



Support Network Newsletter

Volume1, No. 6

March 3, 2016

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## From the Chair: our new committee



I am very excited to bring this newsletter to you. It is an opportune time to introduce myself, as new Chair, and also let you know what is happening. There have been a few changes within Head and Neckers, but change brings great opportunities and new beginnings. You can find out more about me @ [Dianaayling.com](mailto:Dianaayling.com)

Our first meeting of the year was our first formal meeting. We elected our officers and committee for 2016. We voted to adopt our rules for incorporation purposes. We can relax formality until our AGM in March next year.

Our 2016 committee is:  
Diana Ayling, Chair  
Kevin Bowers, Deputy Chair  
Maureen Jansen, Secretary  
David Stevenson, Treasurer  
Tammy von Keisenberg  
Trevor Pugh  
Esther Ong, Advisory Member

Our committee will now take over the day to day functions of the Network. We will keep you fully informed and ensure you are invited to participate in our planning processes.

I wish to thank the Planning Committee for all their hard work in getting us to the point of incorporation.

Diana Ayling  
Chair

## Raise the volume of the unheard voice: Health and Disability Advocacy Service

When we have complex medical needs and might have lost our physical voice, it can be a struggle for our voice to be heard and our needs met. This is where a **Health and Disability advocate** can help us out.

Health and Disability Advocacy Services “advocates” are available to help head and neck cancer people. Their role is to work with patients to resolve treatments and care issues with health professionals. **Kellie Dore**, who spoke at our March meeting, is an Auckland advocate for the Health and Disability Advocacy Service. The service offers free, independent, and confidential assistance to anyone receiving treatment by doctors, and in hospitals. Kellie spoke about the nature of the service and how it can assist head and neck cancer people.



People can phone in for advice. The advocates identify the issues and support patients to work with health professionals to resolve concerns. If the issues are more serious, advocates help to write a complaint and submit it to the relevant health organisation. Kellie pointed out that there are tight time frames for the organisation to respond to the complainant. The advocates can arrange face to face meetings with health professionals so that issues can be worked out collaboratively.

The Health and Disability Commissioner is independent from this advocacy service. The Commissioner investigates complaints regarding treatment and health care. The Commissioner then publishes his/her decisions on the website. [www.hdc.org.nz](http://www.hdc.org.nz)

Kellie Dore  
Nationwide Health and Disability  
Advocacy Service  
Phone: 09 5252700  
Toll Free: 0800 555050

Kellie drew our attention to the Consumer Code of Rights which was developed following the Cartwright Inquiry. The code has 10 rights, and you can view them here. [Summary of the Code](#).

If you feel you need the help of an advocate you can contact Kellie.

**“We shall draw from the heart of suffering itself the means of inspiration and survival.” – Winston Churchill**

## I am a survivor: Peter Smith

Well, where do I start? November/December 2007, I went to my doctor a number of times complaining about a sore throat. The GP said it was my sinuses making my throat sore. Went back again and asked what the white thing was hanging down from the tonsil area. Dr took a look and said, "Oh my God!" That was it. Went back again and saw his wife who was also a doctor. She told me her husband had been in touch with Wellington Hospital Cancer Centre. In December I went for tests and it was not very nice the way they did it. They didn't give me any spray in my throat, just cut a piece of the white thing hanging down inside my mouth. It hurt like hell and bled a lot. Then I had a needle put in the side of my neck for a blood test.



Yes, I had cancer. I had to give up my part time courtesy driver job at a local tavern. Went in for more tests then went to the radiation department where they made a face mask to fit the shape of my face. Before the radiation treatment, I had to go to another hospital to have a coloured liquid inserted into me to show where I had the cancer (Wakefield Hospital, January 2008). I had to lie still for at least 1 ½ hours while they put the fluid into me then went to another room where they took x-rays. I had to lie still there too for 1 ½ hours while the x ray machine took photos. And I do mean lie still, not move a muscle.

