

No child should die of diabetes: A closer look at the IDF Life for a Child programme and its work in developing countries

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Article points

1. Children and young people in developing countries often have limited access to diabetes care.
2. The International Diabetes Federation's Life for a Child (LFAC) programme aims to eliminate childhood deaths from diabetes in countries where there are high levels of deprivation.
3. LFAC offers mentoring programmes, education, camps and peer support as well as supporting research and helping health professionals give children and young people around the world better diabetes care.

Key words

- Access to health care
- Developing countries
- Diabetes
- Diabetic ketoacidosis
- Education
- Poverty

Authors

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The Life for a Child programme's vision is that no child should die of diabetes. It is currently helping 17 000 children and young people with diabetes in 47 countries and in locations from Tashkent to Timbuktu. This article takes a closer look at its work and education campaigns, one of which aims to raise awareness of diabetic ketoacidosis so that deaths can be prevented. It also encourages the mentoring of diabetes centres in developing countries by expert centres in developed countries and supports research into the care of young people with diabetes. It also aims to improve access to diabetes care for children, regardless of their location, and provides peer support by setting up diabetes camps and teaching young people how to manage their condition.

A mother in the Democratic Republic of the Congo diagnoses her sick son's diabetes by tasting his urine because the doctors have not considered testing for diabetes; a 15-year-old with diabetes in Uzbekistan has inadequate access to insulin and subsequently suffers recurring bouts of life-threatening ketoacidosis and is unable to attend school; and a father of a 5-year-old in India spends all his savings on promised cures from unlicensed doctors, only to see his child get thinner and sicker. These are just some of the very real challenges facing children, young adults and their families in the developing world which have been encountered by the International Diabetes Federation (IDF) Life for a Child (LFAC) programme.

Since 2001, LFAC has worked directly with established local diabetes services to help them provide the best possible health care for children and young people with diabetes. Depending on local needs and resources, support involves supplying insulin, syringes, blood glucose meters and test strips, HbA_{1c} testing, education materials, training for health professionals and vocational training. Currently, over 17 000 children and young people in 47 countries receive assistance from LFAC (*Box 1*).

As one of the most common, life-threatening childhood diseases, type 1 diabetes currently affects about 497 000 children under 14 years, with a further 79 000 cases newly diagnosed every year (IDF, 2013). It is estimated that a similar number of young people aged 15–25 years also live with diabetes.

Diabetes management is complex for patients and their carers, and involves daily insulin injections and careful monitoring of blood glucose, food intake and exercise. A child with diabetes in a developing country faces obstacles that would be unimaginable to their counterparts in the developed world. Insulin, blood glucose meters and test strips are, in many cases, either inaccessible, unaffordable or both. Medical staff may be inexperienced in the diagnosis and treatment of childhood diabetes. Complications develop early and quality of life is poor. Fear and uncertainty regarding vital supplies and for their health in the future is ever present.

Children and young people in developing countries die undiagnosed with their symptoms mistaken for common illnesses such as malaria and gastroenteritis. Even when they have received a diagnosis, treatment may be delayed and the child may die anyway.

Access to insulin is still not available worldwide.

Families that can afford the insulin may have to make long, difficult journeys of up to 200 miles to get it, taking time off work, resulting in loss of wages which may well be meagre. Parents may have to make the decision to allow their child with diabetes to die if they are unable to afford insulin, forced to choose between providing food for a large family or spending money on medication for one child.

These desperate and challenging decisions are considered when LFAC is approached for help. The programme works with existing services provided by governments and diabetes associations to build strong foundations of care.

Social exclusion and misunderstanding are particularly distressing for children and young people with diabetes in developed countries and this can be even more difficult for the children in countries with high levels of deprivation.

LFAC partners in Ghana have recently set up support groups in different regions of the country for young people with diabetes to meet regularly with each other to socialise, share experiences and learn more about their condition. While only small numbers initially attended the sessions, word has spread and more and more young people are joining and finding support and lasting friendships and they now feel less isolated. Dr Nana Ama Barnes, who conducts these sessions, says: "It's not easy to initiate engagement of these young ones, but once they start attending they just can't stop!"

In many cultures, the stigma of having diabetes can be very destructive. While struggling to manage their diabetes, young people may fail to complete school 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. Other cultures believe that diabetes is cured by local remedies, so even when insulin is available, it may be refused or withheld with disastrous consequences. LFAC seeks to address this issue by assisting local health professionals to start support networks, as in Ghana, or by encouraging the use of social media and phone apps, as in Tanzania.

