

LIFE  
FOR A  
CHILD

The  
International  
Diabetes  
Federation's

**LIFE FOR  
A CHILD**  
Program



International  
Diabetes  
Federation

# EXECUTIVE

In developing countries, many children and adolescents with diabetes die very quickly.

Other young people struggle to survive with insufficient access to insulin and without access to monitoring supplies or trained diabetes healthcare providers. Unable to control their blood glucose, they develop complications early in life. In low-income countries, it's not uncommon to find youths and young adults with devastating complications such as eye damage and kidney failure. For these young people, the years spent developing complications are desperately unpleasant and unhappy.

In 2001, the International Diabetes Federation (IDF) launched the Life for a Child Program to provide children in developing countries with the diabetes supplies, care and education they need to survive. It is run in partnership with Diabetes Australia-NSW and HOPE *worldwide*.

This IDF program works to strengthen existing paediatric diabetes services so that they can provide the best possible care, given local circumstances, to all young people with diabetes in their area.

**We estimate that there are about 80-100,000 youth in need around the world.**

The support provided depends on local needs and the resources available to Life for a Child. Insulin is the first priority but assistance is also provided as needed in other key areas, including: blood glucose monitoring, syringes, HbA1c testing, education for people with

## OUR GOALS

**Life for a Child supports the provision of the best possible healthcare, given local circumstances, to all young people with diabetes in developing countries, through the strengthening of paediatric diabetes services in these countries.**

# SUMMARY

diabetes and healthcare providers, capacity building and sustainability.

Life for a Child began operating in three countries in the Western Pacific; nine years later, the program supports more than 4000 young people in 27 countries – young people whose lives have been transformed thanks to this assistance.

The bedrock of funding for Life for a Child comes from individual donations but the program also receives donations of supplies from companies. Thanks to this support, the program is expanding rapidly. However, while great strides are being made, we estimate that there are some 100,000 very needy young people with diabetes around the world. Further support is required to reach them all.



# FOREWORD

Jean Claude MBANYA

For children in the developed world, the journey of life with diabetes involves a complex care regimen – frequent self-monitoring, multiple insulin injections, learning about diabetes, regular visits to a paediatric diabetes care centre – to control blood glucose, avoid acute and long-term complications and live a full and healthy life. But for too many children in poor countries, their diabetes journey is very different – from beginning to end.

Without insulin, a child with type 1 diabetes will die within a week. In the developing world, many die without being diagnosed; for those who are, their family faces a sickening dilemma: pay for the insulin their child needs to survive or leave him to die. For people who live on a dollar or two a day, the cost of insulin (up to 20 USD per vial) and testing strips (50c - 1 USD each) forces parents to choose between one child's healthcare or rent, clothing, food and education for the rest of their family.

## Without insulin, a child with type 1 diabetes will die within a week.

Children with diabetes in low-income countries who are 'fortunate' enough to be diagnosed and receive insulin live in constant fear: if they cannot get hold of insulin for a few days, they will die. Self-monitoring is largely unheard of. Many young people have access to just enough insulin to stay alive but not enough to prevent them from constantly feeling unwell. This and the lack of monitoring results in recurrent bouts of ketoacidosis or severe hypoglycaemia, chronic ill health, and all too frequently an early death. In parts of sub-Saharan Africa, life expectancy with diabetes is less than a year.

For those who survive, many are unable to complete their education, and lose their opportunity to become self-supporting adults. Complications like kidney failure, blindness, and severe nerve damage develop early, and a child's

lifespan is dramatically and tragically shortened.

Until the healthcare systems of many developing countries are able to put in place effective systems to ensure an affordable supply of diabetes medication and care, children with diabetes will need the support of initiatives like the IDF Life for a Child Program.

As President of the International Diabetes Federation, I share the dream of Life for a Child: no child should die of diabetes; all children should have adequate access to the insulin, monitoring supplies and education they need to live a happy, healthy life. Insulin is a lifeline for a lifetime with diabetes. Help us to extend that lifeline to the young people with diabetes who need it most.

Jean Claude Mbanya  
President  
International Diabetes Federation



# PREFACE

Martin SILINK

The discovery of insulin in 1921 was one of the most dramatic moments in modern medical history. The news of this life-saving medication spread with astonishing rapidity. Within two years this gift to the world from Toronto led to widespread insulin availability in many countries.

It is hard to believe that 89 years later there are children with type 1 diabetes who by the accident of geography live in parts of the world where this miracle drug is still unavailable or unaffordable. The net result is the same: without insulin these children simply die, often undiagnosed with their deaths often attributed to other illnesses such as gastroenteritis, dehydration, cerebral malaria or pneumonia. In other situations, insulin may be available in inadequate doses or only intermittently. The net result is poor growth, the early onset of devastating complications such as blindness and kidney failure, and poor quality of life.

