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# changing diabetes® in children

## The Changing Diabetes® in Children programme

Novo Nordisk, together with a range of partners, established the Changing Diabetes® in Children programme in 2009. The programme's primary aim is to improve delivery of care to children with type 1 diabetes in resource-poor settings. This publication provides an account of the programme's achievements and challenges between 2009 and 2014.

## PROGRAMME PARTNERS

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WORLD **DIABETES** FOUNDATION



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Account of the Changing Diabetes® in Children programme

Period: 2009–2014

Novo Nordisk A/S

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## foreword

For over 90 years, Novo Nordisk has focused on the development of products to benefit people with diabetes. However, despite the fact that insulin, a life-saving product for people with type 1 diabetes, has been available for close to a century, a fair number of people in low- and middle-income countries continue to die prematurely from diabetes. This is especially true for children with type 1 diabetes who depend completely on insulin every day. A child in sub-Saharan Africa diagnosed with type 1 diabetes often has a life expectancy of less than one year. As a leader in diabetes care we have an obligation to use our resources and expertise to help these children.

At the request of a number of stakeholders and in response to the very clear need for action in developing countries, Novo Nordisk launched the Changing Diabetes® in Children programme in 2009. We set an internal ambition to reach 10,000 children and aimed to capacitate health systems to deliver the necessary diabetes care to these children.

From the beginning it was clear that, while we could contribute with insulin, resources and expertise, it was going to take the collective effort of a range of partners to address the challenge. The International Society for Pediatric and Adolescent Diabetes (ISPAD), Roche and the World Diabetes Foundation (WDF) joined forces with us, each contributing their unique competences and expertise to build solutions to address specific needs in the various countries. In addition, 20 local organisations, ranging from Ministries of Health to diabetes associations, have rallied together to help implement the country projects.

Looking back on the past five years, I can see that we underestimated the task on many fronts. In many countries, infrastructure needed to be put in place, not only for the treatment of children but also for the storage and transport of insulin and supplies. Further challenges have included the distances children sometimes have to travel to reach clinics and the very real poverty in which some children live. However, the thing that I underestimated most was the dedication and willingness of numerous individuals and organisations to achieve the ambition of reaching



**Lars Rebien Sørensen**, chief executive officer, Novo Nordisk A/S and **Stuart Tembo**, IDF Youth Ambassador – launch of the Changing Diabetes® in Children programme, Paris, France, 2009.

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10,000 children with comprehensive diabetes care. Rarely have I had the privilege of seeing different parties work together for a long period of time towards achieving the same goal.

Five years after we initiated the programme, I am happy to see that it provides ongoing diabetes care to over 13,000 children in nine countries.

While we initially committed to a five-year programme, Novo Nordisk, together with all the partners, has extended the programme by an additional three years. Over the next three years, our focus will be to consolidate the work that has been done and implement individual sustainability plans for each country.

The Changing Diabetes® in Children programme continues to demonstrate that big ambitions and clear targets are achievable if we work in partnership and draw on the competences and expertise of all stakeholders.

Thank you to all our partners – in partnership we can change diabetes.

**Lars Rebien Sørensen**  
Chief executive officer, Novo Nordisk A/S



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OF THE ESTIMATED

**387** MILLION

PEOPLE LIVING WITH  
DIABETES WORLDWIDE

**5–8%** LIVE WITH  
TYPE 1 DIABETES<sup>1</sup>.

TYPE 1 DIABETES CURRENTLY  
AFFECTS AN ESTIMATED

**497,000** CHILDREN

WORLDWIDE UNDER THE AGE OF 14<sup>1</sup>.



SARA AHMED  
Ethiopia

A person's hand is shown holding a small, white and blue insulin box. The background is an open refrigerator with shelves containing various items like lemons and a large water bottle. The text is overlaid on a white semi-transparent box on the right side of the image.

## about type 1 diabetes<sup>1,2</sup>

The incidence of type 1 diabetes among children is increasing in many countries, particularly in children under the age of 15. It is estimated that some 79,000 children under the age of 15 will develop type 1 diabetes annually worldwide. Unlike type 2 diabetes, type 1 diabetes is not related to lifestyle or being overweight, and there is no known way to prevent it. Today, it is estimated that 497,000 children have type 1 diabetes worldwide. About half of these children live in resource-poor settings, often without the necessary diabetes treatment facilities. These children have high mortality rates, and in some sub-Saharan African countries life expectancy is less than one year after diagnosis.

### WHAT IS TYPE 1 DIABETES?<sup>3</sup>

Type 1 diabetes is an autoimmune disease, where the body's immune system attacks and destroys healthy body tissue by mistake. In this case, the immune system destroys the insulin-producing cells of the pancreas. This type of diabetes accounts for 3–5% of cases globally. It is most common in children and adolescents, but can develop later in life. People with type 1 diabetes are dependent on insulin injections for survival. Blood sugar levels have to be closely monitored and the insulin dosage adjusted accordingly, depending on food intake and physical exercise. Type 1 diabetes is a chronic condition with no cure, as yet. However, Novo Nordisk is committed to investing in research that may hopefully one day provide a cure.

### INSULIN TREATMENT SAVES LIVES

Scientist Frederick Banting and medical student Charles Best from Canada first discovered insulin in 1921. A year later it was tested on 14-year-old Leonard Thompson, who became the first person to receive insulin treatment. His condition improved significantly. Until the discovery of insulin as a treatment, people with type 1 diabetes simply did not survive. This discovery therefore paved the way for the life-saving medicine to be used for other patients<sup>4</sup>. In 1924, Novo Nordisk began producing the hormone in Denmark. Recognising that patients need to be able to comfortably inject themselves with the correct dose of insulin, the company also subsequently designed a special syringe – the Novo Syringe.

Almost a century later, people with type 1 diabetes in many countries still cannot access insulin or basic medical supplies such as syringes and strips – either because they are not affordable or not readily available – and die soon after developing diabetes. For a family in a developing country, having a child diagnosed with diabetes can pose an unsurmountable financial burden<sup>5</sup>.

# the programme at a glance

The Changing Diabetes® in Children programme aims to bring all elements of necessary diabetes care closer to the children who need it and, at the same time, build capacity for the diagnosis and treatment of children with type 1 diabetes at both community and country level.

## SIX COMPONENTS OF THE PROGRAMME

From the start, the Changing Diabetes® in Children (CDiC) programme has worked with the National Ministries of Health and local partners in the respective countries to build diabetes capacity and strengthen capabilities within the normal functions of the healthcare system. In each country, the programme delivers on six components, which have been designed to support children with type 1 diabetes by providing the essential elements of care.

### Improvement of existing infrastructure

and supply of medical and laboratory equipment to establish dedicated centres for the treatment of children with type 1 diabetes.

**Training and education of healthcare professionals** and diabetes educators to develop diagnostic skills and the expertise to manage type 1 diabetes in children.

### Provision of insulin and blood glucose monitoring equipment

and supplies to the children for the duration of the programme.



### Best practice sharing

and insights gained on developing healthcare interventions specific to minority populations such as children with diabetes in low-resource settings.

**Patient registry system** to facilitate systematic data collection and patient follow-up.

### Patient education material

for children and their families, adapted to the local context.

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## HUB-AND-SPOKE MODEL

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Organised around a hub-and-spoke concept, originally piloted in Tanzania in 2006, the programme strives to develop long-term solutions for improving availability, accessibility, affordability and quality of diabetes care for children with type 1 diabetes. The setup of the programme in the individual countries varies according to the geography of the country and the available infrastructure within the existing healthcare system.

### Hubs

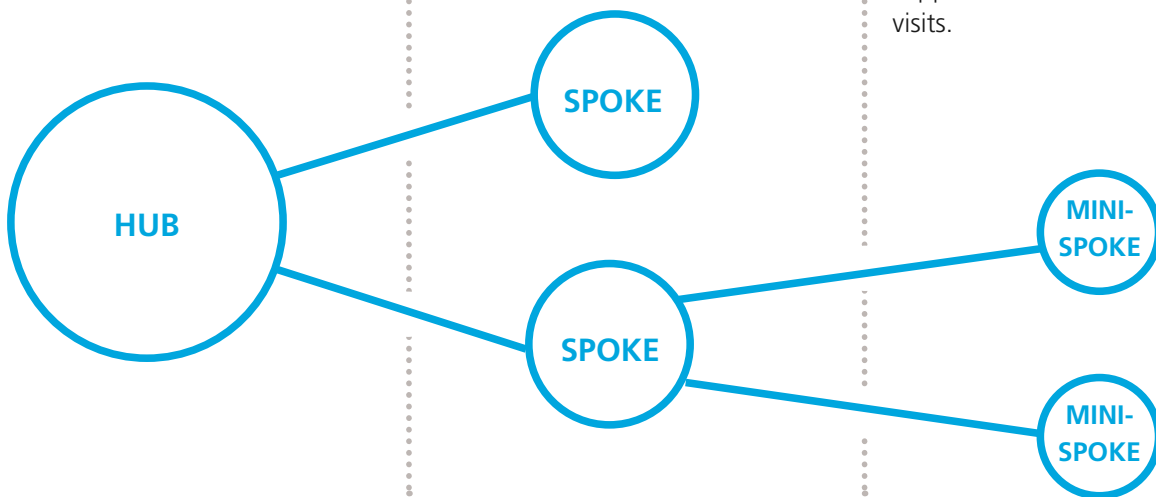
The 'hubs' are main clinics and work as referral clinics.

### Spokes

The 'spokes' are smaller clinics established to improve access to diabetes care for children and adolescents with type 1 diabetes by reducing the distance they have to travel.

### Supply distribution spokes

In instances where the geography of a country has made it necessary, additional 'mini-spokes' have been put into place to ensure that children have access to insulin and supplies between scheduled clinic visits.



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## A MULTI-PARTNER COLLABORATION

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The programme is the result of a private–public collaboration between several partners, including Novo Nordisk, Roche, the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the World Diabetes Foundation (WDF).

In each country, the programme is implemented by a group of local partners, with the National Ministry of Health playing a key role to ensure that the programme is anchored within the existing healthcare system.

The programme also works to facilitate the sharing of learning and insights between country partners through workshops and regional trainings. There is some coordination with IDF's Life For A Child programme in terms of patient education tools and training manuals developed under the CDiC programme.



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## building long-term solutions

The CDiC programme was launched in 2009 to run for a five-year period. However, in 2014, it was decided to extend the programme for another three years, running until the end of 2017. The purpose of the extension is to strengthen the sustainability of the individual country projects beyond 2017.

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Going forward, the CDiC programme will focus on consolidating the work that has been done since 2009. A detailed sustainability plan for each country has been developed, aimed at a complete takeover of the projects by local stakeholders.