Diabetes education

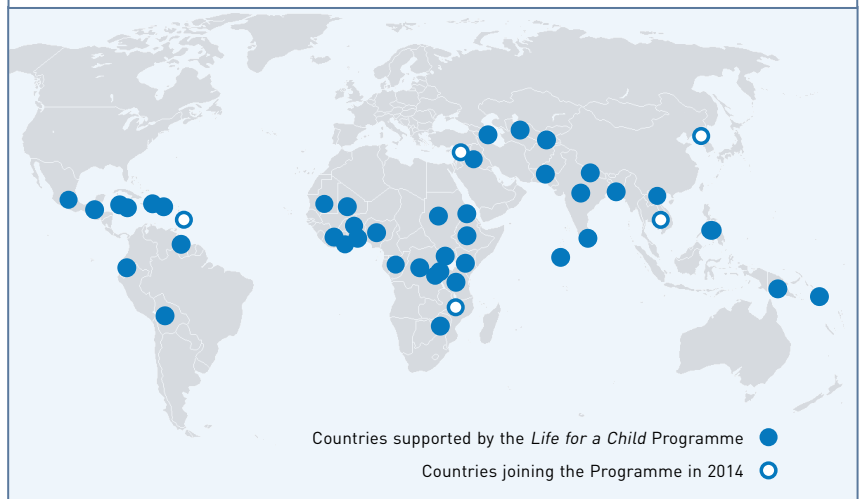
LFAC has developed an education website with a

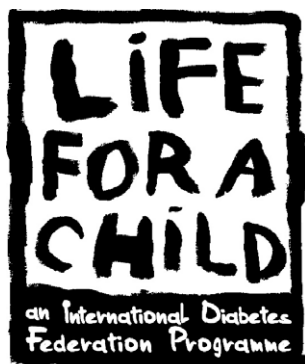
library for children and young people with diabetes, their families and health professionals. There are now pages in 13 languages, including English, French, Spanish and Arabic.

Two of the LFAC resources have proved particularly popular and have been translated into other languages. *Moseka and her Young Friends*, a graphic novel that shows how a young person can live with diabetes with the right support, was originally developed in French by Dr Marguerite de Clerck in Democratic Republic of the Congo and subsequently translated into English, Kinyarwanda and Swahili. *Professor Bumblebee's Guide to Type 1 Diabetes* is a 12-minute animated DVD developed

Box 1. Countries supported by the Life for a Child programme.

AFRICA	Tanzania	THE AMERICAS
Burkina Faso	Togo	Bolivia
Burundi	Uganda	Cayman Islands
Central African Republic	Zimbabwe	Dominican Republic
Democratic Republic of the Congo	CENTRAL ASIA	Ecuador
Eritrea	Azerbaijan	Guatemala
Ethiopia	Iraq (Kurdistan)	Guyana
Ghana	Syria	Haiti
Ivory Coast	Tajikistan	Jamaica
Kenya	Uzbekistan	Mexico
Liberia	SOUTH ASIA	St Lucia
Malawi	Bangladesh	WESTERN PACIFIC
Mali	India	North Korea
Mauritania	Maldives	Papua New Guinea
Nigeria	Nepal	Philippines
Republic of the Congo	Pakistan	Solomon Islands
Rwanda	Sri Lanka	Vietnam
Sudan		





by Diabetes NSW in Australia. It explains, very simply, what happens in a child's body when they have diabetes and it is particularly popular with young children. Initially made in English, it has now been translated into French, Spanish, Vietnamese, Tagalog (Filipino) and, more recently, Tajik and Urdu. It can be found on YouTube at <http://bit.ly/1CNkpPF>.

