



TENOVUS SCOTLAND
SUPPORTING MEDICAL RESEARCH

• NUSOVUS •

Patron HRH The Princess Royal

Hon President: The Rt. Hon. The Lord Macfarlane of Bearsden Chairman: Professor Sir Roddy MacSween

Chairman's Comments

Having very recently completed my Chairman's Report for our 41st Annual General Meeting I had to give some thought as to what, if anything new I could contribute as comment for Nusovus. The Annual Report in general remained up-beat but as a background to our continued achievements in providing 'pump-priming/starter' grants to young researchers, there were notes of caution and even to some concern about our future in the light of the credit crunch, recession, the collapse in the stock markets and the consequent likelihood of a serious fall in income. I am no financial guru (as these observations are likely to confirm) but it seems to me we require to look carefully at our overall financial position and how best to deal with the problems both at the national and regional levels. Mr Peter Roger our new Treasurer and our investment manager advised the National Committee in May that we should continue to hold the major share of our reserves in equities and that in respect of bank deposits, the rates of interest will rise due to the Government's huge funding requirements. On these issues we will require to be guided by our experts.

Charity giving in Scotland was down by some 8% in 2008, and in addition givers are becoming more concerned as to what uses their donations are being put. Some charities are being offered donations in kind and while one can readily think of situations where this would be appropriate Tenovus Scotland will remain cash-dependent. We must be prepared to openly indicate how donations are used and to demonstrate our achievements on a regular basis. This might require regular ‘open days’ for our potential and current financial supporters; we should continue identifying projects for which we might make direct approaches to some Charitable Trusts or financiers to provide funds for support in some specific areas; the quid pro quo might be that we would have to indicate that such and such a project was funded by Tenovus Scotland with financial support from such a Trust or entrepreneur. I do not have problems with this approach, but I realise that it might require the setting up by all regions of ‘Regional direct approach’ groups in addition to events committees. There is maybe a need for all of our treasurers to arrange a get-together to consider these matters.

Let me say that in preparing my Chairman’s Report I was aware of the continued enthusiasm at regional level and that morale remained high. The above suggestions are meant to address the seismic changes being enforced in the role of charities such as Tenovus Scotland.

Roddy MacSween

Genes - not stones - can break your bones

*Stuart H Ralston MD, FRCP, FRSE, ARC Professor of Rheumatology,
University of Edinburgh – Winner of the 2008 Margaret MacLellan
Award*

Bone diseases are prevalent throughout the world, affecting all ages and ethnic groups. Osteoporosis is the most common bone disease, which is estimated to affect about 30% of women and 12% of men at some point in life. In this condition, there is loss of bone tissue with increasing age, which causes thinning of the bones and impairs the skeleton's ability to withstand the stresses and strains of daily life. This leads to the development of bone fractures which cost millions to treat each year and cause disability and suffering for those affected.

Another bone disorder that is particularly prevalent in the UK is Paget's disease of bone which affects about 2% of people over the age of 55. In this condition, the normal process by which bone tissue is renewed and repaired runs out of control. As a result, the affected bones become enlarged and softened, leading to deformity, arthritis and an increased risk of bone fracture. Sometimes, the bone enlargement exerts pressure on the nerves of the spine and skull, leading to paralysis, deafness or blindness. Although Britain is the "world capital" of Paget's disease, the condition is also common in countries where Britons have emigrated such as Australia and New Zealand, strongly suggesting that it is caused by a "faulty gene" as I will discuss later.

A variety of rare bone disorders have also been identified in which the bones are abnormally thin and fragile (like a severe form of osteoporosis)

or abnormally dense and thickened. The diseases associated with thinning of the bones cause fractures but at an earlier point in life than is typical in osteoporosis. Although one might expect the bone to be strong in diseases associated with thickened bones this isn't always the case. In some of these diseases, the bone is not laid down in an organised manner and because of this it is weaker than normal.

These diseases illustrate that in the case of bone metabolism (very much like the temperature of the porridge in Goldilocks and the three bears) you don't want too little and you don't want too much, you want just the right amount.

Many factors influence the way that our bones are modelled and repaired including our diet, the amounts of exercise that we take, levels of sex hormones, and certain drugs treatments – particularly steroids which are used in the treatment of asthma and inflammatory diseases.