Establishing sustainable solutions requires more than delivering insulin and supplies; it entails building capacity and developing appropriate tools that can be used beyond the programme. In recognition of this, each of the current components of the programme has been examined to determine what steps should be taken to ensure sustainability of the investment already made.

### Training of healthcare providers

As the programme has matured, there has been a shift in focus from keeping children alive with a supply of insulin to providing comprehensive care, which is a necessity if further health improvements are to be made. Basic training of healthcare professionals has been provided, but there is a need for further refresher courses and more advanced training. Currently, the programme is working to build the capacity of local trainers, who will progressively be able to take on the task of training new healthcare professionals going forward.

### Diabetes education and camps

There is strong support from project partners for continuing the diabetes camps in the future. The camps bring substantial added value to the children, parents and healthcare providers. Healthcare providers significantly improve their understanding of the day-to-day challenges facing the children. The aim is for country partners to ensure local sponsorship for these camps and involve parents and guardians to a larger degree in hosting them.

### Continued advocacy and awareness raising

The CDiC programme will continue to advocate for better care and work to build awareness about type 1 diabetes among all stakeholders, including the general public.

### Scholarships and vocational training

There is a need for formal education for a minority of the most vulnerable children, as they have no prospects of attending school or other formal education, which could lead to a future source of income. For this reason, a new component has been included in the programme starting in 2015. Novo Nordisk will now make funds available to provide scholarships for younger children and vocational training for adolescents.

### Knowledge sharing between project partners

Sharing best practices and knowledge is important if those working with CDiC are to learn from each other and improvements are to be made in the quality of care delivered. There have been opportunities at international meetings and congresses for CDiC staff to meet and share ideas on treating children with type 1 diabetes, and the goal is to continue to support similar platforms.



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## DEVELOPING TOOLS AND RESOURCES TO ENSURE ONGOING CAPACITY BUILDING AND IMPROVEMENT IN CARE

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### Basic training manual for healthcare professionals in developing countries

In 2010, CDiC produced a training manual for healthcare professionals working with children and adolescents with diabetes in resource-poor settings. The manual was written by experts from the International Society for Pediatric and Adolescent Diabetes (ISPAD). The training manual is available in French and English.



### Patient education material specifically created for developing countries

In 2012, CDiC produced a range of patient education materials for children with type 1 diabetes living in resource-poor settings. The materials were developed to support healthcare professionals to communicate vital information to previously and newly diagnosed children with type 1 diabetes and their families. The materials build on a set of recurring characters and settings.

The training materials are available in English, French, Amharic (Ethiopia) and Swahili.



### CDiC-data – a custom-designed registry

The CDiC has initiated the development of an electronic data registry in consultation with local partners to enable systematic data collection and monitoring and follow-up of patients. The electronic registry has been developed by Université Numérique Francophone Mondiale (UNFM) in consultation with local partners, and tested at various clinics. Further to this, customisations have been made according to individual country requirements. The system is owned locally and the data collected are used by clinics and local partners to monitor and improve quality of care.

Learn more and  
access CDiC  
resources  
[www.bit.ly/1BPdWCL](http://www.bit.ly/1BPdWCL)



View a film  
about the CDiC  
programme  
[www.bit.ly/195KI67](http://www.bit.ly/195KI67)



*“We extended the programme by three years in order for the individual programmes to have enough runway to ensure that they are sustainable. They [the country programmes] didn’t all start at the same time. Some came in late, so we extended the programme to ensure the best possible scenario for the programme to be sustainable.”*

Lars Rebien Sørensen,  
Chief executive officer, Novo Nordisk A/S

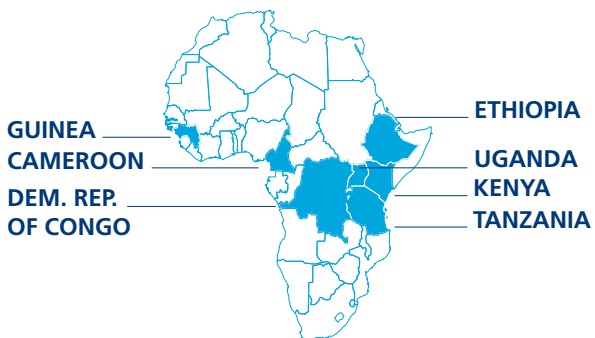
# programme status



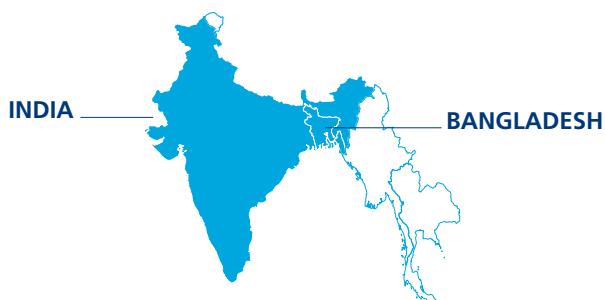
## PROGRAMME REACH

**NINE COUNTRIES** with seven in Africa and two in South-East Asia

### AFRICA



### SOUTH-EAST ASIA



## NUMBER OF CHILDREN ENROLLED

**AMBITION: 10,000 CHILDREN BY 2014**

**13,199 CHILDREN ENROLLED** as of December 2014

figure 1: children enrolment over years

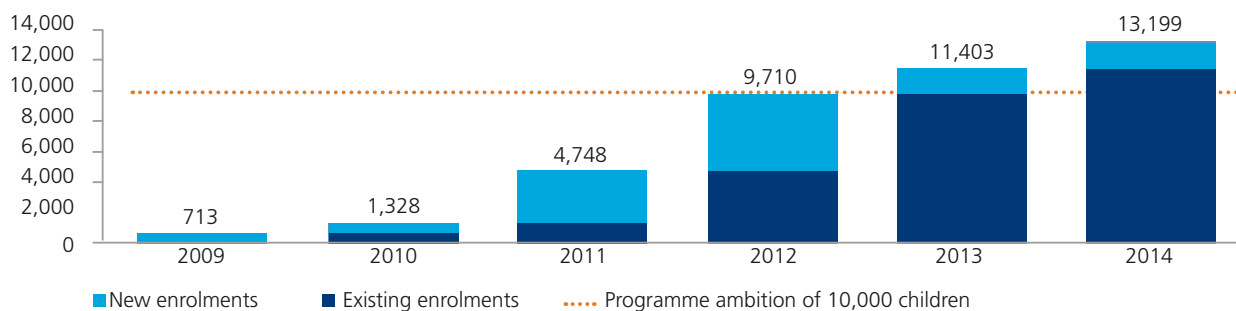
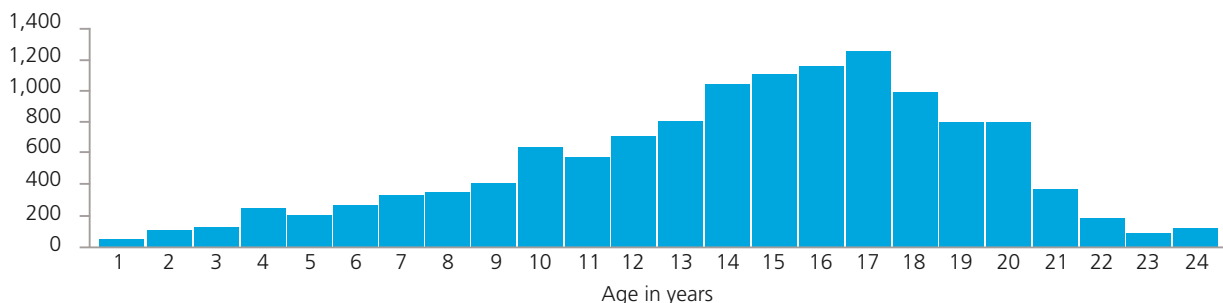


figure 2: age distribution of enrolled children



While the CDiC programme is specifically for children under the age of 21, in instances where country partners have evaluated it necessary, the programme continues to provide support to some children in their early adult years.

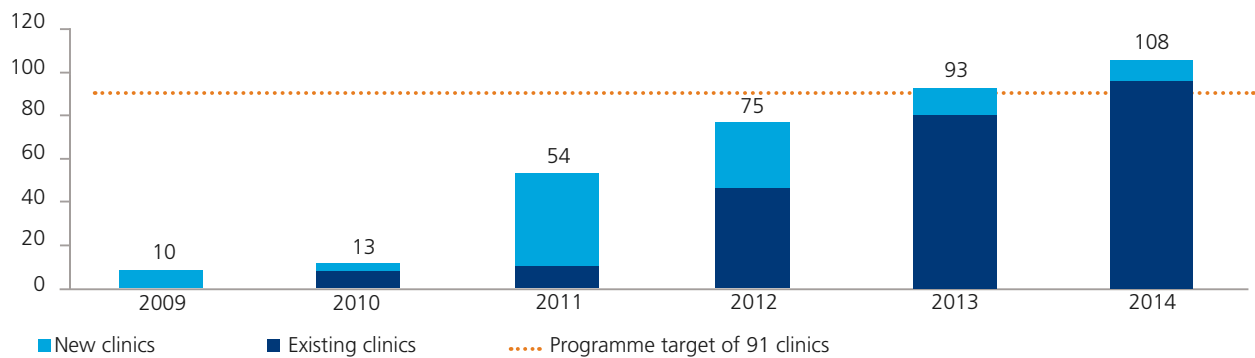


## NUMBER OF CLINICS ESTABLISHED

**TARGET: 91 CLINICS BY 2014**

**108 CLINICS HAVE BEEN ESTABLISHED** as of December 2014

figure 3: clinics established by year

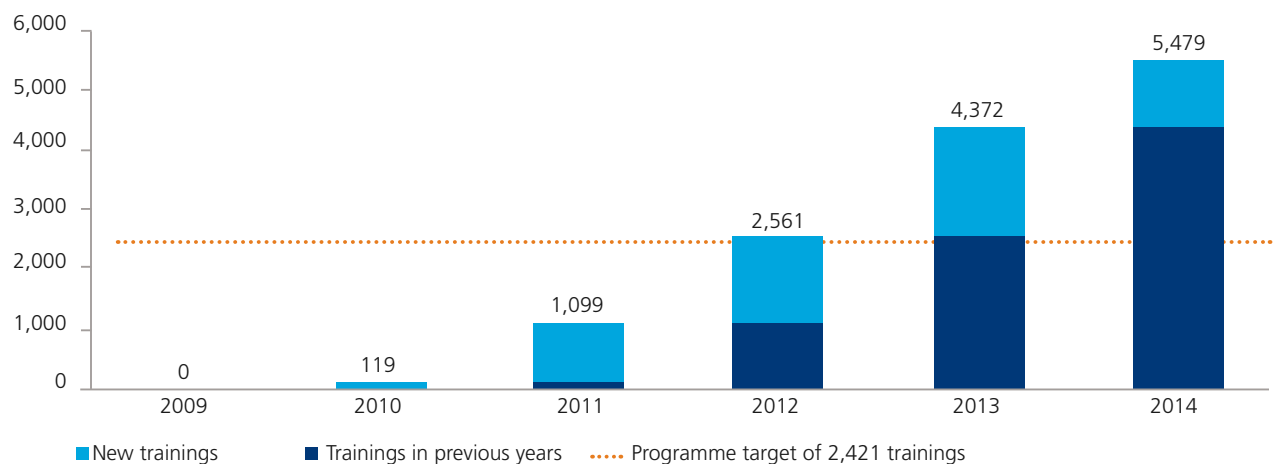


## NUMBER OF HEALTHCARE PROFESSIONALS TRAINED

**TARGET: 2,421 HEALTHCARE PROFESSIONALS BY 2014**

**5,479 HEALTHCARE PROFESSIONAL TRAININGS** have been facilitated as of December 2014

figure 4: healthcare professional trainings by year



The performance data provided throughout this publication are based on data obtained directly from the local CDIC partners in December 2014.



