

19 May 2008

Julian Inch
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Dear Julian

We wish to present the following as a submission to District Health Boards New Zealand on behalf of the estimated 800,000ⁱ people who suffer from allergic diseases. The submission outlines the need for urgent improvements in allergy services. Similar submissions are being presented to the 21 District Health Boards as well as the Ministry of Health. These submissions are supported by New Zealand residents around the country.

In this submission we present information about the significant burden relating to allergic diseases being experienced by people living in New Zealand

- Lack of resources to enable the effective management of allergic diseases at primary levels means thousands of patients including children are likely to be suffering unnecessarily; and some people will be at risk of recurring life-threatening reactions;
- Patients with severe and complex allergic conditions may be at risk because they cannot access publicly-funded secondary and/or tertiary-level services;
- The financial cost for individuals including loss of wellbeing through their allergies not being well-managed, may be more than \$5 billion per annum, assuming the effects are similar in New Zealand to those in Australiaⁱⁱ.

The Burden of Allergic Disease:

- Allergic diseases have been increasing in prevalence, complexity and severity in recent decades¹;
- New Zealand has one of the highest prevalence of allergic disease in the developed world, affecting up to 20% of the population, mainly young people of working age and their children^{1,2};
- Allergic diseases are a significant underlying cause of avoidable hospital admissions including for asthma and anaphylaxis; and/or repeat GP visits for conditions such as eczema, ear and chest infections, conjunctivitis, and colic in infants^{3,4};
- Recent studies on the quality of life for people with allergic diseases has found the adverse impact is significant and largely hidden, even for the relatively 'mild' condition of rhinitis⁵⁻⁸;
- A 2007 economic analysis of the impact of allergic disease in Australia¹ estimates the current cost as AU\$7.8 billion/year. In per capita terms the financial cost per person with allergies including the loss of wellbeing was estimated at AU\$7,200 per annum.

In a letter written 17 December 2007 to the Minister of Health [Appendix 1] and other New Zealand health officials, the Australasian Society of Clinical Immunology and Allergy

ⁱ www.moh.govt.nz/moh.nsf/wpg_index/About-DHBs: Total pop: 4,161,000. Population with allergic disease based on prevalence rate of 19.6%¹.

ⁱⁱ Based on AUD \$7,200 pp¹: Used NZD \$7,000 pp x 795,956 = \$5,571,700,000

(ASCIA) referred to the economic report on allergic disease¹, and commented that for New Zealand:

'The current number of specialist units and number of allergy/immunology specialists per unit in New Zealand is well below international benchmarks and inadequate to manage the burden of disease, and a number of regions experience significant difficulties in accessing specialist care. Without prompt corrective action, the workforce will move towards a situation of escalating undersupply, with the current projected level of graduate output being insufficient to maintain current services, let alone meet expected future requirements. The relatively few units and the low numbers of allergy/immunology specialist per unit also has implications in terms of: (a) patient services; (b) undergraduate and postgraduate education of medical, dietetic and nursing staff; (c) the availability of specialist services out of hours, or during sick, recreational, conference or sabbatical leave; (d) the ability to recruit and retain specialist staff (the risk of "burn-out" in single specialist units should be considered); and (d) the ability to conduct New Zealand-specific research'. (p.4)

Allergy New Zealand is a national organisation which represents the interests of people with allergic diseases. Based on reports and case studies sent to us (examples attached, Appendix 2), we believe that many people in New Zealand experience the following:

General practitioners

Limited support from General Practitioners (GPs) often due to their lack of access to current guidelines, training, information and resources for the diagnosis, treatment and management of allergic diseases. As a consequence:

- There are often significant delays in patients being referred for appropriate diagnostic tests and/or treatment;
- On the other hand, lack of access by GPs to resources such as diagnostic services can result in the referral of patients to secondary and/or tertiary level services (public or private) which would otherwise not be necessary;
- Although allergy is a chronic disease, patients' conditions, such as food allergy, atopic dermatitis or allergic rhinoconjunctivitis in children, are not being reviewed as regularly as they should, or advice provided on on-going management including dealing with stress and anxiety in relation to some conditions;
- Patients may not be educated by their prescribing GP on the effective use of medicines including how to recognise anaphylaxis and/or use the adrenaline auto-injector most commonly prescribed for anaphylaxis;

Diagnostic services

The provision of laboratory tests for allergy such as skin prick and RAST is *ad hoc* and appears to be related to budgetary concerns rather than best practice for the diagnosis of allergic disease. Therefore many patients feel their conditions have not been properly diagnosed, and the treatment and advice provided is incorrect or inadequate for the effective (and in some cases, safe) management of their (or their child's) condition.

There is also concern that some DHBs are, or may be, considering not funding laboratory tests commissioned by private specialists, which is a particular disadvantage to patients in the many DHB regions where there are no publicly-funded allergy specialists available.

Adrenaline auto-injectors (EpiPen)

At least 20,000ⁱⁱⁱ people including 3,500^{iv} children age 0-7 years may be at risk of anaphylaxis and therefore prescribed an injection of adrenaline to be administered intra-muscularly in case this life-threatening emergency occurs. However while Pharmac funds the ampoules of adrenaline to be used with a needle and syringe, New Zealand's allergy and clinical immunology specialists do not consider these safe for patients to use⁹, and recommend an auto-injector. This view is shared by most international professional allergy and clinical immunology bodies and allergy/anaphylaxis patient groups.

It is therefore a concern that the only auto-injector available in New Zealand (the EpiPen®) is not on the Pharmaceutical Schedule in spite of PTAC recommending in 2004 that it be funded with a 'medium level' of priority. Many families and individuals therefore cannot afford it, and there is no education strategy in place to assist others including teachers and other caregivers of children at risk of anaphylaxis to administer it in case of an emergency.

Specialist paediatric allergy services

Currently Auckland is the only DHB which provides a tertiary-level paediatric allergy/immunology service. This service is funded as a regional service (Auckland, Counties Manukau, and Waitemata). Parents report that they are unable to access this service from other DHBs for children with complex allergic conditions including multiple food sensitivities, severe eczema, failure to thrive and/or anaphylaxis. Reasons for lack of access include lack of knowledge by primary and in some cases secondary level health professionals of the referral guidelines for this tertiary service, long waiting times, and/or lack of funding from the DHB to support a referral.

Where families or individuals have decided in desperation to pay the costs associated with seeing a private allergy specialist^v (all but one of whom are based in Auckland), they then often have difficulty accessing other publicly-funded specialist services locally, such as a gastroenterologist for a biopsy, or a dietitian for ongoing support. Many families may therefore be paying a significant amount to access services which are publicly-funded in other areas, and being penalised in the process. It is also likely that a majority of children who should have been referred to a secondary if not tertiary-level paediatric service in regard to their allergies, have not been, and therefore are not receiving the medical care their conditions warrant.

Specialist referral for anaphylaxis

Anaphylaxis is a life-threatening medical emergency and more than 50% of cases are likely to occur in community settings from food, or wasp or bee venom, or medicines (e.g. antibiotics). International guidelines^{vi} indicate patients, following emergency treatment for an anaphylactic reaction, should be referred to an allergy specialist. Such a referral is necessary to prevent or minimise the risk of subsequent reactions by diagnosing the trigger, and setting up or

ⁱⁱⁱ Based on .5% of the population (4,161,000) being at risk of anaphylaxis in a community setting