*All I wanted to do when I got home was sleep. And I mean sleep...*

I then started my radiation treatment in January 2008, continuing until the 3<sup>rd</sup> week of March. I went to the Wellington Hospital Cancer Department. I was picked up every day, five days a week and then brought home by a volunteer driver. As the weeks went on I began to feel the effects of the radiation. It was not a nice feeling. All I wanted to do was sleep. And I mean sleep. I did ask the tech who operated the machine how many people have radiation treatment and the answer was 30/40 per day. And those same people came every day.

By the middle of February, I was feeling like hell. The treatment only lasted a few minutes but the face mask was clipped down onto the table I was lying on and once more I was told not to move. That wasn't a great feeling either. As for going to tenpin bowling, forget it. No way.

Treatment ended in March 2008. I did have chemo treatment twice and that wasn't too hard on the body. But I was not out of the woods yet. I still had to go back into Wellington Hospital for checkups for any lumps in my neck. Negative – nothing. By this time, I was eating soft food like soups, ice cream, creamed rice, peaches, yoghurt, baby food and any other food that was soft. And I could still drink coffee and tea. But boy, did I sleep. Then I found out I had no moisture glands. My mouth was dry and I had to have Biotene Oral Balance moisturizing liquid every day. At this stage I was a healthy male with a weight of 85 kgs. From the time I had my radiation treatment though, I felt like nothing on earth, very tired, did not feel like doing anything. I had to push myself to go for a walk, starting at ½ an hour then extending the length of time. Nor did I get back to tenpin bowling until July 2008 and that was a learning experience in itself. I was bowling like a C grader but that was to be expected after what I'd been through.

As the weeks went on I got a bit better. I was still going for checkups at Wellington Cancer Centre. During this time, I had visits from two fellow bowlers who offered to help me through my ordeal like taking me shopping, to doctors' visits and hospital appointments which I am truly thankful for. At this stage I was still wearing my old dentures but they were very old and loose. The Dr suggested I get some new ones from Kenepuru Hospital, Porirua. After new dentures I was feeling better. From July 2008 to April 2009 I got back into tenpin bowling two days a week and very little else. I got back into walking exercise, extending the distance I was walking to about an hour where I lived at Titahi Bay near a beach. I was also still eating soft foods and drinking tea and coffee. Still going for checkups at Wellington Hospital. I would

catch a bus, then a train and then another bus to Wellington hospital. Sometimes I would get a shuttle van from Kenepuru Hospital, Porirua. Also, I entered a 55 plus tenpin bowling tournament September 2008 and did all right after what I had been through. At Christmas 2008 I was invited out for Xmas dinner but all soft foods. Health-wise I was feeling okay. But in April 2009 I discovered a knob hanging off the back of my throat near the tonsil area. At that time, I was going to Tauranga for a senior tenpin bowling tournament. That was okay. I had an appointment at the Wellington Hospital for another checkup.

After I got back from Tauranga I told the doctor about the white knob. Yes, the cancer had come back. He consulted with other doctors and said I could live with it or he could operate. Without hesitation, I said operate. So on August 8, 2009, at about 9 am I was taken into the Hutt Hospital. I was wheeled

*Without hesitation, I said  
operate.*

into the operating theatre where a team of doctors and specialists were led by Dr Swee Tan, surgeon. When they put me on the table, I looked up and saw the big arc lights and said, "Beam me Up Scotty" and a needle was put in my right arm. I went to sleep, waking up in the recovery room at 9 pm that night. It was a 13-hour operation, tubes were coming out of my body everywhere, there was a plaster cast on my right arm and a tube coming out of my neck. I was put into a recovery room for a week and I was spoilt for a whole month while I was in there. I lost weight, dropping from 85 to 55 kgs. Looked anorexic and I have photos to prove it.

I was then put into a normal ward and then I had a peg<sup>1</sup> tube put in my chest where I had to have 500 mls of liquid food every night. The tube wasn't long enough to go into my stomach and a new, longer tube was put in which I have to this day. It is replaced every 6 months.<sup>2</sup>

*I would not want to  
see anybody else go  
through what I went  
through.*

After I came home from Hutt Hospital, I only spent two days at home when I became violently ill. I rang for an ambulance and ended up back in Wellington Hospital for a month with a lung infection. Got back to normal after that or at least I tried to. Had visits from the nurse and dietician once a month. Also had home help once a month to clean my unit for me. In November 2009 I was still living in Titahi Bay, Porirua City, in a Housing NZ unit. It was a good area because there was a

small shopping centre over the road plus a fire station and drop in centre. There was also a beach where I could walk for exercise.

