

Global coalition to fight prostate cancer

A global coalition of prostate cancer survivors, doctors and scientists has been formed to fight the disease. The president and chief executive officer of the Prostate Cancer Foundation of New Zealand, Barry Young, is to serve on a working group formed to develop the global organisation.

Barry said he was invited to a meeting to discuss the formation of the global coalition in Washington DC in mid-July. The meeting took place during the World Cancer Congress of the UICC (Union Internationale Contre le Cancer).

"Just about every country around the world has one or more organisations dealing specifically with prostate cancer, but until now there has never been an international prostate cancer forum through which these organisations could co-ordinate their efforts. It is a most important development and New Zealand is part of it," said Barry.

He explained that the new organisation would be an adjunct to the UICC which is a Geneva based global organisation dealing with all cancers. Over 3,000 people from all parts of the world attended the World Cancer Congress in Washington in July and with this conference operating back to back with the US Center for Disease Control and Prevention conference there were over 6,000 delegates in Washington at the one time discussing cancer control

strategies from around the world.

The theme of the UICC World Cancer Congress was 'Bridging the Gaps: Transforming Knowledge into Action'.

"It became very clear we are well launched into the age of molecular medicine with the suggestion being made that science has crossed a significant threshold to the extent that it is possible to intervene in the mechanisms of cancer and pre-empt death.

"This suggestion was made by Dr Andrew von Eschenbach, former director of the National Cancer Institute (US), and currently acting commissioner of the powerful US Food and Drug Administration. He said we now have the opportunity to become predictive, personalised, pre-emptive and participatory in dealing with cancer and that we have begun to transform the course of the disease itself," said Barry.

The eight-member working group charged with establishing the global coalition to fight prostate cancer is drawn from Belgium, Canada, Ireland, the United States and New Zealand.

"Without prejudice to what this group might finally decide, the mission statement circulated prior to the meeting in Washington does indicate the vision being used for this project. It said the mission is:

- to identify and disseminate emerging information on prostate cancer
- to promote awareness of prostate cancer and

understanding of the importance of early diagnosis and appropriate management of the disease (including clinical trials and second opinions)

- to campaign for provision of and access to optimum treatment
- to describe and promote supportive care and quality of life for prostate cancer patients and their families
- promote a multidisciplinary approach to quality care and the central role of the patient in determining care
- to acknowledge and promote excellence in clinical practice
- to promote prostate cancer research

"These objectives are very much in line with those of the Prostate Cancer Foundation of New Zealand so our enthusiasm for participating and sharing these experiences within the structure of a global organisation is understandable," said Barry.

Foundation streamlines its administration

Members of the Foundation have decided to streamline the administration of the organisation. Branch representatives will now liaise directly with the chief executive officer who will in turn report to the national executive.

The annual general meeting was told that nothing would actually change at branch level except that decisions could be taken and implemented more quickly.

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Eric Diggelmann, Trevor Green and Barry Young elected Life Members



Val and Eric Diggelmann (above) have decided to retire from active participation in the Foundation. They have been with the organisation since it was founded as the Prostate Awareness and Support Society 10 years ago. They were also the leaders of what became the Foundation's most successful branch---Tauranga.

Eric was a member of the original committee of PASS and then became vice president, president and immediate past president. He will retain the title immediate past president.

It will be hard to imagine the Foundation without Val and Eric. It is not just that they were always there when needed, but the fact they have worked in such a way that they encouraged others to put

time and effort into the Foundation whether this was at a local branch or national level.

Many of us have known that Eric has not been in the best of health for some time but this has never affected his attitude towards helping others. This seems an almost glib thing to say but in Eric's case it is just so true. Whenever a member of the national executive might phone Eric with a problem they would come off the phone feeling different about the problem. It may not have been solved but the attitude towards it and a determination to solve it would have been reinforced.



Trevor Green (left) and Barry Young

Branch concept

Members to choose what suits them

The Foundation has decided to make changes to how its branches operate. President Barry Young told the AGM that branch development had been modelled on the very successful branch at Tauranga but reality now dictated a different concept.

