



President's Report

October 2008

I am pleased to present an update for members on the recent activities of the Association.

Major achievements for the year include:

- Endorsement as a registered charity with DGR status
- Development of an advocacy platform
- Launch of 'A Statement of Issues affecting Australians with Type 1 Diabetes'
- Growth of sustainable revenue streams
- Presentation of original research at national and Australasian conferences

1. Charity status

In November 2007, the Association was endorsed as a Deductible Gift Recipient (DGR) by the Australian Tax Office. The endorsement was made effective from 1st July 2007.

The endorsement allows us to accept tax-deductible donations from individuals as well as being eligible for a broader range of Trusts and Foundations' grants where DGR Status is a requirement.

Requirements of the endorsement such as having a bank account dedicated to receipt of donations, issuing receipts and noting the DGR status on letterhead have all been enacted.

2. A Statement of Issues affecting Australians with Type 1 Diabetes

The Association initiated and facilitated a process throughout 2008 to develop an advocacy platform about Type 1 Diabetes, by developing 'A Statement of Issues affecting Australians with Type 1 Diabetes' in partnership with key stakeholders.



L-R: A/Prof Maarten Kamp, Endocrinologist and President, Australian Diabetes Society, The Hon Guy Barnett, Senator for Tasmania, Anthony Lambert-Johnston and Kate Gilbert spoke at the launch on 29 August 2008 and took questions from the audience of 120 health professionals.

The Type 1 Diabetes Opinion Leaders Group was formed in 2008 to jointly develop the Statement and stimulate discussion about solutions and improvements.

The Statement was launched by The Hon. Guy Barnett, Senator for Tasmania on 29 August 2008 at the Australian Diabetes Society and Australian Diabetes Educators Association Scientific Meeting in Melbourne.

The Statement of Issues affecting Australians with Type 1 Diabetes comprises the following:

1. **Access to specialist medical advice** is very limited, especially in rural and regional areas
2. **Complexity** of Type 1 Diabetes is neither well understood nor managed
3. **Coping with long-term complications** of Type 1 Diabetes is left to the individual with very limited support
4. **Hospital admissions**, planned and emergency, for people with Type 1 Diabetes are managed poorly when a diabetes team is not involved
5. **System for the essential long-term monitoring** of Type 1 Diabetes is inefficient and highly ineffective
6. **Adolescence and young adulthood** is a critical stage with the worst outcomes
7. **Access to the best treatments and medical technologies** is dependent on the ability to pay, not medical need
8. **Training teachers and schools** about the basic needs of children with Type 1 Diabetes occurs haphazardly
9. **Peer learning** opportunities for people with Type 1 Diabetes are essential but very limited and difficult to access
10. **Leadership and advocacy** for Type 1 Diabetes needs to be strengthened urgently

Some of the solutions proposed include:

- A Centre for Excellence in Type 1 Diabetes to be established in Australia with early tasks to include developing evidence-based guidelines for Type 1 Diabetes in adults, which currently do not exist.
- Telephone-based 24-hour secondary consultation service for GPs and hospital doctors to access expertise in Type 1 Diabetes.
- An automated system for routine complication screening recall and review to increase rates from the current 20%.
- Pre-determined Diabetes Plans that can be immediately enacted upon admission to hospital or in other emergencies.

As part of this project, some significant documents were developed:

- **Type 1 Diabetes in Australia, 2008** - a comprehensive and concise review of the literature
- **101 Solutions for Type 1 Diabetes** – a collation of all suggestions proposed by the Type 1 Diabetes Opinion Leaders Group and through the public submission process
- **Rationale for a Statement of Issue** – a project plan and rationale

Correspondence with our politicians was also entered into, with letters and responses published on the website.

Targeted publicity was also undertaken, with articles about the Statement being published or in publication with the following:

- Health Issues Centre Journal
- Chronic Illness Alliance newsletter
- Diabetes Management Journal
- Health and Social Campaigners' Network International Bulletin
- Courier Mail magazine feature article

More information about the issues and solutions developed, and the process and contributors, can be found at www.d1.org.au/issues.