^{iv} Based on 2006 Census data; proportion of people under 15 years was 21.5% (894,615). Est. the number age 0-7 years is 40% of this figure; of which 1% may be at risk of anaphylaxis to food allergy. However there are no data for epidemiology of FA in New Zealand¹⁰ and it is difficult to determine the number at risk of anaphylaxis. It is noted that hospital admissions for anaphylaxis in Australia increased markedly between 1993-1994 and 2004-2005 across all age groups, particularly in those aged 0 to 4 years. In this age group hospitalisations for anaphylaxis increased from 4.1 to 19.7 per 100,000 population over the 12-year period. The increase in this age group was mainly attributable to an increase in admissions for anaphylaxis caused by food, as opposed to other triggers.⁴

^v Professional member of the Australasian Society of Clinical Immunology and Allergy (ASCIA)

^{vi} ASCIA. Anaphylaxis: Education Resources for Health Professionals. www.allergy.org.au

reviewing the patient's anaphylaxis management plan including the relevant allergen avoidance strategies and/or desensitisation if appropriate.

However in a recent New Zealand study it was found that of those treated in a hospital emergency centre for anaphylaxis and who had a history of allergic reactions, only 25 per cent had been seen previously by an allergy specialist¹¹. Recurrence of anaphylactic reactions and further hospital admissions appear to be more likely without such referrals.

It is also a concern that in another study, most doctors surveyed at a New Zealand public hospital were unclear about acute treatment guidelines for anaphylaxis, in particular the recommended dose and route of administration of adrenaline¹². It is felt therefore unlikely that doctors would be aware of the need to refer patients on to an allergy specialist, and to compound this even further there is a severe shortage of allergy specialists in New Zealand (SPR .19/100,000)¹.

However anaphylaxis is not a rare event and rates appear to be increasing. Recent Australian studies indicate an increase in rates of hospital admissions for anaphylaxis by 8.8% a year in the period 1993-1994 and 2004-05¹⁰; and the Auckland study also found one of the highest rates of anaphylaxis recorded internationally¹¹.

Finally although ACC has acknowledged in writing to Allergy New Zealand [Appendix 3] that it will cover claims for anaphylactic reactions to food as well as stinging insect venom, very few health professionals including DHB staff, or patients, seem to be aware of this.

Management of food allergy

The most common food allergens are cow's milk (dairy), eggs, peanuts, tree nuts, fish, shellfish, soy and wheat, all of which are staple items in New Zealand diets. Because even small amounts ingested can cause reactions, including anaphylaxis in some, patients are advised to completely avoid the food concerned. Patients with food allergy, in particular children and infants with cow's milk allergy and/or multiple food allergies, should therefore be regularly assessed by a specialist and also advised by a dietitian to ensure appropriate nutrition is maintained while they are on an often very restricted diet. Parents may also need advice from a dietitian on the re-introduction of food where the child has outgrown their allergy to it so the restrictions on their diet are time-limited as far as possible. The risks associated with inadequate nutrition during development are demonstrated by cases of cow's-milk allergic children developing rickets^{13, 14}; and health can also be compromised in adults through long-term food avoidance (from allergy, intolerance, or aversion), e.g. avoidance of dairy food contributing to the early development of osteoporosis¹⁵.

All patients with food allergy should be given advice on how to avoid the food concerned and thus minimise the risk of subsequent reactions. A dietitian is the most appropriate health professional to provide this advice. However referrals to a DHB dietitian in most areas are not the norm for patients with food allergy, and dietitians themselves report training and resources in this specialised field as inadequate.

In addition, for low income families particularly, the costs of finding suitable replacements, including food that does not contain any trace of these allergens, can be very high. However there is no specific provision for special foods on the Pharmaceutical Schedule for people with food allergy, unlike the provision of gluten-free foods for patients with celiac disease. The criteria for accessing the Child Disability Allowance from WINZ is not clear in relation to food allergy, or income support such as a Disability Allowance except for those already on a benefit.