IBRAHIMA BARRY  
Guinea

View a short film  
about Ibrahima  
and how diabetes  
impacts his life  
[www.bit.ly/1AZXWdt](http://www.bit.ly/1AZXWdt)





## changing diabetes® in children in africa

Children with type 1 diabetes in less-developed countries are often not diagnosed and, even if diagnosed, they frequently cannot access suitable diabetes care and treatment. Type 1 diabetes can quickly become fatal if not treated properly, regularly and timely. General lack of awareness of the condition also means that missed diagnosis is a common problem in developing countries.

Common barriers to diabetes care for children in Africa include:

### **Poverty**

For people living in poverty, the annual cost of diabetes care often exceeds a family's annual income.

### **Awareness**

Limited awareness about diabetes in children among healthcare professionals often leads to neglected cases or misdiagnosis of the disease. Awareness about diabetes in children is typically even lower among the general population. Combined with scarce interaction with health systems, this results in undetected cases.

### **Lack of infrastructure**

Great distances and insufficient travel options in rural areas often hinder patients from seeing healthcare professionals. Furthermore, proper treatment is prevented by a general shortage of qualified healthcare professionals, diabetes specialists and patient follow-up services, as well as a lack of medical equipment, supplies and medicines.

### **Traditional medicine**

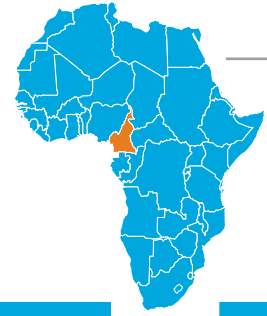
In Africa, according to traditional beliefs, every illness has a cure. In the context of these beliefs, the scientific description of diabetes as a chronic non-communicable disease exposes the limitations of biomedical medicine and motivates people who subscribe to these widely held beliefs to turn to traditional healers. This can result in fatal outcomes for children with type 1 diabetes (see John Kijazi's story on page 29).

The Changing Diabetes® in Children programme is working in seven countries in sub-Saharan Africa in an effort to build sustainable solutions to these barriers.

## **AFRICA**

CAMEROON .....	14
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ETHIOPIA .....	18
GUINEA .....	20
KENYA .....	22
TANZANIA .....	24
UGANDA .....	26

# changing diabetes® in children in cameroon



## Project background

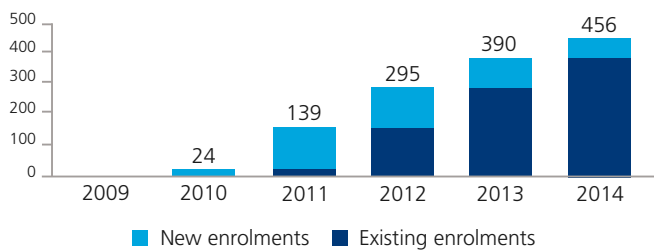
PROJECT INITIATED: 2010

### COUNTRY PROJECT PARTNERS

- Ministry of Public Health of Cameroon
- Health of Population in Transition (HoPiT)

## Project indicators

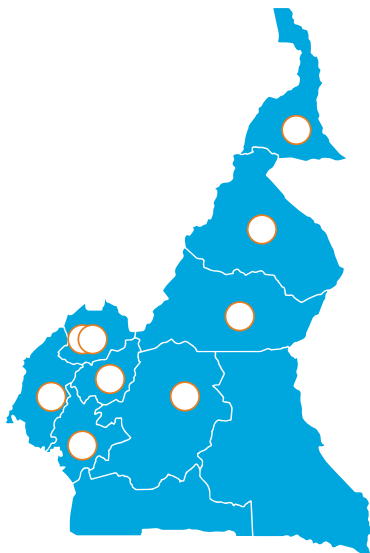
CHILDREN ENROLLED: 456



HEALTHCARE PROFESSIONALS TRAINED: 675

The project has focused on training healthcare professionals in emergency wards across the country with a view to ensuring that children presenting with symptoms of type 1 diabetes are correctly diagnosed and started on the appropriate treatment.

CLINICS ESTABLISHED: 9



○ Clinic locations

### ADVOCACY FOR SUPPORT FROM THE MINISTRY OF HEALTH FOR CHILDREN WITH TYPE 1 DIABETES

The health focus in Cameroon has predominantly been on communicable diseases. Now that the data from the registry are available, they are being used to raise awareness of type 1 diabetes at the level of the Ministry of Public Health in order to supply insulin free of charge to those who need it.

### ESTABLISHING CLINICS WITHIN THE EXISTING HEALTHCARE STRUCTURE

In 2010 there were only two clinics in the country offering care to children living with diabetes: the Central Hospital of Yaoundé and the General Hospital of Douala. The project has worked to establish clinics within the structure of existing diabetes clinics. All clinics fall under the Ministry of Public Health. Today, there are a total of nine clinics across the country.

#### GIRESSE'S STORY

Giresse was in primary school when he was diagnosed with type 1 diabetes. His teacher recommended to his parents that he should go to a clinic for a check-up. She had noticed that he frequently needed to be excused from class to urinate.

Since being diagnosed, Giresse has learnt the importance of diabetes self-management. He tries his best to follow a healthy diet, practise physical sport and regularly check his blood sugar. But like many other people who are dependent on insulin, Giresse is in constant fear of nocturnal hypoglycaemia and says: "Before going to sleep at night, I always ask myself if I will be able to wake up in the morning."

## USING DATA TO SHOW THE WAY FORWARD

Prevalence data on type 1 diabetes in Cameroon, as with most countries in Africa, are very scarce. However, with the Changing Diabetes® in Children programme, a registry has been set up and training provided for its successful implementation. Access to data via the registry is proving to be a vital tool in a number of aspects. The data that are now available can provide direction in determining the type of educational messages aimed at children with type 1 diabetes to educate them about managing their condition. At the level of determining health policy, the evidence gathered from the data can also be used to support arguments advocating for an improvement in standards of diabetes care, as well as for financial support for children with type 1 diabetes. The data are centralised at the Central Hospital of Yaoundé, where project partners such as the Ministry of Public Health of Cameroon have access to it.

Access the  
CDiC Cameroon  
website  
[www.bit.ly/1wHEBd4](http://www.bit.ly/1wHEBd4)



## Cameroon in numbers

POPULATION: **22.25 MILLION**<sup>6</sup>  
GDP (CURRENT USD): **29.57 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>59</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>94%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>95</b>
2009 physicians (per 1,000 people) <sup>9</sup>	<b>0.077</b>

*“The CDiC programme has had a big impact on the quality of care of children. It has helped us adapt and apply textbook knowledge of type 1 diabetes to our local context and better understand what is essential for the children in Cameroon. But now, with a registry, we also have data to show us where we can do better.”*

Dr Suzanne Ngo  
Paediatric endocrinologist  
CDiC project  
Yaoundé

GIRESSE T  
Cameroon



# changing diabetes® in children in the democratic republic of congo



## Project background

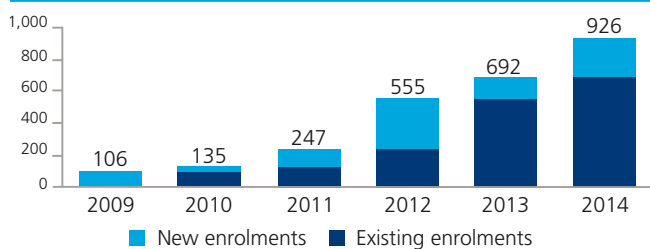
PROJECT INITIATED: 2009

### COUNTRY PROJECT PARTNERS

- Ministry of Health of the Democratic Republic of Congo
- Bureau Diocésain des Oeuvres Médicales (BDOM)
- Medische Ontwikkelingssamenwerking (MEMISA)

## Project indicators

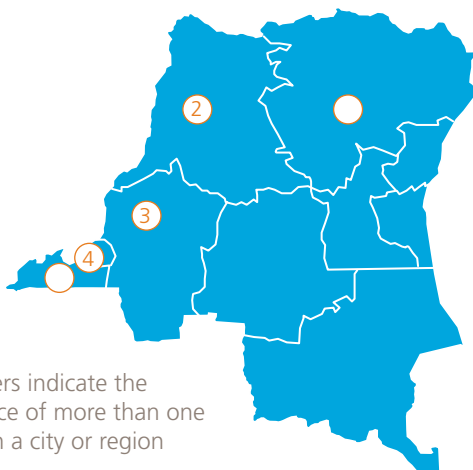
### CHILDREN ENROLLED: 926



### HEALTHCARE PROFESSIONALS TRAINED: 435

Workshops were held to educate healthcare professionals not specifically involved in the programme in the diagnosis and immediate care of children with type 1 diabetes. They ensure that staff employed in emergency wards and at other facilities are able to identify type 1 diabetes and also know what immediate action to take prior to referring them to a specialist centre.

### CLINICS ESTABLISHED: 17



Numbers indicate the presence of more than one clinic in a city or region

○ Primary clinic locations (satellite clinic locations not shown)

### IMPROVING ACCESSIBILITY OF DIABETES CARE

Seventeen clinics have been established in the Democratic Republic of Congo. Prior to the Changing Diabetes® in Children project, there was only one clinic for children with diabetes, supported by the International Diabetes Federation, in the capital of Kinshasa, which has a population of approximately 8 million people. Now there are four clinics in the city that are managed through the Bureau Diocésain des Oeuvres Médicales (BDOM), a private institution under the Archdiocese of Bukavu in the Democratic Republic of Congo. A further seven centres and six satellite clinics, 13 in total, have been established in the provincial regions under MEMISA's supervision. MEMISA is a non-profit organisation that promotes quality healthcare.

