



First Edition 2013

Newsletter of the

Department of Endocrinology & Diabetes



KIDS AT CAMP

The diabetes team runs two holiday camps per year for children with type 1 diabetes. Each camp is fully staffed by diabetes nurse educators, a



dietitian, social worker and volunteer staff recruited through Diabetes WA.

The three day/two night October camp takes place at Ern Halliday. This camp is targeted towards children 9–10 years of age. The five day/four night January camp takes place at Point Walter in Bicton and targets children 11-12 years old.

CAMP SPOOK-TACULAR

Thirty-three children attended camp Spook-tacular in October 2012 and took part in a variety of activities including beach games, making sand sculptures, arts and crafts and the spook-tacular disco. Both children and staff had a fantastic time dressing up and dancing at the disco.

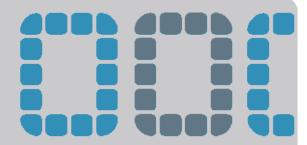
Camp members had a surprise visit from Rob Palmer from Better Homes and Gardens who also lives with type 1 diabetes. Rob spent the afternoon with the children talking about living with diabetes and sharing stories. Rob gave a master-class on how to make a box-kite and spent time flying them with the children.

CAMP ROCK STAR – POINT WALTER'S GOT TALENT

Thirty children came to a very hot and exciting Point Walter in January 2013. Everyone had a great time with plenty of games and fun activities on the river, in the pool and on the flying fox. Campers had an air guitar competition and plenty of laughs as they dressed up as rock stars.

Although the camp is primarily about having fun and meeting others living with type 1 diabetes, there is also an element of education woven into the games. Children are encouraged to adopt safe and healthy self care practices. January's camp saw two children become confident enough to begin doing their own injections. Most of them also became more confident and aware of carbohydrate counting.

research



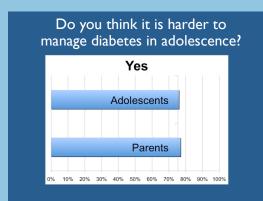
WHAT'S GOING ON IN RESEARCH

Like other chronic conditions, Type 1 diabetes mellitus (T1D) has an enormous psychosocial impact on patients and their families. Adolescence is a particularly challenging period.

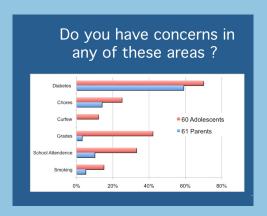
The objectives of a recent research project by the PMH team was to ascertain the themes surrounding the difficulties both adolescents with T1D, and their parents, face with their day-to-day routine and to compare their viewpoints of psychosocial challenges.

A total of 64 adolescents with T1D and 61 parents were recruited from Princess Margaret Hospital's Adolescent Diabetes Clinics between February and July 2012. Both parents and adolescents completed the questionnaires.

Results identified BGL testing, insulin dosing and emotional stress as the most difficult aspects of diabetes management. Ninety-five percent of patients thought they had sufficient information and education about diabetes, while 77% of parents and 65% of adolescents thought it was harder to manage diabetes in adolescence.



Adolescents think their "parents worry too much about diabetes". Both groups agreed that they are more concerned about diabetes management than common adolescent issues such as grades, curfew, and smoking. Although the majority (52%) of adolescents identified no problems with managing their diabetes at school, 28% found it difficult to make time.



This questionnaire has reinforced that patients commonly find adolescence an emotional time during which T1D management is difficult and highlighted some areas which require attention. Following this initiative the Department of Endocrinology and Diabetes at Princess Margaret Hospital will use the "Problem Area in Diabetes Assessment Tool" (PAID) to track levels of distress and predict diabetes development and milestones to potentially reduce the psychosocial impact of diabetes upon lives of adolescents with T1D.

KIDS AT CAMP









WHAT CAUSES TYPE 1 DIABETES IN EARLY CHILDHOOD?

