

Addressing inequalities

in access through

long-term collaboration

✉ Graham Ogle and Ron Raab

Diabetes is a life-long chronic condition. Herein lies one of the major challenges to addressing global inequalities in diabetes care. The costs of insulin and monitoring are often beyond the resources of people with diabetes or their country's healthcare system. While it is easier to secure temporary price reductions or short-term financial support in the form of donations or grants than it is to find long-term ongoing support, diabetes needs in most countries are not temporary. These needs can only be met when systems and structures are implemented that make diabetes supplies both available and affordable on a long-term basis. The authors describe collaborations to provide answers at local, national and international levels.



Local solutions

In a number of countries – India, Philippines, and Romania, for example – private-sector clinics have been established by a diabetes association or group of healthcare professionals, where full fees are charged for

those who can afford to pay them. The income raised, combined with resources generated through fund-raising activities and government support, is used to subsidize care for those who are unable to pay or can afford only a part of the care they need.

Such an approach requires effective partnerships, dedication and careful business management on the part of the people involved. Despite these demands and many other challenges, a number of such initiatives have been functioning successfully for some years.

A countrywide response

Insulin and oral glucose-lowering medications are listed by the World Health Organization (WHO) as essential medicines. As such, they should be provided to the user free of charge or at a substantially reduced cost, and be made available in all public healthcare centres and hospitals. This is the case in most developed countries, and a few developing countries (some Pacific Island nations, for example).

In all such settings, while problems may arise with availability, the basic human right of people with diabetes to essential care is respected.

IDF child sponsorship – Life for a Child

All too often, children with diabetes in developing countries die soon after diagnosis; or they are unable to effectively control their condition, resulting in poor quality of life and early development of disabling and life-threatening complications. The IDF child sponsorship initiative, Life for a Child, aims to help these young people by supporting diabetes centres in the provision of insulin and other essential components of care.

Launched in 2000, the programme is coordinated in Sydney, Australia, and functions with the assistance of Diabetes Australia, and HOPE worldwide. Funding is provided by individual donors – generally people with diabetes and their families – in a number of countries, including Australia, the Netherlands, and the USA. Most of the donors contribute on a ‘dollar-a-day’ (or a local equivalent) basis. Additional funds are donated by private-sector companies and diabetes associations. Partners include Insulin for Life, Rotary International, Diabetesvereniging Nederland (the Dutch Diabetes Association), Eli Lilly and its employees, LifeScan, and Johnson & Johnson.

Life for a Child currently supports the care of over 500 children with diabetes in 13 countries around the world. Support is provided to established diabetes centres. Priority needs (medication, supplies, monitoring and education) are determined, a budget agreed, and the neediest children are identified and supported individually.

Life for a Child is having a positive impact on young people around the world but many more are in urgent need of support.



The overriding objective of Life for a Child is to provide optimum care. Financial trails, as well as the children’s health outcomes, are carefully monitored. Some key achievements include:

- implementation of a nationwide response to children’s needs in three countries
- effective promotion of self-monitoring
- extension of support from country capitals to centres in outlying regions
- provision of HbA_{1c} testing equipment
- establishment of diabetes registers
- recognition of children with type 2 diabetes
- provision of support for diabetes camps.

Life for a Child is also involved in advocacy at various levels internationally. While these activities continue to have a positive impact on the lives of young people around the world, many more children in underserved countries are in urgent need of support. Our goal is to reach 1000 children by the end of 2008. Life for a Child welcomes requests for assistance, which will be considered and met where possible as resources become available.

For further information or to become a donor, please visit www.lifeforachild.idf.org or contact Anne Rogers at anner@diabetesnsw.com.au



Furthermore, once a decision is made by government to provide essential anti-diabetes drug, it is rarely rescinded. However, many developing countries do not provide insulin. Even in countries where it is listed as an essential medicine, systems for purchasing and distribution are often non-existent or inadequate.

Advocacy and awareness

Sustained advocacy is required in settings where insulin is either not available or not officially recognized as an essential drug. The coordinated efforts of diabetes-representative associations, professional groups, and other healthcare providers, supported by information and resources from IDF and WHO, have proven effective in this field. A variety of approaches can be taken in order to raise public awareness of the needs of people with diabetes: the organization of national

and regional events and conferences; the patronage of well-known people with diabetes – successful sporting figures or artists, for instance; and visits by internationally recognized figures working in diabetes.

