

A made-in-India solution to a tragic health scourge

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ABSTRACT

The test diagnosed six-year old Pia with Type 1 diabetes, an autoimmune disease destroying her insulin-producing pancreas cells. The cost of diabetes management seems prohibitive, and some families fear the women will not bear healthy children.

FULL TEXT

The first sign was the ants in her urine. Someone noticed the swarming insects, and suggested she get her blood sugars checked.

The test diagnosed six-year old Pia with Type 1 diabetes, an autoimmune disease destroying her insulin-producing pancreas cells. If she didn't begin daily injections, she would start vomiting and lapse into coma.

When Pia's parents visited the pharmacy, however, another rude shock awaited. Insulin and syringes were horrendously expensive, with the bill for a month's supply coming to over 30 per cent of household income.

In theory, insulin is on India's list of free medicines for poor families, but supplies often run out. Most patients buy the drug privately, and Pia's family faced what health economists call "catastrophic health expenditure."

During a recent visit by staff from Carleton University and the Children's Hospital of Eastern Ontario (CHEO), we discovered that when faced with similar circumstances, some Indian parents have cut their children's insulin doses. They do this to reduce costs, but later learn that they have done far more harm than good, stunting their children's growth and creating more health complications.

Type 1 diabetes – unlike the more common Type 2 – frequently presents in childhood. Its incidence worldwide is rising, but no one knows why; lifestyle, exercise and body weight are not to blame.

In the greater Ottawa region, some 900 children and youth live with the disease, benefiting from a provincial health plan that provides for most of their needs.

In countries such as India, however, the burden of daily insulin injections drives many parents to despair. Some stop treatments altogether, condemning their child to death. With so many mouths to feed, they feel they have no choice.

Pia's family, however, was lucky. In Nagpur, a central Indian city of two million persons, they discovered the Dream Trust, a charitable group for children and youth with Type 1 diabetes.

The Dream Trust was started 15 years ago with donations from Sharad Pendsey, a Nagpur-based physician, and his family. Now, it is supported by private donors, the International Diabetes Federation's Life for a Child program, and international insulin manufacturers.

With this help, the trust gives free insulin, syringes and checkups to any needy child who walks through its door. As a result, Dr. Pendsey and his staff – physician Rutuja Sharma and diabetes educator Seema Chalkhore – have kept hundreds of children alive for years.

Not everything is rosy, however.

In Canada, parents test the blood sugars of children with Type 1 diabetes at least four times a day. That information helps parents determine daily insulin doses, avoid hypoglycemia – a low blood sugar condition that

can trigger seizure or coma – and limit hyperglycemia, a pernicious high blood sugar condition. Dream Trust patients, by contrast, survive on two or less blood tests per month. Constrained by the high cost of test strips, doctors guesstimate insulin doses by children's weight. Over time, this method may lead to complications; for now, the children survive. The Dream Trust has thus developed a bare-bones treatment scheme that relies on few of the diagnostic tools we take for granted.

In the trust's offices, patients told us one heartbreaking story after another. Many had been diagnosed while suffering from ketoacidosis, a high blood sugar condition that occurs in the absence of insulin. Symptoms include severe dehydration, decreased consciousness and even coma. Several children had languished for long periods in wretched public hospitals. Their doctors had little time to explain the disease's complexities, and families were drowning in confusion and debt. Their children's growth was stunted, and they were repeatedly falling sick. Once families discovered the Dream Trust, their lives changed. Dr. Pendsey's staff gave them training and supplies, as well as a special ceramic container to keep unrefrigerated insulin cool during hot months. The Trust even gives small sums to girls struggling with school costs, realizing that without education, many will face lives of penury and stigma.

Gender, we learned, often adds an additional layer of suffering to existing medical burdens. In some areas, girls with Type 1 are considered damaged goods, and the families of eligible boys do not consider them suitable partners. The cost of diabetes management seems prohibitive, and some families fear the women will not bear healthy children.

In a world where girls are expected to marry early and live with their husband's family, women with Type 1 diabetes face a life of isolation and shame. With adequate education, however, some may find another path to happiness. What might we do to help?

Surprisingly, we discovered that Canadian medical expertise is largely irrelevant. The Dream Trust's methods are well suited to its context, and CHEO physicians can teach its staff and patients little of direct use. Pressure on Indian authorities to craft a better healthcare system is clearly warranted. This task is one for Indians themselves, but global health advocates can add their voice.

Ordinary Canadians can also make a difference. First, we can donate small sums to a special account created by the CHEO Foundation. Charity will not transform India, but it will dramatically impact individual lives. After all, it costs only \$350 to keep one Nagpur-area child supplied with insulin for a year.

We can also ask pharmaceutical companies some hard questions: Why aren't they shipping off-patent test strips to poor countries, or providing voluntary licences to generic manufacturers? According to the World Trade Organization, moreover, governments can issue compulsory licences for essential diagnostic tools – including, arguably, blood test strips – and exempt them from patent protection. The take-home point is this. The world is full of remarkable people such as Dream Trust's staff. Few of us have the time or inclination to join them, but we can all help by providing the support they need to succeed.

James Ron is an associate professor at the Norman Paterson School of International Affairs, Carleton University (jron@connect.carleton.ca). His three-year-old son was diagnosed last year with Type 1 diabetes. Alexandra Ahmet is a pediatric endocrinologist and assistant professor at CHEO, where Caroline Zuijdwijk is both pediatrician and pediatric endocrinology resident.

Credit: James Ron, Alexandra Ahmet and Caroline Zuijdwijk; Citizen Special

DETAILS

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