medical community and general public.

You may be able to help. If you think your treatment has been affected by this issue, we would like to hear from you. You may need to check with your doctor if one of the situations in Professor Stockigt’s article appears to apply to you. Real instances of treatment based on out-of-date drug information would greatly assist in raising this problem with the appropriate medical and government bodies. We would guarantee the confidentiality of any information you provided us.

The other medication article appears with compliments of the Pharmaceutical Guild of Australia. The Guild provides a free service where they assist people who take several medications to review what medications they take, when and how – with the co-operation of their doctor, of course. I have to take only one medication a couple of times daily – and I sometimes can’t remember whether I have or not. I can imagine how confused

I would get if I had to take several. This service can help you if that is what you do every day.

Some information about what is coming up. Later this year – on 29 July – we are having our major information day in Melbourne at the Camberwell Civic Centre. Put it into your diary. This is an opportunity for you to hear from – and ask questions of – a leading endocrinologist. This event is always very informative and popular. There will be more details in our next newsletter.

Other meetings are being organised by our local support groups in Brisbane, Perth, Canberra, Sale, Foster and inner Melbourne. This newsletter further contains details of all those.

Again, I would urge anyone living in Melbourne who wishes to help us – especially in the office to give our office manager, Brenda, a call. Here is a way you can get out of the house for a few hours a week and get to meet other people – and help others at the same time!

Meanwhile I hope you are all looking after yourselves and keeping well.

Christopher McDermott

THANK YOU to Alun Stevens

Following the annual general meeting in late 2006, Alun Stevens has decided to take a rest from his work with Thyroid Australia.

Alun – with his wife Megan – was instrumental in establishing Thyroid Australia back in 1999. Since that time, he has put an enormous effort – and very considerable time into the organisation. He has been President and Treasurer at various times and Company Secretary. These “behind the scenes” jobs, that most members would not be aware of, are crucial to the running of an organisation. The tasks are time consuming and not immediately or obviously rewarding.

Alun has also been the “webmaster” for Thyroid Australia since its inception. Most of you reading this would have visited our comprehensive website. Indeed, for many of you, your first contact with us was probably through our website. I am pleased that Alun will continue to manage the website.

Another important role that Alun has undertaken in the past is to give public talks on basic thyroid information. Many of you in Victoria – and in Queensland – may have attended these talks. The material he has presented has also formed the basis of the information used by our telephone volunteers – and in other education and public information initiatives we have undertaken.

I would like to thank Alun – on behalf of all our members and on behalf of the many hundreds (perhaps thousands) of people we have assisted over the last eight years - for all the work he has contributed to Thyroid Australia.

Alun will be spending more time on his business interests which have become – not surprisingly – very successful and much more demanding of his time. I wish him continuing success with his companies.

Christopher McDermott

RITCHIES COMMUNITY BENEFIT SHOPPING

Thyroid Australia would like to introduce to you a new way of being able to assist Thyroid Australia to remain in business and continue to assist thyroid sufferers, their families and friends.

The way Thyroid Australia can benefit from your shopping at a Ritchie's store is this: one per cent (1 %) of the total purchases made at a Ritchie's store is donated back to Thyroid Australia. This 1% donation back to Thyroid Australia occurs if a minimum of \$1,000 is spent at any Ritchie's store in a calendar month. The \$1,000 is a combined total of EVERYONE'S purchases made at ANY Ritchie's Store in the month. For example, if ten (10) people spend \$25 a week over the 4 weeks in one calendar month, this totals \$1,000, giving Thyroid Australia \$10. Of course, the more people using the cards and tags, the more money we receive. This total does not accumulate and re-sets at the beginning of the next month.

Ritchie's have over 4000 clubs, schools and organisations registered and involved in their CB program, of which many receive regular monthly donations through their members shopping at Ritchies. So far Ritchies have given away over \$19.2 million dollars.

If you would like to participate, please contact us and we will send you a Ritchies Community Benefit (CB) brochure, card and key tag for you or a family member or friend which can be used at any Ritchies stores throughout Victoria, and some parts of Queensland and New South Wales (a list of stores is contained in the attached brochure).