However the genes that we inherit from our parents are one of the most important determinants of susceptibility to bone disease. I first became interested in the role of heredity in bone disease when working with Dr Iain Boyle at Glasgow Royal Infirmary in the early 1980's. There, I had encountered many patients who had a family history of bone disease, or in whom bone disease had developed at an early stage in life, suggesting that genetic factors may have played a role in the disease occurrence.

Full of enthusiasm, I attempted to secure funding from the Wellcome Trust to pursue the idea that osteoporosis might be due to inherited defects in one of the genes that makes collagen – the major protein of bone. Unfortunately, the project was rejected being considered unlikely to succeed and “long shot”. Undeterred, I applied to *Tenovus* for pilot funding. To my delight, my application was successful and the results of the pilot studies were positive. With this data, I was able to obtain further funding and the work eventually led to the identification of a common variant in one of the collagen genes that predisposes to osteoporosis and bone fractures. Although this was one of the first variants to be associated with osteoporosis, it is now known that variations in a large number of

genes play a role in the disease. Testing for one of these genetic variants on its own is unlikely to be informative for the diagnosis of osteoporosis, but as more genes are discovered there is the prospect that multiple genes could be tested in a microchip which might allow us to detect people at risk of developing osteoporosis before the disease has become too advanced.

Paget's disease of bone is another condition where genes play a crucial role. Unlike osteoporosis it looks like Paget's disease is caused by abnormalities in a small number of genes (perhaps 4-6) any of which can cause the condition. One gene has been identified in particular (called "*SQSTM1*") which is highly predictive of developing Paget's disease. What this means is that it is possible to test for the presence of *SQSTM1* abnormalities in the children of people with Paget's disease and find out who in the next generation is at risk of developing the disease. We are currently working on a project to do this which is funded by the MRC and ARC. In this study, we are offering children of patients the opportunity to undergo genetic testing and take part in a clinical trial. This will involve giving the children "at risk" of Paget's active treatment or a dummy treatment to see if we can prevent the disease occurring. This is truly an exciting project and a real example of "bench to bedside" research.

The final group of diseases I should mention are the many rare bone conditions, which often start early in life during childhood or early adulthood. These diseases have devastating consequences for those affected in predisposing to fractures and causing bone deformity. The genetic abnormalities which underlie most of these diseases have now been discovered, so we know why they occur.

There have been tremendous advances in understanding the genetic factors that predispose to bone disease over the 25 years or so since I obtained my first *Tenovus* grant. Unfortunately advances in treatment have not kept pace and a major challenge for the future will be to translate our improved understanding of disease causation into a better outcome for the patients. That is one of the key objectives that I wish to pursue in the years to come.

Round Up

Edinburgh

Visit to Colon Cancer Genetics Group

Members of the Edinburgh Regional Committee were invited to the Western General Hospital to view some of the important research work carried out by Dr Richard Brady on *Investigation of*

the role of SRC a cancer protein in the anti-tumour effects of aspirin in colon cancer.

Extremely informative illustrated talks on the research work funded by Tenovus Scotland were delivered by Professor Malcolm Dunlop, Dr Lesley Stark and Dr Richard Brady. Kay Rich presented Dr Brady with a Tenovus Plaque.



Left to right:- Dr Niall Finlayson, Professor Malcolm Dunlop, Mrs Kay Rich, Mr James Watson, Dr Lesley Stark, Dr Richard Brady and Dr Donald Bain.

Grampian

Following a successful wine tasting dinner held at the local Royal Northern and University Club on 24 April 2009, friends, family and supporters were entertained by a rather exclusive 3-course dinner with coffee. The key issue here was that a number of people not familiar with Tenovus and its activities were introduced to the concept of the charity and its support of basic research in the North East.

In May a sale of garden plants was held at the Kingswells venue near Aberdeen and again produced not only a profit for the charity (more than £1,800) but a substantial local introduction to residents for the application of funds to local medical research.

Currently (and as we go to press) the annual Tenovus Trophy, a golf event to be held on Thursday 13 August 2009 at the Inchmarlo Golf Club and Resort on Royal Deeside is underway and teams of four players will be competing eagerly for the attractive silver trophy. Enquiries for the event (teams of 4) should be directed to Margaret Krukowski (*email: d1mak@hotmail.com*).