### KONGO KADAMIMBI'S STORY

Kongo Kadamimbi is one of the children enrolled in the local CDiC programme. He is reliant on the programme for diabetes care. The introduction of the CDiC programme has resulted in far fewer children with type 1 diabetes dying because of misdiagnosis and lack of treatment. According to Louise Hanyange Shutsha, former programme coordinator for the CDiC programme in the Democratic Republic of Congo, prior to the programme, a child living in the rural provinces who developed diabetes was certain to die within a year.

"The availability of free insulin, education and access to treatment via satellite clinics has helped improve the situation significantly for these children," says Ms Shutsha.



## CREATING SOLUTIONS THAT MEET THE INDIVIDUAL NEEDS OF CHILDREN WITH DIABETES

There are a number of challenges for children living with type 1 diabetes in the Democratic Republic of Congo, especially for those in the provinces. A prevailing factor is the high degree of socio-insecurity for patients whose families are very poor. Even in Kinshasa, where some of the parents do have work, salaries are low. Although the children in rural areas do receive insulin free of charge through the CDiC programme, many families do not have a fridge at home to keep the insulin cold.

With the support of MEMISA, satellite clinics have been established and these are equipped with fridges to store insulin for the children. Solar panels have also been installed to ensure a reliable source of energy to keep the refrigerators running. Some of the children come to collect insulin at the clinic as needed and may only keep one dosage of the medication at home at one time. As a result, there are times when they may not have insulin at home and they may have to reduce the dosage of insulin to make it last in some cases, impacting their blood sugar levels. Because of these and other challenges, such as the vast distances that children in outlying areas have to travel to receive treatment at a clinic, having the knowledge to be able to recognise the warning signs of episodes of low or high blood sugar is an important tool in saving lives.

## DRC in numbers

POPULATION: **67.51 MILLION**<sup>6</sup>

GDP (CURRENT USD): **32.69 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD)<sup>7</sup> **15**

2012 out-of-pocket health expenditure (% of private expenditure on health)<sup>7</sup> **67%**

2013 mortality rate for under five-year-olds (per 1,000 births)<sup>8</sup> **119**

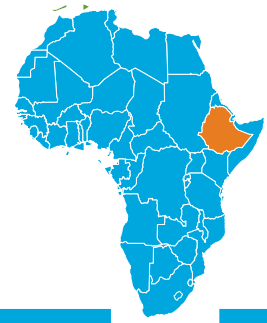
2004 physicians (per 1,000 people)<sup>9</sup> **0.107**

*“What I’ve found to be a most valuable aspect of the programme with regard to the future sustainability is patient education. The increased capacity of children to take care of themselves as a result of the education they’ve received with the CDiC materials means that they’re able to resolve some emergency situations by themselves.”*

Louise Hanyange Shutsha  
CDiC programme coordinator  
Kinshasa



# changing diabetes® in children in ethiopia



## Project background

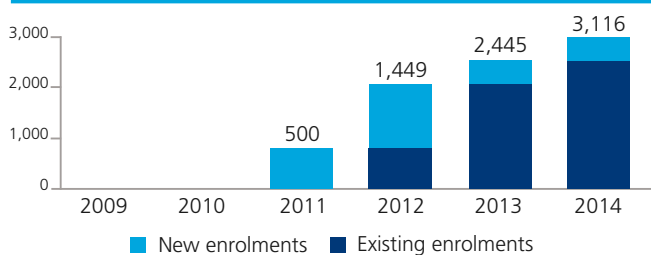
PROJECT INITIATED: 2011

### COUNTRY PROJECT PARTNERS

- Ministry of Health of Ethiopia
- Ethiopian Diabetes Association (EDA)

## Project indicators

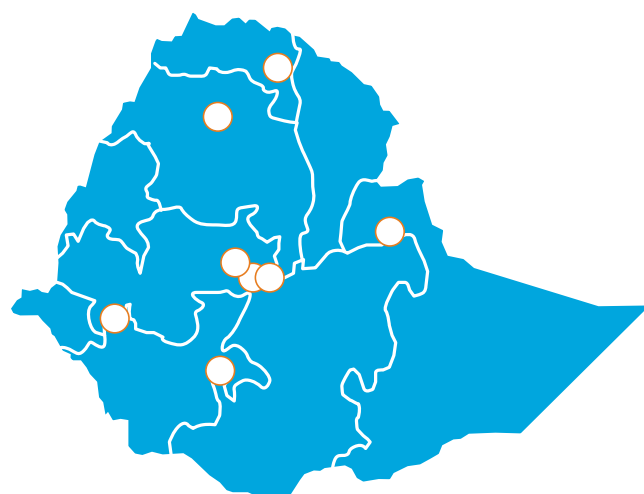
CHILDREN ENROLLED: **3,116**



HEALTHCARE PROFESSIONALS TRAINED: **174**

Training for healthcare professionals regarding the diagnosis and treatment of type 1 diabetes has taken place each year since the programme started.

CLINICS ESTABLISHED: **8**



○ Primary clinic locations

### INCREASED AWARENESS OF TYPE 1 DIABETES LEADS TO WIDER SUPPORT

A clinic has been set up in the northern region of Gondar. Most of the patients attending the clinic come from families that farm crops for a living. Food security is a major issue. It is therefore often not a question of having the choice to follow a healthy diet to maintain blood sugar levels, but rather one of not having any food at all. Following the establishment of the clinic and efforts to increase awareness among healthcare professionals and the general public about type 1 diabetes, more and more children have come forward to receive treatment. This has led to interest in the project from other non-governmental organisations working in the region.

### SABA SAMUEL'S STORY

Saba Samuel was celebrating her first birthday when she got sick. At the hospital she was treated for pneumonia and a bladder infection. After being given several injections that did not seem to be working, her parents took her to another hospital. Dr Bereket Fantahun, the only paediatric endocrinologist in Ethiopia, explains: "When parents bring their child to hospital, what may happen is that the physicians may not consider diabetes mellitus. The first thing they consider is malaria." In her opinion, more paediatricians, nurses and general practitioners need to be trained. Although adult diabetes units are well established, according to Dr Fantahun, "Paediatrics is a forgotten area." There are a number of good paediatric residency programmes at various university hospitals in Ethiopia, but few who qualify want to specialise in endocrinology. This is the current challenge.

## DATA COLLECTION IS KEY TO UNDERSTANDING TYPE 1 DIABETES

Ethiopia has the highest number of children enrolled in an African country, with 3,116 children enrolled in the Changing Diabetes® in Children programme. As many as 1,000 of the registered children are from a single area situated outside of the capital of M'kele in the Tigray region. The large number of cases reported from one area has posed questions – some of which have not been previously considered for further study. For example, whether there is a possibility that environmental factors may have contributed to the high number of incidences of type 1 diabetes in Tigray compared with other regions. The general population living in this area have, over time, been exposed to chronic malnutrition as a result of prolonged famine, drought and war. Further study is required to determine whether and to what extent these factors may play a role.

Meeting the needs of children with type 1 diabetes requires concerted effort, not only from the Ethiopian Diabetes Association, but also from the Ministry of Health and other stakeholders. However, first the data must be available. Systematic data collection using the software supplied for the registry has been one of the challenges of the project in Ethiopia so far. Staff at clinics are generally trying to cope with multiple responsibilities and do not always have the capacity to record the data electronically. Training has been provided for those responsible, and plans are being put in place to assign someone in each clinic to facilitate the process of capturing the data on the registry. Once the data are available, concrete suggestions can be put forward to the government to persuade health authorities to make provision for insulin and self-monitoring of blood glucose equipment as part of the national health insurance scheme.

Among the achievements of the project are a partnership with the Federal Ministry of Health and the formation of a non-communicable disease unit. Initial steps have also been taken to quantify how much insulin is needed to fulfil the demand within the country.

## Ethiopia in numbers

POPULATION: **94.1 MILLION**<sup>6</sup>  
GDP (CURRENT USD): **47.53 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>18</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>80%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>64</b>
2004 physicians (per 1,000 people) <sup>9</sup>	<b>0.025</b>

*"There's no question that this programme is one of the great things that we could do for our people. We're proud of and we are extremely happy with the programme."*

Dr Ahmed Reja  
Chief executive director  
College of Health Sciences  
Addis Ababa University  
Addis Ababa

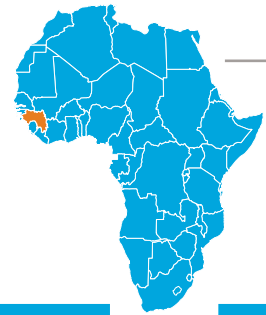
Access a short film about the CDiC programme in Ethiopia

[www.bit.ly/1BvQys1](http://www.bit.ly/1BvQys1)



SABA SAMUEL AND HER MOTHER  
Ethiopia





# changing diabetes® in children in guinea

## Project background

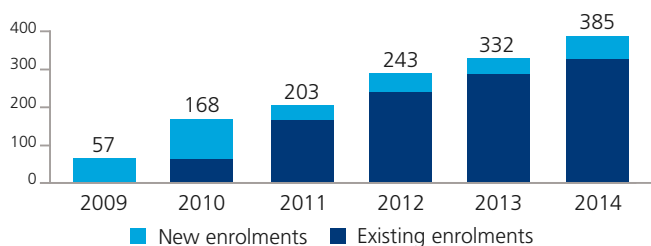
PROJECT INITIATED: 2010

### COUNTRY PROJECT PARTNERS

- Ministry of Health and Public Hygiene of Guinea
- Donka Teaching Hospital
- Association Guinéenne d'Education et d'Aide aux Diabétiques (AGEAD)

## Project indicators

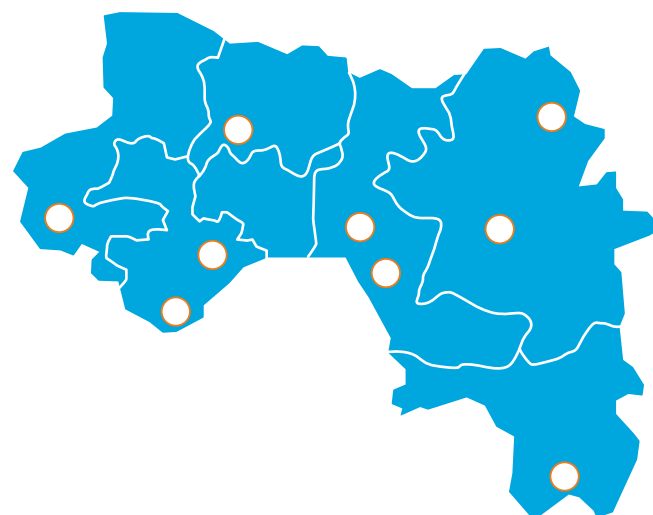
CHILDREN ENROLLED: 385



HEALTHCARE PROFESSIONALS TRAINED: 795

Over the project duration, four training courses have been held where physicians and nurses received education regarding the management of type 1 diabetes. The plan has been to extend the training to other regions in an effort to build diagnosis and treatment capabilities among all healthcare professionals.

