

THRIVING, NOT JUST SURVIVING

Jason Baker and Graham Ogle

Until recently, survival rates for children with diabetes in many African countries were dismal – few survived to adulthood. Now, due to dedicated efforts of local centers, supported by IDF Life for a Child (LFAC) Programme and other programmes, this situation is happily changing. Numbers are rapidly rising in various countries. But what happens when these young people age-out of these programmes, which by necessity have age limits as otherwise they cannot support newly-diagnosed children? Most government health services can't yet provide the insulin and other supplies needed at an affordable cost. The young adult must purchase them, and often they simply can't afford them.

However, if they can gain an education and skills so that they can earn an adequate income, they can look after themselves – problem solved! This is easier said than achieved but it can be done, if people believe in these young men and women, encourage them, and provide them with vocational training and microcredit opportunities. The charity Marjorie's Fund has taken up this challenge, fostering these initiatives and also providing ongoing diabetes education. In Rwanda, this involves support and enhancement of the unique programme of the Rwandan Diabetes Association, a six-month residential programme that provides vocational training and diabetes education programme for young adults supported by LFAC.

Marjorie's Fund also has innovative programmes underway in three other countries. These efforts are reaping benefits one by one, young adults with diabetes are also thriving, in turn inspiring the younger children coming after them.

Marjorie's Fund

Imagine being a young adult, whose family must choose between paying to treat your chronic, long-term medical condition or having shelter, food on the table or educating your siblings. Tragically, these types of family decisions will direct the trajectory of your life with type 1 diabetes into independent adulthood. Will you struggle to survive or will you have a chance to fully realize your potential and thrive?

Marjorie's Fund is a leader in the effort to



empower adolescents and young adults living with type 1 diabetes to effectively manage their condition and thrive. In many parts of the world, support programmes that exist to help children with type 1 diabetes obtain medications, testing supplies, and education on diabetes management, have a cut-off for people at age 26. Frequently there is a dearth of local infrastructure, programmes or economic opportunity to enable young adults with type 1 diabetes to obtain essential but very expensive diabetes care.

Without adequate supplies and support, these young adults inevitably become chronically unwell and develop devastating complications in their early lives. The cost is high and despite generations of family members sharing the economic burden, the struggle almost always ends in a painful, untimely and early death. Marjorie's Fund is fighting to change this unjust circumstance.

Marjorie's Fund was founded in memory of Marjorie Namayanja—a Ugandan health educator and advocate whose story epitomizes the struggle between life and death, between surviving and thriving, and is the inspiration behind Marjorie's Fund. Marjorie was just three years when she was diagnosed with type 1 diabetes. She was provided with enough insulin and glucose testing supplies to allow her to survive into young adulthood, but not enough to avoid diabetic complications. She was just 29 years old when she died, succumbing to diabetes-related kidney failure.

Marjorie required weekly dialysis treatments to stay alive, but could only afford a few, infrequent sessions, leading to a slow, painful death. Throughout this unpleasant time, Marjorie continued her efforts to educate both patients and healthcare providers on how to better manage type 1 diabetes in hopes of preventing

others from suffering her fate. Until her premature death, Marjorie recounted her story as a speaker at various medical conferences and fought to change a system which had limited her own care because of a lack of resources.

Marjorie continues to touch the lives of others with type 1 diabetes through Marjorie's Fund. We promote diabetes self-management and directed methods to obtain sustainable access to diabetes treatment resources. We aim to help patients residing in resource-poor settings create viable means for diabetes care and ultimately impact their likelihood of leading productive lives.

We provide financial and curriculum support to the Rwandan Diabetes Education Center (RDEC), an initiative started by the Rwanda Diabetes Association (Association Rwandaise des Diabetiques). A novel education programme has been developed where students are taught to be proficient in diabetes self-management skills, learn how to grow diabetes-friendly foods, and learn a trade to help support the cost of their insulin and diabetes testing supplies.

Early results from evaluations of the Center's graduates are promising. A case in point is Marie



Marjorie Namayanja with Jason Baker before her untimely death

who was diagnosed with type 1 diabetes at the age of 17 in a small village outside of Kigali, Rwanda, and was struggling to survive. After graduating from the RDEC and armed with diabetes self-management training and baking skills, she started a small business selling baked goods to her local village. Marie earns enough money to purchase her insulin and glucose testing supplies, and has a garden where she grows vegetables using agriculture skills she learned at the Center. She now has home, food, and health security and is looking ahead to a bright future.

Masereka Robert of Kasese, Uganda, now 27 years old, has lived with type 1 diabetes since the age of 17. As a teenager living in an isolated, rural region of Uganda on the border with Congo, Robert received insulin and testing supplies from programmes targeting children. Eventually the time approached when he would be aging out of this support. In order to survive, Robert worked as a barber, earning enough money to purchase a small supply of insulin and testing strips, just enough to keep him alive.

Robert realized a need to mobilize his local diabetes community to give himself and them a better chance to thrive so he co-founded the Diabetes Consultation Association (DCA) with the goal of providing education, improved diabetes treatment supply allocation, and the chance for better economic health to local people living with diabetes. Significant barriers exist, however, to achieve this lofty ambition and to help the 100 DCA members living with type 1 diabetes find the care they need.

Since 2013, Marjorie's Fund has collaborated with Robert, the DCA and the nearby Kagando Mission Hospital to enhance healthcare access and emergency diabetes supply provisions for people living with type 1 diabetes. Marjorie's Fund is now forming the Marjorie's Fund Diabetes

Education Center in Kasese, Uganda using the pioneering and unique model established at the RDEC.

Marjorie's Fund also supports similar educational initiatives in India, The Gambia and in the United States. In New York City, it is working to build a larger support network for adolescents and adults living with type 1 diabetes, and linking them to international beneficiaries to create a larger and more intimate diabetes support community.

The amazing success of programmes targeting children living with type 1 diabetes has increased the number of adolescents and adults surviving with type 1 diabetes in resource-poor settings, most of whom need help. Marjorie's Fund is interested in ensuring that the management of type 1 diabetes care is improved, regardless of economy, geography or age. Those involved in Marjorie's Fund want children with type 1 diabetes to not only survive childhood, but to live long, healthy, productive lives and thrive as adults. Marjorie's poor access to care ultimately succumbed to her complications, but with the help of Marjorie's Fund others need not.

For further information on Marjorie's Fund and how to help their initiatives, visit www.marjoriesfund.org.

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