Further plans are afoot in collaboration with Peter Goodfellow and the Lost Gallery in Strathdon to organise another art exhibition with champagne and canapés at a central Aberdeen location. It is anticipated that this will attract a round of new friends and supporters for an artistically geared event.

In addition, Tenovus Grampian has secured the services of Peter Goodfellow, our local supporting artist to produce a range of Christmas cards, the final one of which will be selected by the National Committee in the early Autumn prior to sales nearer Christmas. All of this encourages not only local participation but national recognition of the importance of the charity in fund raising during periods of current financial difficulties for all charities in Scotland.

Strathclyde

Two trees, with commemorative plaques, have been planted to celebrate the 40th anniversary of Tenovus Scotland, one at the University of Glasgow by Sir

Kenneth Calman, and the other at the University of Strathclyde by Lady Arbuthnott.

We are very pleased to report that over £3,000 was raised from the most recent fundraising event organised by our Events Committee. This was a “Sparkling Afternoon Tea” in mid-June, where our friends were served delicious sandwiches and cakes in a stunning family home in Thortonhall and were able, in between the showers, to explore the beautiful and extensive gardens. The event was extremely well attended and hugely enjoyed by all. Stalls selling stationery items, bags, jewellery and artificial flowers, were an added attraction.

Our next event will be a Quiz Night at the Hughenden Clubhouse, Hillhead Sports Club, on Friday, 23 October. This promises to be a fun-filled evening and we hope that as many people as possible will attend and be prepared to put their general knowledge to the test to raise funds for Tenovus Scotland. If you would be interested in attending please contact Mrs Sue Ogden on 0141 221 6268 or e-mail her at stra.sec@tiscali.co.uk for further information.

Tayside

Mr Bill Chalmers stood down at our recent AGM after serving for many years on the Tayside Committee. Bill was a loyal supporter who provided excellent musical entertainment at many of our social functions. We thank him for his contributions and look forward to seeing him at future events. In his place, we welcome Professor David Levison to the Tayside Committee; David is a former Dean of the Medical Faculty who brings expertise and valuable local knowledge of the research activities of Tayside to our deliberations.

Our social programme continues to be active through the activities of Mrs Ann Gray and the Ladies’ Committee. An “At Home” was held on 29th April 2009 at Ninewells Hospital and Medical School. Over 100 guests enjoyed a finger buffet in the Ian Low Centre before hearing how donated funds are being used to support research of the highest quality in Tayside. Professor Sir David Lane spoke on “The

Discovery of Tenovin – new p53 Activating Molecules”; he described a programme of work that has arisen from generous Tenovus funding and is pointing to the exciting possibility of new treatments for cancer. Dr Ewan Pearson gave a talk on “Diabetes and Genes” and acknowledged how Tenovus had given impetus to their work; a new aspect was the finding that genetic information could lead to some diabetic patients being weaned off insulin and avoiding daily injections with good diabetic control. These two outstanding presentations were greatly enjoyed by an appreciative audience.

On 2nd March 2009, the Ladies’ Annual Bridge Lunch was well attended and much enjoyed. A total of over £1,000 was raised for Tenovus Funds.

