



28 June 2008

Ms Ros Jackson
President
Diabetes Australia – ACT
Grant Cameron Community Centre
27 Mulley Street
Holder ACT 2611

Dear Ms Jackson,

Re: Type 1 Diabetes in the ACT

I am writing to congratulate your organisation on the excellent ‘Diabetes Burnout’ event, of which I was delighted to be a part, last weekend in Canberra. It was wonderful to see around 40 people with Type 1 Diabetes brought together, and also see a significant proportion contribute to a lively discussion about the needs of people with Type 1 Diabetes in Canberra.

At 31 December 2007, there were approximately 2,000 people with Type 1 Diabetes living in the ACT.¹

Members of the audience raised some significant concerns about lack of both support and medical services for people with Type 1 Diabetes in the ACT, including the following:

- Access to specialist care such as endocrinology in Canberra is poor (one member had been told there was a 3 month wait for ‘urgent’ appointments) and inequitable (the private system was cited as providing better access but it was of concern that not everyone can afford to pay for private services);
- Support for those using insulin pumps to manage their Type 1 diabetes is extremely limited: most travel to Sydney for this support and have difficulties accessing ongoing support locally.

Specific suggestions for how DA-ACT could improve your services for people with Type 1 diabetes were:

- Provide more comprehensive information about services provided, for example, on the website;
- Review the DA-ACT website so that it is accessible for those who have vision impairment;
- Hold regular forums focused on Type 1 diabetes (2-4 per year);
- Convene regular but informal meeting place, such as fortnightly/monthly coffee nights; and
- Provide updates on new technologies and research for Type 1 diabetes – reporting back from conferences that your staff and other local health professionals have attended.

Suggestions for other improvements that are required, for which attendees at the event would like to see DA-ACT acting and advocating, included the following:

- “Any services at all for adults, especially older adults, with Type 1 would be an improvement!”;
- Dedicated Credentialed Diabetes Educator in Canberra be allocated to support Type 1 Diabetes;
- Register and recall system for annual complications screening; and
- A manual for living with Type 1 Diabetes with strategies for dealing with a range of scenarios, from blood glucose variations associated with menopause to multiple autoimmune conditions.

¹ Data from the National Diabetes Services Scheme (NDSS) registrants database supplied by Diabetes Australia (National Office), April 2008.

Members of the audience also made specific note of their gratitude for the Type 1 Diabetes-focused event having been convened, and specifically thanked Cate Hosick for her commitment to the Type 1 diabetes community. One gentleman commented that he had “learnt more in 2 hours today, than in the 2 years since his diagnosis”, and urged more gatherings of people with Type 1 Diabetes to be arranged.

Significant enthusiasm was expressed by those in attendance to directly support future developments and activities to improve services for people with Type 1 Diabetes; we hope that you are able to maintain the momentum and utilise this support offered.

Our organisation is currently facilitating a process to develop a Statement of Issues Affecting Australians with Type 1 Diabetes, with contributions from eight health professional bodies, six non-government organisations (including Diabetes Australia) and three voluntary consumer groups being represented on the newly-formed Type 1 Diabetes Opinion Leaders Group, alongside 14 people with Type 1 Diabetes and four parents of children with diabetes. We will be pleased to contribute the Canberra-specific outcomes of the discussion from your event into this process. The Statement will be launched at the ADS-ADEA conference in Melbourne on 29th August 2008.

The Type 1 Diabetes Network endorses the call for improved services for people with Type 1 Diabetes which has been made by the Canberrans at last weekend’s forum, and congratulates attendees on the constructive and practical suggestions that were generated.

We would welcome, and would be pleased to share with our members, any feedback that you are able to provide in due course on initiatives to address or advocate for the improvement in these important areas.

Yours faithfully,

Kate Gilbert
President

cc: Incoming Chief Executive Officer, c/- Romina Bognolo, Executive Assistant to the CEO
cc: Cate Hosick, Diabetes Nurse Educator, DA-ACT