CLINICS ESTABLISHED: 9



○ Primary clinic locations

### INTEGRATED INTO THE NATIONAL NCD PROGRAMME

The CDiC project in Guinea is to be included in the Ministry of Health's national programme for non-communicable diseases (NCD), with a view to ensuring that children with diabetes continue to receive treatment and support beyond the duration of the programme.

### ESTABLISHING CLINICS WITHIN THE EXISTING HEALTHCARE STRUCTURE

Initially, two hubs were established in Conakry. Subsequently, seven additional units were set up, covering all regions of the country. These are currently fully functional to provide consultation, education, monitoring and hospitalisation of children with type 1 diabetes.

#### BILKHISSA BALDE'S STORY

Bilkhissa Balde is a 15-year-old girl from Guinea, who lives with her father in Conakry. She has learned how to manage her diabetes by regularly visiting the CDiC clinic. She was diagnosed after experiencing some of the common symptoms: frequent urination and problems with her eyesight. A simple blood test confirmed that she had type 1 diabetes. When Bilkhissa was first diagnosed, finding insulin in Conakry proved to be a challenge for her father as it was only available in some pharmacies and was sometimes completely out of stock. Bilkhissa now visits the CDiC centre in Conakry, where she receives regular check-ups, education, a glucometer, strips and free insulin. "The programme has helped me in many ways," says Bilkhissa. "I always have insulin and it's for free. I'm well taken care of at the hospital, and they have taught me many things."



## BRINGING CARE TO CHILDREN WHERE THEY NEED IT

Children with type 1 diabetes in Guinea no longer die because they are unable to access treatment. However, many children who are identified as having type 1 diabetes are only being diagnosed when symptoms become serious and medical treatment is sought. Once diagnosed, there are still a number of children who do not maintain good blood sugar control and are at risk of developing complications in the coming years if the situation is not improved.

More education tools need to be developed to help the children and adolescents better understand how to manage their diabetes, diet and physical activity. Guinea is working with other countries involved in the Changing Diabetes® in Children programme and also with other participating partners to produce suitable tools to convey the message of education in a better way.

The journey to the nearest clinic to collect insulin and medical supplies can be very far for some of the children and adolescents to travel. For example, 15-year-old Safiatou Diallo has to walk several kilometres from home to catch the nearest bus and then a taxi – a journey that can take six hours – to reach the Changing Diabetes® in Children clinic in Labé.

To address this challenge, a mobile clinic fitted with monitoring equipment has been launched and will travel to the areas where the children live. A specialised diabetes care team will deliver services from the mobile clinic. This will also support staff working in outlying areas. The aim is to improve the quality of the care that the children receive and to ensure regular follow-up visits with the children.

Access a short film  
about Bilkhissa and  
her life with diabetes  
[www.bit.ly/1ANbDO5](http://www.bit.ly/1ANbDO5)



## Guinea in numbers

POPULATION: **11.75 MILLION**<sup>6</sup>

GDP (CURRENT USD): **6.14 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD)<sup>7</sup> **32**

2012 out-of-pocket health expenditure (% of private expenditure on health)<sup>7</sup> **93%**

2013 mortality rate for under five-year-olds (per 1,000 births)<sup>8</sup> **101**

2005 physicians (per 1,000 people)<sup>9</sup> **0.1**

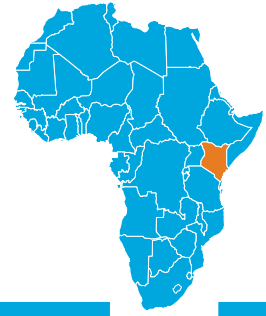
*“If the children accept their condition, understand what they have to deal with, and that it is possible to attain their dreams, then it’s possible for them to better manage their condition.”*

Dr Naby Balde  
Specialist endocrinologist  
Donka Teaching Hospital  
Conakry

BILKHISSA BALDE  
Guinea



# changing diabetes® in children in kenya



## Project background

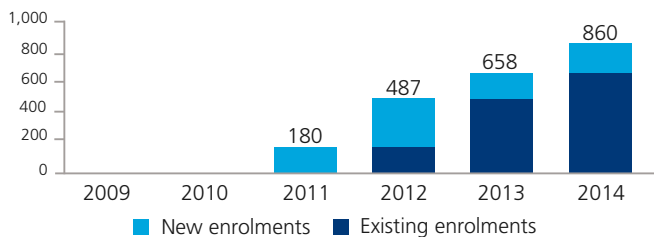
PROJECT INITIATED: 2012

### COUNTRY PROJECT PARTNERS

- Ministry of Health of Kenya
- Kenya Diabetes Management and Information (DMI) Centre

## Project indicators

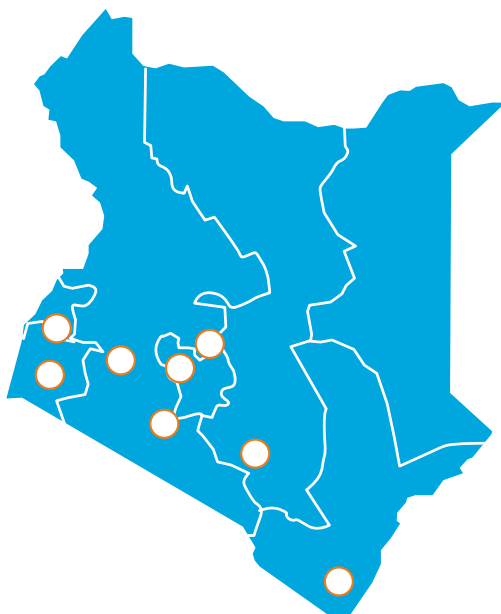
### CHILDREN ENROLLED: 860



### HEALTHCARE PROFESSIONALS TRAINED: 165

Since Kenya joined the programme in 2012, 165 healthcare professionals have been trained in the management of type 1 diabetes.

### CLINICS ESTABLISHED: 8



○ Clinic locations

### ESTABLISHING CLINICS WITHIN THE EXISTING HEALTHCARE STRUCTURE

In Kenya, the Ministry of Health manages seven clinics at various county hospitals. An eighth clinic, the Kenya Diabetes Management and Information (DMI) Centre in Nairobi, is run as a separate unit. The children attending the clinic at the DMI Centre are given supplies such as insulin and glucose monitoring strips. They also receive patient education and access to a counsellor who consults with them and their parents on a one-on-one basis. Children attend the DMI Centre approximately once a month in addition to their regular visit to the county hospital clinic where a physician monitors the clinical aspects of their case. There are over 319 children registered with the DMI Centre.

### GEOFFREY OMONDI ODINGA'S STORY

Geoffrey Omondi Odinga of Nairobi was diagnosed with type 1 diabetes at the age of eight. Often he found it hard to stay in good control, and sometimes he fainted in class. School became distressing; his classmates mocked him for being 'different'. Then his life collapsed completely when he lost both his parents. Geoffrey gave up school and began begging in the streets. Fortunately, Geoffrey found his way to the Changing Diabetes® in Children programme. Today he is an active 16-year-old who has regular access to insulin and blood glucose monitoring. He has learned how to inject himself and store his insulin properly, and he knows how to balance his medication with a healthy diet and exercise. He is also back in school, where his favourite subject is Swahili. He knows he has a future.

## EMPOWERING PARENTS, TEACHERS AND CHILDREN TO OVERCOME FEAR AND STIGMA

Children with type 1 diabetes may experience stigma because they are frequently absent from school and, as a result, do not perform well academically. Regular insulin treatment as well as education have been instrumental in reducing illness. This is evident in the decrease in the number of hospital visits and diabetes-related deaths among children due to uncontrolled diabetes.

Part of the education efforts that have been implemented with the CDiC programme is done through home visits where the child's social conditions are assessed. Follow-up visits are subsequently made to parents or guardians to advise them about how to manage their child's condition. Furthermore, parent meetings are also held regularly at the main county hospital clinics, where topics relating to caring for a child with type 1 diabetes are discussed – so far, as many as 837 parents have taken part. Over time, the parents have become more willing to share their own experiences as the stigma of type 1 diabetes is overcome through increased awareness and dialogue. Parents are even talking about forming an association that will seek to advocate for State-supplied free access to insulin for children past the age of 18, who are no longer attended to via the CDiC clinics for children and adolescents with type 1 diabetes.

In the past, there have been incidences where children have been discriminated against at school and been refused admission to schools on the basis of their condition. Therefore, the CDiC programme has initiated a schools' awareness campaign where talks are given to pupils to help promote understanding and tolerance of the condition. Teachers are also receiving training on the management of type 1 diabetes and specific issues they have raised in consultation are being dealt with in training. So far, 87 teachers have been trained and there are plans to train another 100 teachers early in 2015.

## Kenya in numbers

POPULATION: **44.35 MILLION**<sup>6</sup>

GDP (CURRENT USD): **55.24 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD)<sup>7</sup> **45**

2012 out-of-pocket health expenditure (% of private expenditure on health)<sup>7</sup> **77%**

2013 mortality rate for under five-year-olds (per 1,000 births)<sup>8</sup> **101**

2011 physicians (per 1,000 people)<sup>9</sup> **0.181**

*"Children with type 1 diabetes were being stigmatised because they were sick a lot and not performing well at school. But now, with the programme, we know what to do; we know that we can talk about it. The children themselves are also talking and writing essays about their condition – a few of the children have been interviewed on television as part of general awareness campaigns."*

Eva Muchemi  
Executive director  
Kenya Diabetes Management and  
Information Centre  
Nairobi



GEOFFREY OMONDI ODINGA  
Kenya



# changing diabetes® in children in tanzania



## Project background

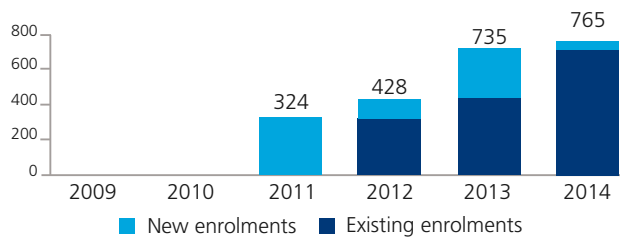
PROJECT INITIATED: 2010

### COUNTRY PROJECT PARTNERS

- Ministry of Health and Social Welfare of Tanzania
- Tanzania Diabetes Association (TDA)

## Project indicators

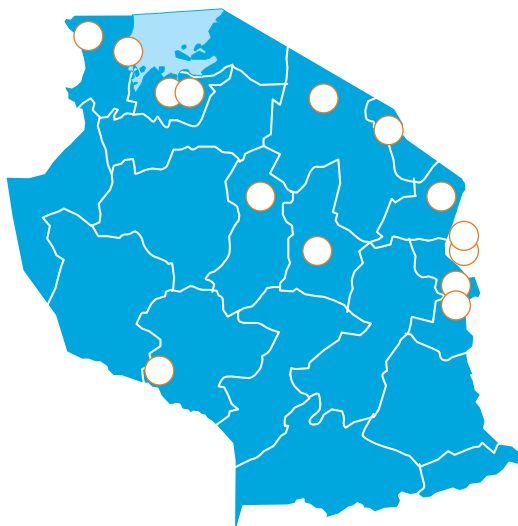
CHILDREN ENROLLED: 765



HEALTHCARE PROFESSIONALS TRAINED: 167

Healthcare trainings have been conducted for nurses and physicians from the various regions. Furthermore, standard treatment guidelines for type 1 diabetes have been developed for the clinics and submitted for approval to the government authority.