There are also a number of benefits to the CB shoppers by shopping at Ritchies and these are listed below.

We hope you consider this venture a wonderful way to contribute to, and support, Thyroid Australia. Should you have any queries, please contact me at the office.

PLEASE REMEMBER
We need your support to give ours

Best wishes

Brenda Stocks
Office Manager

Some extra benefits that Ritchies offer to their customers

- In our supermarket and liquor stores we have red ticketed items that are exclusive to Community Benefit cardholders whereby you receive these items at the cheaper prices.
- All of our Ritchies Stores have come on board with the petrol offer with either BP or United Petrol Stations. When you spend \$25 in purchases in any of our grocery or liquor departments you will receive the discounted offer at the bottom of your receipt.
- There is a 4 cent off saving of leaded/unleaded petrol and on gas as well.
- Ritchies offer our customers a variety of Australian owned products within our stores.
- Ritchies Liquor departments will match prices from any other leading liquor department. Just bring the catalogue in and get the item for the same price as well as your 1% being donated back to your club.
- Once you have a CB card or key tag either one can be used at ANY of our Ritchies Stores throughout the Metro, Mornington Peninsula, Country and NSW stores. The money donated still comes back to your organisation. For example if you are on holidays and staying in Rosebud or up at Yarrowonga you can use your card whilst there and your club will benefit.

RITCHIES
WHERE THE
COMMUNITY BENEFITS



Editor Update

Hi!!! Our names are Cornelia and Sue.

We will be your editors for this year's Thyroid Flyer. Robyn, your previous editor is having a well earned break so she can focus again on her family and take time out after writing her epic book (if you haven't yet ordered a copy, we highly recommend it. It is essential reading for anyone with hypothyroidism!)

Being your editor is definitely a very exciting yet challenging role as there are so many topics that the committee at Thyroid Australia wish to cover, but only these few pages every few months to cover them!!!

We hope to bring you a bit on the latest information relating to your thyroid condition, plus also a few hints and reminders that should be common knowledge, but may have been missed, even by our long term members.

If you are a new member, Welcome!! If you are an existing member, Thankyou!! Thankyou for supporting Thyroid Australia over the years. We hope you will remain a member for many years to come as we need your ongoing support as we receive no government funding (even I was surprised at that!)

Thyroid Australia is a not-for-profit organisation which was founded on the passion to provide leading edge information for people with a thyroid condition. It was founded by volunteers and is still run by volunteers.

Your membership enables Thyroid Australia to continue to provide the most up to date information to its members and maintain the legacy started only 8 years ago. The aim was to create an organisation that could help answer the two most common questions asked by people who have just discovered they have a thyroid condition, namely "Why me?" and "How can I get better?" Thyroid Australia was founded on the passion to provide support and information that assists in answering these two key questions. As noted previously, we often cover information that may not yet be currently covered in the CMI's of your thyroid medication.

Thyroid Australia is now referred to by medical organisations throughout the world, a testament to the long hours dedicated to sourcing and reviewing the latest medical literature by board members and the many volunteers. This information is reviewed by the Medical Advisory Committee for accuracy and relevance. The current board and committee look forward to continuing this legacy to ensure that Thyroid Australia continues to provide its members a service that is committed to their needs by providing timely and up to date information.

We look forward to having you on board as our members and readers and look forward to any feedback that you may have. Please e-mail me with your feedback and suggestions titled: "To The Editor" to e-mail: support@thyroid.org.au

Happy reading!!! Cornelia and Sue



Cornelia C Cefai BSc Hons MBA

I discovered 4 1/2 months after having my second baby that I had a thyroid condition. I had heard of thyroid conditions before, I even studied them while undertaking my Science degree at university, but always thought they were quite rare. Initially my reaction was, "Typical, my luck to get a rare condition!" Over the next few years I went to many doctors and did what they told me and life was sort of OK (well actually at times it was totally out of control!) but I tried to cope as best I could...that's what mothers do, don't they? I never discussed my condition with many people, I had a rare condition didn't I? So no need to bore others with my problem!