## The Program will reach close to 10,000 children by the end of 2010

Such scenarios are entirely preventable. The vision of the IDF Life for a Child Program is to ensure that no child should die because of their diabetes. The Program was established in 2001 and is truly a partnership between the IDF, HOPE *worldwide*, and Diabetes Australia-NSW. Its very existence depends on the hard work and commitment of champions in many parts of the world, the generosity of individual families who sponsor a child at a dollar a day, and the benevolence of various organisations that are donating the infrastructure for the Program and the vital supplies needed to keep these children alive. From humble beginnings the IDF Life for a Child Program has grown so that now, a decade on, the Program will reach close to 10,000 children by the end of 2010. It is our estimate that at least 70,000 children live in such desperate circumstances that they need our help.

In many countries the Program needs to provide not just insulin and syringes but also the vital glucose monitoring that is needed to use insulin safely. Health professionals and the families themselves need diabetes education in order to use this "wondrous medicine" with safety. The diabetes world is responding to this need and collaborations to deliver essential diabetes education training are being formed with special societies such as ISPAD, ESPE, and FEND. As the Program expands, other organisations such as Rotary as well as individual champions are volunteering their time and expertise to mentor and support key centres in various developing countries.

On behalf of the IDF Life for a Child Program, I would like to thank the generosity, hard work and selfless contributions of so many who are making a major difference to the lives of children with diabetes and their families in the developing world.

Professor Martin Silink  
Chairman  
Life for a Child Program



# SUPPORTING STATEMENT

by Diabetes Australia New South Wales



As part of the IDF Western Pacific Region, Diabetes Australia-NSW strives to be a driver of the effective management of diabetes within the Asia-Pacific Region. People with diabetes in Australia are fortunate to have access to professional healthcare specialists who work together to effectively manage their condition and any complications that arise. More often than not, this medical network of endocrinologists, diabetes educators, dietitians and organizations such as Diabetes Australia-NSW is not accessible to children and their families in developing countries.

The IDF Life for a Child program provides a fantastic avenue to make a positive difference on a global level to children and adolescents in low-income countries living with the world's fastest-growing chronic disease. Since 2000, Diabetes Australia-NSW has provided Life for a Child with personnel, office space, program and donor management, publicity and financial management to ensure the ongoing success of the initiative.

As the CEO of Diabetes Australia-NSW, I am proud to support such a worthwhile and vital program – one that continues to improve the health and enhance the quality of life of those living with diabetes in the most needy regions of the world.

Nicola A. Stokes  
CEO  
Diabetes Australia-NSW



by HOPE *worldwide*



HOPE *worldwide* is proud to have supported the IDF Life for a Child program since its inception in 2001. Our mission internationally is to bring hope and change lives. In the developing world, diabetes claims many children's lives, and leaves others in desperate circumstances, living a precarious existence from day to day.

The Life for a Child Program is able to bring these children hope and a future, where they have the capacity to control their diabetes, remain healthy, and pursue their dreams. HOPE *worldwide* supports the program by providing the services of the Program Manager; infrastructure, finance and logistic support; administrative oversight in the first three countries where the program helped; and facilitation of tax-deductible donations.

We look forward to further contributing to the Program as it grows in size and scope, facilitating and inspiring the transformation of youth diabetes services in scores of countries around the world.

Richard Parrott  
President  
HOPE *worldwide* (Australia)

## UNMET NEED

In the developed world, people with diabetes, with ready access to all aspects of care, are able to lead healthy and productive lives. In contrast, in many developing countries, particularly in sub-Saharan Africa and also some parts of Asia and South America, insulin is often unavailable or unaffordable. Many clinics and health centres do not even have the facilities to measure blood glucose.

Very few people with diabetes are able to self-monitor. Some countries do not have any capacity to measure HbA1c. In the developing world the cost to the family of healthcare for a child with diabetes is often \$300-700 US

per year. This may be half or most of the family's annual income.

Many children with diabetes in developing countries die days or weeks after diagnosis, or, unable to manage their diabetes properly, develop early and devastating complications, such as kidney failure, blindness and nerve damage. For those who survive, quality of life is poor. Many young people are forced out of school, and will never be able to gain employment or find a life partner.

The IDF Diabetes Atlas 4th edition estimates that there are 480,000 children under the age of 15 years with type 1 diabetes worldwide (see Chart page 11)<sup>1</sup>. A similar number of young people aged between 15 and 25 years are living with diabetes.

However, only very limited source data is available from many countries. The scarce information indicates late diagnosis,<sup>2</sup> high early mortality,<sup>3</sup> frequent very poor control and resulting complications,<sup>4</sup> and low life expectancy, particularly in rural areas.<sup>5</sup>

We estimate that 100,000 children and adolescents with diabetes in 70 countries around the world are in urgent need of support.