During this time, I applied for a transfer back to Auckland. In June 2010, my niece's husband and a mate came down to Titahi Bay with a large furniture truck and loaded all my belongings on it. I was taken out to Wellington Airport to fly back to Auckland where I was met by my niece and taken to my new address in Ellerslie. I found out that my older brother Nick was very ill with emphysema, cancer, a lung infection and heart problems. He died in July 2015.

I got my life back by going back to tenpin bowling three days a week and joined a fitness centre in Ellerslie within five minutes walking distance from where I live.

In 2015/2016 things are also changing. I'm only bowling twice a week now and going to the gym four days a week to build up my fitness and strength for my bowling. I do have vertigo but not very often. I also get cramp in my neck, legs and feet. Other than that I feel okay at times. Weight is 70 kgs. I am on 1000 mls of special food a night.

So that's it in a nutshell, people. I would not want to see anybody else go through what I went through.

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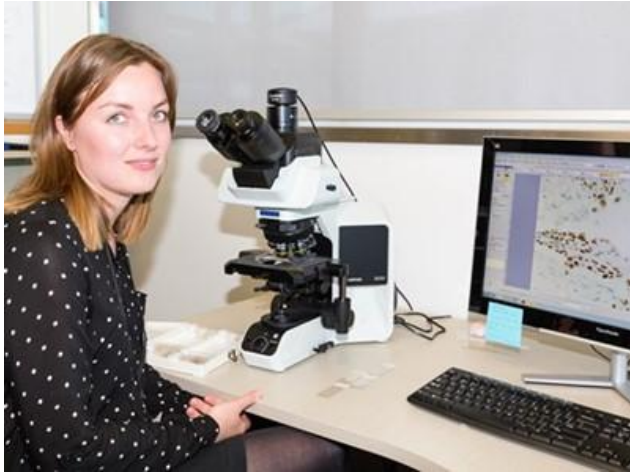
<sup>1</sup> PEG stands for percutaneous endoscopic gastrostomy, a procedure in which a flexible feeding tube is placed through the abdominal wall and into the stomach.

<sup>2</sup> Peter's reconstructive surgery was so extensive that his gullet was constricted and he can't swallow.

## Paradigm shift in tongue cancer research

Why does cancer spread? Why does it recur after treatment? One theory is the “cancer stem cell hypothesis”. It states that only a small subpopulation of cells within a tumor are capable of starting cancers. These are called cancer stem cells or “tumor-initiating cells”.

The Gillies McIndoe Research Institute in Wellington is researching cancer stem cells. The work of Dr SweeTan and his team at the GMRI has been labelled a paradigm shift by international experts.



One of Dr Tan’s team members, research student Ranui Baillie (pictured), recently made a discovery that could change the way tongue cancers are treated. Ms Baillie identified a unique population of cancer stem cells in tongue cancer and a patent registration has been filed in the United States covering this work.

Dr Tan says evidence of the existence of cancer stem cells has been accumulating in other cancers but this is the first time a unique population of these cells has been identified and characterised within tongue cancer, the most common and deadly form of oral cancer.

“These cells are thought to be the driving force behind the development and progression of cancer,” he says.

## Next meeting - a new adventure for Head and Neckers



The April 7 meeting will be held at Cornwall Park. We will have something to eat and drink, a conversation and a stroll among the trees. We also have a form to fill in on the five priorities Head and Neckers want to focus on in 2016 and the future. You will receive an email or letter informing you of the time and the exact meeting spot. (We won’t make you walk up One Tree Hill.)