The crossroad for me was discovering Thyroid Australia. Immediately those many questions that remained un-answered were answered. Thyroid Australia provided me information that really made a difference and made me ask my doctors many new questions. Today my life has totally turned around! I often think I feel better now than before I was first diagnosed. Maybe I had been suffering from a mild thyroid condition all my life? Thankyou Thyroid Australia for all your help.

Also, I discovered my condition is NOT rare. In fact thyroid conditions are amongst the most common endocrinological condition faced by women in particular, of all ages. Hmmm...you can imagine I hardly keep my mouth shut these days regarding thyroid conditions. My family and friends have put up with me changing the topic of discussion so many times. Hmmm....not sure how much longer they will endure this? Maybe I can now turn this passion towards helping you as your editor? I look forward to sharing my passion for this topic with you and look forward to hearing your story. Please drop me a line and tell me how you found out about Thyroid Australia and how it changed your life! Till then take care!

Cornelia

Sue Shelly BSc

I was diagnosed with Hashimoto's 6-8 months after delivering my second child. My illness before diagnosis was brief by comparison to other thyroid patients. I could not comprehend how one failing gland could impact so heavily on every aspect of my physiological function.

My doctor had armed me with 15 minutes of information regarding the condition. I was overwhelmed and confused at the same time not understanding what it really meant. I had so many unanswered questions.

I logged on the Thyroid Australia website and sifted through information relating to my condition and was astounded to read how common it was in females and especially post partum. Armed with this information I began researching and promoting women's thyroid issues. Thyroid Australia and its volunteers have provided me with a wealth of knowledge and now its time to continue the journey into thyroid research to assist other members. I look forward to sharing research articles with you.

Sue

Member Story and Volunteer Update

If only I had gone to the doctor sooner!!!!

But what would I have told him or her?

“I am feeling tired, unwell, emotional”.....HMMMM?

My name is Irene and about three years ago I was feeling unwell and I had no “real” symptoms to complain about other than being tired and constantly emotional. I would often cry for no reason and could not concentrate for long periods and I forced myself to go to work. I didn't want to socialise with my friends, as I didn't feel like joining in laughter and pretended that I was happy. I felt I was a different and confused person and not the happy, bubbly girl who use to like being with people who are fun to be with and who made me laugh. Now all I wanted to do was cry and hide from everyone. When my husband or family asked me why I was crying or 'what's wrong?', my excuse was that I'm going through menopause and it is a hormonal thing, I also talked myself into believing it too, and that is way I didn't see a doctor sooner.

During this time my youngest son got married and I didn't see him for weeks at a time. His excuse was that they are too busy and for me it felt like - what I imagine to be - going through a divorce. For years you live together as a family and than one day they are gone. Then one day while cooking dinner I felt pain across my upper chest and the pain was strong enough for me to stop what I was doing and drove to my local doctor, as I thought it could be my heart. On examination I was relieved when the doctor said my heart was OK, but she sent me to have a full blood test. The results came back stating that I had 'severe hypothyroidism'. Now I had a reason why I was feeling so 'down and out'. I am taking Thyroxine daily and am feeling much better and am a happier person and have stopped crying!! I also have more energy and feel I am finding my old self again. Had I gone to see the doctor sooner, I would have been a lot happier!! Happy Irene!!

By Irene, January 2007

Call for Members Stories

Do you have a story to tell?

Your story could make a difference.

We constantly receive calls from new members noting how a member story has touched them and made them feel “not so alone.” Discovering you have a thyroid condition, or any condition for that matter, is often quite life changing. Many questions are asked. The most common are “Why me?” and “How can I get better?” Thyroid Australia was founded on the passion to provide support and information that assists in answering these two key questions.

Please send your story titled “Member Story” to:

email: support@thyroid.org.au

mail: TA, 333 Waverley Rd. Mount Waverley VIC 3149

Note, your story does not need to be very long. A few paragraphs is often plenty! We look forward to hearing from you.