CLINICS ESTABLISHED: 14



○ Clinic locations

### ONGOING CHALLENGES WITH POOR CONTROL

The number of hospital admissions for hyperglycaemia has dropped significantly, signifying an improvement among patients in controlling their blood sugar levels. However, poor blood glucose control among the enrolled children continues to be a challenge.

### REDUCING THE DISTANCE CHILDREN NEED TO TRAVEL TO ACCESS CARE

Eight new clinics have been established and six existing clinics strengthened. Seven of the clinics work as 'hubs' and the remaining seven clinics work as 'spokes'. The hubs are the main clinics and work as referral clinics, whereas the spokes are smaller clinics. The aim of establishing smaller clinics is to improve access by reducing the distance children are required to travel to get diabetes care.

### MATILDA HERMAN'S STORY

At the age of 17, Matilda Herman was diagnosed with type 1 diabetes after she was taken to hospital in a coma. Her earlier symptoms were attributed to malaria, which is very common in Tanzania, and she had been treated accordingly. It was only when she was admitted to hospital that her condition was correctly diagnosed. What followed was a year-long battle to regulate her blood glucose, which kept her out of school a lot. She says: "At first I still had this childishness and was not taking the condition very seriously. I went ahead and ate everything like normal, like other children. I was in and out of hospital and had to quit school after falling too far behind to pass my exams." However, since going to Muhimbili National Hospital's Diabetic Clinic, where she was given the proper advice about her diet, things are going much better.



## FUNDING ENTREPRENEURSHIP TO SUPPORT FAMILIES OF CHILDREN WITH TYPE 1 DIABETES IN TANZANIA

In Tanzania, diabetes treatment is free for children. However, the system is overstretched, particularly in certain regions. This means that children and adolescents with type 1 diabetes often have to resort to buying the medication from a private pharmacy, where a single vial of insulin costs around 9 US dollars. It is a tough situation for many. The question is what happens to these young people attending the CDiC programme when they reach adulthood and no longer qualify for a regular supply of free insulin. This is the problem that the Tanzania Diabetes Association (TDA) is trying to resolve.

One potential solution put forward has been to fund entrepreneurship through microfinance. In 2011, the TDA made some funds available for the pilot project. Twenty of the families of children who attend the Muhimbili National Hospital's Diabetic Clinic considered to be 'most-in-need' were each given a loan of 500,000 Tanzanian shillings (274 US dollars) to finance a business venture.

Matilda Herman and her mother Agnes Muhina are one of the families taking part in the microfinance initiative. Two years prior to enrolling in the project, at the age of 17, Matilda was diagnosed with type 1 diabetes. Before the microfinancing opportunity came along, Matilda's family were living off 50,000 Tanzanian shillings per month. The loan is helping them to expand a cool drink wholesale business that Matilda's sister started in the area. They have also since been able to move from rented property to a home of their own. The funding has given them hope and ideas for the future. Their next venture is to build a water tower and a chicken coop – two more businesses that will pay towards Matilda's savings of 60,000 Tanzanian shillings for future diabetes treatment.

The terms for repaying the loan are relatively informal, being based on a certain amount of faith and cooperation. According to Dorothy McLarty, a coordinator working on the project, "The families are very concerned about their children and every month they come to the TDA office to pay the minimum, if not more".

## Tanzania in numbers

POPULATION: **49.25 MILLION**<sup>6</sup>  
GDP (CURRENT USD): **33.23 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>41</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>52%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>52</b>
2009 physicians (per 1,000 people) <sup>9</sup>	<b>N/A</b>

*"The Changing Diabetes in Children® programme has demonstrated what can be achieved with a concerted effort. The programme has also brought to light that there's still much more that can and must be done."*

Dr Kaushik Ramaiya  
CEO and consultant physician  
Shree Hindu Mandal Hospital  
Dar es Salaam



MATILDA HERMAN  
Tanzania

# changing diabetes® in children in uganda



## Project background

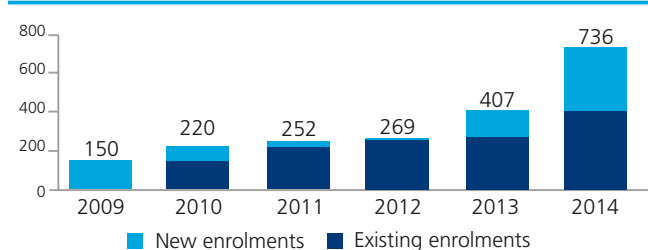
PROJECT INITIATED: 2009 (Nsambya) and 2013 (Ministry of Health of Uganda)

### COUNTRY PROJECT PARTNERS

- Ministry of Health of Uganda
- St. Francis Hospital Nsambya

## Project indicators

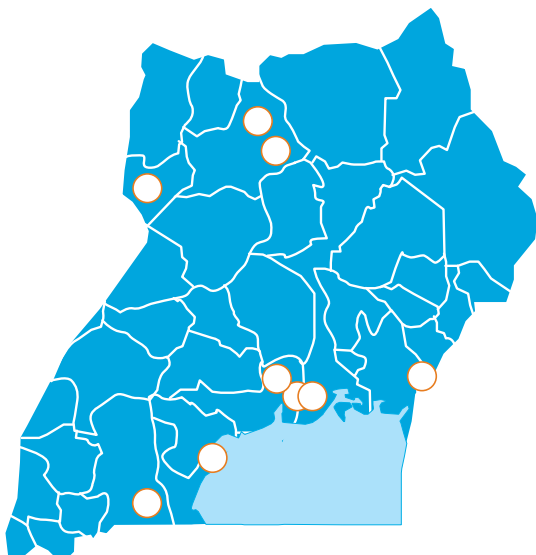
### CHILDREN ENROLLED: 736



### HEALTHCARE PROFESSIONALS TRAINED: 167

A peer-to-peer training model has been used to improve the knowledge of healthcare professionals at clinics established through the Nsambya Hospital-run project. The Ministry of Health has trained two healthcare professionals in each of the four clinics recently set up.

### CLINICS ESTABLISHED: 24



○ Primary clinic locations (satellite clinic locations not shown)

### BUILDING CAPACITY THROUGH A PEER-TO-PEER TRAINING MODEL

Doctors and nurses from several centres established through the Nsambya Hospital's Diabetes Centre have attended 10 training sessions, followed by two weeks of hands-on training. The trained healthcare professionals have in turn trained other healthcare professionals within the health facilities where they are stationed. So far, through the peer training programme, 167 healthcare professionals have received training, including six paediatricians.

A curriculum and manual, *The Process for Practical Guidelines of Managing Type 1 Diabetes*, specifically adapted to the Ugandan situation, is being used in training.

### AKIRAM SEJJOMBWE'S STORY

Akiram Sejjombwe lives with his parents and siblings in Wakiso, a suburb of Kampala in Uganda. He was diagnosed with type 1 diabetes at the age of 13. Akiram loves football and is an avid supporter of Manchester United. When he was diagnosed he was frightened that he would no longer be able to participate in sports and play with his friends, but quickly learnt that by controlling his diabetes he could be as active as his peers. Akiram lives close to the type 1 diabetes clinic in Wakiso, which has made accessing care and attending regular check-ups a bit easier.

View a short film about the CDiC programme in Uganda  
[www.bit.ly/1Au6uWe](http://www.bit.ly/1Au6uWe)

## DEVELOPING DIABETES CARE INFRASTRUCTURE

In Uganda, the CDiC programme was originally piloted through Nsambya Hospital, which is owned by the Roman Catholic Archdiocese of Kampala and run by the Little Sisters of St. Francis. Today, there are over 600 children enrolled at the Nsambya CDiC programme's clinics. All centres receive supplies from Nsambya Hospital's Diabetes Centre, which is the coordinating body. More recently, the Ministry of Health has also become involved in the programme to ensure its sustainability post-2017, when the programme terminates. Approximately 70 children have been enrolled at clinics that the Ministry of Health has set up and is supervising at regional referral hospitals.

As part of the first component of the Nsambya-coordinated programme, two type 1 diabetes centres of excellence for children were established in Kampala. Clinics were subsequently added in Arua and Wakiso respectively. The clinics and centres are established within the structures of existing diabetes clinics serving adult diabetes patients. Clinics have been renovated and equipped with appropriate medical and laboratory equipment as well as a refrigerator for insulin storage.

Since 2013, another four clinics have been set up under the auspices of the Ministry of Health. These are 'hubs' and there are six 'spokes' under the Masaka Regional Referral Hospital clinic. While supply chain logistics are being worked out via the Ministry of Health system, supplies are being obtained from Nsambya Hospital's Diabetes Centre for these clinics.

## DIABETES EDUCATION MATERIALS FOR BOTH CHILDREN AND PARENTS

Patient education has been a significant focus in Uganda. The establishment of an online resource centre and education hub has been a big achievement for the Nsambya programme and this has ensured continued training.

## Uganda in numbers

POPULATION: **37.58 MILLION**<sup>6</sup>  
GDP (CURRENT USD): **21.49 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>44</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>65%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>66</b>
2005 physicians (per 1,000 people) <sup>9</sup>	<b>0.117</b>

*"Blood sugar glucometers are being distributed to children registered with the CDiC programme. At one location, where 15 children have their own personal glucometers for self-monitoring, there has been an overall improvement in the children's blood sugar levels. One of the positive outcomes of this has been a reduction in school absenteeism."*

Dr Florence Tugumisirize  
Head of the CDiC steering committee for  
the Ministry of Health, Kampala

AKIRAM SEJOMBWE AND HIS MOTHER  
Uganda







JOHN KIJAZI  
TANZANIA

View a short film  
about John from  
Tanzania  
[www.bit.ly/1aQ3sad](http://www.bit.ly/1aQ3sad)



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# diabetes and traditional medicine in africa

Millions of people worldwide use traditional medicine to help meet some of their primary healthcare needs. Lower cost and easier access to these treatments contribute to their popularity in many countries where there is a shortage of healthcare provision<sup>10</sup>. In Africa, up to 80% of the population uses traditional medicine for these reasons<sup>11</sup>. This includes people with diabetes.