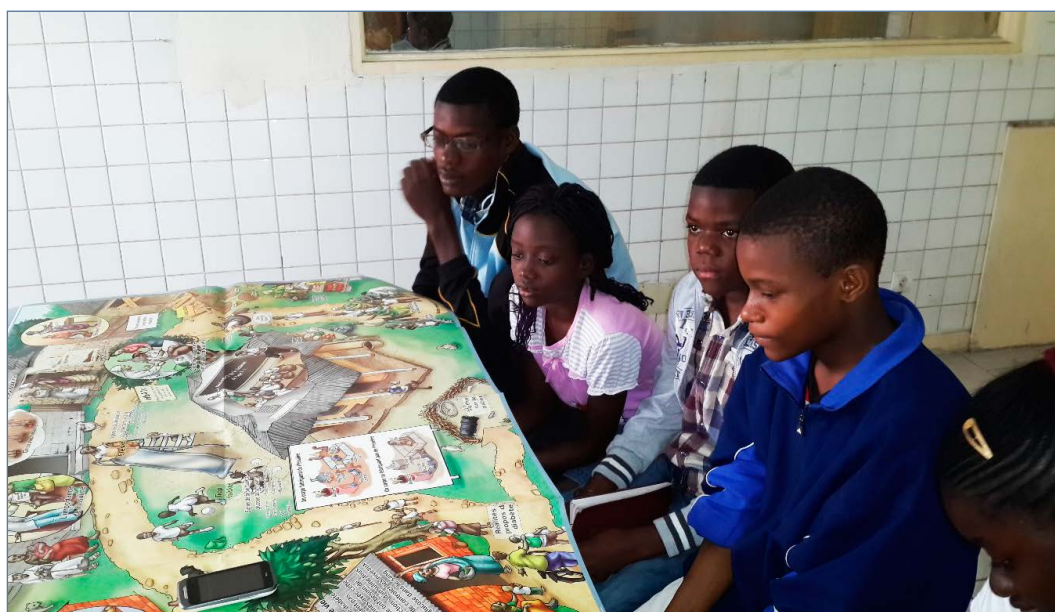
Prevention of deaths from diabetic ketoacidosis (DKA) campaign

It is quite likely that some children and young people in developing countries presenting for the first time in ketoacidosis will die without being diagnosed. The symptoms they present with may be diagnosed as more common illnesses such as pneumonia, gastroenteritis, malaria or typhoid. Even when the correct diagnosis is made, it is sometimes very late and the young person will die or suffer permanent cerebral damage.

This problem has been known for some years, and it has prompted a number of education campaigns around the world. A poster project was effective in Parma, Italy (Vanelli, 2007), and similar programmes have been put in place in South Africa and Australia. Various posters have been used depending on the culture and the target group. In 2009, the IDF developed a four-icon poster depicting frequent urination, weight loss,

lack of energy and excessive thirst. The South African paediatric endocrinologists added a fifth icon of bed-wetting. LFAC has now introduced a six-icon poster – the sixth icon depicting the later stages of DKA – and has invited countries it supports to participate in an awareness campaign (Figure 1). The campaign was developed to alert health professionals to the signs and symptoms of diabetes in order to make a swift diagnosis and provide appropriate treatment to save lives – championing the vision that no child should die of diabetes. Health professionals are the key target audience for this campaign, with posters put up in emergency rooms, paediatric wards, treatment rooms, medical and nursing schools, major health centres, paediatrician offices and diabetes centres. Posters have been developed in 20 languages in 17 countries.

Another important part of the campaign is *The Pocketbook for Management of Diabetes in Childhood and Adolescence in Under-Resourced Countries* (<http://bit.ly/1HOLnmz>). It was developed in collaboration with International Society of Pediatric and Adolescent Diabetes (ISPAD) and IDF by adapting and abbreviating information from their individual guidelines. This pocketbook was specifically developed to be used by clinicians with little experience of diabetes, enabling them to quickly diagnose and manage diabetes effectively.



Children and young people in discussion over a type 1 conversation map in Republic of the Congo.

DIABETES IN CHILDREN AND YOUNG ADULTS KNOW THE WARNING SIGNS

በህፃናትና በወጣቶች ላይ የስኳር ህመም ይከሰታል።
የማስጠንቀቂያ ምልክቶቹን ይወቁ።



excessive thirst
የማይረካ የውሀ ጥም



frequent urination
ቶሎ ቶሎ መሸናት



bed wetting
አልጋ ላይ መልሶ መሸናት



weight loss
ክብደት መቀነስ



lack of energy
ደካም



Vomiting, dehydration, rapid breathing or coma (ketoacidosis)
ሽቅብ ማለት፣ ከሰውነት የፈሳሽ ማለቅ፣ ቶሎ ቶሎ መተንፈስ ወይም ራስን መሳት (ኬቶአሲዶሲስ)

**If anyone shows these signs, check for diabetes immediately.
Treatment is urgent.**

ህፃናቱ እና ወጣቶቹ ላይ እነዚህን ምልክቶች ካዩ በፍጥነት የስኳር ህመም ምርመራ ያድርጉላቸው።
ህክምናው በአስቸኳይ መሰጠት አለበት።







“On a global scale, the programme unifies the world’s diabetes network behind its vision that ‘no child should die of diabetes’”.

