

THYROID PATIENT ADVOCACY UK SPRING (2009) NEWSLETTER



TPA-UK ANNUAL 'GET TOGETHER' 18TH APRIL 2009

We still have some spaces left for anybody who would like to attend our Annual Jamboree in Yorkshire. This is becoming an extremely popular event and is a chance for us all to meet other members and our medical advisers, Dr Barry Peatfield and Dr Gordon Skinner – and this year, to also meet Afshin, the owner of International Pharmacy who is coming all the way to meet us from the USA.

For those coming from afar, there is a list of accommodation for Bed and Breakfast in Guest Houses or Hotels. Most of the accommodation in the village has been booked, but there are still places a couple of miles down the road from my home.

Accommodation list on the last page of the Newsletter.



Squirrel Cottage

For those staying overnight, we can all meet up for coffee at my cottage at 10.30a.m. or thereabouts. The address of my home is **Squirrel Cottage, Ickornshaw, Cowling, Nr Keighley, BD22 0DH, North Yorkshire** Tel: 01535 636014. We will then travel to Keighley (sharing cars because of parking difficulties) to meet with everybody else at 'Alfe's Restaurant', Church Green, Keighley, at 12.00p.m. Al has acquired some land at the back of his Restaurant for his customer's private parking – so please park tidily so we can get as many of you parked there as possible.



'Alfe's Restaurant' specialises in Thai and Chinese Food. We have a choice of a three course buffet (£8.00 per person) or you may wish to choose something from the set Menu. If you would like English food only, or you require a special diet, Al will be happy to arrange this so long as you give him prior notice. It is VERY important that everybody contact Al to book

your meal of your choice, and at that time, he may require a deposit. Although this is a very informal occasion, Al still needs to know how many of us need to be catered for and his Chef needs prior notice of what to cook. To this end, please check out Alfe's restaurant: <http://www.alfes.co.uk> where you can check out the Menu and choose what you would like to eat.

You can also check out what is included in the 3 course buffet. You should contact Al via Email contact: alfes@googlemail.com or by telephone to place your order (01535 613888). At the same time, please also let me know also if you will be attending and whether you will be bringing with you a partner/friend etc, as we need to know the number of people who will be attending. Click on 'Gallery' to look at the restaurant (which we have taken over from 12.00 noon until 5.00p.m. You can also check the 'location'. His new car park lies directly behind his restaurant for the use of his customers only – and he is allocating the whole of this to TPA-UK. Access to this is down the little entrance at the side of his building.

TPA-UK ANNUAL 'GET TOGETHER' 18TH APRIL 2009

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We are meeting at the Restaurant at 12 Noon and lunch will be served almost immediately. After lunch, Dr Peatfield will give a talk about the Palaeolithic Diet and Dr Skinner will talk about the recent unhappy event brought about by the Royal College of Physicians and BTA et al drawing up the new guidelines on the diagnosis and the management of primary hypothyroidism and probable implications that might arise. There will be a question and answer session to follow, which I imagine could be quite heated. If you have any questions concerning your orders from International Pharmacy, Afshin will be happy to answer them.

To try to get in as many questions and answers in as we can, we have decided that this year, if you have a specific questions, please send them to Lilian at lilian15@ntlworld.com. Any questions arising at the time, you will, of course, be able to ask.

We also thought it would be good if we could type up all the questions and answers after the meeting and post them on the forum in case these would be of benefit to other members unable to attend the function. To this end, if you (or anybody you know) have any form of recording machine which would 'fit the bill', and you are willing to give us access to this for the day, we would be very grateful. Again, please contact Lilian if you can help.

I can promise that for those of you who have never attended our TPA-UK annual jamboree, you will not be disappointed. We have members coming from all corners of the UK (and beyond). Have a look at some of the photo's that were taken last April (These are in the Photo's section of our Forum website.

