

Children and diabetes: success and challenge in the developing world

Graham Ogle, Angie Middlehurst and Robyn Short-Hobbs

The International Diabetes Federation's Life for a Child Programme was established in 2001 with support from the Australian Diabetes Council and HOPE worldwide. With secure sustainable funding, LFAC not only contributes monetary or in-kind donations to help children with diabetes in developing countries, but also provides medical training, education and mentoring for health professionals in under-resourced regions. Keeping up with the digital age, LFAC now offers support materials online in nine languages. In the following feature, the LFAC management team presents current challenges and achievements connected to building stronger foundations of care for children most in need.

Imagine the courage of a mother in the Democratic Republic of Congo diagnosing her own sick child's diabetes by tasting his urine because the child's doctors have not yet considered a diagnosis of diabetes. Imagine the suffering of a 15-year-old with diabetes in Uzbekistan who has inadequate access to insulin resulting in recurring bouts of life-threatening ketoacidosis, making it impossible to attend school. Imagine the frustration of a parent to a five-year-old boy in India, who spends his entire savings on the promises of unlicensed doctors, only to see his son get thinner and sicker before his eyes.

These are just some of the very real challenges facing children, young adults, and families in the developing world; challenges countered by the International Diabetes Federation's Life for a Child (LFAC) Programme. Type 1 diabetes is one of the most common, life threatening childhood diseases and currently affects approximately 490,000 children worldwide under 14 years, with a further 77,000 cases newly diagnosed every year.¹ It is

estimated that a similar number of young people aged 15-25 also live with diabetes.

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Since 2001, LFAC has worked directly with established local under-resourced diabetes services to help provide the best possible health care for children and youth with diabetes. Depending on local needs and the supplies available to LFAC, supportive measures include insulin, syringes, blood glucose meters and test strips, HbA_{1c} diagnostic tests, education materials, health professional training, capacity building and vocational training. Presently, more than 11,200 children and youth in 43 countries receive LFAC assistance.

Diabetes management is complex for patient and carer alike, requiring daily insulin injections and careful monitoring of blood glucose, food and exercise. A child diagnosed with diabetes in a devel-

oping country faces obstacles unknown to their counterparts in the developed world. Insulin, blood glucose meters and test strips are either inaccessible, unaffordable, or both. Medical staff may be untrained in the diagnosis and treatment of childhood diabetes so complications develop early and quality of life is poor. To make matters more tragic, insulin is not available to all who need it even though the medication was discovered over 90 years ago and still remains the only life-sustaining treatment. Fear and uncertainty regarding vital supplies and the future are ever present.

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To meet the needs of these children, young adults, and health professionals, LFAC collaborates with governments, diabetes associations, diabetes and community health services on various levels to build capacity and strong foundations of care. Challenges, including practical needs or barriers, vary from country to country. LFAC accomplishments include:

- Shipping donated insulin to all countries participating in the Programme that request help. Insulin is the first priority, because a child with type 1 diabetes may die within a week without this life-saving necessity. In 2012, 25 countries received LFAC shipments.
- Overcoming numerous logistics and customs hurdles in the delivery process. Once in-country, long road-trips are sometimes required to distribute the insulin. In Zimbabwe, diabetes association staff travelled 2,600 kilometres across ten provinces to distribute supplies.

- Provisioning of donated blood glucose meters and test strips which has resulted in thousands of children, together with their families, learning to understand blood glucose readings, engaging in the treatment of diabetes, and appropriately adjusting insulin and food intake.
- Facilitation of doctor and nurse training, including distribution of educational materials, and technical or mentoring advice. The International Society for Paediatric and Adolescent Diabetes (ISPAD) has proved to be a tremendous ally in the Programme's drive to increase diabetes education of health professionals. Since January 2012, ISPAD members have conducted site visits in 16 LFAC-supported countries where local professionals were supported with diabetes training and mentoring. Most recently an ISPAD workshop in Azerbaijan trained 30 health professionals about the complexities associated with paediatric diabetes.
- As additional support for children with diabetes, their families, and health professionals in less resourced countries, LFAC developed a website for free diabetes education materials in English, French, Spanish, Arabic, Tagalog (Filipino), Azeri, Vietnamese and Bahasa (Indonesian). Materials such as 'Professor Bumblebee's Guide to Type 1 Diabetes' DVD have been particularly useful in simplifying the complexity of diabetes for children through a fun, visual medium. Available on the LFAC YouTube Channel (<http://www.youtube.com/user/LifeforaChild>) in five languages, it was recently translated into Tajik.



