May/ June 2011 **NEWSLETTER**

Dear Friends, thank you all for your kind friendship and help. Please may I tell you about one of our most important activities.

A Diabetes Programme for the Poor.

All human life is interconnected. Every person is sacred and of immense value and every individual is responsible for others (corporate social solidarity) as well as self. This applies to environment, social structures, behaviour and caring. People must have dignity and basic health care must be available for all.

The Kailakuri Diabetes Rehabilitation Programme shares the Kailakuri aim of health for the poor by the poor. People with diabetes must be enabled to control their diabetes and return to normal health and life.

Bangladesh is one of the world's poorest countries with a population approaching 160 million. Due to poverty at least 40% lack access to one or more of the following: basic nutrition, adequate clothing, shelter, safe water and sanitation, medical care, education and common justice. When five to ten percent of adults (four to eight million) suffer diabetes, then at least 40% (one and a half to three million) will need help in accessing appropriate care. Social services and structures are generally unable to meet the needs of common people because of numbers, other priorities, lack of awareness, failure to adapt to the problems of the poor, failure to meet the requirements of solidarity, lethargy or corruption.

Sujit Rangsa : Sujit, a 31 year old Garo tribal Christian is now head of the Kailakuri diabetes programme. He comes from an extremely poor family seven kilometres from the Indian border and developed diabetes at the age of 16. In 2000 at the age of 20 he came to Kailakuri, 80 km south of his home. He had been unable to sit school certificate and was 45 Kg (BMI 19). The Kailakuri centre opened four years before had 213 patients under supervision. The paramedics were responsible and caring and there was a lot of teaching. Rashid whose father had had diabetes was in-charge.

Sujit's health improved (now 58 Kg, BMI 25). He became a paramedic in 2003 and has always been very conscientious. He subsequently passed school certificate at open college, married and has two sons. (As a diabetes patient he thought he had no chance of marriage until sweet petite Sheema appeared on the scene). The older son Rodro suffered birth trauma and is severely handicapped, still unable to sit or feed himself at the age of seven. Sujit took charge of the programme in 2009.

The Kailakuri Diabetes Programme.

Diabetes is a life long disease caused by failure to utilise blood sugar. The programme is caring for 1120 patients of whom 60% are on insulin injections and 40% on tablets, 97% Muslim and 53% female. Half of the insulin patients are under 30 but only 9% of tablet patients. Almost all our patients are very (or extremely) poor. Most have already been diagnosed before coming to us. Screening is by symptoms, patient

examination and blood (or urine) testing. They pay small fees for entry into the programme, travel to Dhaka and for Kailakuri hospital admission and then small monthly fees. All patients are means tested by home visit. The cost of the programme last year was USD 59,000 (BDT 4,300,000, NZD 79,000) coming to about USD 40 per patient making it an extremely low cost programme, amounting to one third of Kailakuri expenditure. The Diabetes Association of Bangladesh BIRDEM Hospital provides concession priced insulin without which the programme tribal Christian is now head of the Kailakuri diabetes programme. All new patients needing insulin are taken to Dhaka to register. Thereafter they are managed at Kailakuri. A monthly report and requisition go to Dhaka to get the insulin, at present 1300 vials per month.

Survival and freedom from crippling complications depend on good blood sugar control, the basics of which are diet, drugs, exercise and blood or urine sugar monitoring. It is essential to prevent the acute complications of very low or very high blood sugar, either leading to coma and death. And for this it is necessary to find a balance between technical precision, cost, disruption of daily life, easy understandability, motivation, emotions and social factors. The KHCP is sometimes criticised because of extreme simplicity and low cost, but it is hard to find an effective competitor in the field.

Abdus Sattar: At the age of 63 Sattar is now anelderly Muslim and according to custom tints his hair and beard with an orange dye. He is always happy, says his prayers from time to time, goes to the mosque occasionally and has no malice against anybody, a typical village Muslim.

He developed diabetes at the age of 25, was diagnosed two years later and came to us two years after that in 1986, the newest of our seven patients. All his life he has been extremely poor. He had about six years of education. In those days it was the Thanarbaid Health Care Project under the Church of Bangladesh and he recalls the care and teaching he got from the staff. Diabetes care was very low cost for the patients. For the first time he was able to keep his diabetes controlled.