For those who will be staying in overnight accommodation, on Friday evening (17th) I have booked a large table at 'The Alma' so for those who wish to join us, please let me know as quickly as possible so we can book a place for you too. The Alma is a beautiful place just a couple of miles down the road from our cottage. Have a look at their web site <http://www.thealmainn.com/>.

The Alma Inn at Laneshawbridge



I have booked the table for 7.30. Friday evening. You don't have to have a meal, and if you just want to meet up for a social gathering, that would be great – but I for one will be eating – their food is exquisite and reasonably priced.

After we leave Alfe's on Saturday evening, anybody who wishes to join us is also welcome at Squirrel Cottage where we can continue with the chat, have a glass (or two) of wine and nibbles.

We look forward to meeting you all and if you have any questions meanwhile, please get in touch with me.

DR PEATFIELD'S METABOLIC CLINIC

Sunday, Monday and Tuesday (19th-21st April).
Squirrel Cottage, Ickornshaw, Cowling, Nr Keighley BD22 0DH.



We still have some spaces left (main on Tuesday 21st April if anybody would like a consultation with Dr Peatfield. His Fees are £140 for a one and a half hour consultation. This covers up to 3 follow up telephone consultations. Please let me know as soon as possible if you would like to see him. You can see his other clinic venues by visiting our web site www.tpa-uk.org.uk and on the Home Page, look in the right hand column under 'Update: Dr Peatfield's clinics'.

ROYAL COLLEGE OF PHYSICIANS, BRITISH THYROID ASSOCIATION et al., NEW GUIDELINES ON THE DIAGNOSING AND MANAGEMENT OF PRIMARY HYPOTHYROIDISM

Most of you will be aware that the above organisations have published new guidelines on the diagnosing and treatment of primary hypothyroidism. These guidelines should be advisory, NOT mandatory, but there is a big question mark over this at present. You can read the details in our website www.tpa-uk.org.uk under 'TPA-UK NEWS' in the right hand column.

The President of the British Thyroid Association (BTA), said in the RCP press release: "This statement, supported by a large number of patient and professional groups, gives a clear indication to patients and their doctors how their thyroid condition may be best diagnosed and treated".

This statement is false: The RCP has failed to consult those patients in diametric opposition to the guideline in the UK. Such groups include 'Thyroid Patient Advocacy-UK' www.tpa-uk.org.uk, 'Thyroid-UK' www.thyroiduk.org and 'Thyroid Disease' www.thyroid-disease.org.uk to mention just three, who, between us, represent thousands of such sufferers in the UK. There are also hundreds of smaller local thyroid support groups in the UK who were never consulted.

In our TPA-UK survey of 1500 hypothyroid patients undertaken in 2005-2006, the dissatisfaction of many patients is highlighted. This survey has very good credentials that it points to inconsistencies within the data presented by the RCT, BTA et al., as being 'definitive'. We are asking the RCP, BTA et al., why they have chosen to take no account of these statistics when a copy was sent to Professor Anthony Weetman in 2006 (then President of the BTA) and every member of the BTA Executive Committee. The BTA never acknowledged receipt, nor have they ever taken these statistics into account before publishing the new guidelines. This UK hypothyroid survey MUST be held up as valid, contradictory evidence to the RCP guideline as the figures speak for themselves.

**ROYAL COLLEGE OF PHYSICIANS, BRITISH THYROID ASSOCIATION et al.,
NEW GUIDELINES ON THE DIAGNOSING AND MANAGEMENT OF
PRIMARY HYPOTHYROIDISM continued**



Of 1500 respondents, 93.8% (n=1407) had not been told of medicines other than L-thyroxine by their medical practitioner. 38.8% (n=768) felt they had “not been dealt with very well” or “not very well at all” by their doctor whilst seeking a diagnosis of their symptoms; 233 (15.5%) had given up paid employment; 300 (20%) had taken time off work as a result of thyroid illness; 500 (33.3%) felt their close relationships had been affected by thyroid illness and 632 (42.1%) had stopped or altered their exercise routines as a result of their symptoms. When asked of those patients undergoing L-thyroxine therapy, “Do you feel that you have fully regained your optimal state of health?” a staggering 1176 (78.4%) answered “NO”. What did the BTA say in reply? – NOTHING!