Diabetes is a constant and unrelenting condition, and it is only through understanding and mastering the condition that these children can grow, mature, and lead a happy fulfilling life. The diagnosis of diabetes is daunting and frightening, and getting off to a 'good start' with simple, concise, and often repeated education sessions for the child and parents is essential for families to gain confidence in managing diabetes at home and at school.

A lack of understanding related to diabetes in the school setting can disrupt education, cause insecurity and inhibit children from reaching their full potential. A simple explanation of diabetes and its management, by parents or a health professional dispels myths and allays the fears of child, parent and teacher. Social exclusion and misunderstanding are par-



ticularly distressing aspects of diabetes for children and youth. Adolescence can be a particularly trying time of change, uncertainty and rebellion because diabetes tasks intrude on day-to-day life, remove spontaneity and increase the feeling of being different and not fitting in with a peer group. Transition clinics specifically targeting this age group

(16-25 years) can assist in maintaining contact with youth through clinic attendance, and encourage adherence to diabetes management. Prevention of young people falling into the 'black hole' only to emerge years later with diabetes complications is a challenge for health professionals worldwide.

Camps, or day activities if resources are limited, are widely acknowledged to be extremely beneficial to children and youth, enabling them to meet others with diabetes, feel less isolated and increase personal understanding and management of diabetes in a relaxed, non-threatening and fun environment. LFAC encourages the development of diabetes camp programmes, assisting financially where possible. It has been heartening to hear that in Ecuador, Haiti, Nepal and Rwanda, young people's lives have been transformed by the experience of diabetes camp.

For children with diabetes, war or natural disaster not only threaten personal safety but also access to life-saving treatment. Families may be forced to flee their homes, losing contact with experienced medical staff and functioning health services, with no place to keep insulin cool or no access to the medication at all. During 2012, partner organisations Santé Diabète in Bamako, Mali, and Association des Diabetiques du Congo (ADIC) in Goma, Democratic Republic of Congo, experienced armed conflict firsthand. LFAC staff did an incredible job tracking and assisting children and families with essential medicines and clinical care as needed.

The LFAC Programme unifies the world's diabetes network behind its vision 'that no child should die of diabetes'.

When diabetes becomes unmanageable, young people may fail to complete schooling or find a job. In some countries, lack of social awareness around diabetes, combined with extreme poverty, diminishes marriage opportunities and can lead to social and economic isolation. In India, young women have been known to hide the fact that they have diabetes from their future husband.

Type 1 diabetes is a life-long condition affecting children and their families in a myriad of ways. Living with diabetes is difficult in any country, although children and youth in less-resourced settings face greater obstacles. LFAC exists to level the playing field, empowering children and young adults with diabetes access to the tools they need to live full and happy lives, and bolstering their hope of a bright future. On a global scale, the LFAC Programme unifies the world's diabetes network behind its vision 'that no child should die of diabetes'.

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At ADA's 73rd Scientific Sessions Graham Ogle was presented with the *Harold Rifkin Award for Distinguished International Service in the Cause of Diabetes* for his role in establishing and strengthening diabetes services in many parts of the developing world.

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http://www.idf.org/idf_publications

Donations:
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References

1. International Diabetes Federation. *IDF Diabetes Atlas, 5th edn., 2012 Update*. IDF, Brussels, 2012.



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