3. Government and other submissions

In the past year, a range of submissions on behalf of people living with Type 1 Diabetes have been made by the Association. A dedicated webpage has also been created to communicate this work with our members, and notes in the Association's newsletter.

Topics of submissions:

- **Managing Risk in Primary Care**
– to Commission for Safety & Quality in Healthcare, *October 2008*
- **Insulin Pumps and the Prostheses List**
– to The Hon Nicola Roxon, Minister for Health, *October 2008*
- **Type 1 Diabetes in the ACT**
– to Chair and CEO, Diabetes Australia-ACT, *June 2008*
- **Introducing the Type 1 Diabetes Opinion Leaders Group**
– to state and federal ministers for health and Parliamentary Diabetes Support Group, *June 2008*
- **Indefinite Referrals**
– to Medicare Consumer Consultative Committee via Chronic Illness Alliance, *June 2008*
- **Consumer input to the NDSS Supply Chain Review**
– to The Hon Nicola Roxon, Minister for Health, *January 2008*
- **Pre-Budget Submission**
– to the Federal Treasurer, *January 2008*
- **Dana insulin pump Guarantees normal blood glucose**
– to Australian Competition & Consumer Commission and Therapeutic Goods Administration, *January 2008*
- **Submission to the Victorian Health Promotion Framework**
– to Victorian Government, *September 2007*

Details of submissions and responses receive can be found at www.d1.org.au/issues.htm

4. Starter Kit for Adults with Type 1 Diabetes

Abbott Diabetes Care have continued to provide in-kind support to produce and distribute this essential resource. To date, the Starter Kit has been distributed as follows:

Total to September 2006	2006-07	2007-08
1,796 Kits distributed	1,470 Kits distributed	983 Kits distributed
181 Diabetes Centres	Additional 65 Diabetes Centres	Additional 27 Diabetes Centres

For comparison, the Australian Institute of Health and Wellbeing has just released data for new cases of Type 1 diabetes in Australia in 2000-2006. New diagnoses in 2006 are as follows:

Age	Females	Males	Persons
15-19	90	143	233
20-24	59	103	162
25-29	48	91	139
30-34	45	107	152
35-39	48	62	110
40-44	26	61	87
45-49	20	32	52
50-54	17	46	63
55-59	15	25	40
60+	40	65	105
All >15 years	408	735	1143

During 2007, the Association entered into negotiations with the Juvenile Diabetes Research Foundation (JDRF) regarding their plans to launch a product modeled on their KIDSAC for newly-diagnosed children, aimed at newly-diagnosed adults, to be called 't1d kit'. Costings and arrangements were discussed for the Starter Kit to be the information resource included within this package. Unfortunately, agreement was not able to be reached over acknowledgment of necessary sponsors. JDRF launched the t1d Kit at the ADS-ADEA meeting in August 2008 and it was planned to be available in September 2008, and JDRF staff were writing and printing a new educational resource to include in the kit. At time of reporting, late October 2008, the kit is not yet available.

5. Consumer representation activities

The Association is increasingly being invited to represent people with Type 1 diabetes as consumer representatives. Current representation held by the President includes:

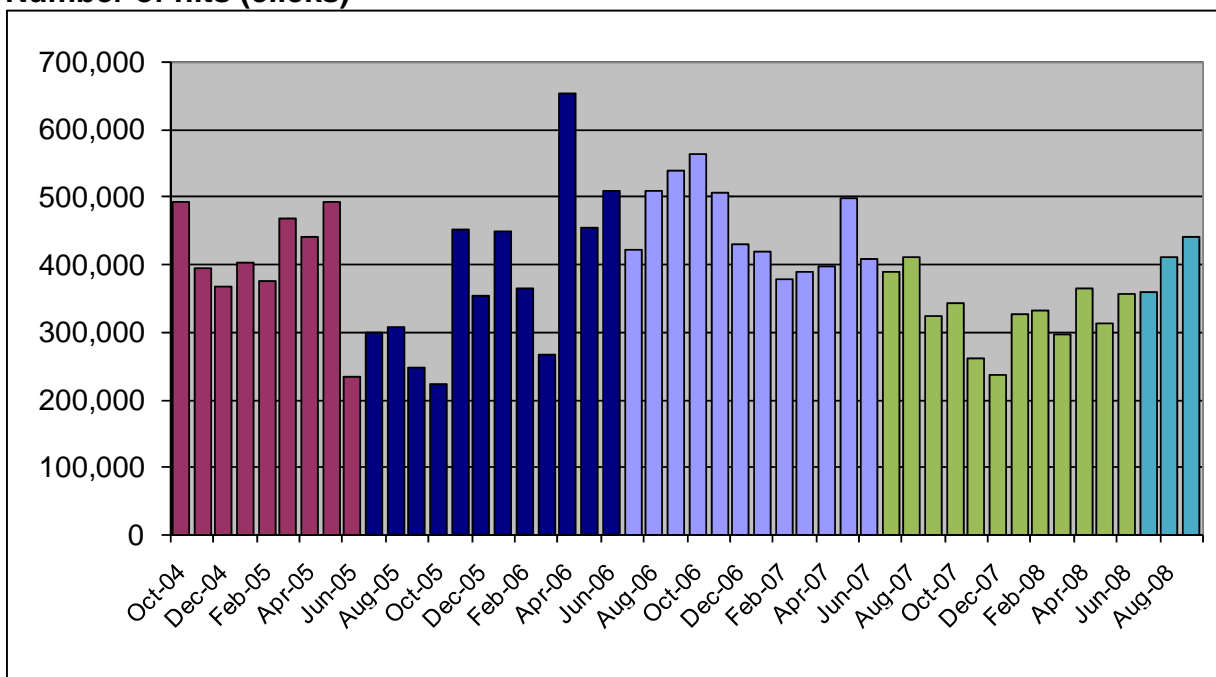
- Deakin University Diabetes Education Course Advisory Committee – 2 meetings/year
- Australasian Paediatric Endocrine Group annual conference – invited speaker about the experience of living with Type 1 diabetes at Parliament House, Canberra (November 2008)
- Australasian Society for Psychological Research into Diabetes – Consumer Representative on Board of Directors (effective November 2008)

6. Reality Check website

Total number of visits and hits to the Reality Check website has stabilised and decreased marginally in 2007-08, whilst the number of members of the online community grew considerably.

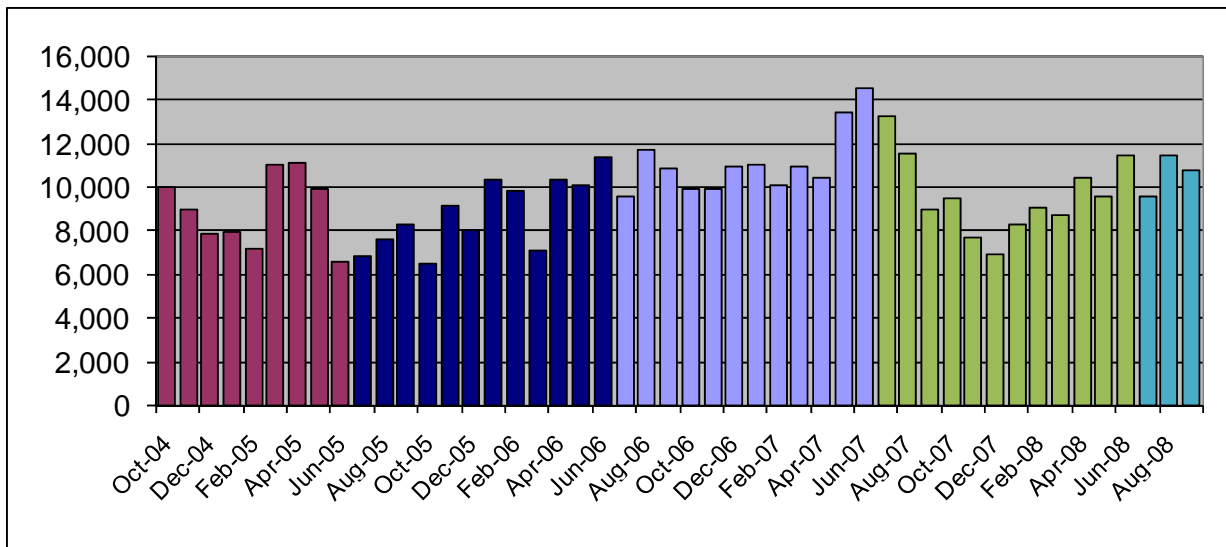
	2005-06	2006-07	2007-08
Lowest monthly hits	220,921	377,876	236,362
Highest monthly hits	651,287	562,865	410,697
Total hits for year	4.57 million	5.47 million	3.94 million