I have written to ask the President of the Royal College (Sir Ian Gilmore) if he would meet with a small group of such representatives from these organisations who are in diametric opposition to these guidelines as we feel it only fair we should be given the opportunity to discuss our concerns with him.

I will let you know his response.

**SENDING A RESPONSE TO THE ROYAL COLLEGE OF PHYSICIANS
REGARDING YOUR THOUGHTS ON THIS NEW GUIDELINE AND THE
EFFECT IT MIGHT HAVE ON YOU.**

If you have previously written a response or a complaint to the Royal College of Physicians, please would you send a copy to me if you wish Lee to publish it on our web site? We feel this could be a very important move to show the world that we are doing what we can to open some dialogue between patients, doctors and the Royal College. We need to show this in case the RCP fail to take any account of our comments or complaints – which the British Thyroid Association has failed to do to date. Those who are opposed to these guidelines must be given the opportunity to be heard and we hope the RCP will give us the answers to our questions. As far as I am aware, the RCP have not responded to anybody’s specific comments or complaints yet, and only sent out a standard letter to everybody acknowledging receipt (see below for more details of this).

If you do not wish your name and address to be shown on your particular response, we will remove it. Please will you send a copy to sheila@tpauk.com

We have been told that the Royal College of Physicians has been inundated with responses and complaints, and Linda Cuthbertson (PR Manager) RCP has been sending the following message to everybody:

“The Royal College of Physicians reiterates that it has produced a position statement on hypothyroidism, endorsed by other organisations and based on the best available clinical evidence. It is the College as a whole, and the other organisations, not individual members of committees, that take responsibility for the guidelines, therefore it is not appropriate to supply details of individuals who have approved the guidelines as their contributions will vary widely.

The College is not able to comment on or investigate the care of individual patients, as this is the responsibility of the patient’s own GP or consultant.”

**SENDING A RESPONSE TO THE ROYAL COLLEGE OF PHYSICIANS
REGARDING YOUR THOUGHTS ON THIS NEW GUIDELINE AND THE
EFFECT IT MIGHT HAVE ON YOU continued**



This is an appalling statement from the RCP and we must bring to their attention the Royal College of Physicians' "Clinical Guideline on Radioiodine in the management of benign thyroid disease. <http://www.rcplondon.ac.uk/pubs/contents/0621b67a-4880-4a1b-9942-57a666e-fee4a.pdf>

We must all ask the RCP WHY the public is being denied the names of the individuals who made up the working party involved in the drawing up of the guidelines on the Management of Primary Hypothyroidism when all the names of the working party involved in the Radioiodine guidelines were published. The Royal College of Physicians must have a standard format for issuing ALL Guidelines and these should be followed throughout. The Chair Person of that working party was the ex-President of the British Thyroid Association, Professor Tony Weetman!

Tony Weetman (Chair)

*Dean, School of Medicine and Biomedical Sciences, University of Sheffield;
British Thyroid Association*

Mary Armitage

*Consultant in Endocrinology, Royal Bournemouth Hospital; Clinical Vice President,
Royal College of Physicians of London*

Sue Clarke

*Consultant Nuclear Medicine Physician, Guy's Hospital; Joint Specialty Committee
on Nuclear Medicine*

John Frank

*Consultant in Nuclear Medicine and Radiology, Charing Cross Hospital; British Nuclear
Medicine Society*

Jayne Franklyn

Professor of Medicine, University of Birmingham; British Thyroid Association

Peter Lapsley

Patient and Carer Network Representative, Royal College of Physicians of London

John Lazarus

Professor of Clinical Endocrinology, Cardiff University; British Thyroid Association

Val Lewington

*Consultant Nuclear Medicine Physician, Royal Marsden Hospital; Joint Specialty
Committee on Nuclear Medicine*