In many countries, these supported centres become the model for paediatric diabetes care nationally, and build networks throughout their country providing good quality care in other locations. This has happened in Bolivia and Rwanda, where the supported centre in the respective capital cities now provide support to smaller centres in the provinces.

Each request for assistance from a healthcare centre in the developing world is assessed thoroughly. For a request to be considered, it must come from a recognized diabetes centre. If Life for a Child sees a match between the centre's needs and the program's possibilities, a mutual decision is made about priority needs, and a budget is agreed to provide specific supplies or support to the children who are in most need. Support is monitored closely. Supported centres must provide rigorous financial and clinical feedback, including an individual annual clinical data sheet on all the children receiving assistance.

The support provided varies from country to country, depending on what the government can do and the local priorities. Most countries receive funds, some receive only supplies; some receive funds and supplies. Life for a Child provides assistance in the following areas:

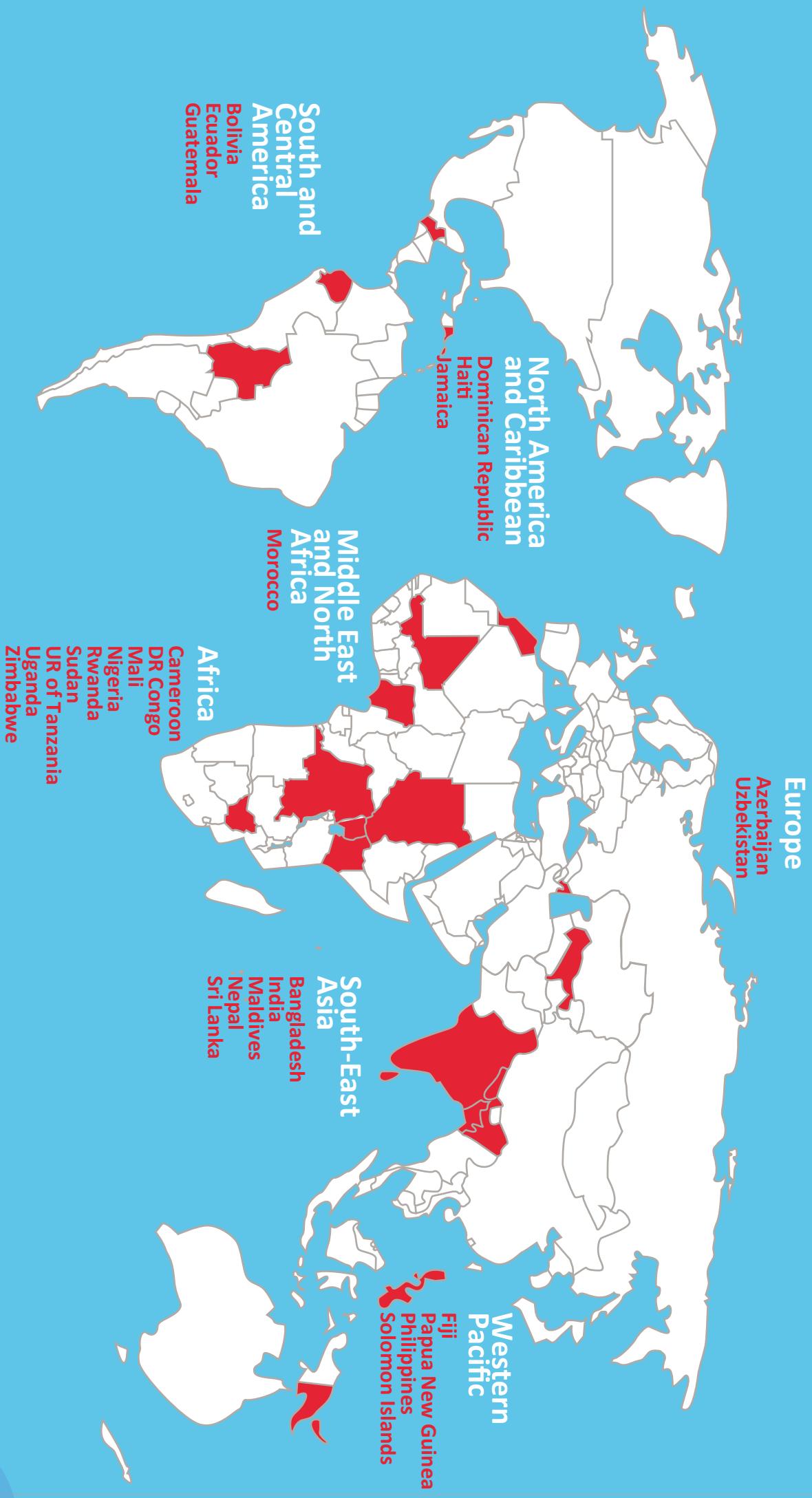
- **insulin**
- **syringes**
- **glucose meters and test strips**
- **HbA1c testing**
- **diabetes education for young people and their families**
- **health professional education and training**  
– provision of clinical advice, guidelines and textbooks; review of clinic systems and outcomes; training by expert health professionals, twinning with developed country centres
- **strengthening infrastructure and capacity building**
- **advocacy and ensuring sustainability.**