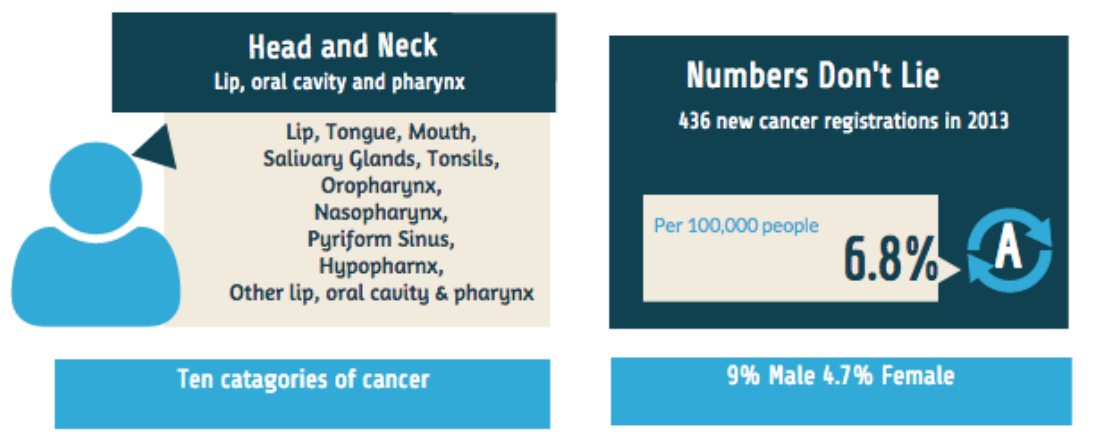
We can arrange transport.

## Head and neck statistics from the Cancer Registry

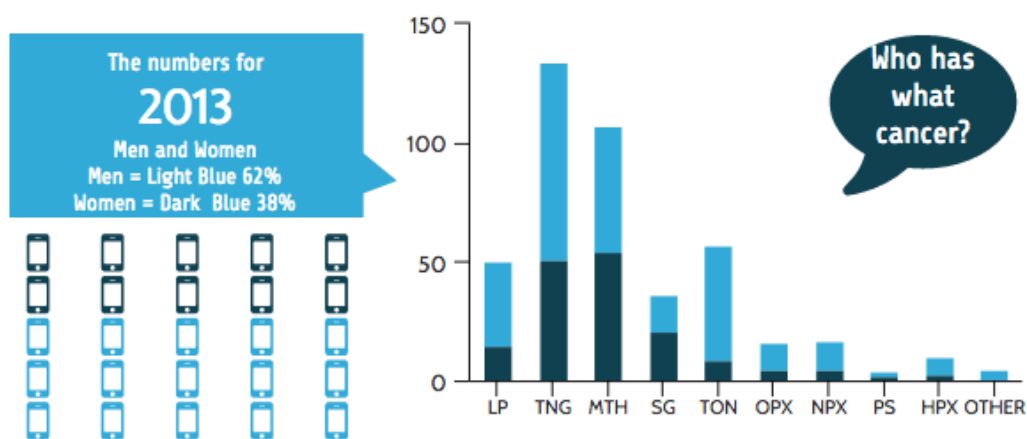
The following page shows the latest statistics compiled by Diana and placed in an infographic.

# Head and Neckers Cancer & DATA

This information is from high-level data on cancer registrations in 2013, ahead of the annual Cancer: New registrations and deaths 2013 publication.



## From The National Cancer Registry



This data is for the whole of New Zealand.

