

# **A conversation with the International Diabetes Federation's Life for a Child, December 20, 2017**

## **Participants**

- Dr. Graham Ogle – General Manager, Life for a Child, International Diabetes Federation
- Emma Klatman – Health Systems Reform Specialist, Life for a Child, International Diabetes Federation
- Chelsea Tabart – Research Analyst, GiveWell

**Note:** These notes were compiled by GiveWell and give an overview of the major points made by Life for a Child.

## **Summary**

GiveWell spoke with Dr. Ogle and Ms. Klatman of Life for a Child (LFAC), a program of the International Diabetes Federation, to learn about LFAC's work on type 1 diabetes in children. Conversation topics included the problem of type 1 diabetes, LFAC's organizational structure and program model, and LFAC's room for more funding.

## **The problem of type 1 diabetes**

Type 2 diabetes (which usually begins in adulthood) is characterized by insulin resistance and insulin deficiency, although individuals with type 2 diabetes are still able to produce some amount of insulin. Type 1 diabetes (which usually begins in childhood or adolescence) is characterized by an absolute insulin deficiency in which an individual's pancreas is not able to produce insulin. Symptoms of type 1 diabetes include high blood glucose levels, weight loss, and excessive thirst and urination. Children with type 1 diabetes may be misdiagnosed as children in a bedwetting phase.

If an individual with type 1 diabetes is not treated, they will develop a condition known as diabetic ketoacidosis (DKA), whereby the level of acid in the body's blood becomes dangerously high. Symptoms of DKA include strange breathing (deep and frequent breaths), severe dehydration, and impaired consciousness. DKA is fatal unless managed properly.

Health professionals only need to administer a blood glucose level test to determine that a child has diabetes, yet it often takes a significant amount of time before a child is diagnosed. In highly developed countries such as the US or Australia, approximately 20-30% of children with diabetes already show signs of DKA at the time of their diagnosis. In developing countries, 60-70% or more of children with diabetes show signs of DKA at the time of their diagnosis, and it is thought that many more die misdiagnosed with another medical condition.

## **Treatment for type 1 diabetes**

A person with type 1 diabetes must take insulin in order to live, which is why no randomized controlled trial on the effectiveness of insulin exists. In the 1920s, prior to the discovery of insulin, people with type 1 diabetes were treated with almost starvation-level diets but still perished with time.

Treating individuals with insulin is dangerous, as a high dosage can cause hypoglycemia (excessively low blood sugar) which can cause confusion and other symptoms, and can progress to coma and death. To properly treat type 1 diabetes, individuals must monitor their blood glucose levels frequently (generally through a finger prick test).

Individuals with type 1 diabetes and their families should be educated on the condition and its treatment. Individuals with type 1 diabetes should also be treated by health professionals experienced in managing the condition.

### *Standard of care across the world*

The quality of care for patients with type 1 diabetes varies across countries. In many countries in Africa—including Rwanda, Mali, and Tanzania—governments have never provided free insulin, and public knowledge about type 1 diabetes is low. Until recently, most of the children with type 1 diabetes in those countries have been dying.

In countries such as India, Azerbaijan, Mexico, and Bolivia, children with type 1 diabetes generally receive enough insulin to remain alive but are still likely to encounter serious health complications due to inadequate care.

In highly developed countries, individuals with type 1 diabetes receive adequate care, although the condition is still difficult to manage.

## **Prevalence of type 1 diabetes**

Caucasian people are more genetically predisposed to have type 1 diabetes, although there may also be some environmental factors that make type 1 diabetes more common in Caucasian individuals. Type 1 diabetes is a relatively uncommon condition in some of the developing countries in which LFAC works. Between the countries in the world with the highest and lowest incidence of type 1 diabetes, there is an approximately 40 to 60-fold variance in rates of type 1 diabetes.

In many developing countries, children with type 1 diabetes have been misdiagnosed with another condition and are not properly diagnosed until shortly before death or after death. Therefore, the true incidence rate of type 1 diabetes in those countries is difficult to determine.