Children and adolescents can be enrolled in IDF's Life for a Child program up to the age of 23 years, and supported until 25. Most have type 1 diabetes, but young people with type 2 diabetes are also assisted.

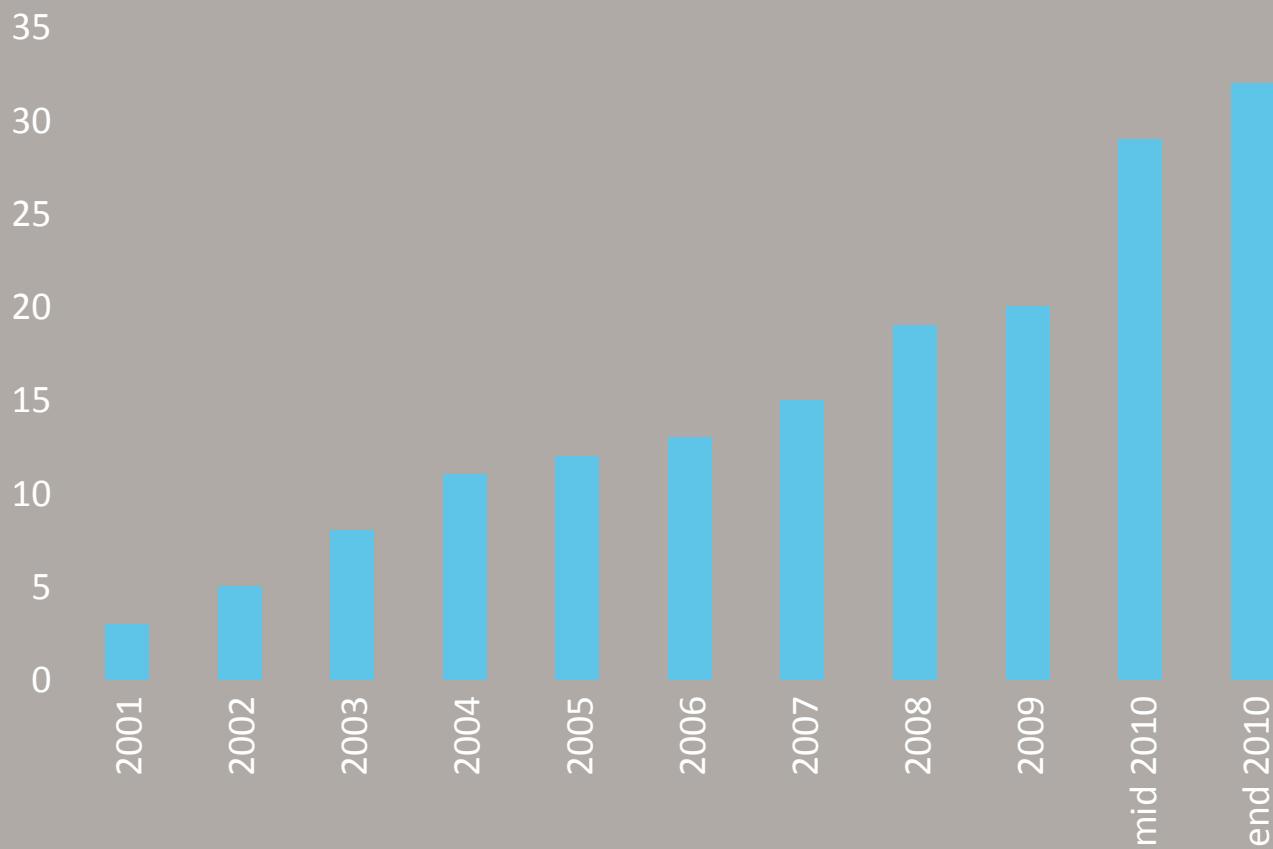
## HOW THE PROGRAM WORKS

Life for a Child always works by strengthening existing in-country services, working with hospitals and associations that are established, reputable centres of care for children with diabetes. There are doctors and nurses throughout the developed world who know how to manage diabetes and who are passionate about caring for young people with the condition; they simply do not have access to the resources they need to provide this life-saving care. With support from IDF's Life for a Child program, under-resourced healthcare centres are able to improve the quality and scope of the care they provide.