Figure 1. Life for a Child’s diabetic ketoacidosis awareness-raising poster in English and Amharic from Ethiopia.

Mentoring

LFAC has established working relationships between diabetes specialists from centres in developed countries with 18 LFAC-supported countries. Many effective collaborations have resulted, including

Prof Trevor Orchard, University of Pittsburgh and Dr Deborah Edidin, University of Chicago with Rwanda; Dr Holley Allen, Springfield, Massachusetts and Diabeter, Rotterdam with Nepal; Dr Declan Cody, Our Lady’s Children’s Hospital, Dublin with



Figure 2. Adolescents dancing at the Vocational Training School in Rwanda.

Life for a Child is looking for health professionals with an interest and experience in paediatric diabetes who are keen to become mentors to a centre in a developing country. For more information on the Life for a Child programme, please contact: Angie Middlehurst, LFAC Education Manager: angiem@diabetesnsw.com.au

For information about donating to LFAC, visit www.lifeforachild.org/donate

Ghana. These experts assist with site visits, mentoring and training, clinical advice and research initiatives.

Vocational training

LFAC fosters local vocational education and training and finance initiatives where possible and these have already been set up in Bangladesh, Nagpur (India), Rwanda and Tanzania.

Training workshops

LFAC also works closely with ISPAD to conduct workshops in Nepal, Zimbabwe, Vietnam, Ghana and other countries, with a further one planned for Tajikistan.

These workshops last 2–3 days and are aimed at doctors and nurses who are interested in the management of paediatric diabetes.

Camps

Camps, or day activities if resources are limited, are widely acknowledged to be extremely beneficial to children and young people, enabling them to meet other young people with diabetes, feel less isolated and increase their personal understanding and management of diabetes in a relaxed non-threatening environment. LFAC encourages the development of camps, assisting financially where possible. Young people in Ecuador, Haiti, Nepal and Rwanda have had their lives transformed after attending such events (*Figure 2*).

LFAC provides part financial support for one

diabetes camp per country and it is currently developing simple guidelines in collaboration with Diabetes Education and Camping Association (DECA) to help countries to set up the camps.

Research

LFAC also supports research studies into diabetes in children and young people, with funding from The Leona M and Harry B Helmsley Charitable Trust and other donors. Research includes:

- The Epidemiological Study of Childhood and Youth Diabetes in Developing Countries, which aims to determine the type of diabetes in new cases of childhood diabetes, and the incidence and prevalence of type 1 and other types of diabetes in Azerbaijan, Mali, Pakistan, Bangladesh, Haiti and Sudan.
- Development of registers to determine incidence and prevalence of diabetes in countries including Maldives, Mauritania, Mali, Bolivia, Togo, Nepal, Rwanda and Fiji.
- Efficacy of insulin storage techniques: comparing different methods of insulin storage, including various types of clay pots as well as other cooling devices.
- Index of Diabetes Care for Children and Youth: a study of care for children and young people with diabetes in 71 countries.
- Study of the direct costs to families of the supplies needed for minimal care for children with type 1 diabetes in 14 countries where the public health system cannot provide such supplies.
- Complications and mortality: a study of various treatment regimens and development of complications in Rwanda.

Conclusion

Type 1 diabetes is a life-long condition which affects children and their families in many ways. Living with diabetes is not easy in any country, and additional obstacles are faced by children and young people in more deprived settings. LFAC attempts to level the playing field, empowering children and young adults with diabetes by giving them the tools they need to live full and happy lives, bolstering their hope for a bright future.

On a global scale, the programme unifies the world's diabetes network behind its vision that "no child should die of diabetes". ■

IDF (2013) *IDF Diabetes Atlas* (2nd edition). IDF, Brussels, Belgium. Available at: <http://bit.ly/1iiBkyH> (accessed 23.07.15)
Vanelli M (2007) Education and public information: preventing diabetic ketoacidosis in Italy. *Diabetes Voice* 52: 39–41