

Diabetes education and empowerment: *a role for youth*

✉ Nick Cuttriss and Jesse Fuchs-Simon

In 1984, José Gabriel, a six-month-old boy living in Quito, Ecuador went into a coma. His family was assured that José would be well as long as he received the prescribed insulin. However, 8 years later, despite spending most of the family's income on his diabetes supplies, José's parents saw him fall into a coma again. In an effort to understand what had gone wrong, José's family raised money for him to travel to see a diabetes specialist. They discovered that for a number of reasons José's blood sugar levels were not being managed correctly – José and his parents had never received guidance regarding the management of the boy's condition. For José and his parents, and for many other young people with diabetes, particularly in developing countries, the lack of diabetes education is as dangerous as a lack of insulin.



In 1996, American Youth Understanding Diabetes Abroad (AYUDA) was set up by two teenagers after they had witnessed the economic and emotional hardships faced by José Gabriel and other young people living with diabetes in Latin America. They envisioned a youth-led organization that would educate young people with diabetes about diabetes issues, and help empower them to work effectively for positive change. AYUDA is now a growing organization, which campaigns to raise diabetes awareness and

promote sustainable development for diabetes communities throughout the world.

AYUDA's initial objective was to help with the need for basic diabetes education in Ecuador. Volunteers set up diabetes support groups in the corridors of a public hospital in Quito. These groups offered educational workshops and provided a forum for knowledge sharing. The experience gained from this early work formed a base for the continuing growth of

AYUDA's activities. Committed to encouraging and facilitating youth involvement, AYUDA now organizes youth leadership programmes and diabetes camps in Latin America. The ultimate aim of these events is to empower young people to play an active and effective role in their own future well-being.

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Education, empowerment and partnership

The three main objectives of AYUDA are to:

- ♦ foster the growth of self-sustaining local and national diabetes organizations throughout the Americas
- ♦ empower young people with diabetes to develop and lead educational programmes (diabetes management and lifestyle, and advocacy)
- ♦ raise diabetes awareness generally and enhance recognition of diabetes communities throughout the world.

Since 1996, AYUDA has worked effectively on a range of projects. It has developed and implemented a number >>



Young people with diabetes today will count among the campaigners, advocates, decision makers, and health professionals of tomorrow.

of sustainable diabetes programmes in Latin America. AYUDA's educational programmes offer workshops on diabetes management and lifestyle issues, and advocacy, while at the same time teaching young people the skills necessary to act as catalysts for positive change.

The cost of diabetes supplies makes it impossible for many children in developing countries to manage their condition optimally.

AYUDA is also working to create and manage diabetes supply banks. It costs approximately 3000 USD per year to care for a child with diabetes; the average income for a family of four in many Latin American countries is less than 1000 USD per year. It is therefore impossible for many children to manage their diabetes optimally. With the help of partners such as Insulin for Life, AYUDA works to ensure that families with limited resources receive

essential daily supplies, such as insulin, syringes, and test strips at subsidized prices or free of charge.

AYUDA also has partnerships with the Diabetes Camping Association, and the Pan American Health Organization (PAHO – regional office of WHO). Current AYUDA activities include:

- ♦ overnight educational and recreational camps for children and adolescents with diabetes and their families
- ♦ diabetes youth leadership programmes
- ♦ exchange programmes between diabetes camps in different countries
- ♦ the creation and management of diabetes supply banks.

Now an internationally recognized youth-led non-profit organization that supports children living with diabetes throughout the Americas, AYUDA has found partnerships with local, national, and international organizations. Achievements resulting from these partnerships include:

- ♦ *Campo Amigo Internacional 2003* – the first international diabetes camp for youth leaders
- ♦ the establishment of local diabetes associations led by young people in several countries throughout Latin America
- ♦ *Campo Amigo Ecuador*, Ecuador's national diabetes camp
- ♦ the publication of *Manejando la diabetes* ('Handling diabetes'), an activity book written in Spanish for children with diabetes – endorsed and distributed by PAHO.

Uniting and empowering youth: diabetes camps

AYUDA named their diabetes camps *Campo Amigo*, after the camp which was organized in Mexico by former President of IDF, María de Alva. The name (in English 'Friend Camp') reflects the broadest objective of diabetes camps: to bring together children and adolescents with diabetes to have fun and make friends in a happy, safe, supportive educational environment. Among the specific aims of *Campo Amigo* is the development of a lasting community, with the camp as the meeting point. Children, adolescents, and their families are united in one large group at camp, and receive continued support throughout the year, via links between the camp and local organizations.

Many young people with diabetes growing up in Latin America are alienated from their peers. A lack of diabetes awareness among teachers and parents often leads to exclusion from school and extra-curricular activities. The planning of all activities on *Campo Amigo* is underpinned by the belief that every child with diabetes is perfectly capable of living a normal life. At the camps, young people learn to look for support from across the diabetes community: from their peers and older people with diabetes, as well as health professionals and carers.

For these young people, the experience of camping with other children can be intense and magical. Strong friendships are built and, often for the first time, the young people begin to understand that they are members of a group of people living all over the world who are just like them – a global family. And they soon realize that together they can make more noise, whether they are singing, hooting and banging drums around the camp fire, or working together to campaign for improved diabetes care in their communities.

The first international diabetes youth leadership camp

In February 2003, AYUDA led *Campo Amigo Internacional* (CAI) – the first international diabetes camp to be organized in the Americas. CAI united youth leaders from ten Latin American countries, the USA, France, and Australia. It was the first youth-organized camp to train young people with diabetes to take an active role in their local and national diabetes communities.



In order to draw up best-practice guidelines for youth-led diabetes camps and associations, more than 50 youth leaders between the ages of 16 and 25 years gathered to share their knowledge and experiences. A model which incorporates the successful practices employed by various diabetes camps and associations was created collaboratively.

A great deal was achieved at CAI: a strong sense of solidarity was created; disparate organizations were bonded together; a spark was ignited that propelled all participants to continue their active leadership roles at home; and clear and concise universal guidelines were designed for the organization of youth-led diabetes camps and associations worldwide. Formerly isolated and in many cases marginalized, the young people who participated in CAI are now very aware of their position in a global diabetes network.

Invest in our future

AYUDA continues to link dedicated young people living with diabetes throughout the world who not only know how to control their condition, but who have also taken on leadership roles in their respective countries. It is time for young people living with diabetes to find their voice. And adults in the diabetes community have a responsibility to listen: young people with diabetes will form the next generation of campaigners and advocates, and will count among the decision makers and health professionals of tomorrow. Support for young people now is a worthy investment for all of our futures.

☒ Nick Cuttriss and Jesse Fuchs-Simon

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Jesse Fuchs-Simon was a co-Founder of AYUDA and is now President of AYUDA. Jesse also recently finished a Fulbright Scholarship conducting the first Type 1 diabetes census in Ecuador.

For more information on AYUDA, visit the website at www.ayudainc.net or email info@ayudainc.net.

Find more information about PAHO at www.paho.org, and for more about Diabetes Camping Association, visit www.diabetescamping.org.

Read about Insulin For Life at www.go.to/insulinforlife