Susan Owens

*Consultant Clinical Scientist, Christie Hospital, Manchester; Institute of Physics
and Engineering in Medicine*

If you have previously sent a response to the RCP, please will you write to them again and ask WHY as much care was not afforded to this latest Guideline as the care given in the Guidelines for Radioiodine in the Management of Benign Thyroid Disease, which cited 70 references to back up their scientific evidence. Such a professional organisation such as the RCP SHOULD NOT BE ALLOWED TO PUBLISH OPINION ONLY - as 'OPINION ONLY' has been published in the Management of Primary Hypothyroidism Guideline. This is a dangerous practice and can be dangerous for patients.

If you do not get a satisfactory response, please write to them again. We must keep on and on and on writing to the Royal College of Physicians insisting they give us satisfactory answers to our questions. Please send an Email to the Royal College of Physicians PR Manager Linda.Cuthbertson@rcplondon.ac.uk

FOR ALL NEW MEMBERS – PLEASE READ



If you opted to receive messages by 'Individual Emails', you may, no doubt, be already regretting that decision. This forum has an enormous amount of traffic, and your Inbox is probably bursting at the seams. We received almost 3000 messages last month alone. So if you would rather receive a Daily Digest (meaning you can get up to 25 messages in ONE Email, or you would rather read and write direct from the website only) go to the Home Page of the forum website: <http://health.groups.yahoo.com/thyroidpatientadvocacy> and you will see just above the broad dark green bar at the top of the Home Page, the words "Edit my Membership". To read and write direct from the forum web site, please opt to receive 'Special Notices' only, otherwise if you chose to receive 'No Emails' you will not receive any notices from me or Lee such as these Newsletters.

In the window, click the bullet point of how you would like to receive messages. Don't forget to click "Save this Change". This should save those of you who do not want to receive Individual messages a great deal of frustration. If you have Outlook Express, if you wish, you can create a separate folder within your inbox and get all the messages from TPA to automatically go into that folder, then you need go to that folder as and when you wish. The instructions on how to do this are in the FILES in our forum website.

TPA-UK INFORMATION PACK

TPA-UK has developed a 56-page Information Pack that provides comprehensive information on all aspects of hypothyroidism, including the symptoms, signs, diagnosis, tests and treatment of hypothyroidism. If you have members of your family or friends who are suffering the symptoms and who do not have access to the Internet, this Pack can be ordered by downloading and printing out the information pack order form http://www.tpa-uk.org.uk/info_pack.php.

Please fill out the form and enclose your cheque for £7.00 OR, you can now also order the TPA-UK Information Pack online. Simply send us an email containing your request, along with your name and postal details. Then, log into your PayPal account (or register with PayPal to make online payments and send/receive money) and send your payment for £7.00 to: sheilaturner@tpa-uk.org.uk



Your chance to help support Thyroid Patient Advocacy-UK

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FREE UK DELIVERY

Free prescriptions for sufferers of hypothyroidism



If your doctor has not told you, please be aware that once you have been diagnosed with hypothyroidism, you are entitled to receive all of your prescriptions free of charge. This means any prescription, not just those for thyroid hormone replacement. In addition, anyone needing regular prescriptions (other than thyroid) may save money by buying a Prescription Prepayment Certificate. This article highlights who is entitled to receive free prescriptions, as well as lists the medical conditions that qualify for an exemption certificate.

Update on the availability of Armour Thyroid

All the larger grains of Armour Thyroid, USP are now available from International Pharmacy. The tablets are different, they don't have the usual 'piggy' smell but the potency remains the same.

We are concerned to learn that many packages are now being stopped at Customs and VAT is being charged. The value of the goods has now to be written on the outside of the package and anything over the price of £18. A customs charge of £8 is now being charge on some packages. These packages are being delivered to the Royal Mail who are adding a further handling charge and sending a card to customers telling them they can collect their package from the Post Office after they have paid a fee of £16 (some cases, even more).