The Environmental Determinants of Islet Autoimmunity (ENDIA) study is finding out what causes Type 1
Diabetes so we can find ways to prevent it. It is a nation-wide pregnancy cohort study into the environmental factors of Type 1 Diabetes. The Chief Investigator of ENDIA is Professor Jennifer Couper (University of Adelaide) and the WA Principal Investigator is Professor Timothy Jones (Princess Margaret Hospital).

There has been a doubling of new cases of Type 1 diabetes in Australia over the last twenty years which may be in part due to environmental factors.

Understanding how the environment contributes to or protects against the disease, may allow us to modify these factors and help prevent Type 1 Diabetes in the future.

If you are planning or expecting a baby, or have a baby less than 6 months old, your family may be eligible to take part in ENDIA. To take part in this study you or your baby's father, or baby's full-sibling, must have Type 1 Diabetes.



protect

HELP PROTECT YOUR RELATIVES FROM TYPE 1 DIABETES.

PMH is conducting a study known as the INIT II study to find out if type 1 diabetes is preventable.

PMH is looking for relatives of people with type 1 diabetes because they may be at increased risk of developing this disease. By being involved in the study they may make an important contribution to find out if type 1 diabetes is preventable.

The study is being conducted throughout Australia and New Zealand.

What's involved?

The first phase of the study involves a screening blood test for antibodies which may indicate whether your relatives are at increased risk of developing type 1 diabetes and therefore may be eligible for the study.

The study treatment involves using a nasal spray.

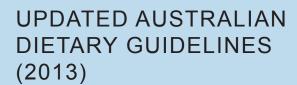
Talk to your relatives today!

Any of your relatives aged 4 - 30 years may be eligible to participate in the study. If a relative of yours would like more information about the study, they should visit **www.stopdiabetes.com.au**, or contact the study co-ordinator.

Alison Roberts (08) 93408486 alison.roberts@health.wa.gov.au

Closed-loop study

Dr Tim Jones and his team at the Telethon Institute for Child Health Research are conducting a world first clinical trial and are moving towards the completion of an artificial pancreas or closed-loop system of managing type 1 diabetes.



The Australian Dietary Guidelines (2013) have recently been updated.

The Guidelines provide up-to-date advice about the amount and kinds of foods we need to eat to promote health and wellbeing and have been revised to reflect the latest body of scientific evidence on nutrition, diet and health.

Following the dietary patterns recommended in the Guidelines, promotes nutrients essential for good health and to reduce the risk of chronic disorders such as heart disease, type 2 diabetes, some cancers and obesity.

The Australian Dietary Guidelines were first issued in 1982. This 2013 revision of the Guidelines has focused on food choice, for example the importance of enjoying a wide variety of nutritious food like whole grain cereals (bread, rice, noodles etc.), instead of the amount of nutrients you should consume (vitamin C, B12 etc.).

Dr Jones wants to determine the effectiveness and safety of the system, its real time use, conduct the first at home trials of the system and reduce the burden of diabetes on children. A fundraising site has been developed: http://www.supportchildhealth.org.au/event/closetheloop

Other diabetes research projects can be viewed at http://www.supportchildhealth.org.au





City Beach man Ian Gordon did more than just complete the challenge of the Rottnest Swim, he raised more than \$12,500 for Diabetes WA.

The City Beach man decided to enter the swim and raise money for the organisation after his son Findlay was diagnosed with type one diabetes just after his third birthday last year.

Gordon's target was \$10,000.

"Just thinking of this little boy (was what kept me going)," he said.



support

Gordon family photo provided by Diabetes WA

Start for diabetes support

■ Phoebe Wearne

WA's first dedicated centre for managing juvenile diabetes could be helping families by next year after the State Government donated land at its Osborne Park Hospital site to the cause.

The Telethon Juvenile Diabetes Family Centre, to be built with funds from Telethon and Lotterywest, will provide children and teenagers with type 1 diabetes and their families with support on top of their mainstream hospital care.

It will house a psychologist, diabetes nurse, support group, education facilities and a state-of-the-art kitchen to help young sufferers learn how to eat to best manage their disease.