The consequence to patients of inadequate diagnosis, advice, treatment and ongoing management of chronic allergic disease includes:

- People, including many children, who are chronically unwell with recurring conditions such as atopic dermatitis, asthma, and otitis media and/or chest infections. This can result in frequent GP visits, hospitalisation, and/or treatments such as grommets, and high use of medications such as antibiotics;
- High levels of stress and anxiety and, in some cases, patients' lives at risk.
- Ongoing impairment on quality of life, including pain and suffering, depression and anxiety¹⁶, social isolation, absenteeism or 'presenteeism' at work (patients and parents) or school, long-term health impairment, and high financial burden;
- Frustration with the health system in general meaning lack of confidence in its ability to deliver quality services of any description;
- Considerable expense in accessing private specialist services; and/or
- Patients seeking "alternative" therapies for their allergies, many of which have little or no evidence to support their value;

However our perception is that in the majority of DHBs:

- There is limited recognition of the needs of the many people in their constituencies who have allergies;
- There is limited recognition of the need for publicly funded access to tertiary specialist allergy services for those with severe and complex conditions;
- There are few resources being allocated to enable guidelines for the diagnosis, treatment, referral and management of allergic diseases to be implemented from primary through to tertiary levels;
- There is also only limited recognition of the role of and impact on the individual and/or family in chronic care management particularly in relation to food allergy and/or anaphylaxis.

While these issues directly affect people with allergies and their families, they also impact on other parts of the health sector, for example:

- *Hospitals* where policies and procedures are needed to minimise risk such as for health professionals who have allergy to latex and may be at risk of anaphylaxis; and the 2-4 per cent of in-patients (up to 6 per cent of child patients) who may also have food allergies⁹;
- *Mental Health Services* such as for patients who have experienced anaphylaxis and suffer from extreme anxiety and, in some cases, post-traumatic stress disorder, and allergic patients generally who are at increased risk of depression¹⁶;
- *Obstetrics and Lead Maternity Services* which need to ensure families are given the correct advice on allergy prevention and/or early detection of allergic disease in infants;
- *Health professionals working with the education sector e.g. Public Health Nurses:* most schools and early childhood services will have children enrolled who have food allergy and/or anaphylaxis. However the provision of training and resources to enable educators and caregivers to minimise risk and respond appropriately in an emergency is variable throughout the country, unlike countries such as Australia and Canada where anaphylaxis guidelines for these sectors are now mandated by legislation¹⁷ and

supported by state and federal funding. Children with food allergy and/or eczema are also at increased risk of bullying, leading in some cases to anxiety and depression;

We acknowledge the limited resources, particularly for small District Health Boards, to be able to provide a specialist allergy service; and at the same time the shortage of allergy and clinical immunology specialists in New Zealand. However the burden on health and quality of life for the many individuals and families living with allergy is significant, and the social and economic cost impacts on all New Zealanders. We submit that it is vital our health system works to alleviate the burden of allergy as a priority.

Therefore on behalf of all New Zealanders living with allergic diseases we respectfully ask District Health Boards New Zealand to:

1. Acknowledge that the lack of access to specialist allergy and clinical immunology services for the New Zealand population is a serious issue that needs to be resolved as soon as possible;
2. Assist the DHBs to urgently to improve access to tertiary-level clinical services for both paediatric and adult patients with severe and/or complex conditions and/or at risk of life-threatening allergies. This should include information and education for relevant health professionals and providers including General Practitioners, in all DHB areas;
3. Make a commitment to collaborate with all DHBs regionally and nationally as well as the Ministry of Health, and with the New Zealand Clinical Immunology and Allergy Group^{vii} (NZCIAG), to find ways to develop as a priority, publicly-funded allergy and immunology services so that provision for patients is equitable, based on need, and to international best practice including those for the management of chronic disease.

Allergy New Zealand would be happy to provide further information and/or coordinate a presentation or participate in further discussion on the matters raised in this submission. We will convey your comments to our members and supporters.

We look forward to hearing from you.

Yours sincerely



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Chief Executive Officer**

^{vii} Dr Marianne Empson, New Zealand ASCIA Council Representative and Chair, NEW ZEALAND Clinical Immunology and Allergy Group (NZCIAG), Auckland.

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