We are trying to sort out the best way of avoiding these extra charges if this is at all possible. To this end, if your order has been delayed because it is being held by the Post Office and you have been asked to pay the fee, unless you need the tablets desperately, we are recommending you leave the package where it is and write to the overseas pharmacy concerned telling them what has happened and ask them if they will send you out a fresh order urgently. The other package will be returned to them automatically in 20 days if it is not collected. Hopefully, the second order should escape customs. It does seem the customs are carrying out their services with great vigour recently.

Make absolutely sure that you order the medication you need well in advance so you don't run the possibility of running out.

**BED AND BREAKFAST ACCOMMODATION AVAILABLE
FOR TPA-UK
GET TOGETHER – 17TH AND 18TH APRIL**



Woodland House (Susan and Sandy Black) – 2 Woodland Street, Cowling,

tel: 01535 637886 (1 twin, en suite available) £26.50 per person per night. The price includes full English breakfast

(half a mile from Squirrel Cottage)

<http://www.nationaltrail.co.uk/PennineWay/site.asp?Pageld=30&SiteId=153&c=1>

Winterhouse Barn (Alwyn and Tony) tel: 01535 632234. Keighley Road, Cowling. 2 twin rooms with shared facilities £35 double room with big English breakfast

(half a mile from Squirrel Cottage)

<http://www.thepennineway.co.uk/winterhousebarn> (FULL)

Cononley Hall (Pam and Andy McGregor) – Main Street, Cononley, Nr Skipton, BD20 8LJ tel: 01535 633923. £40 per person per night with full English breakfast. £10

supplement for single occupancy. If you stay three nights or more £35 pppn.

(about 3 miles from Squirrel Cottage)

cononyhall@madasafish.com

<http://www.cononleyhall.co.uk>

Pickersgill Manor Farm (Lisa Preston) – Low Lane, Silsden Moor, Silsden, West Yorkshire BD20 9JH tel: 01535 655228. Three large rooms - £30/32 per person per

night based on 2 sharing and £35/40 single occupancy. Includes hearty breakfast.

(about 7 miles from Squirrel Cottage)

<http://www.pickersgillmanorfarm.co.uk>

Rye Flatt Farmhouse (Marion Knowles) – 20 School Lane, Laneshawbridge, Colne, Lancashire BB8 7JB tel: 01282 871565. Two double Rooms - £30 per person per

night with full English breakfast. No single room supplement.

(about 3 miles from Squirrel Cottage)

<http://www.rye-flatt.co.uk>

Middle Beadshaw Head Farm – Burnley Road, Trawden, Nr Colne, Lancashire BB8 8PP tel: 01282 865257. Four bedrooms. Double/Twin £50/55 per person per room

with full English breakfast. Single £25/27 per room with breakfast. Email: Ursula@mann1940.freeserve.co.uk - <http://www.a1tourism.com/uk/midbeard.html>

<http://www.a1tourism.com/uk/midbeard.html>

The Dalesgate Hotel - 406 Skipton Road - Utley, Keighley, BD20 6HP tel: 01535 664930. They do single rooms £40 for room + breakfast - £60 double room + full English breakfast. (7 miles from Squirrel Cottage) <http://www.dalesgate.co.uk/main.htm>

<http://www.dalesgate.co.uk/main.htm>

Steeton Hall Hotel – Steeton: Can do single £55 room + full English breakfast.

Double £65. Family Room £80. If three or more rooms are booked whether single or

double) he will do the lot at £50 per room. <http://www.yorkshire-breaks.co.uk/propde-tails.cfm?PropID=2635>

<http://www.yorkshire-breaks.co.uk/propde-tails.cfm?PropID=2635>

The Alma Hotel - Emmott Lane, Laneshawbridge, Colne. Phone 01282 863447

from £65.95 single en suite - £79.95 double en suite - hearty breakfast,

(3 miles from Squirrel Cottage).

<http://www.thealmainn.com/Default.aspx>