In 1987, the year before the terrible flooding (a third of Bangladesh went under water) he was taken on the staff. (The next year we took on quite a few new staff to cope with the work load of visiting flood refugees and the epidemics of diarrhoea and dysentery).

Sattar has four children. Two sons are married living at home independent from their parents. One daughter is married off, another still at home with her parents. Before joining the staff Sattar was a village labourer, always afraid of acute hypoglycemia. When work is not available there is the danger of insufficient food to match insulin dose and acute drop in blood sugar. All patients have the occasional acute reaction and carry sugar in order to counteract it rapidly. (They are also supposed to carry a diabetes I.D. card). The symptoms are fear, tremor, palpitations, dizziness and weakness. Sometimes they behave as if drunk. (One young man from a remote area went into acute hypoglycemia. The village people thought he was drunk and beat him to death.)

An important part of the programme has always been home visit to patients with problems. For many years Sattar had responsibility for the south side of the

programme. He thinks that over the years he has probably visited 1500 homes, all by bicycle. His first cycle was an old lady's cycle which was not very good. Then we bought him a new cycle which got stolen one day at the market. He is now on his third cycle, still running well after 18 years. The "driver" (Sattar) however has developed asthma and had to be taken off home visits. His wife made him give up smoking ten years ago. Otherwise he is in good health with no apparent chronic complications from his 27 years of diabetes (although he has five times had severe hypoglycemic reactions). He used to cycle about 20 km a day, four days a week.

He has seen the relentless increase in patient numbers as the diabetes "epidemic" has increased and our programme become increasingly well known. Always there has been a friendly relationship between patients and staff. Because of the good teaching and motivation, patients now follow the rules and control their diabetes better than before. He recalls the opening of the Kailakuri sub-centre in 1996 which was important for the development of the programme. Two years later one after another sub-centre was opened as numbers increased. Now there are five, meaning much less travel for the patients and reduced pressure on Kailakuri. Patients come from up to 120 km away. When the centre became independent from Thanarbaid in 2002 staff and patients took more responsibility, better medical supervision was possible and the programme improved.

The advantages of the Kailakuri programme are: 1) Easy access for the poor, because external funding is sought, 2) Very good motivation and teaching, 3) Efficiency and enthusiasm because the director (Sujit) is so conscientious and careful.

More about the Kailakuri Programme

Apart from Sujit the staff comprise four sub-centre paramedics, three inpatient paramedics, four trainers, five health assistants, two office staff and a home visitor, 19 in all, of whom eight are diabetics and four over school certificate. Including Kailakuri there are five follow-up centres to which patients come for monthly review. All but one get a weekly clinic to which 50 to 80 patients turn up. With three paramedics in attendance it is possible to assess diabetes control and solve problems. About 600 patients are on insulin and 400 on tablets. Type 1 patients need insulin for survival. Type 2 patients may need insulin for good control. In Type 1 the main problem is insulin production, in Type 2 it is insulin action. Unfortunately about half of our tablet patients are still being lost to follow-up because of default.

Diabetes management at Kailakuri is very much simplified. However the loss of fine precision is more than made up for by patient and family understanding and cooperation, ease of management, staff patient bonding, and motivation.

Most of the time there are eight to 20 patients admitted at the Kailakuri centre: for diabetes training and recovery of health, diabetic ulcers, pregnancy-delivery and other problems.

Abdul Hakim: Hakim is now aged 40, married with two sons. He developed diabetes at the age of 17, started treatment with us at 18 and became a worker at 19.

He had schooling to class 6, both government and Islamic and was able to recite a

third of the Koran when he got diabetes. He says that when he first came to Thanarbaid in 1989, diabetes care was part of general patient care and it was I myself who gave him his first teaching. He was the newest of nine diabetic patients under treatment by the programme. They all knew each other and he recalls with emotion the first eight who died, four from diabetes complications. They grieved when another died. Several were due to lack of family support, three severe hypoglycemia. Family support is much better now, both because of Kailakuri teaching and because diabetes is so much more common and understood in the community. Hakim has always been a person who empathised and identified with others and not only has he developed a wealth of experience in diabetes management but also knows many many patients personally.

