



Children with diabetes in the developing world

In developed countries, children with diabetes have access to comprehensive care, with tailored insulin regimens, self-monitoring, education and psychosocial support, 24-hour access to care, complications screening, and insulin pumps if indicated. They are healthy and active, enjoying life and moving on to make choices in education, relationships and careers like any other young adult.

The stark reality for children in dire need around the globe

In contrast in many developing countries, particularly in Sub-Saharan Africa, even minimal care may not be possible. Insulin is often unavailable or unaffordable. Clinics and district health centres may not be able to measure blood glucose. Few people are able to do self-monitoring of blood glucose levels. Knowledge of childhood diabetes in health professionals may be very limited, with children dying due to mis-diagnosis, or treated with oral medicines. (The incidence of diabetes in children in most developing nations is only 5–20% of that in the developed world – and so it is a very uncommon presentation in many settings.) Some countries do not have any capacity to measure HbA_{1c}. For these reasons, children with diabetes generally either die quickly or remain chronically unwell with poor quality of life. Early and devastating complications are common, and most children with diabetes cannot complete school and have limited marriage and employment prospects.

The cost of care for a child with diabetes is US\$300–1000 per year – which in a developing country may be most of, or even exceed, the family income. Insulin alone, if the government does not provide it, will cost US\$180–300 per year. Self-monitoring is virtually always prohibitively expensive, with test strips costing US60c–\$1 each. Sometimes, at great social and economic cost, families need to move to the city to access care for their child. Other families face terrible choices – there is an ‘opportunity cost’: do the parents choose to pay for the care of their child with diabetes and therefore be unable to afford to send their other children to school, or do they let the child go so the others can gain an education?

In some of the poorest countries, even where there is expert care, around one-third or more of the youth will have HbA_{1c} levels $\geq 14\%$. Control is this poor for various reasons: self-monitoring is not possible, adequate insulin may only be intermittently available and, in any case, control cannot be too tight as hypoglycaemia can be fatal when clinics are closed overnight or on the weekends. At these levels of HbA_{1c}, complications can develop rapidly. Sadly, it is not uncommon to see young people in their teens and early 20s who need cataract surgery or laser therapy for retinopathy, or who are developing chronic renal failure.

The International Diabetes Federation (IDF) Diabetes Atlas (2006) estimates that across the globe there are 436 038 children less than 15 years of age with diabetes. Of these, 54 865 live in the 49 countries defined by the World Bank as ‘Low Income’ (*per capita*) and a further 56 097 in the 56 ‘Lower-Middle Income’ countries. However, data from the IDF Life for a Child Program suggest that the numbers for at least the Low Income countries are over-estimates – mortality appears to be very high in rural and regional areas, and even in many capitals. There are few published data on mortality but, in various areas that we are aware of with populations of 500 000 to a couple of million, there appears to be only a handful (if that) of children with diabetes alive. However, some other countries – for instance, Bangladesh, Tanzania and Morocco – have established networks which have led to considerably larger numbers of children staying alive and often thriving.

Help currently provided by the IDF Life for a Child Program and partners

The IDF Life for a Child Program aims to help these children by assisting diabetes centres to provide insulin and other essential components of care.

The Program commenced in 2000, and is run from Sydney, Australia, with the assistance of Diabetes Australia-NSW and HOPE *worldwide*. Core funds come from individual donors in Australia, The Netherlands, the USA and other countries. Most donors contribute an equivalent of ‘a dollar a day’. In addition, funds are donated by companies and diabetes associations. Partners include Insulin for Life (which collects excess insulin and test strips and sends these to countries in need) and also Rotary International.

The Program now supports the care of around 1100 children and other young people in 18 countries around the world: Tanzania, Rwanda, Democratic Republic of the Congo, Nigeria, Mali, Zimbabwe, Sudan, Azerbaijan, Uzbekistan, Nepal, India, Sri Lanka, Philippines, Papua New Guinea, Fiji, Solomon Islands, Bolivia and Ecuador.

The greatest strength of the Program is that we support and strengthen existing diabetes centres, building their systems and capacity, rather than establishing new centres with foreign direction. These centres then become examples of excellence in care for the rest of the country, training, nurturing and promoting care in smaller centres. The needs vary from country to country – in some, the government can provide insulin but cannot cover the cost of monitoring; in others, insulin must be provided as well. In consultation with the centre, priority needs (e.g. insulin, syringes, monitoring and diabetes education) are determined, and a budget defined. Support is then extended to a specific list of the most needy children. The cost to support a child for a year is US\$200–400. The goal is to provide best-practice cost-effective care for that country.



Advice and technical support are given when requested. Health outcomes of the children are followed through the use of an annual clinical data sheet. We are developing a database for these records and it will be possible to upload to this database from the countries receiving support. Financial trails are also carefully monitored.

The funds disbursed by the Program have grown from US\$12 276 in 2001 to a projected US\$320 000 in 2008 – US\$170 000 in funds and a further US\$150 000 of in-kind donations. Discussions are underway with various other countries, and it is likely that the number of countries receiving assistance will grow to 25 or more by the end of 2009.