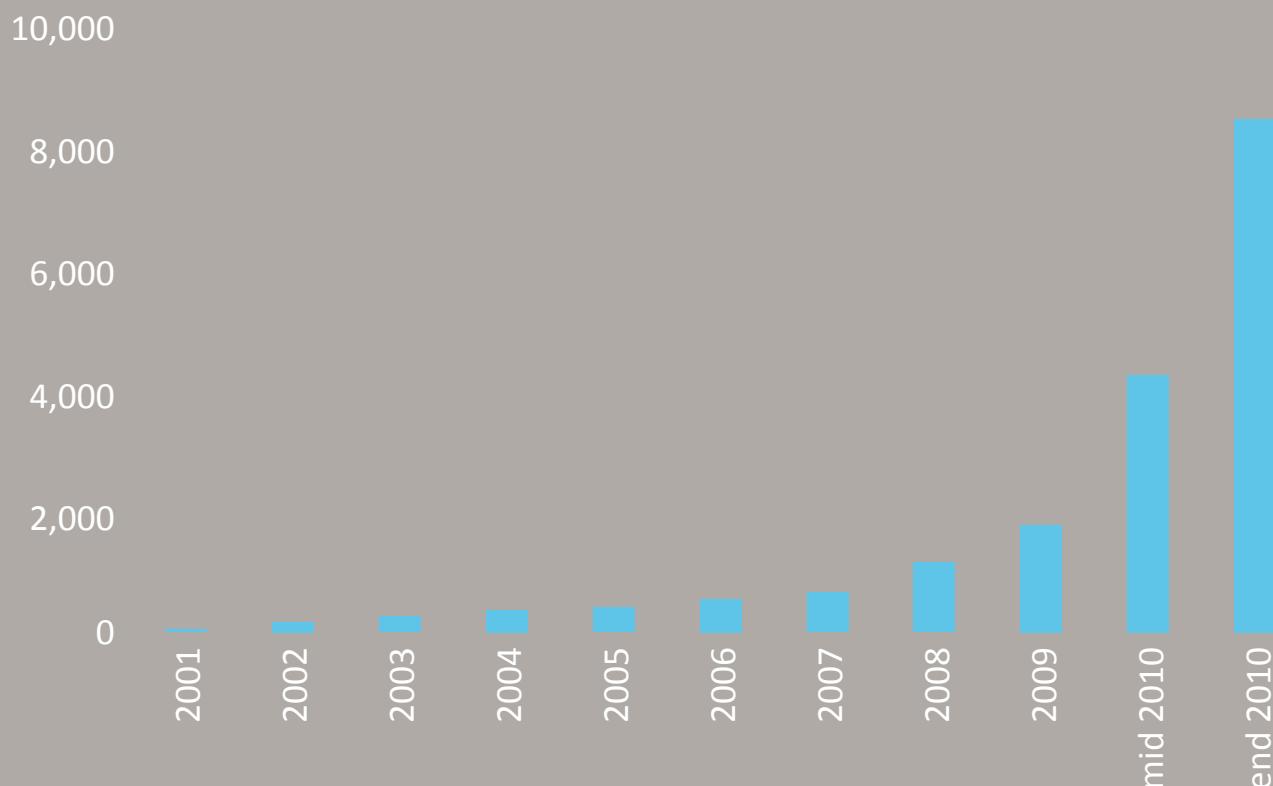
# COUNTRIES WHERE LIFE FOR A CHILD IS ASSISTING