Links with the pharmaceutical industry should be nurtured and exploited to the benefit of people with diabetes in low-income countries. In this magazine, various insulin providers outline a number of the initiatives that they have supported to improve access to insulin and other supplies at reduced cost. The efforts of people working in stakeholder relations in these companies who are involved in such initiatives should be recognized.

Approaches to reduce overuse of insulin should be encouraged. There is a wealth of evidence that in people with type 2 diabetes, lifestyle

Highly effective partnerships have been established with non-profit organizations and pharmaceutical companies.

adjustments based on dietary and exercise interventions can enhance the efficiency of insulin use.

International approach

Cooperation for change

There are many examples of successful long-term collaborations to improve access to diabetes supplies. The four non-profit organizations profiled in this section approach this work in different ways. Insulin for Life collects large volumes of surplus insulin and other supplies, and ensures

Improving access to care – the International Insulin Foundation

Insulin and other essential diabetes supplies are still not readily available in many parts of the world. The life expectancy of a child with newly diagnosed type 1 diabetes in much of sub-Saharan Africa may be as short as 1 year. Furthermore, restricted access to insulin and diabetes supplies often results in disabling and life-threatening complications, such as lower-limb amputations and eye damage. The objective of the International Insulin Foundation (IIF), a registered charity in the UK, is to improve access to diabetes care and insulin in the world's poorest countries.

IIF works to identify sustainable ways to improve health systems in developing countries. In order to achieve this, a clear analysis is necessary of the barriers to the availability of care. To this end, IIF developed the Rapid Assessment Protocol for Insulin Access (RAPIA). The Protocol was devised to assess entire health systems and identify specific roadblocks to proper diabetes care – including availability of diagnostics, organization of specialized diabetes clinics and dissemination of diabetes information – and access to insulin.

The RAPIA has been implemented in Mali, Mozambique and Zambia in collaboration with Ministries of Health, WHO country offices, national diabetes associations and other non-government organizations. Based on these assessments, country-specific action plans have been developed. IIF has assisted in subsequent

implementation stages. Importantly, this work has led to increased awareness of diabetes within the Ministries of Health.

Increasing obesity and longevity are leading to a rising prevalence of type 2 diabetes and other non-communicable diseases. People with diabetes have a poor prognosis in sub-Saharan Africa; yet most cases of diabetes-related death and disability are due to preventable causes. Although the RAPIA focuses on access to care and medicines for those requiring insulin, it provides an assessment framework for chronic care in general, and can thus also help to address the rapid demographic and epidemiological transition that is taking place in Africa.

Efforts are urgently required to increase public awareness of diabetes and improve diagnosis and care. Donations of medicine and equipment are welcome, but these offer only temporary relief. Although some common causes operate, problems relating to the supply of essential medication and delivery of care differ from country to country. These need to be identified and tackled individually, based on findings from the RAPIA.

The ability of health systems in developing countries to manage chronic diseases is recognized as a major challenge to health. To contribute to improvements in such systems, IIF's latest report *Implementing National Diabetes Programmes in sub-Saharan Africa* (available at www.access2insulin.org) highlights points that must be addressed in sub-Saharan Africa.



These include:

- collection of data
- preventive measures
- drug procurement and supply
- accessibility and affordability of medicines and care
- the training and role of healthcare workers
- education and empowerment of people with diabetes
- involvement of diabetes associations and the wider community
- a positive policy environment, backed by the political will to address diabetes-related issues.

The situation for many people in developing countries has many parallels with the time of insulin's early availability, many decades ago, in the industrial world. It is unacceptable, given the levels of wealth and resources currently available worldwide and the ongoing major advances in the delivery of diabetes care, that in developing countries the majority of people with diabetes find the availability or expense of insulin a major hazard to life and health.

For more information on the International Insulin Foundation and its current projects, visit www.access2insulin.org

these reach countries in need in emergency situations and as part of sustainable, ongoing programmes. The International Insulin Foundation conducts projects which are aimed at establishing sustainable nationwide access to affordable and reliable sources of insulin. The IDF Life for a Child programme supports full care for needy children in 13 countries. Rotary International raises funds and provides skills by mobilizing their worldwide network of volunteers.