Implementation has led to a number of developments in paediatric diabetes care. These include: (1) extension of quality care from capitals to regional centres, and in some cases (such as Bolivia and Rwanda) to cover virtually all provinces in the country; (2) introduction of self blood glucose monitoring on a wide scale (e.g. in Azerbaijan); (3) commencement of HbA_{1c} testing; (4) establishment of registers and systematic clinical data collection; (5) recognition of children with type 2 diabetes; (6) supporting inaugural diabetes camps; (7) improved clinic practices and monitoring of clinical indices; and (8) increasing numbers of cases known as

more stay alive. The Program is also involved in research and advocacy at numerous international fora.

Further support

Other agencies are also working in the field. Global bodies such as the International Society for Pediatric and Adolescent Diabetes (ISPAD) have lent support to the Life for a Child Program and are also engaged in training initiatives, with members volunteering to teach and pass on skills. The International Insulin Foundation conducts detailed assessments of insulin supply and access in individual countries, which then guide improvements. The European Society for Paediatric Endocrinology (ESPE) has independently established a training school in Nairobi. Various twinning relationships have also been established between developed and developing country centres.

• The Program welcomes support from new donors, and requests for assistance are welcome – please see <http://www.lifeforachild.org>

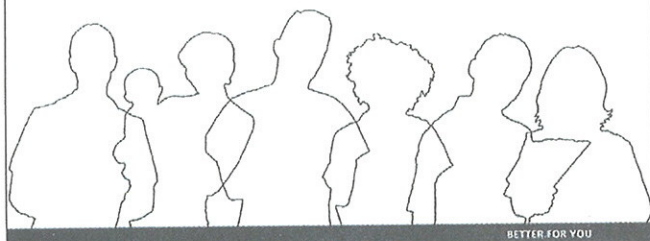
Dr Graham Ogle, FRACP, Program Manager, IDF Life for a Child Program, Regional Director (South Pacific), HOPE worldwide

Setting up your Insulin Pump Therapy service: the Gloucester model

Gloucestershire Royal Hospital
December 11th 2008
Course Fee £120

This one day course will cover the basics of insulin pump therapy with lectures and hands on practical sessions aimed at doctors, nurses and dietitians who are considering setting up a pump service or who wish to gain an overview of pumps. Children's pump therapy, antenatal care and psychological aspects will be covered by experts with practical tips on business planning and service configuration. Email Irene.Stewart@glos.nhs.uk for a registration form.

Gloucestershire Hospitals NHS Foundation Trust



BETTER FOR YOU

Dates for Your Diary

1 December 2008

Structured Education – How do you know you are doing a good job? Diabetes Education Network Annual Conference, Hyatt Regency Hotel, Birmingham, UK. Contact Suzanne Lucas. Tel: +44 (0)1634 668 129, e-mail: suz.lucas@uwclub.net

4 December 2008

Improving pregnancy outcomes in women with pre-existing or gestational diabetes, Church House Conference Centre, London, UK. Contact Heather Stephens. Tel: +44 (0)161 835 9494, e-mail: heather@innove.co.uk

5 December 2008

RCN Dermatology Nursing Forum Annual Conference: skin care is everyone's business, Imperial College, London, UK. Contact Royal College of Nursing. Tel: +44 (0)29 2054 6460, website: www.rcn.org.uk

11 December 2008

Setting up your Insulin Pump Therapy service: the Gloucester model, Gloucestershire Royal Hospital, UK. Contact e-mail: Irene.Stewart@glos.nhs.uk

13 January 2009

Healthy ageing: the role of nutrition and lifestyle, The British Nutrition Foundation, Conference Centre, Sainsbury's Head Office, London, UK. Contact Mrs Christine Price. Tel: +44 (0)20 7404 6504, e-mail: c.price@nutrition.org.uk, website: www.nutrition.org.uk

11–13 March 2009

Diabetes UK Annual Professional Conference, SECC, Glasgow, UK. Contact Diabetes UK, 10 Parkway,

London NW1 7AA, UK. Tel: +44 (0)20 7424 1157/1158/1160, website: www.diabetes.org.uk

24–27 March 2009

13th Pan Arab Conference on Diabetes, Concorde Al-Salam Hotel, Cairo, Egypt. Contact Mahmoud Ashraf Ibrahim, Secretary of the Annual Pan Arab Conference on Diabetes, 19 Nasouh Street, Zeitoun, Cairo 11321, Egypt. E-mail: mahmoud@arab-diabetes.com, website: www.arab-diabetes.com

26–28 March 2009

5th International Symposium on Diabetes and Pregnancy, Sorrento, Italy. Contact Diabetes and Pregnancy 2009 Symposium Secretariat. Tel: +41 22 908 0488, e-mail: dip@kenes.com, website: www2.kenes.com/diabetes-pregnancy/Pages/Home.aspx

27–29 March 2009

Annual Conference of the British Association of Prosthetists and Orthotists, De Vere Whites Hotel, Bolton, UK. Contact Administrator Morag Wilson. Tel: +44 (0)845 166 8490, e-mail: morag@bapo.com, website: www.bapo.org

5–9 June 2009

69th Scientific Sessions of the American Diabetes Association, New Orleans, USA. Contact American Diabetes Association. Website: www.diabetes.org

19–21 May 2009

The Royal College of Ophthalmologists Annual Congress, Birmingham, UK. Contact Gaby Saunders. E-mail: events@rcophth.ac.uk, website: www.rcophth.ac.uk