Health Minister Kim Hames toured the 1630sqm block of land, valued at \$1.08 million, with centre chairman Jeff Newman yesterday.

Professor of endocrinology and dia-



betes Tim Jones, who is based at Princess Margaret Hospital and will lead the project, said the centre would complement the medical care children received at PMH and fulfil an unmet need for support for teenagers after they left PMH.

"PMH provides great medical care,

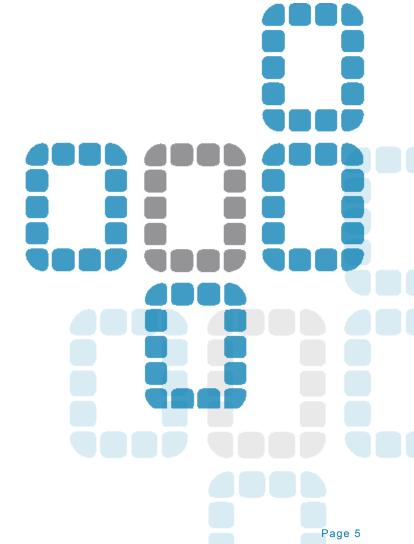
"PMH provides great medical care, but when you've got chronic disease you need support in the community and you need support for your whole life." Professor Jones said.

and you need support for your whole life," Professor Jones said.
"It also will provide support for children when they leave PMH, so that transition period, that dangerous time between 16 and 20."
Mr Newman said he hoped the cen-

Mr Newman said he hoped the centre would help young sufferers accept their diabetes and carry on with their lives without seeing it as a burden.



On site: Jeff Newman, Kim Hames and Tim Jones yesterday. Picture: Steve Ferrier



what to expect

Sometimes it can be extremely overwhelming for families when attending diabetes clinic - especially for the first time. As well as dealing with the condition itself, there is a whole team of health professionals, to meet.

When next attending clinic, keep an eye out for the DIABETES SERVICE - WHAT TO EXPECT leaflet.

The leaflet provides valuable information about the PMH Diabetes Service – including what to expect after diagnosis and the people who make up the diabetes team who will look after you. And don't forget YOU are part of the TEAM.

Feedback please

If you have any ideas about how the newsletter can be improved please contact Madeleine (Project Officer) on **9340 7978**.

The Princess Margaret Hospital for Children (PMH) Diabetes Service

Diabetes Service
What to expect
a guide for patients
and their families

diabetes first-aid

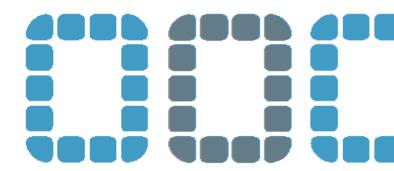
Diabetes WA is also available to provide general education at schools in relation to type 1 and type 2 diabetes. At present, Diabetes WA is providing these sessions at cost price, for teaching groups unable to attend the PMH sessions.

Indervidual teachers are able to attend/link-up to PMH teachers' seminars. Details are shown adjacent, under the heading 'school'.

You may also wish to subscribe to the Diabetes WA e-Newsletter through the following link:

http://www.diabeteswa.com.au/News_and_
Events/Subscribe_to_eNewsletter





school

TYPE 1 DIABETES & SCHOOL

If you know a school/teacher that would like to increase their understanding and knowledge of diabetes management in schools, PMH runs regular videoconference seminars.

These run from 1:30 - 3:00 on the following dates.

Insulin Injections

- 10th May and 13th September

Insulin Pumps

- 24th May

Topics presented by a multi-disciplinary team include: understanding diabetes; insulin injections or pumps; diabetes first aid; diet; exercise; school management plans and impact/adjustment to diabetes. Questions will also be answered.

- * Online registations for seminar attendance at www.pmh.health.wa.gov.au/services/ endocrinology/seminar/index.php
- * Video conference linkages can be arranged through: telehealth.cahs@health.wa.gov.au or phone 9340 7045.