**Figure 1: NUMBER OF COUNTRIES SUPPORTED  
including 2010 projection**



**Figure 2: NUMBER OF CHILDREN/YOUTH SUPPORTED  
including 2010 projection**



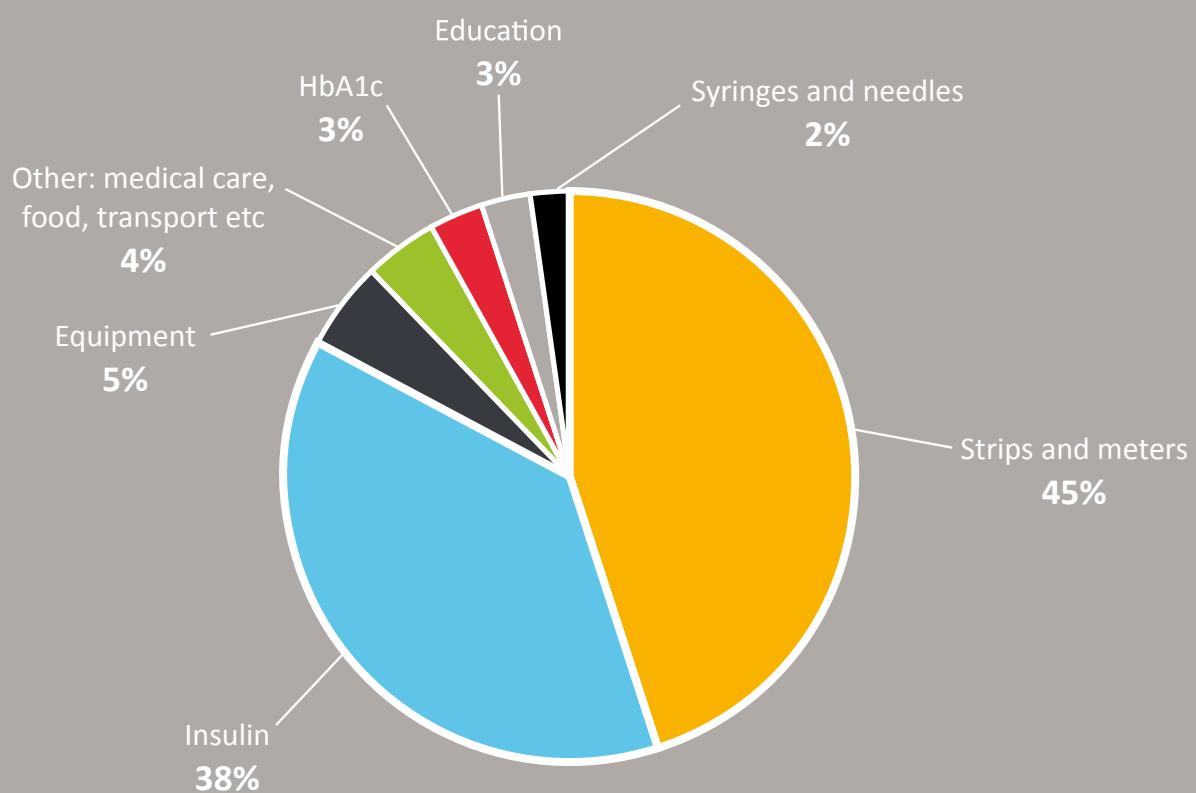


# NO CHILD SHOULD



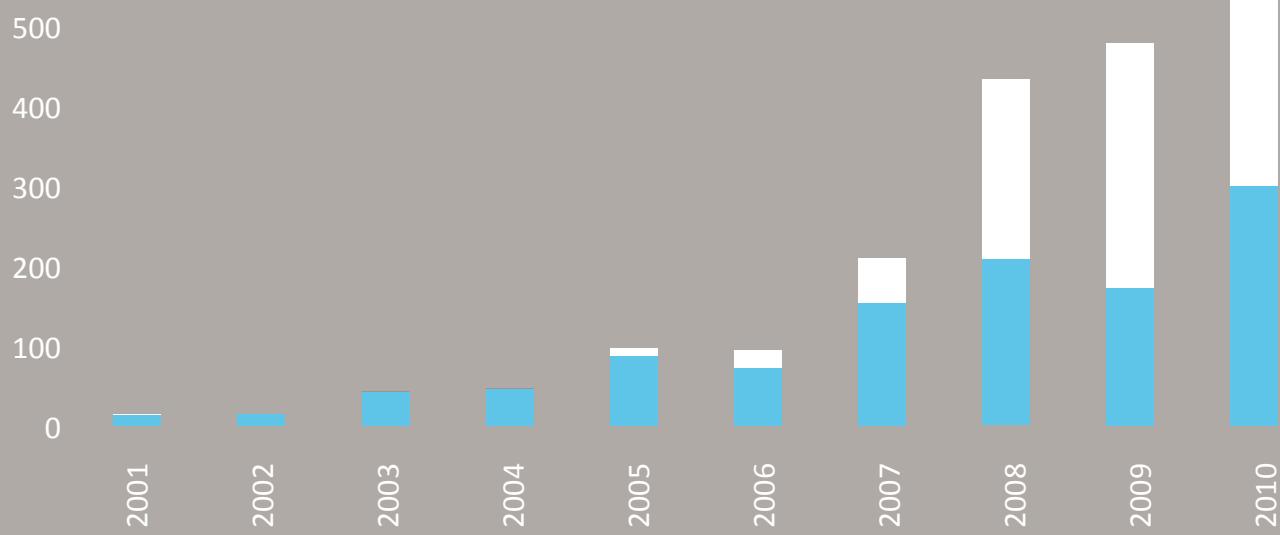
# DIE OF DIABETES

### Figure 3: USE OF FUNDS IN 2009



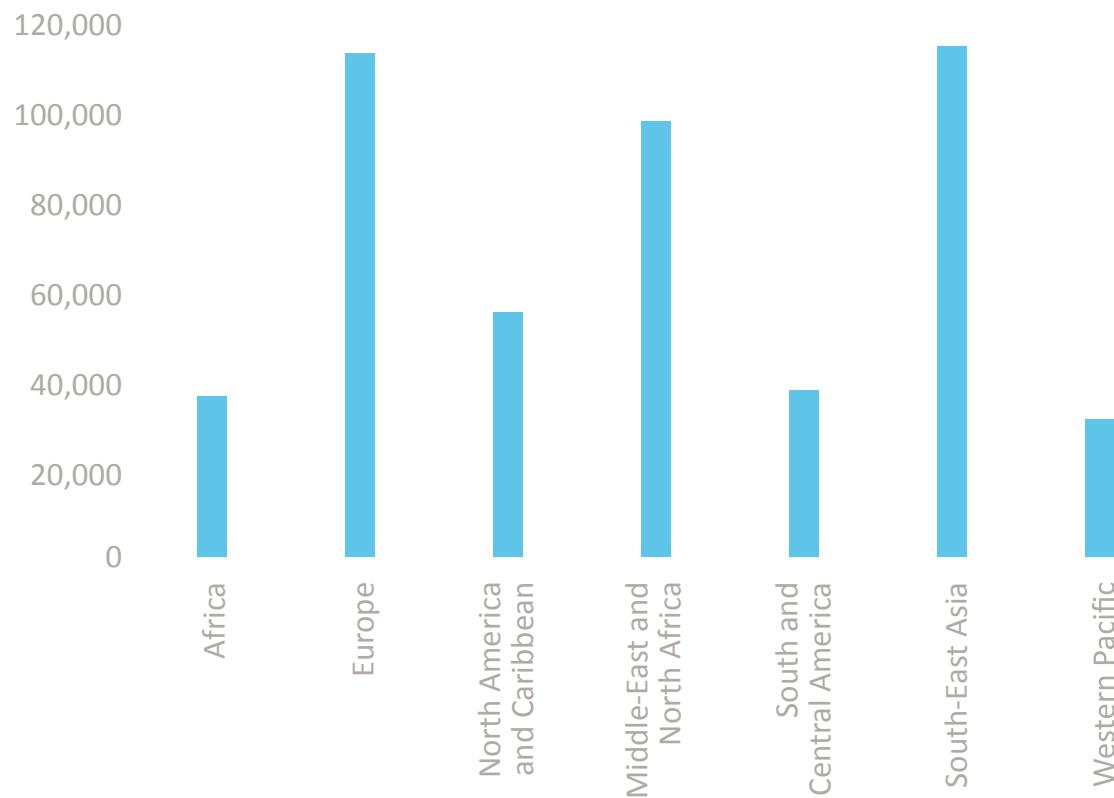
2,300

### Figure 3: MONETARY & IN-KIND DONATIONS by Calendar Year (in '000 USD), including 2010 projection



2,300

## Figure 5: CHILDREN UNDER 15 YEARS WITH DIABETES<sup>1</sup>



# CHILDREN STORIES



## Soumaila

Soumaila is 15 and comes from a village in Mali. He was diagnosed with diabetes early in 2009, and his family moved him to the capital Bamako to stay with a relative there, so as to be close to medical care.

He is in fine health, doing well at school and excelling in mathematics. He loves long-distance running and football, and his favourite player is the Ivorian Drogba. His dream is to one day be a diabetologist, like Dr. Nientao and others who care for him.



## Mauricio

Mauricio is from Cochabamba in Bolivia, and benefits from insulin and blood glucose monitoring equipment provided by LFAC



Child with diabetes in the paediatric ward of the BIRDEM Institute in Dhaka in Bangladesh. BIRDEM is possibly the single busiest diabetes facility in the world. LFAC has recently sent in insulin for 1,000 children and youth, and also provided point-of-care HbA1c testing.



Nazan and Maimouna are two teenagers with diabetes in the city of Sikasso in Southern Mali. Nazan has had diabetes for three years and Maimouna for five years. Both are doing well.



## Aiisha and Fatimata

Aiisha is six years old and lives in Ségou on the bank of the Niger River in Mali. She was diagnosed with diabetes when she was two. Last year her twin sister Fatimata also developed diabetes. They are both thriving, benefitting from insulin and supplies from LFAC. They have had no recent episodes of ketoacidosis. Their father commented they never sit still as they enjoy playing so much!



## Samantha

Samantha lives in Ecuador. She developed diabetes when she was two, and is now an expert in self-management, even teaching a newly diagnosed patient and the nurses during a hospitalisation.