Number of hits (clicks)



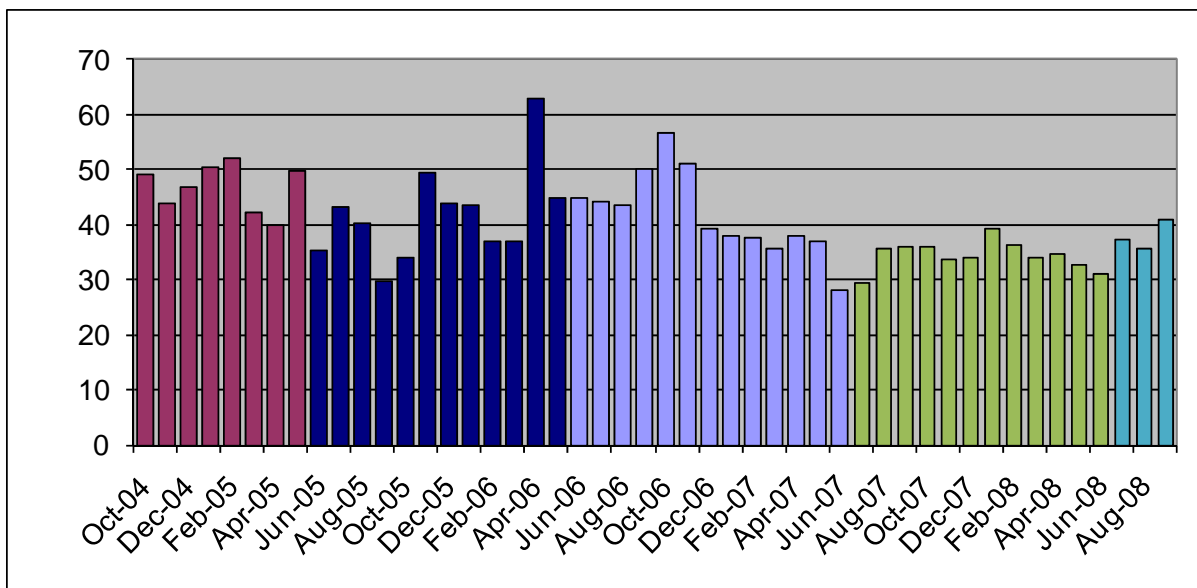
Number of discrete visits to the site

This is an indicator of the number of individuals and/or the frequency that individuals visit the site.



Number of hits per visit

(an estimate of the amount of time individuals are spending on the site each time they visit)



Online community

The most popular component of the website remains the online community, which has grown from 766 active members in July 2007 to 1,070 members in October 2008.

Volunteers Anthony Bernauer, Tash Broughton, Adrian Connard, Kate Gilbert and Melinda Seed continued to moderate the site very successfully using a weekly roster during 2007-08, and met by teleconference periodically to discuss emerging issues.