The simplicity of the Kailakuri programme is essential. The programme is important because of the quality of patient care (due to high motivation) and the intensity of teaching. It is unique in this respect. The simplicity of the diabetes diet (30 gm carbohydrate exchange marker system) is necessary because of the variability of village life (physical work and food availability). Almost all the patients follow their diets. They test their urine five times a day by the old Benedict system (boiling urine with copper and iron salts). The cost of test strips for blood sugar is prohibitive at 30 to 50 cents a strip. The compromise of blood testing only three times a week renders the test almost valueless because blood sugar levels change so much. Probably 70% of Kailakuri patients faithfully test their urine as taught and adjust their drug doses accordingly. Despite patient to patient variation in levels at which blood sugar spills over into the urine, staff know the patients, understand the significance of their tests and are able to advise them accordingly. Hypoglycemic reactions when they occur are almost always due to abnormal physical exertion. Severe uncontrolled diabetes (keto-acidosis or hyperosmolar syndrome) is caused by sudden stopping of insulin or tablets, because of lack of money to travel to the sub-centre for drugs, because of illness appetite loss or because of emotional of family problems. The low cost of the Kailakuri programme is essential for the poor.

Hakim has had a huge experience with diabetes patient care. For a period of six months he was in charge of the entire programme. Independence from Thanarbaid was necessary for the development of the programme, setting up of sub-centres was necessary, and the preparation of the diabetes programme constitution in 2004 essential for the security of the programme. He doesn't see much value in the committees (I differ with him on this). Extremely important are the weekly meeting discussions attended by all staff. They all know about the problem patients. Staff also attend the weekly teaching-training sessions of the Kailakuri project. Sub-centre paramedics need to understand both diabetes and other diseases. They must be empathetically intelligent, know the patients and behave empathetically towards them.

All new patients are home visited for means testing. They are also visited if they default or if there is some other problem. This is of the utmost importance but difficult with only one home visitor.

Conclusion: The greatest dangers are acute hypoglycemia (due to mismatching of diet, drugs and exercise) and stopping of insulin or tablets. Chronic complications (foot ulcers, kidney or eye damage, strokes, heart attacks) occur very late in Type 1's but much earlier in Type 2's because they have usually had diabetes for a number of

years before diagnosis. Blood pressure control is important in these patients.

The best diabetes management option for the poor is: simplicity, intensive teaching, simple diet regulation (stroke marker system), urine test monitoring (stroke recording system), blood tests when in doubt and patient dose adjustment.

Many patients do not fit easily into the standard categories of Type 1 and Type 2. We wonder whether more research is needed into other contributing factors: eg: effect of rice milling on glycaemic index, malnutrition in early life, widely prevalent toxins such as nitrates in well water, organo-phosphorus-insecticide food contamination, urea contamination of rice and brown sugar (to improve colour), arsenic contamination of well water or the omnipresent coil burning fumigant smoke used to repell mosquitoes. Research is also needed for the development of very low cost sugar testing methods and service delivery. Kailakuri could be a model for this.

The Kailakuri Diabetes Rehabilitation Programme is a very good diabetes primary health care programme which should be copied. Its sustainability depends on 1) ideology, motivation and teaching, 2) funding and 3) a certain level of medical supervision. It is no. 3 that is the most precarious at the present time. We need a younger long term doctor who believes these things and is ready to act accordingly. Please help us.

Best wishes and thanks.

(Edric Baker) Medical Officer in-charge

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Edric's Health. Edric recently needed prostate surgery (non-malignant). There have been some post-operative complications which are not completely resolved at this time. Please pray for a good recovery.

Intern From New Zealand. Wellingtonian medical student Louis Kirton has just spent one month working at Kailakuri where he was able to do some basic laboratory procedure training and carry out a very useful diabetes survey which he has now written up. Thank you Louis.

Donations: Payment by direct bank credit:

Bank Account Name: Kailakuri Health Care Project - Link Group. Account Number: 010 486 0185024 46

Name of Bank and Branch: ANZ, Whakatane. If paying by direct credit, please note payee name so that you can be identified.

Alternatively a cheque made out to the Kailakuri Health Care Project - Link Group and posted to: KHCP-NZ Link Group, C/- D G Baker, 33 Waiewe St., Whakatane.