"We have found that even our larger branches have difficulty in maintaining their original style of operating. Members are now less interested in operating an incorporated society with all its attendant responsibilities of meetings, reports and a formal structure, but would rather be part of a possibly smaller, less formal organisation.

"This should not be interpreted as less enthusiasm because this is not the case. It

is more to do with new people wanting to work differently and focus their attention on core activities. We are now saying to our branches that how they choose to operate is their choice. If they don't want to be an incorporated society and prefer to have their administration handled by the national office then we have no problem with this. The result is that people will be working within their own communities in a way they feel is suitable to their community and also comfortable for them.

"Branches that wish to continue to have meetings to provide mutual support and camaraderie will continue to do so but unless they want to they won't have to elect officers and so on," said Barry.

New role for Ray Mulqueen

Ray Mulqueen has accepted a new role within the Foundation. He is to become the Foundation's first Executive Ambassador.

For a number of years Ray, as vice president, has been involved in establishing branches in the South Island and has probably spoken at more meetings and gatherings than any other member of the Foundation.

The new role will enable Ray to continue with the work to which he is so dedicated without being locked into other executive responsibilities.

Foundation officers

Officers elected at the Annual General Meeting of the Prostate Cancer Foundation of New Zealand Inc. in Christchurch on July 23, 2006 were:

President and CEO

Barry Young

Vice president & treasurer

Trevor Green

Immediate past president

Eric Diggelmann

Executive

Jack Irwin, Kareen Sutcliffe, Chris Jones, Paul Anderson

Executive ambassador

Ray Mulqueen

Secretary

Carolyn Young

Possible future development being considered

Delegates at the AGM were shown a possible future organisational structure by executive member Jack Irwin. The new structure took into account the creation of a national office and featured a number of new positions to help spread the load of Foundation activity.

The suggested organisational structure was distributed to branch representatives and they are to report back to the national executive with their recommendations.

Go Movember!

Briefing to Foundation members

Planning for the Movember project is proceeding under the guidance of Chris Jones. Members of the Foundation were given a briefing about Movember at the AGM by one of the founders of the project, Adam Garone from Melbourne, and gave Movember their unanimous support.

Work is now proceeding to adapt the various computer and organisational systems designed for Australia to suit New Zealand.

Chris says Movember is a great opportunity for the Foundation to raise awareness about prostate cancer and also raise money to help fight the disease.

"It is interesting to see how many younger men and women become involved in Movember in

Australia and we can see no reason for this not to happen here. We will certainly be looking to make this happen," said Chris.

"Most of the registrations of the participants and their sponsorships will be done on a specially created website but there will still be a lot of work to be done on the ground so we will be looking for volunteers to help organise what will be a great deal of fun," said Chris.

Movember is a project that encourages men to grow moustaches during the month of November. They seek sponsorship for their efforts with the proceeds being donated to the Prostate Cancer Foundation.

AstraZeneca partners in sponsorship

AstraZeneca's long-term support for Prostate Cancer Foundation activities has continued with recent assistance to enable Foundation president, Barry Young, to attend the World Congress of the Union Internationale Contre le Cancer (UICC) in Washington DC.

"The help given to us by AstraZeneca is on an unrestricted basis. In other words there are no strings attached," said Barry.

"At our recent AGM the members of the Prostate Cancer Foundation moved a vote of thanks to AstraZeneca for their continuing help."

AstraZeneca sponsors the Foundation's 0800 Helpline

0800 627 277

and the website:

www.prostate.org.nz

Importance of Movember

by Barry Young, president and CEO

As we move into the planning stages of the Movember project it is important for people to realise just how significant this is as an awareness and fund raising event for the Foundation. Other than money raised by memberships, and some sponsorship for already designated activities, it is likely to be the only money we receive to help fund our work.