7. Munted Pancreas website for parents

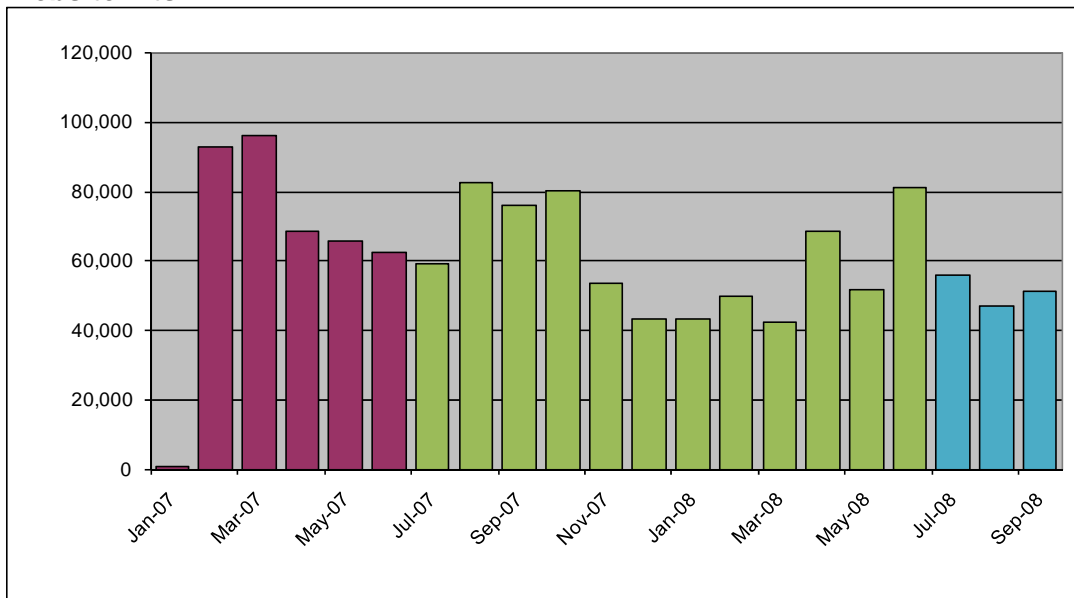
The online community for parents of children with diabetes, founded by Shelley Campbell in January 2007 continues to grow. Shelley has now been joined by Bill Murray as volunteer manager of the website.

The forum has grown from 78 registered members in July 2007 to 160 in October 2008.

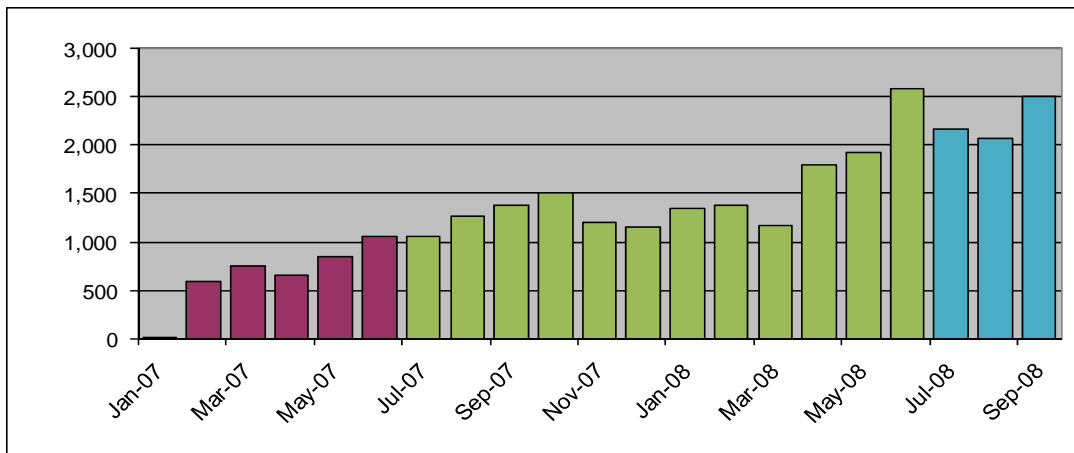
Feedback about the online community developing at Munted Pancreas has been extremely positive, for example:

“I have been regularly on the site of Munted Pancreas these past 3-4 weeks and I am hooked!! I have really enjoyed the discussions with the other parents on a vast variety of subjects related to T1D. Most of the parents seem to be as cool as cucumbers, whilst what I see around me is mostly parents of kids with T1D who can be quite stressed...Very inspiring indeed to read stories of parents who are coping, who are positive and strong.”

