Camden & Campbelltown Hospitals

Health
South Western Sydney
Local Health District

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Parliamentary inquiry into allergic diseases and anaphylaxis.

Submitted by CH Katelaris AM

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Introduction

I am a consultant in Clinical Immunology and Allergy and currently Professor of Immunology & Allergy at Western Sydney University and Head of Unit, Campbelltown Hospital. In addition, I have a private practice at Westmead. I have worked for more than 40 years in the specialty in clinical practice across public and private sectors looking after adult and paediatric patients and as a clinical researcher in allergic diseases. I have spent my entire working life in the west and south west regions of Sydney and additionally, I have experience doing clinics in Darwin.

I wish to address the following terms of reference:

3. The adequacy and consistency of professional education, training, management/treatment standards and patient record systems for allergy and anaphylaxis;

4. Access to and cost of services, including diagnosis, testing, management, treatment and support.

1. **Professional education and training.**
   There is a lack of middle level expertise and almost complete lack of specialist allergy services in rural areas.
   There is a lack of in -depth knowledge about allergic disorders at primary care level.
   At Western Sydney University we have established a unique course – Masters in medicine (allergic diseases). We offer three levels of postgraduate experience- a Graduate Certificate, Diploma and Masters course part time and predominantly on line with a clinical component

whereby students are placed in specialist clinics for 50 hours to have hands on experience under the guidance of a consultant physician.

This course is providing in depth training to GPs and paediatricians and as a result we have a number of graduates providing focused allergic diseases expertise in rural and regional areas servicing the need of patients.

There are a number of barriers particularly for GPs to undertake this training:

- Need to pay university fees;
- loss of time and income from their own practices
- no extra income for their expertise
- Difficulty finding placements for clinical work component closer to home

Proposal:

- For those servicing rural and remote communities – a grant or scholarship to study
- Payment of Incentives to clinics for taking trainees

2. Cost and access to medications

a. Burden of multiple allergic disorders in families and cost of medications

Specific treatments such as intranasal steroids and immunotherapy products for upper airway allergy-allergic rhinoconjunctivitis and rhinosinusitis- are not available on PBS and for many families they are not obtainable due to cost. There is substantial evidence suggesting that management of the upper airway inflammation is important to improve quality of life and co morbidities such as asthma.

b. Access to special drugs not on PBS for rare conditions

There are a number of examples of rare and unusual conditions managed by allergy specialists where there is evidence for off-label use of existing medications but there is no PBS reimbursement to provide these to patients. In these cases, we rely on “compassionate access” either through hospitals or directly from pharmaceutical companies. While this works for some, it is inequitable as others do not have advocates to obtain these treatments or are denied them. Examples include: swallowed Budesonide for treatment of eosinophilic oesophagitis; Icatibant for patients with hereditary angioedema not meeting the PBS criteria for supply yet responding well to this treatment; Omalizumab for other forms of systemic allergy and urticaria other than chronic spontaneous urticaria (CSU). A mechanism for access with funding is needed for these small patient groups.

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c. **Great delay in having reimbursement for new drugs for special groups and rare conditions.**

While our PBAC system is robust and important, demonstration of cost effectiveness is almost always impossible for patients with rare disorders and also for patients with a number of allergic conditions as old drugs currently used to treat these patients are cheap but often ineffective, and commonly associated with unacceptable side effects. Two examples here are Dupilumab for severe atopic dermatitis (eczema) – a condition that extracts a huge impact on quality of life for both patient and family and is disfiguring and distressing. Dupilumab has revolutionised management of those severely affected and is truly life-changing.

A second example is Lanadelumab for Hereditary Angioedema – a rare genetic disorder associated with prolonged swelling that can affect the airway and be life-threatening. Lanadelumab is a monoclonal antibody used for prophylaxis to prevent swelling attacks and has revolutionised management of this condition.

3. **Need for service enhancement in South West Sydney**

Allergy is predominantly an ambulatory care service and our work is focused in extremely busy clinics in both adult and paediatric Allergy & Immunology.

We work in the centre of a major population growth area – in the 2016 Australian census data, the number of children and adolescents was greater in the outer south west (Campbelltown, Narellan, Picton and Blacktown areas) compared to all other regions of the greater Sydney area. Birth rates in Macarthur have soared by 26% in the past 2 years. Within New South Wales, the birth rate is greatest in South Western Sydney and Western Sydney compared to all other regions. Allergic diseases particularly food allergy and eczema are at the greatest prevalence in infants and young children.

In 13 years I and my colleagues have established comprehensive adult and paediatric Allergy and Immunology services at Campbelltown Hospital.

We have particular expertise in a number of specific areas including severe asthma, severe atopic dermatitis (eczema), all aspects of drug allergy including perioperative anaphylaxis, as we are a reference centre for the ANZAAG group. we spend considerable time investigating antibiotic allergy to de- label spurious antibiotic allergy where possible.

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We are a centre of excellence in chronic swelling conditions such as chronic urticaria and HAE. We have multidisciplinary services in interstitial lung disease, neuroimmunology and paediatric immunology/allergy. We have a very busy paediatric food allergy clinic and offer food challenges when these are required to check for tolerance.

We serve not only our surrounding community but patients from the south – Wollongong and beyond, and many patients from western districts – Goulburn Bathurst, Orange, Dubbo, Wagga. About one third of our workload is for " out of area" consults.

We have a triage approach to consults so that the most urgent are seen in a timely period however this means that other patients wait an unacceptable time for a consult. In Paediatrics we have a wait list of 6-8 months for all but the most urgent patients. Servicing this need places a great deal of pressure on our doctors and nurses and at times we are very overbooked which risks safe practice. Last year we saw 3,200 children in our clinics. We have 385 children on our food challenge wait list and with present resourcing this means on average a two year wait for a food challenge.

In the adult service we saw over 2000 patients in the last 12 months; our nurses delivered over 800 occasions of service – drug tests and challenges, food challenges, training patient to self -administer medications and so on.

Our workforce consists of 1 full time and 2 part time nurses who are paid for by my doing clinical trials to gain funding to have them do hospital service work – in other words they come free to the LHD but this is not a sustainable model and is not a good model for succession planning as it relies on the extra work we take on to perform clinical trials.

On the medical side there are NO fulltime specialists – we have four specialists (1x 0.6 FTE, 1x 0.7 FTE ,1x 0.2 FTE, 1x 0.3 FTE) who between us make up 1.8 FTE. In addition, we have two paediatric immuologists each 0.2 FTE appointment.

Our specialty lends itself to other models of care delivery. We wish to set up telehealth services and a consultative service for our rural colleagues to be able to access advice promptly but this requires personnel to do so. We could have some of our WSU Masters graduates assist in clinics if there were a funding model for such a service.

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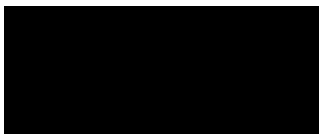
I know we compete for staff funding with services such as diabetes and cancer but the prevalence and importance of allergic diseases, the morbidity and costs to individuals and the community, needs to be understood as well, and I am very grateful that we have this parliamentary inquiry to throw a spotlight on this area of need.

Respectfully submitted



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