Importantly, these organizations cooperate, sharing information and

ideas, connecting people and expanding networks. Rotary International works with Life for a Child, for example, to provide support in Bolivia, Nigeria and Sri Lanka; and Insulin for Life is partnered with Life for a Child in initiatives in Bolivia and Rwanda. As described in this section, highly effective partnerships have been established between these and other organizations, as well as pharmaceutical companies.

Task Force

Representatives of these groups and a number of industry partners, as well as IDF staff and officers are members

of the IDF Task Force on Insulin, Test Strips and Other Diabetes Supplies. The Task Force is involved in a range of activities, including advocating for the continued availability of lower-priced insulins, such as those of animal origin, and reductions in the cost of other insulin supplies. A report in this issue describes the work of the Task Force.

Supporting brothers and sisters

Cross-border links between diabetes groups can be very effective. IDF promotes twinning initiatives, for example between associations in Denmark and Lithuania, and France

IDF and Rotary International – a natural collaboration

The collaboration between Rotary International and IDF is now in its fifth year. The IDF programme, Life for a Child, was launched at the IDF Congress in Mexico City in 2000. This programme has reached out to children with diabetes in several countries by sponsoring the needs of individual children with diabetes. Funds come from committed individuals and the specific programmes of donor organizations. In recognition of the need to expand the scope of the programme to other countries, the IDF Task Force on Insulin, Test Strips and Other Diabetes Supplies authorized an approach to Rotary International.

Rotary is the world's largest and oldest service club. With over a million members in nearly every country in the world, Rotary has a long history of funding health-related programmes in developing countries.

Rotary uses a personal model for support. There are a number of clubs in each of the 525 Rotary districts. Individual clubs and districts propose local and international projects. To encourage international collaboration, Rotary Foundation developed a system of matching grants. A donor club or district identifies and recognizes a need – in this case improving access to insulin for children. Money is allocated by both parties. Rotary Foundation then matches these funds when the programme and matching grant proposal is approved. The recipient Rotary club or district receives the funds from Rotary Foundation and operates as a non-government organization (NGO) responsible for the administration of the programme.

Such an initiative depends on the collaboration of the local diabetes association and healthcare professionals as providers of diabetes care and

expertise. Thus, strong links are established between the clinic and diabetes association and local Rotarians. Long-term involvement between the diabetes community and Rotary is a key objective.

The IDF Life for a Child initiative has developed a specific manual of operations, which includes careful oversight of the programme and its finances. The programme encourages the use of a respected NGO to manage resources.

It is important that the diabetes community is aware of the opportunities offered by collaboration with Rotary clubs at the local level. The local diabetes community is encouraged to reach out to Rotarians to inform the clubs of the needs of children with diabetes. Those interested in working with Rotary can contact Larry Deeb at lcdeeb@attglobal.net

Improving the cost and availability of insulin – Insulin for Life

Established in 1999, Insulin for Life Global (IFL) is an Australian-based non-profit organization that collects and distributes insulin and other diabetes supplies that would otherwise be wasted. These are sent in emergency situations and on an ongoing, sustainable basis to recognized organizations and with agreed monitoring systems.

The major objectives of IFL are to:

- collect and donate insulin, syringes, test strips and other supplies in urgent situations
- donate supplies to several countries and diabetes associations continually, based on a philosophy of equity of access

- encourage the development of similar collection and distribution centres in other countries (IFL has helped establish similar programmes in Europe and the USA)
- help develop and implement sustainable improvements in the supply of insulin in countries in need.

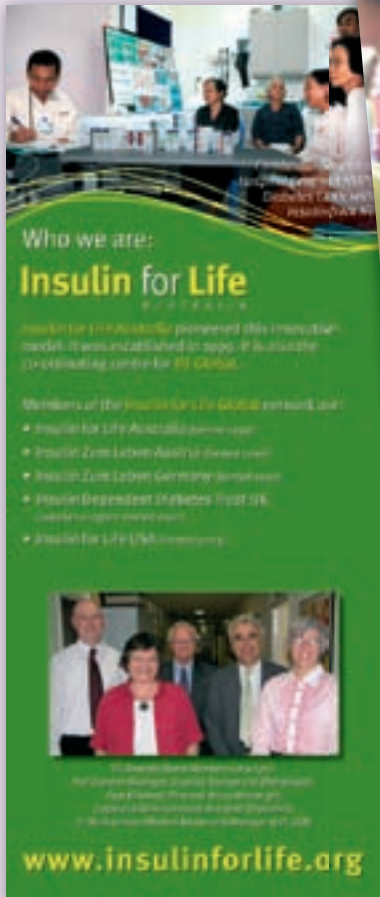
The lack of access to affordable insulin is a major cause of death and disability in people with diabetes in many regions. In contrast, in developed economies, the price is usually greatly subsidized