Website hits



Website visits



8. Email newsletter Yada Yada

We have continued to produce a monthly email newsletter all about Type 1 Diabetes.

Subscribers to the Association's newsletter have grown from 2,800 in July 2007 to **3,600 in October 2008**, an increase of 29% solidly building on the previous year's growth of 500 or 22%. It should be noted that the Association has a policy of regularly cleaning the database such that subscriber numbers quoted are active and current email addresses.

A newsletter archive has now been created to extend the accessibility of the valuable information contained within newsletters, especially to new members and potential advertisers.

Advertising in the newsletter has grown substantially this year such that most newsletters have contained two advertisements, and two long-term arrangements for placing advertisements are in place.

Newsletters continue to be produced in approximately alternate months by volunteers Kate Gilbert and Melinda Seed.

9. Events

In July 2007, the Association partnered with Diabetes Australia-Victoria to present a seminar about Diabetes Burnout at Melbourne Town Hall which attracted more than 200 people (pictured). Speakers were Kate Gilbert and health psychologist Dr Sarity Dodson (pictured below)



The Diabetes Burnout event was repeated in Shepparton, in partnership with Goulburn Valley Diabetes Centre, though only 15 people attended.

In April 2008, the President was invited to address the Sweet conference in Brisbane addressing both health professional forum about communicating with young people with diabetes and lessons form a successful peer support network, and also addressing the evening session for consumers, speaking about personal experiences and diabetes burnout.

During 2007-08, the Reality Check online community has increasingly organised a number of informal get-togethers around Australia. A dedicated section of the Reality Check online forum, and a procedure for promoting events within the main forum, was instigated to support these activities.

10. 10th Anniversary

January 30th 2008 marked 10 years since the first 'Reality Check' event, a dinner of 20 people in Melbourne and a small gathering of long-term members of the Association was held at The Emerald Hotel in Melbourne to celebrate. Our thanks to those who attended to mark the occasion.

11. Academic presentations and publications

In the past year, several abstracts have been presented to academic conferences around Australia and New Zealand.

A 20-minute oral presentation was made at the Australian Society for Psychological Research into Diabetes in Melbourne in August 2008:

K. Gilbert, S. Dodson, DIABETES BURNOUT: Adults with Type 1 Diabetes describe specific symptoms and successful strategies for prevention and management

Two posters were presented at the Australian Diabetes Educators Association in Melbourne in August 2008:

K. Gilbert, S. Dodson, DIABETES BURNOUT: Adults with Type 1 Diabetes describe specific symptoms and successful strategies for prevention and management

K. Gilbert, M. Seed, S. Thornley, The impact of Diabetes Nurse Educators on complication screening, self-management practices and access to new treatments amongst Australian adults with Type 1 Diabetes

A paper was also accepted for presentation at the Health Services & Policy Research Conference in Auckland in December 2007, and the President was awarded a travel grant to assist with costs to attend and present the paper:

K. Gilbert, M. Seed, Australasian young adults' Transition from paediatric to adult Diabetes Services: a complex picture of choice and access.

The Association was also invited to submit an article for publication in the Diabetes Management Journal Article and 'Reality Check: a website for and by People with Type 1 Diabetes' was published in June 2008. It is available to view and download at www.d1.org.au/resources.htm#prom.

Finally, the President has been invited to attend the World Diabetes Congress Montreal 2010 to speak on Internet and Diabetes – as an invited speaker, funding to attend will be provided by the International Diabetes Federation.

