

Submission on the Inquiry into the tobacco industry in Aotearoa and the consequences of tobacco use for Maori

To the Maori Affairs Select Committee

This submission is from John Forman, 228 Tinakori Rd, Thorndon, executive director of NZORD, the New Zealand Organisation for Rare Disorders.

Though this is a late submission, I understand the committee's deliberations are continuing, so I request that the committee accept and consider it. I wish to appear before the committee to speak to this submission.

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Introduction

NZORD is an umbrella group set up to provide information, support and advocacy for patients and families affected by rare disorders, and to assist with the development of support groups for them. We build collaborative relationships with health professionals, health planners and researchers to improve knowledge about rare diseases, improve clinical care, and develop treatments and cures for rare diseases.

The most significant problem associated with rare disorders is the generally low priority they attract in health service planning and delivery. Rarity often means limited expertise to manage the clinical care needs, difficulties getting appropriate referrals across District Health Board boundaries, and that therapies are expensive to develop and this results in high costs for novel therapies to treat them. The committee is no doubt fully aware of the reluctance of Pharmac to fund such treatments. The result of these combined factors is a tendency for a much lower quality of health care and difficulties in access to services and treatments, for those with rare diseases.

Rare diseases affect about 8% of the entire population - that cuts across all ethnic and racial groups. That means 8% of Maori are affected by rare diseases too.

The impact of smoking on health and quality of life for those with rare disorders.

In our submission to the Ministry of Health (copy attached) on their 2008 consultation on tobacco displays, we emphasised that the significant and serious health burdens widely imposed by smoking, are probably the major cause of the restricted health service access and poorer quality of clinical care and treatment for those with rare disorders.

Though this is an indirect cause, the connection is readily made when it is noted that smoking-related cancer, stroke, heart disease, respiratory disease, and other serious diseases directly caused by smoking, effectively block our access to the health care that would ideally be provided for those with rare disorders. Our needs are invariably swamped by the huge demands of those common smoking-related diseases on health budgets and clinicians time.

The impacts are the same for Maori with rare diseases. Significant controls on tobacco use would greatly improve the health of Maori who would otherwise smoke, but would also greatly improve the portion of health resources that would become available to Maori with rare diseases. The health gains would be multiplied.

We ask the committee to consider this additional point as a strategic approach to tobacco control:

- The consistent message from the tobacco industry in support of tobacco marketing and use is that it is a “legal product”. Along with this statement they promote the theme of personal choice of the tobacco user.
- Our recommendation in relation to the committee’s overarching approach to tobacco control is to consider ways in which tobacco can lose its “legal product” status. We suggest that consideration is given to classifying tobacco as a restricted substance, thus easing considerably the means by which promotion, distribution and use may be regulated.

Yours sincerely,

John Forman
Executive Director

NZORD submission to the Ministry of Health on Tobacco Displays - February 2008.

This topic may seem a bit unusual for NZORD to be commenting on. The impact of smoking on the health of the population is certainly not a rare thing. It is one of the most common avoidable causes of health problems in society. But further analysis shows it is a matter of great interest to us because of its effect in blocking our access to health service through the sheer volume of health problems that smoking causes. Here's the core of our submission to the Ministry of Health:

Submission summary:

Though there may be little discernable direct health impact on rare disease patients from tobacco use in society as a whole (unless of course the patient is also a smoker or is exposed to smoke), there is significant indirect impact in terms of lack of priority for our health needs, and severely restricted access to the health services we need.

Smoking is one of the most significant risk factors for a range of diseases which are high on the health priority lists and which do capture a significant slice of health budgets. The indirect consequence of tobacco use therefore place a severe constraint on access to resources for research, treatments and clinical care for rare disorders.

Any action to effectively restrict smoking uptake will reduce the burden of many common diseases over time. This presents a significant opportunity to improve our access to health care and services. For this reason we support the second part of option 3 in the consultation document - a complete ban on display of tobacco products.

Commentary:

A 1997 report by Brian Easton estimated that smoking cost the New Zealand health sector \$205 million in direct costs in 1990. Without tobacco's direct and indirect costs, Easton estimated there would have been an extra \$785 million dollars that could have been used for other purposes. Easton, B. (1997) "The Social Costs of Tobacco Use and Alcohol Misuse" Public Health Monograph Series no. 2. In 2005 an update of this report estimated the total cost of tobacco use to NZ society as \$1.7 billion. "Report on Tobacco Taxation in New Zealand", vol 2, Appendices, pps 21-29. Clearly, Tobacco diverts funding from other important health care areas – such as rare disorders and improved genetics services.

The recently released Public Health Bill seeks strategies for reducing non-communicable diseases, such as cardiovascular disease and diabetes. We support this objective and note that cigarette smoking is the number one contributor to onset of cardiovascular disease, and is a significant contributor to many other diseases that have high impact on numbers of patients affected and on total cost to the health sector and society.

We note the Health Research Council has funds to support only 20-25% of its applications. Of the nine research portfolios, the non-communicable disorders

portfolio includes cancer, cardiovascular disease, diabetes, respiratory disease, and others, of which smoking is a significant risk factor for nearly all of these conditions. Other categories of non-communicable disease such as genetic disease (the majority of which are rare) are given a low priority by the Health Research Council. http://www.hrc.govt.nz/root/HRC%20Policy/Research%20Policy/Research%20Portfolios/Research_Portfolio_Strategies.html

In 2003 the National Health Committee produced a report on Molecular Genetic Testing in New Zealand, reporting that the services are seen as “not well-resourced” and “well short of international standards.” The recommendation from the NHC included an urgent need to upgrade these services to provide a viable and essential part of a modern health service. Genetic services are a crucial basic necessity for diagnosis and treatment of rare diseases, yet the Ministry of Health and District Health Boards have declined to implement this important report because genetic services are “not a priority” activity. This clearly demonstrates direct disadvantage to our interests resulting from the presence of significant preventable disease driven by smoking, that is given a higher priority.

Health benefits for rare disease patients and their families could come from added investments in screening programmes such as newborn metabolic screening. New Zealand was initially a pioneer in this area, but over the years has lagged behind, largely because of lack of priority for this sort of investment compared to common diseases with significant total costs. Opportunities to prevent or treat some rare diseases have therefore been lost to us.

A significant number of rare diseases now have therapies available that have high unit costs because of small patient numbers. This often leads to poor cost effectiveness analysis in a tightly budgeted health system and a reluctance by health administrators to fund these medicines. Reduction in the substantial direct and indirect cost of tobacco use would improve the chances of rare disease patients getting their essential medicines funded.

Reduction in tobacco driven disease has the potential to free up significant resources and provide a realistic opportunity for rare diseases to get a more equitable share of health services and research.

We reiterate NZORD’s support of a complete ban on tobacco displays (Option 3). We dismiss the potential disadvantage of smokers’ difficulty in knowing where to purchase cigarettes, as having no credibility or significance in the wider context we offer on this discussion. We note the NZ Herald’s recent report on an Australian study which found that “40 per cent of smokers who were trying to stop or reduce smoking were tempted to buy a pack when they saw a retail display. Nearly a third of smokers in the study agreed that removing the displays would help them to quit.” Johnston, M “Cigarette shop displays too tempting, says study”, [New Zealand Herald](#), February 7, 2008.

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