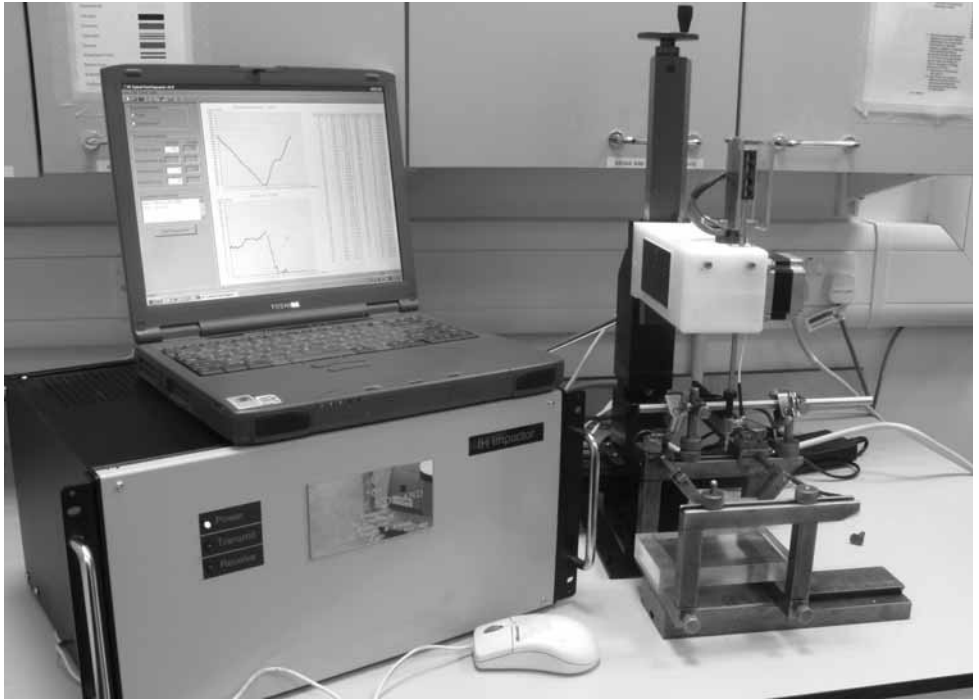
The Queen’s Gallery in Dundee held an Exhibition of Paintings which was opened with wine and music on Friday 22nd May 2009. Mrs Joyce McGlone, the owner, asked the exhibitors to provide a

number of small paintings that were auctioned for Tenovus funds. This raised over £1,700 and we are most grateful to Joyce and the artists for their support.

A Ladies’ Lunch will be held on 19th September 2009 in the West Park Conference Centre of Dundee University. Mrs Isobel Cleland will be the speaker and it is hoped that this event will be well supported.

Our ever popular Annual Dinner will be held on Friday 4th September 2009 in the Invercarse Hotel. The speaker is to be Tricia Stewart who will tell her story as one of the original Calendar Girls.

Despite the present economic situation, Tenovus Tayside are pleased to report that, because of generous donations, it will be able to distribute over £500,000 on both small and major grants during the coming autumn. We give our sincere thanks to all our loyal supporters who make it possible for Tenovus to continue to support first-class medical research in Tayside.



The Infinite Horizon Impactor was donated by the under-noted for research into spinal injuries





Christmas Cards



The card is approximately 15cm square.

The message reads:- "Best Wishes for a Merry Christmas and a Very Happy New Year"

Weight of one card with envelope 18grms.



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ORDER FORM

Please dispatch packs of the **2009 @ £5.00** per pack of 10 cards for which I enclose a cheque for £ made payable to TENOVS SCOTLAND.

PLEASE PRINT

Name

Address

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.Post Code



W W W W W W W

Please send your order to:-

General Secretary (Cards)

TENOVUS SCOTLAND, 234 St Vincent Street, Glasgow G2 5RJ

Cease Mailing Data Protection Act

As General Secretary I hold a note of your names & addresses on a Memory Stick and as such I am obliged to check periodically that you have no objection to my holding these details, however if you wish to stop receipt of the Annual Report and Nusovus please complete the form below and return to:

**General Secretary
Tenovus Scotland
at Royal College Of Physicians & Surgeons (Glas)
232-234 St Vincent Street
Glasgow G2 5RJ**

I hereby request you to remove my/our name/s from the Charity Database as from receipt of this notification,

- a) National (Annual Report & Nusovus)..... Please tick
b) Regional (Notification of future fund raising events)please tick

DATE..... SIGNED

Address

Town..... Post Code.....

Tenovus Scotland

SUPPORTING MEDICAL RESEARCH

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www.tenovus-scotland.org.uk

When completed, please return this form to the above address

A GIFT AID DECLARATION

Title..... Forenames..... Surname.....

Address

Town..... Post Code.....

I wish Tenovus Scotland to treat all donations that I have made since 6th April 2009, and all donations I make from the date of this declaration until I notify you otherwise as GIFT AID DONATIONS.

Please note that you must pay an amount of income and/or capital gains tax at least equal to the tax that TENOVUS SCOTLAND reclaims on your donation in the tax year (currently 28p for each £1 you give).

DATE..... SIGNED

I enclose a donation of £..... My cheque is enclosed, made payable to 'TENOVUS SCOTLAND' .

Website www//tenovus-scotland.org.com