All abstracts, presentation slides and posters are published on the Association's website at the following link: www.d1.org.au/resources.htm#abstracts

12. Consumer information about diabetes and pregnancy

Collaboration with Diabetes Australia to distribute the Diabetes and pregnancy resource to all women of childbearing age registered on the NDSS began in 2006. The Association received advice from Diabetes Australia-Victoria in January 2008 that they were beginning the review, print and distribution of the booklet and we have been collaborating with them on the project through 2008. At the time of reporting, October 2008, a final draft of the booklet had been submitted to the Federal Department of Health and Ageing for review and it was expected to be printed and distributed all women with type 1 diabetes aged 18-40 years registered with the NDSS and also a flyer promoting the booklet would be mailed to all women with type 2 diabetes aged 18-40 and women with type 1 diabetes aged 16-18 years in December 2008.

A finding of the evaluation of the diabetes and pregnancy resource in 2006 was that online access to the information was highly desired. Diabetes Australia-Victoria has agreed to lead this initiative but are yet to progress the initiative any further. A sum of \$2,500 is required to convert the printed information booklet to a mini-website.

13. Revenue

As reported in detail through the Treasurer's report, the Association has achieved our ambitious revenue target for 2007-08 and established some sustainable income streams in advertisements in email newsletter Yada Yada and private donations.

A small grant from the Federal Government was received to purchase equipment for the Association: a laptop and printer. At the time of reporting, we have also had early advice that a grant application to assist with re-development of the Reality Check website has been successful. In 2008, the Association was also awarded a GoogleGrant, to provide free advertisements for the Reality check website through the Google AdWords program.

14. Volunteer support

The Association remains entirely dependent on the support of a small number of volunteers.

Melinda Seed, Treasurer and Sydney co-ordinator of the Association continues to provide a tremendous contribution to both the strategic direction and the day-to-day running of the Association.

Volunteer moderators continued to oversee the Reality Check online community during 2007-08: Adrian Connard, Natasha Broughton, Tony Bernauer, Kate Gilbert and Melinda Seed operating on a roster system with one of the 5 moderators on duty each week. Shelley Campbell continued to oversee the growth of the Munted Pancreas online community for parents and was joined as co-moderator in 2007-08 by Bill Murray.

15. Future plans

The Association's Management Committee remains committed to the Association's objective to:

Create opportunities for people with Type 1 diabetes to share knowledge and experiences in order to attain an optimum quality of life.

A wide range of opportunities lie ahead of the Foundation as we move into our second decade and continue to build membership, expertise and reputation.

15.1 Four priority areas identified

In January 2008, the President and Treasurer met in Melbourne to review the Association's business plan. A SWOT analysis was conducted and four priority areas were identified for the focus of the Association's future activities:

1. People with type 1 diabetes have access to information to enable them to make informed decisions about their healthcare and self-management	<ul style="list-style-type: none">• Starter Kit maintained• Clinical guidelines for Type 1 adults• Provide opportunities to share knowledge and experiences• Re-development of website• Educational resource for adults with type 1 who were diagnosed as children
2. Increase subscribers to 10,000 or 10% of those with Type 1 Diabetes.	<ul style="list-style-type: none">• Re-development of website• Educational resource for adults with type 1 who were diagnosed as children.
3. Empowered and active Type 1 Diabetes community	<ul style="list-style-type: none">• Provide opportunities to share their knowledge and experiences• Statement of Issues and launch event• Consult/collaborate with other diabetes organisations and health professionals and professional organisations
4. Develop funding sources to sustain organisation	<ul style="list-style-type: none">• Target \$10,000 income in base year, increase of 10% pa.

15.2 Forming a Business Plan Working Group

In 2008-09, the Management Committee will form a business plan working group which will meet by teleconference bi-monthly (December, February, April and June) to:

- review and refine the priority areas
- develop a new business plan for the Association
- consider issues relating to, but not limited to, the governance, staffing and succession planning needs of the Association; and
- begin to implement the business plan.

We would like to invite members interested in joining this time-limited, task-specific working group to contact the President or Treasurer at your earliest convenience.

I would be more than pleased to take questions and expand upon any of the information provided in this report at the AGM or other times as members wish.

Kate Gilbert, President
Email: kate@d1.org.au
Phone: 0402 515 825

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