Traditional medicine generally refers to a combination of plant-, animal- and mineral-based medicines. These may be used separately or with spiritual therapies, manual procedures and exercises to diagnose, prevent and treat illnesses, or maintain or enhance overall health<sup>12</sup>. Common treatments for diabetes include herbal medicines, nutritional products, spiritual healing and relaxation techniques<sup>13</sup>. Traditional medicine is frequently the first line of treatment for people with chronic conditions. Often its use is continued alongside prescribed treatment, either in the form of self-medication or to 'supplement' the care they receive in clinics and hospitals with treatment from traditional healers<sup>12</sup>.

To a great extent, ancestral beliefs, customs and traditional lifestyle play a part in the reasons why people use herbal medicines and alternative therapies. In African society, disease is linked to evil spirits and it is believed, for example, that plants have magical powers that can cast off evil spells<sup>10</sup>. According to traditional beliefs, every illness also has a cure. In the context of these beliefs, the scientific description of diabetes as a chronic non-communicable disease exposes the limitations of biomedical medicine and motivates people who subscribe to these widely held beliefs to turn to traditional healers<sup>13</sup>. One study from Conakry University Hospital in 2003 found that a third of patients with diabetes used herbal medicine with just over a third stating they used

traditional medicine because they were searching for a complete cure for diabetes<sup>10</sup>.

## The importance of cooperating with traditional healers

Traditional healers are commonplace in Africa and are a trusted source of knowledge within tight-knit rural communities. They are familiar with people's social circumstances and employ this knowledge to perform diagnoses and healing rituals<sup>14</sup>. Some traditional healers draw on modern scientific wisdom in their interpretations and advise people to visit a healthcare centre if diabetes is suspected.

Providing education to traditional healers regarding the symptoms of diabetes and its complications could help them to act as frontline players in primary diabetes care<sup>12</sup>.

Greater cooperation between healthcare providers and traditional healers within a regulated framework could be beneficial in the long term, by encouraging the traditional healers to disclose the use of traditional medicines – some of which may be beneficial and safe. Better cooperation between healthcare providers and traditional healers could also strengthen the system of early referrals for diabetes and its complications to formal health services.

## JOHN KIJAZI'S STORY

John Kijazi, a primary school pupil in grade 6, was diagnosed with type 1 diabetes in 2010. For the first few weeks after his release from hospital, his parents would take him to the local dispensary to have his blood sugar levels checked and to be injected with insulin. The blood glucose tests were costly. John's mother therefore began giving John the injections herself, but she died a few months later, leaving his father with the sole burden of caring for John.

His uncle offered to help and pay for John to visit a traditional healer in order to obtain a permanent cure for John's condition. It was suggested they visit Babu, a renowned healer in Loliondo, Arusha – a five-hour trip from Dar es Salaam. Many people in Tanzania make the journey believing that

Babu's 'cup of wonders', a mixture of herbs given to those who are ill, can cure their ailments. John and his uncle went together to Arusha, and on his return, John stopped using insulin, but his condition did not appear to improve. John was less impressed than his father about the effects of the 'cure'. Without telling his father, he used the money he and his brother were given for school tuition to visit Muhimbili National Hospital to have his blood sugar levels checked.

John is now enrolled in the CDiC programme at a clinic in Dar es Salaam where he receives diabetes education about how to manage his diabetes, as well as supplies, including insulin. One day he hopes to become a doctor so that he can help others with diabetes like himself.





Children at the CDiC clinic in Bangalore, India

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## changing diabetes® in children in south-east asia

South-East Asia is one of the world's most populous regions. Close to one-fifth of all adults with diabetes in the world live in this region. The region has one of the highest estimates of prevalence of type 1 diabetes in children, with over 77,900 affected<sup>1</sup>. In 2013, an estimated 12,600 children under the age of 15 developed type 1 diabetes in the region<sup>1</sup>.

Apart from therapeutic issues, barriers to care include factors such as insulin acceptance, availability, storage and compliance. In addition, lack of comprehensive awareness about the disease in the patient population, and fear of multiple daily insulin injections and the associated risk of low blood sugar have led to limited acceptance by patients and low prescription levels among physicians.

### SOUTH-EAST ASIA

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# changing diabetes® in children in bangladesh



## Project background

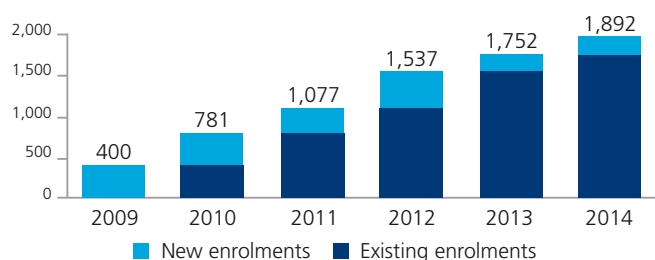
PROJECT INITIATED: 2009

COUNTRY PROJECT PARTNER

- Diabetic Association of Bangladesh (BADAS)

## Project indicators

CHILDREN ENROLLED: **1,892**



HEALTHCARE PROFESSIONALS TRAINED: **249**

To date, 249 healthcare professionals have been trained in Bangladesh. The objective of the training has been to build additional diabetes care capabilities among general healthcare practitioners.

CLINICS ESTABLISHED: **3**



○ Primary clinic locations

### IMPROVEMENT IN CHILDREN'S HEALTH

Blood sugar levels have dropped among children enrolled in the programme. While there is room for improvement in controlling their diabetes, it is clear that initial declines in blood sugar levels reflect the valuable role the clinics play in detecting disease and initiating treatment in children whose type 1 diabetes was previously undiagnosed and uncontrolled.

### ANNUAL CHILDREN'S CAMP

Since 2009, four annual children's camps have been held with the purpose of educating children with type 1 diabetes about how to live with the condition. Between 50 and 100 children attend each camp.

### NIME AHMED'S STORY

Prior to being diagnosed with type 1 diabetes, Nime Ahmed's family did not know what insulin was, let alone how to use it. Fortunately Nime lives in Dhaka, close to a clinic where he receives care and guidance. Nime's mother explains that without the provision of free insulin they would have to leave Nime's fate to Allah, as there is no way that they could afford to procure the necessary insulin and care.

View a short film  
about the CDiC  
programme in  
Bangladesh



[www.bit.ly/1ANdd2k](http://www.bit.ly/1ANdd2k)



## BRINGING CARE TO CHILDREN WHERE THEY NEED IT

More than 3,000 people with diabetes go to the diabetes clinic at the Bangladesh Institute of Research and Rehabilitation for Diabetes, Endocrine and Metabolic Disorders (BIRDEM) in Dhaka, Bangladesh, every day. BIRDEM is one of the largest diabetes clinics in the world. For children with type 1 diabetes, obtaining care can often be difficult when there is already such a dense population of adults with type 2 diabetes. Being able to provide treatment for so many is often an ideal that is out of reach, but this clinic is devoted to helping them. The CDiC clinic in Dhaka specialises in the specific problems and needs of children with type 1 diabetes. Over the past five years, the programme has supplied free insulin and medical supplies such as glucometers and strips free of charge to children enrolled in the programme. Education is also provided to teach the children and parents how to maintain good blood sugar control. However, understanding how to use insulin is difficult when you cannot read – even with clear instructions on hand these children face a challenging life at home. These families often struggle to afford the most basic necessities for survival, such as food. Often the choice they have to make is whether or not to buy rice to eat or pay for medical treatment.

Professor Azad Khan, who is the president of the Diabetic Association of Bangladesh, runs the clinic in Dhaka. His association has established a network of clinics in Bangladesh in order to be able to reach more adults and children with diabetes. Despite their efforts, only 25% of people with diabetes in Bangladesh are in close proximity to care. With help from the CDiC programme, new clinics for children are being set up in rural areas of Bangladesh. At the hospital of Faridpur, the diabetes clinic provides services to over 100,000 people in the region, mostly farmers and labourers. The hospital of Faridpur is educating a large number of nurses and social workers in order for them to raise awareness about diabetes and treat patients.

## Bangladesh in numbers

POPULATION: **156.6 MILLION**<sup>6</sup>  
GDP (CURRENT USD): **129.9 BILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>26</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>97%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>41</b>
2009 physicians (per 1,000 people) <sup>9</sup>	<b>0.356</b>

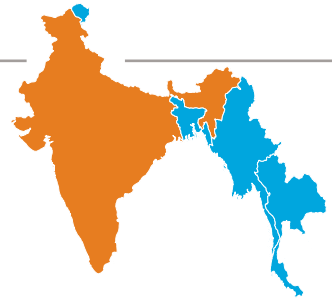
*“Changing diabetes in a developing country requires empowered patients and improved awareness, availability, affordability, accessibility and quality of care. We believe that these challenges should be met in partnership with stakeholders that all have sustainable business models.”*

Professor Azad Khan  
President of the Diabetic  
Association of Bangladesh  
Dhaka



NIME AHMED AND HIS MOTHER  
Bangladesh

# changing diabetes® in children in india



## Project background

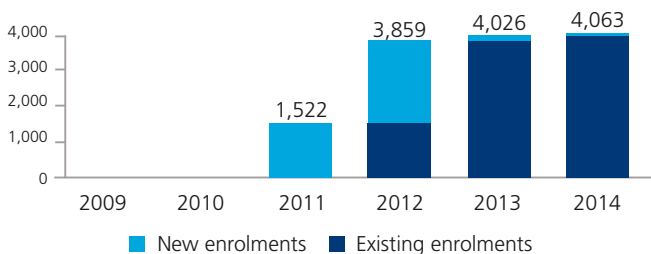
PROJECT INITIATED: SEPTEMBER 2011

### COUNTRY PROJECT PARTNER

- The Novo Nordisk Education Foundation

## Project indicators

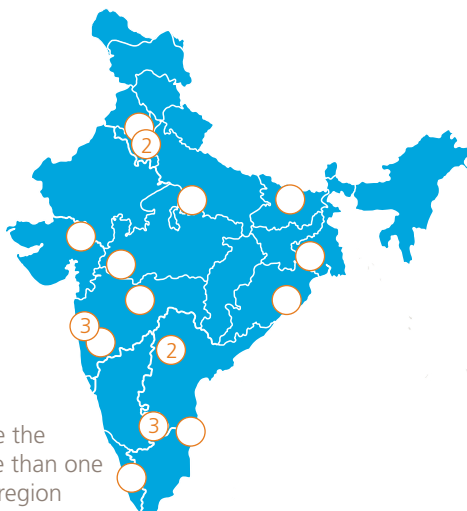
CHILDREN ENROLLED: **4,063**



HEALTHCARE PROFESSIONALS TRAINED: **2,920**

Capacity building, through structured and accredited training workshops for healthcare professionals, which includes both doctors and diabetes educators, is an integral part of the CDiC programme. These training programmes are conducted by the CDiC centre directors and other eminent key opinion leaders to enhance the capabilities of healthcare professionals in the diagnosis and treatment of children with type 1 diabetes.