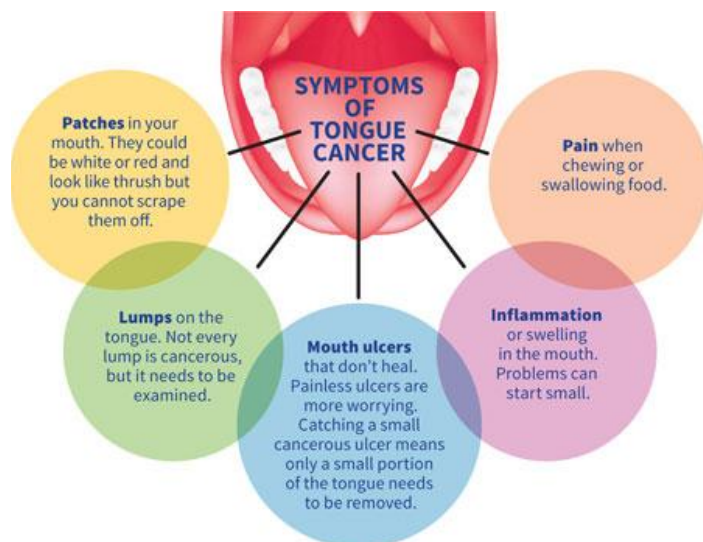
Free Infographic Maker  VENNGAGE

<https://infograph.venngage.com/p/79258/new-zealand-head-and-neck-cancer-statistics-2013>

## An unusual path: Oral Lichen Planus

We all know that smoking and drinking are risk factors for many types of head and neck cancer. When the two are combined they cause even more risk. The human papilloma virus is another factor which has been hitting the headlines lately. Chance and bad luck must play a big part too.

Some people have none of these risk factors and still get head and neck cancer. A lot of people drink and smoke or have HPV but remain cancer free.



There is a small set of people who had oral lichen planus, a seemingly harmless disease of the skin and mucosa which in 1% of patients can change to squamous cell carcinoma. It's surprising to see that out of the 20 to 30 people who attend the meetings at Domain Lodge in Auckland, at least three had head and neck cancer develop from OLP. Life experience and statistics don't always match up!

What is oral lichen planus? It takes the form of a rash inside the mouth marked by thin white lines. The oral cavity becomes sensitive to spicy foods and even toothpaste. It could be an autoimmune disease but the evidence for that isn't clear yet. Sometimes it turns into erosive lichen planus where one patch, often on the tongue, turns into a painful lesion. Eating becomes very painful and the pain can even keep you awake at night.

There's no cure. The only thing that ever helped me was a course of oral cortisone. What tends to happen with these lesions is that the GP will send you to an oral surgeon who declares the lesion standard lichen planus which might go away by itself. In my case I was also sent to a dermatologist who gave me an allergy patch test, declared I was allergic to mercury and amalgam and recommended having my amalgam fillings replaced. This made no difference at all and about five years later I looked in the mirror, saw how red and angry the lesion was and asked to see the oral surgeon again. The rest is history.

Since my diagnosis in 2007 I've learned that any sore in the mouth which lasts longer than two weeks should be seriously looked at and probably biopsied. Tongue biopsies hurt like hell but they can prevent a heap of trouble.

I don't think there is a clear explanation for why some OLP lesions become cancerous. There seems to be a condition called a lichenoid reaction where a developing cancer has lichenoid features so is not really OLP, it is squamous cell carcinoma, the main type of oral cancer. Whatever the truth of the matter is, suspicious lesions should be biopsied.

Should we get caught up in the causes of our cancer? Probably not. We can avoid known risk factors now we know how horrible head and neck cancer is, but feeling bitter or guilty about the past is a waste of our emotional energy. What we can do is advocate for better screening by dentists. Advocate for smoking cessation. As for alcohol, I couldn't possibly say.

*Maureen Jansen*

For links to head and neck resources and forums on the internet go to:

<http://headandnecknetwork.blogspot.co.nz/p/resources.html>

## Our goals



## Our Goals

1. Supporting head and neck cancer people, their families and carers.
2. Educating people, their families, carers and the community about managing head and neck cancer.
3. Advocating for better services and outcomes for head and neck cancer people
4. Raising awareness in the community of the head and neck cancer.
5. Working closely with other cancer related organisations for the purposes stated above.

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## Contact us

Diana: [dianaayling@outlook.com](mailto:dianaayling@outlook.com)

Kevin: [kbowers@xtra.co.nz](mailto:kbowers@xtra.co.nz)

Maureen: [mjansener@gmail.com](mailto:mjansener@gmail.com)

Temporary website: <http://headandnecknetwork.blogspot.co.nz/>

Our meeting place is Domain Lodge, 1 Boyle Crescent, Grafton, Auckland, 09 308 0161