What a great many people do not realise is that because the Prostate Cancer Foundation of New Zealand is not a member of the Cancer Society of New Zealand it does not receive any of the proceeds from the Cancer Society's 'Daffodil Day' nor from the society's 'Relay for Life', even though some of our members help out during both of these events.

Nor do we receive any government funding.

We have to run this battle against prostate cancer pretty much on our own.

Indeed if it wasn't for the proceeds of two Christmas lunches run for us by the Mad Butcher and Suburban Newspapers in Auckland a couple of years ago, and some local spin-off from last year's Australian Movember activities, our only income would have been from membership and our loyal sponsors.

So why are we not members of the Cancer Society of New Zealand? A few years ago we felt we should join the Society as we are all in the business of fighting cancer. But we were told during a face to face meeting with two senior society officers, that we could not join because of our policy that recommends men have themselves checked for prostate cancer PRIOR to symptoms appearing.

We were told that unless we

adopted the Cancer Society of New Zealand policy of recommending that men without symptoms NOT be tested we could not join. We declined to change our policy.

In Auckland our local branch was told that they could not use the Auckland Cancer Society rooms for meetings unless they paid a fee like other organisations not members of the Cancer Society of New Zealand. So our local chaps hold their meetings at a nearby McDonalds.

Ironically we are welcomed warmly at every other regional Cancer Society throughout the country and for this we thank them.

But it does not change our need to create our own funding activity and this is why we need Movember to help change the face of men's health and give a huge boost to our awareness programme.

Transforming knowledge into action

World Cancer Congress

Science and technology now make it possible to change the world in ways that a few years ago would have been thought impossible. Dr Andrew von Eschenbach told delegates at the recent UICC World Cancer Congress in Washington.

Dr von Eschenbach, former director of the United States National Cancer Institute, and currently acting commissioner of the US Food and Drug Administration, sees revolutionary changes ahead as the result of molecular medicine.

"While we are rapidly emerging through the process of discovery we must be certain that we are able to deliver intervention," Dr von Eschenbach told a general plenary session entitled 'Transforming Knowledge into Action'.

"We must change if we are to create that world where no-one suffers and dies from cancer. There is a tendency to reject the elegant solutions that are now being offered by scientists because it is thought of as too costly, too difficult, too sophisticated and too much of a distraction."

"We are beginning to understand the problem at the genetic and molecular level. It is a metamorphosis in which our future will look different. We will have major leaps forward in health care and the delivery system.

"Our past is based on a model in which what we know about cancer we know at a microscopic level using our five senses. Now, as we have crossed that threshold, the entire paradigm has

changed. We can intervene in the mechanisms and pre-empt death. We have begun to transform the course of the disease itself," said Dr von Eschenbach.

"We now have the opportunity to become predictive, personalised, pre-emptive and participatory. We can use tools that can predict before we apply them and we can learn how to personalise them. We will be pre-emptive when we prevent progress of disease and patients will be more actively involved.

"This is about leadership, vision and the opportunity to change the world and free us from continuing to struggle using old-world solutions," said Dr von Eschenbach.

New Zealanders in Washington



There were hundreds of papers presented at the UICC World Cancer Congress so New Zealanders met to compare notes on what they had each heard and learned. From left to right: Barry Young; Joan Petersen, Manawatu Cancer Society; Inga O'Brien, NZ Cancer Society; Denise Robbins, NZ Cancer Voices.

Wider access to Zoladex

Men with an earlier stage of prostate cancer will have fully subsidised access to the treatment Zoladex. From July Zoladex has been funded by Pharmac for treatment of locally advanced (earlier stage) prostate cancer.

Auckland Hospital director of radiation oncology, professor Benjamin, said that clinical trials have shown that the combination of hormone treatment and radiation treatment in locally advanced prostate cancer has a much better survival rate than using just radiation therapy alone.

AstraZeneca New Zealand general manager, doctor Lance Gravatt, said until now Zoladex had only been reimbursed as a palliative treatment for prostate cancer with advanced disease.

The new agreement with Pharmac not only widens the access to Zoladex but will ensure its availability to January 2011.

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