CLINICS ESTABLISHED: **21**



Numbers indicate the presence of more than one clinic in a city or region

○ Primary clinic locations (satellite clinic locations not shown)

## PROJECT OBJECTIVES

1. Improve access to diabetes care and improve the quality of life for children with type 1 diabetes from financially challenged families
2. Improve the capacity of the local healthcare system for better diagnosis and treatment of type 1 diabetes
3. Increase attention of policymakers and the government on the needs of children with type 1 diabetes

### IMPROVING CAPACITY

Since 2011, 37 healthcare professional training workshops have been conducted. In 2013, these workshops were accredited by the local state medical councils.

### A NETWORK OF CLINICS FOR CHILDREN WITH DIABETES

There are 21 main clinics situated in major towns across India for children with type 1 diabetes. Satellite clinics linked to main clinics have been established to bridge the long distances that children from smaller towns have to travel in order to access treatment. There are 27 satellite clinics, 10 of which are in Karnataka, the eighth largest state in India in terms of population.

### SIDHARAM KULLEGOUDA'S STORY

Six years ago, Sidharam Kullegouda was diagnosed with diabetes at the age of five. Shortly thereafter, his parents decided to move from their village of Karnataka to Bangalore, to be closer to a diabetes centre that can provide care. Sidharam's care is now under the supervision of Dr K M Prasanna Kumar at the Bangalore Diabetes Hospital, where he attends the clinic once a month on a Sunday. Most children in India attend school six days a week from Monday to Saturday; so for this reason the clinic is open on Sundays. Senior doctors, paediatric endocrinologists, diabetologists, social workers, biochemists, lab technicians and other professional staff are available on Sundays to run the clinic. Due to the high number of children each Sunday, the clinic has been extended to Saturdays as well.



## PROVIDING DIABETES CARE TO THOSE LIVING BELOW THE POVERTY LINE

Poverty, both at individual and community level, is the single most important barrier to proper diabetes care in children diagnosed with type 1 diabetes. When the Changing Diabetes® in Children programme started three years ago, children of families below the poverty line were selected to be enrolled. In India, families with very low income (less than 4,800 rupees/76 US dollars per month) receive a Below the Poverty Line (BPL) card from the government. Aside from this criterion, the selection of which children to enrol in the programme is largely at the centre director's discretion.

## ONGOING PATIENT EDUCATION – CRITICAL TO SELF-MANAGEMENT

Because diabetes has to be managed continuously, educating the children about their condition and its management is critical. Patient education is provided to children enrolled with the programme via diabetes camps that are held throughout the year in various regions of the country. There have been 311 camps since the launch of the programme and, as a result of the camps, children are showing positive results in terms of blood sugar control.

There are three components to the camps: diabetes education, experience sharing and fun activities. Motivational camps are also organised to help many of the children to tackle psychosocial issues and live normal lives. It is also compulsory for the parents of the child with type 1 diabetes and the child's siblings to attend these camps. So far the camps have reached out to more than 13,000 children. Several innovative child-friendly patient education tools, which include toys to teach the basics of diabetes and comic books covering diabetes education, are distributed at the camps. These have been created to help the children understand how to self-manage their diabetes. A diabetes education curriculum for children has been designed and is being implemented.

## India in numbers

POPULATION: **1.252 BILLION**<sup>6</sup>  
GDP (CURRENT USD): **1.877 TRILLION**<sup>6</sup>

### HEALTH OVERVIEW

2012 health expenditure per capita (USD) <sup>7</sup>	<b>61</b>
2012 out-of-pocket health expenditure (% of private expenditure on health) <sup>7</sup>	<b>86%</b>
2013 mortality rate for under five-year-olds (per 1,000 births) <sup>8</sup>	<b>53</b>
2012 physicians (per 1,000 people) <sup>9</sup>	<b>0.702</b>

*“Simply giving free insulin will not achieve the ultimate purpose of the programme. The goal is for either the children or the parent to become self-sufficient in managing their condition. That is the whole idea of starting the Changing Diabetes® in Children programme.”*

Dr K M Prasanna Kumar  
Diabetologist and endocrinologist  
Bangalore Diabetes Hospital  
Chairman of CDiC in India  
Bangalore



SIDHARAM KULLEGOUA  
India



PIHU KUMARY WITH HER FATHER  
India



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# breaking down the barriers for children with diabetes in india

In the face of the huge pandemic of type 2 diabetes, the problems faced by children with type 1 diabetes are often overlooked. Families need help to cope with the condition, while learning about diabetes and its management. This calls for support not just from healthcare professionals and family but also from society. Good awareness and support are essential in ensuring optimal care and improved quality of life for children and young people with diabetes. The Changing Diabetes® in Children programme in India has initiated a range of efforts to break down some of the barriers for children.

## **Working with the media to raise awareness**

To drive awareness about diabetes among the general population, a number of advertorials about type 1 diabetes have been placed in leading newspapers and journals, including *The Times of India*, *The Week*, *Smart Life* and *JOSH (Journal of Social Health and Diabetes)*.

## **Talking about diabetes in schools**

Too often, children with type 1 diabetes are denied admission to school. This is due to both a misunderstanding of what the condition is and to fear over how to manage the condition. In India, the CDiC programme has initiated a 'Talking Diabetes in School' campaign to drive awareness. The primary objective is to create a supporting environment for children with type 1 diabetes and stop any type of discrimination.

## **A range of specially developed diabetes education tools**

To make diabetes education more accessible and effective for children, CDiC India has developed a number of innovative diabetes education tools. The tools are specifically developed with the child's needs in mind. Tools already developed include a series of story books, toys and a board game. In addition, visual tools have been developed for diabetes educators to assist them in teaching children and their families to manage type 1 diabetes. The education materials and tools are distributed to children enrolled in the programme via participating centres.

## **Diabetes camps for children**

It is important for children to learn to manage their diabetes as it is a condition that they will have for their entire life and that needs to be managed 24 hours a day, seven days a week. In India, over 300 patient education camps have been held to teach children how to manage their diabetes. The camps focus on three components: diabetes education, experience sharing and fun activities.

*"Our continued efforts for proper diabetes care for these children along with the systematic children diabetes camps conducted during the year, are yielding positive outcomes, since more children are now having good control."*

Dr K M Prasanna Kumar  
Diabetologist and endocrinologist  
Bangalore Diabetes Hospital  
Chairman of CDiC in India  
Bangalore

## working in partnership

The Changing Diabetes® in Children programme is a collaborative effort from a number of partners that each contributes with specific expertise and competences. Each of the partners has contributed to defining the programme using its global and regional resources to help implement the various country projects.



NOVO NORDISK

Headquartered in Denmark, Novo Nordisk is a global healthcare company with more than 90 years of innovation and leadership in diabetes care. The company also has leading positions within haemophilia care, growth hormone therapy and hormone replacement therapy. Novo Nordisk employs approximately 41,500 employees in 75 countries, and markets its products in more than 180 countries.

Novo Nordisk strives to conduct its activities in a financially, environmentally and socially responsible way. The strategic commitment to corporate sustainability has brought the company onto centre stage as a leading player in today's business environment, recognised for its integrated reporting, stakeholder engagement and consistently high sustainability performance.

Novo Nordisk initiated the CDiC programme in 2009 in an effort to improve access to diabetes care for children with type 1 diabetes.

[www.novonordisk.com](http://www.novonordisk.com)



ROCHE

Headquartered in Basel, Switzerland, Roche is a leader in research-focused healthcare, with combined strengths in pharmaceuticals and diagnostics. Roche is the world's largest biotech company, with truly differentiated medicines in oncology, immunology, infectious diseases, ophthalmology and neuroscience. Roche is also the world leader in *in vitro* diagnostics and tissue-based cancer diagnostics, and a frontrunner in diabetes management. Roche's personalised healthcare strategy aims at providing medicines and diagnostics that enable tangible improvements in the health, quality of life and survival of patients. Founded in 1896, Roche has been making important contributions to global health for more than a century. Twenty-four medicines developed by Roche are included in the World Health Organization Model Lists of Essential Medicines, among them life-saving antibiotics, antimalarials and chemotherapy.

In 2013, the Roche Group employed over 85,000 people worldwide, invested 8.7 billion Swiss francs in research and development and posted sales of 46.8 billion Swiss francs (about 9 billion US dollars). Genentech, in the United States, is a wholly owned member of the Roche Group. Roche is the majority shareholder in Chugai Pharmaceutical, Japan.

[www.roche.com](http://www.roche.com)

The success of the CDiC programme would not be possible without the dedication and hard work of all the partners, doctors and nurses involved in caring for the children every day.





## INTERNATIONAL SOCIETY FOR PEDIATRIC AND ADOLESCENT DIABETES (ISPAD)

The International Society for Pediatric and Adolescent Diabetes (ISPAD) is a professional organisation that brings together doctors, nurses, dieticians, psychologists, scientists and other professionals who are driven to improve the well-being of children and families afflicted by diabetes throughout the world. ISPAD accomplishes this by improving understanding of the etiology and epidemiology of diabetes, and providing education to physicians and other healthcare professionals as to the proper care of children and adolescents with diabetes, as well as developing guidelines for appropriate diabetes care.

ISPAD is the only worldwide organisation concentrating on all aspects of diabetes in children and adolescents focusing on the underlying science and quality of care that these young people receive. ISPAD membership has grown by over 30% in the past two years, increasing the number of members to over 1,305.

[www.ispad.org](http://www.ispad.org)



WORLD DIABETES FOUNDATION

## WORLD DIABETES FOUNDATION

The World Diabetes Foundation is an independent trust dedicated to the prevention and treatment of diabetes in the developing world. The Foundation was established in 2002 with funding from Novo Nordisk A/S.

Its aim is to alleviate human suffering related to diabetes and its complications among those least able to withstand the burden of the disease. The Foundation supports sustainable partnerships and acts as a catalyst to help others do more.

From 2002 to 2014, the World Diabetes Foundation funded 373 partnership projects in 110 countries, focusing on awareness, education and capacity building at local, regional and global level. For every dollar spent, the Foundation is able to raise approximately 2 dollars in cash or as in-kind donations from other sources.

[www.worlddiabetesfoundation.org](http://www.worlddiabetesfoundation.org)





Learn more about the  
Changing Diabetes® in Children programme and  
Novo Nordisk's other initiatives to improve access to  
diabetes care.

[www.novonordisk.com/cdic](http://www.novonordisk.com/cdic)

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