Office Manager Profile

Brenda is our office manager based at Mount Waverley, Melbourne. Though not technically a volunteer, the work Brenda does is invaluable to Thyroid Australia.

Brenda is married with a 6 year old daughter. When Brenda's not working in the office, she enjoys going out for dinner, going to the movies, going for long, energetic walks, and traveling.

Brenda is situated at our office in Mt Waverley and responds to all emails, phone calls, processes memberships, keeps track of our financial situation, responds to all enquiries, and anything else that crops up from time to time.

Brenda is in desperate need for volunteers to help in the office for a variety of tasks including photocopying, collating, filing, database entry, and all manner of office administration.

If you have an hour or two spare on a weekly, fortnightly or monthly basis, Brenda would love to chat to you about working in the office, to assist with the growing duties.



Thyroid Australia

Ulysses Butterfly Pins

Show your support for Thyroid Australia by wearing a Ulysses Butterfly pin.

Beautifully made in pewter and enamel by craftsmen in Ballarat. Suitable for men and women.



Centre section is bright blue.

Cost: \$7.00 (includes \$2.00 postage and packaging).

Send us your name, address, and a cheque or money order for \$7.00 (please, no cash or credit card payments) and we will get a pin out to you as soon as possible.

TELEPHONE SUPPORT VOLUNTEERS

These Thyroid Australia members have agreed to support others with thyroid conditions in their times of need. They follow our guidelines in an effort to provide reliable information to callers. Telephone Support Volunteers are generally not medically trained, but they will provide a personal viewpoint based on their own experience. The names of the Volunteers are given on the left according to the conditions with which they can assist. Their phone numbers, and their contact times are given on the right.

Please be considerate about when you ring. No calls on Sundays please. Our Volunteers also have family and business responsibilities and might not be available when you call. They will return your call if you leave a message when requested to do so.

	Name	Phone Number	Monday - Friday	Saturday
Hypothyroidism				
Kay Laurel Madeline	Christopher	(03) 9417 1720	7.00pm - 9.00pm	10.00am - 8.00pm
Michele Rick	Cornelia	(03) 9431 6414	7.00pm - 8.00pm	12.00pm - 4.00pm
Hashimoto's Thyroiditis (HT)	Gail	(03) 9850 3854	6.00pm - 8.30pm (Mon-Wed only)	
Gail Kay	Geri	(03) 9822 1942	10.00am - 4.00pm	
Liz Rick	Jane	(03) 9597 0426	10.00am - 4.00pm	12.00pm - 4.00pm
Hyperthyroidism	Jenny	(03) 5689 1251	10.00am - 8.00pm	
Christopher Jenny	Julie	(03) 9764 2426	8.00pm - 9.30pm	10.00am - 8.00pm
Karen Maria	Karen	(03) 9380 8505	10.00am - 4.00pm (Mon-Thur)	10.00am - 4.00pm
Graves' Disease (GD)	Kay	(03) 9560 4688	3.00pm - 8.00pm	3.00pm - 8.00pm
Christopher Jane Karen	Laurel	(03) 5255 1436	10.00am - 4.00pm	
Jenny Maria Lisa	Lisa	(07) 5529 9840	7.00pm - 8.00pm	10.00am - 8.00pm
Thyroid Hormone Replacement	Liz	(03) 9370 1568	7.00pm - 9.00pm	10.00am - 8.00pm
Kay Gail	Madeline	(03) 5144 4470	1.00pm - 5.00pm	
Liz	Margaret	(03) 9741 2524	7.00pm - 9.00pm	7.00pm-9.00pm
Antithyroid Medication			or (03) 5158 0308 if unavailable at above number	
Christopher Jenny Karen	Maria	(02) 9832 3958	6.00pm - 9.00pm	1.00pm - 5.00pm
Congenital Hypothyroidism	Michele	(03) 5821 6681	10.00am - 4.00pm	12.00pm - 4.00pm
Julie Sara	Rick	(07) 3808 4961	7.00pm - 9.00pm (Mon-Wed)	
Thyroid Eye Disease (TED)	Sara	(03) 5342 0023	10.00am - 4.00pm (not Wed or Thurs mornings)	
Jane Karen	Sue	(02) 6259 5342	7.00pm - 9.00pm (Mon&Tues)	10.00am-4.00pm
Margaret Maria	Sue H	(02) 6278 3348	7.00pm - 9.00pm	7.00pm - 9.00pm
Eye Surgery				
Margaret				
Psychological Concerns				
Geri				
Post Partum Thyroid Problems				
Sue H Cornelia				
Radioactive Iodine (RAI)				
Sue				
Thyroid Cancer				
Geri				
Thyroid Surgery				
Jane				