by the healthcare or insurance system; the yearly cost of insulin is usually well below 0.5% of average annual income. If people in developed economies were required to pay the same relative amount for insulin, the cost to the user would be around 1000 USD per month – 50 times more than is currently the case.

The cost of insulin to people with diabetes varies greatly between countries. This is a problem, particularly in those economically developing countries where the full, unsubsidized price of insulin is high, as the user will need to meet this cost over many years or decades. In many such countries, insulin can cost more than 50% of a family's annual income.

Since 1986, IFL has donated insulin, test strips, syringes, glucose monitors, insulin pens, needles, and other items with a value of nearly 4 million USD to 51 countries. Enough insulin has been donated to keep 42 000 people alive for 3 months.

The programme is growing. There are IFL-affiliated organizations in Austria, Germany and the UK, and a collection centre in Auckland, New Zealand. An IFL centre is located in the USA at the University of Oklahoma Diabetes Center. The Insulin for Life model has been adopted by Insulin Zum Leben Germany, Insulin Zum Leben Austria and the Insulin Dependent Diabetes Trust UK. The volume of supplies being distributed is increasing, and there is great potential for further growth in the number of independent and affiliated collection and distribution centres. Instead of being thrown away, unneeded



supplies are now saving lives. We should ensure such medicines are not wasted!

Countries in all IDF Regions have been supplied, in cooperation with diabetes associations, diabetes clinics, physicians and educators, and non-government organizations, including service clubs such as Rotary. Individuals and organizations in a number of countries contribute towards operating costs, which are only 5%-10% of the value of the supplies. In general, regular recipient organizations contribute to some of the transport and handling costs of sending the donated supplies.

Without the support of individuals and organizations in America, Australia, Germany, Japan and New Zealand, this lifesaving programme would not continue. The German Diabetes Association in particular has been a major, long-term supporter and a source of much encouragement. IDF, the European Association for the Study of Diabetes, the European Society for Paediatric Endocrinology and the American Diabetes Association, for example, have held publicity events at their meetings in support of IFL Global.

IFL has been active on the issue of the effect on price of the withdrawal of the often considerably cheaper animal-sourced insulins in countries where the price is not subsidized. IFL welcomes the efforts of insulin-producing companies to ensure access to affordable insulin in the world's poorest countries.

For more information on Insulin for Life and its current projects, visit www.insulinforlife.org

and Rwanda, among countries that are geographically close, or have historical links. For such partnerships to flourish, expectations must be reasonable, efforts made to ensure a flexible and open approach, and work carried out in an atmosphere of mutual trust. The focus at all times should be on promoting understanding and awareness. Momentum needs to be nurtured and skills and best practices shared. For more information on involving diabetes groups in such twinning initiatives, readers are encouraged to visit the IDF website (www.idf.org/insulin).

Visits can help people become engaged emotionally and establish connections.

Often, until they have seen the situation themselves, people from developed countries might not be able to envisage the scale of disparities in the provision of healthcare or the impact that these have on people with diabetes and their families in poor regions. Visits can help. People become engaged emotionally and establish personal connections; long-lasting relationships based on trust can develop best practices shared more effectively than through the use of text books. Centres in some developed countries host trainees from low-resource countries, who are able upon returning to their country to pass on newly acquired skills.

Reaching out to make a difference

Numerous other collaborations exist. These include the development of Consensus Guidelines by the International Society for Paediatric

and Adolescent Diabetes, and its Science Schools; the programmes of the World Diabetes Foundation; activities of IDF's Task Force on Clinical Guidelines and the Consultative Sections on Diabetes Education and Childhood and Adolescent Diabetes.

We are encouraged by the growing number of effective collaborations; people around the world have decided to try to make a difference in other people's lives. Much remains to be done; we encourage everyone to seek opportunities to help as best they can.

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