## ACHIEVEMENTS

Life for a Child achievements include:

- the extension of good-quality care from capitals to provincial areas
- national programs in some countries
- the introduction of self-monitoring and HbA1c testing in a number of countries
- the improvement of clinical protocols
- the establishment of registers
- recognition of children with type 2 diabetes
- support of inaugural diabetes camps
- support of training workshops and provision of education materials
- twinning of diabetes centres in developed and developing countries.

Various countries have reported:

- markedly lower mortality rates
- far fewer admissions for ketoacidosis
- more children able to attend school regularly
- children with improved health and wellbeing.

# FUTURE PLANS

1. Increase both the numbers of countries supported, and, where needed, the number of children in each country

Projections:

Year	Children supported	Number of countries
end 2010	8,000	30
end 2011	15,000	37
end 2012	21,000	45
end 2013	26,000	52

2. Identify long-term donors for meters and strips, and HbA1c testing
3. Improve education for people with diabetes and healthcare providers
4. Establish a web-based database that can be used by all countries participating in the

program to monitor and improve clinical care and facilitate registry development, advocacy and research

5. Establish a small grants program for infrastructure and capacity building
6. Achieve local sustainability in as many countries as possible through local and international advocacy
7. Identify and implement solutions to the challenge of helping young adults over 25 years, including:
  - educational scholarships
  - linking in with local vocational training centres
  - microcredit programs
  - alternative sources of diabetes supplies.

## STEERING COMMITTEE

### Program Chairman:

**Professor Martin Silink**

Professor Silink is Professor of Paediatric Endocrinology, University of Sydney and Children's Hospital Westmead, and immediate Past-President of the IDF.

### Program Manager:

**Dr. Graham Ogle**

Dr. Ogle is a paediatric endocrinologist with extensive experience in the developing world.

### Other Steering Committee members:

#### **Ms. Nicola A. Stokes**

CEO, Diabetes Australia-NSW

#### **Dr. Lilian Jackson**

General Manager Health and Education Division, Diabetes Australia-NSW

# CONTRIBUTORS AND SUPPORTERS

Life for a Child is managed by the International Diabetes Federation in partnership with

- Diabetes Australia-NSW
- HOPE worldwide

Other key partners are:

- Insulin for Life
- Rotary International
- Professional associations, including the Federation of European Nurses in Diabetes (FEND), the International Society for Paediatric and Adolescent Diabetes (ISPAD) and various clinical departments around the world



International Diabetes Federation



## References

1. *IDF Diabetes Atlas*, Fourth Edition. International Diabetes Federation, Brussels, 2009
2. Rwiza HT, Swai ABM, McLarty DG. Failure to diagnose ketoacidosis in Tanzania. *Diabet Med* 1986; 3:181-183
3. Sidibé AT, Traoré HA, Liman-Ali IT, Dembélé M, Traoré AK, Cissé I et al. Le diabète juvénile au Mali. *Rev. Franc. Endocrinol Clin* 1999;40:513-520
4. Majaliwa ES, Munubhi E, Ramaiya K, et al. Survey on acute and chronic complications in children and adolescents with type 1 diabetes at Muhimbili National Hospital in Dar es Salaam, Tanzania. *Diabetes Care*. 2007;30:2187-2192.
5. Beran D, Yudkin JS, de Courten M. Access to care for patients in insulin-requiring diabetes in developing countries: Case studies of Mozambique and Zambia. *Diabetes Care* 2005;28:2136-2140

# HOW CAN YOU HELP?

## Direct Financial Support

Financial support is needed so that the program can expand to cover all children and adolescents in need.

The Life for a Child website ([www.lifeforachild.org](http://www.lifeforachild.org)) gives guidance on how to make a donation. Donations are tax deductible in a number of countries.

Some diabetes associations support Life for a Child by publicizing it among their members and collecting funds on the program's behalf. We welcome this kind of support!

Support from groups or countries can be directed toward one particular country, region, or specific need.

## Fundraising

If you would like to raise funds for Life for a Child, or be an advocate in your area, please contact us.

## Supplies and logistics

Donations of diabetes supplies are crucial for the program's success. We particularly need sustained donations of blood glucose meters, test strips and HbA1c testing equipment.

Life for a Child sends donated supplies around the globe and would benefit enormously from support from international logistic companies.

## Education and Training

There is a great need for diabetes education – for people with the condition and healthcare providers – in most of the countries supported by Life for a Child. There are opportunities for self-funded training visits by expert diabetes healthcare professionals. Twinning relationships are being established between centres in developing countries and others in developed countries.

## CONTACT

**For detailed information about the Life for a Child Program, please contact:**

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**Tel: 61-2-95529955**  
**Fax: 61-2-96603633**

**For information on making a donation to the Life for a Child Program, please contact:**

**Dominique Dewandre or Negina Gencheva**  
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NO CHILD SHOULD DIE OF DIABETES