LFAC is working to improve data on type 1 diabetes prevalence. In Rwanda, for example, LFAC has estimated that approximately 900 people under the age of 25 are living with type 1 diabetes out of a population of 12 million, and if mortality could

be reduced then this number would be around 1,600. (Only 33 were known to be alive when the program started in 2005.)

## **Overview of LFAC**

### **Organizational structure**

LFAC commenced operations in 2000 in three pilot countries and now operates in 41 countries, serving approximately 18,000 children. It is led by the International Diabetes Federation, which is headquartered in Brussels and serves as the umbrella organization for national diabetes associations in 168 countries. Although LFAC is an International Diabetes Federation program, it is managed from Sydney, Australia by Diabetes NSW & ACT, a state diabetes association that is also a member organization of Diabetes Australia.

LFAC also operates a US-based entity called IDF Life for a Child (USA) Inc., which helps with fundraising. IDF Life for a Child (USA) Inc. was incorporated in Florida two years ago as a 501(c)(3) non-profit corporation.

### **Program model**

LFAC implements its intervention through partner organizations based in target countries. For example, in Mali, LFAC sends insulin, test strips (for regular blood glucose monitoring), and HbA1c tests (administered every three months to measure overall blood glucose levels) to its Malian partner organization Santé Diabète. LFAC also provides additional funds to Santé Diabète for diabetes education, organization of care, and logistics.

Before it decides to begin working in a country, LFAC ensures that its partner organization in the country is already caring for children with diabetes and has the capacity to expand operations.

### *Impact*

LFAC has substantial data on the medical impact of its work, some of which is published in peer-reviewed journals. LFAC is attempting to create a model of its program's impact by comparing the cost of its intervention to the costs incurred in the absence of its intervention. Its model will vary across countries, as it depends on whether or not children will die or live with severe complications in the absence of LFAC's intervention.

## **Room for more funding**

### **Estimated annual costs**

One of the reasons LFAC is able to implement its intervention with minimal funds is that it receives donations from pharmaceutical organizations. Insulin for most countries is donated by Eli Lilly and Company. Test strips in Mali, for example, are donated by LifeScan (a Johnson & Johnson company), and Trividia Health helps with reduced-price strips for a number of other countries.

Eli Lilly & Company has also arranged for the insulin it donates to be delivered by Direct Relief, a non-profit based in Santa Barbara that distributes medical supplies. Formerly, LFAC incurred the costs of cold storage for the insulin, which it shipped from South Africa.

LFAC's annual cost per child treated includes approximately:

- \$10 for insulin – Although most of the insulin LFAC provides to countries is donated, it still purchases insulin in a few countries. It also incurs clearance costs for delivering insulin to some countries.
- \$45-50 for test strips – Although test strips are donated for some countries, LFAC purchases test strips at a reduced cost for most countries.
- \$23 for HbA1c tests
- \$30-70 for organization of care, recordkeeping, and diabetes education
- \$40 for operations in Sydney (including staff time)

### **Past and current annual budgets**

LFAC's annual budget in the past was approximately \$1.4 million. Its current projected annual budget is \$700,000.

### **Uses of additional funding**

If LFAC received additional funding, it could expand its activities in three main ways:

1. **Expand to new countries** – Seven to ten countries are waiting to receive aid from LFAC. Without additional funding, LFAC would only expand to a new country if it thought its help was of extreme importance.
2. **Expand coverage** – LFAC could expand the number of people it helps in countries that it already serves. Nigeria, Pakistan, and Mexico are examples of countries where LFAC could help many more children with more resources.
3. **Provide higher quality care** – LFAC's preferred use of additional funding is to provide higher quality care in countries with large populations, particularly Ethiopia, Bangladesh, and Pakistan. Although LFAC supports a large number of children in these countries, it is not able to provide them with adequate care. For example, children in these countries do not receive enough test strips, and both health professionals and diabetes patients in these countries have not been educated on how to use the test strips properly. With additional funding, LFAC would be able to provide high quality care (including stronger monitoring, higher levels of treatment, and diabetes education) to approximately 6,000 people in Ethiopia and Bangladesh combined.

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