We would like to expand our list of Telephone Support Volunteers and need more members willing to share their experiences. We provide all Volunteers with a pack of reliable information as well as access to the articles on the Publications List. New Support Volunteers are asked to attend a short workshop to ensure that everyone works off the same knowledge base, and to allow them to gain some insights from others who have been performing this task already. Suitable arrangements will be made for those members from outside of Melbourne.

If any member would like to help us as a Telephone Support Volunteer, please leave a message for our Telephone Contact Coordinator on (03) 9888 2588 (10am to 3pm, most weekdays) or send an e-mail to support@thyroid.org.au

Office Volunteers Required



Thyroid Australia is always in need of regular office volunteers. There are a variety of jobs to choose from, such as basic filing, compiling information packs, database entry, answering calls, preparing mailouts and photocopying. Please contact our office if you have some time to spare and are able to help in any of these areas. Volunteer help is vital for the running of this organization.

Thyroid Flyers generously supported by

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www.massattack.com.au

Solving your weight loss puzzle

Dates for your diary - Meetings and Support Groups

We hope everyone had a peaceful and enjoyable Christmas and a well earned rest over the summer period. Below are the dates for meetings throughout Australia for 2007. If you are planning a meeting, please let Brenda know and it can be added to our next newsletter.

Please cutout this page and pin it to your notice board or fridge — NOW!

Brisbane

Venue: Prince Charles Hospital,
Education Centre Conference Room,
Rode Rd, Chermside, QLD, 4032
(Enter via Webster Rd)
1st Sunday of the month
March through October

Workshop/Support group

2.00pm to 4.00pm
March 4, May 6, July 1, Sept 2

Seminars with guest speakers

2.00pm to 4.30pm
April 1, June 3, Aug 5, Oct 7
NOTE: Sunday 3rd June
'Thyroid Disease Health Concerns'
Speaker: Robyn Koumourou
Author of book "Running on Empty"
Bookings essential!
Contact Thyroid Australia

Gold Coast / Tweed Heads

Dates not yet announced for 2007
Contact Thyroid Australia

Perth

First meeting 2pm, Sat, 14 April
For more details contact -
thyroidwa@inet.net.au

Canberra

Contact Thyroid Australia if you are interested in attending meetings in Canberra on a regular basis as there are a few people keen to get a group started

Melbourne

Annual meeting
Camberwell Civic Centre
29th July 2007

Annual event not to be missed
Invite family and friends
More details in next newsletter

Inner Melbourne

Nth Carlton Railway Station
For more information contact Thyroid Australia

Sale

Central Gippsland Health Services,
Community Meeting Room
Support Group Meetings 2007
May 9th, Aug 8th, Nov 14th
For more information, please contact
Madeline 51 444 470,
or Nola 51 442 305

South Gippsland

Foster Community Health Centre
93 Station Rd, Foster, VIC
Support Group Meetings
Fourth Monday of Each Month 10.30am
Contact Thyroid Australia

Annual Melbourne Meeting

Camberwell Civic Centre — 2007

Any health or community organization or business wishing to have an information stall at our Information Day on 29th July, please contact the Thyroid Australia office on (03) 9888 2588



Please copy or detach and mail to the address below. Or email to address below with "New membership" in subject heading

Request for Membership Application Form and Information

I am interested in learning more about my thyroid condition and about Thyroid Australia.

Please send this information to:

Title: Name:
Address:
..... Phone:.....
Date: Signature:.....

Disclaimer

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THYROID AUSTRALIA LTD

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