

# Diabetes in Children



Proceedings of  
**1<sup>st</sup> International  
Consensus Meet on  
Diabetes in  
Children**

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12<sup>th</sup> & 13<sup>th</sup> January 2013, Bengaluru, India

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*This book would not have been a reality if not for the combined effort and support of all our CDiC Center Directors, all other Doctors, their diabetes educators, nursing staff, administrators, other support staff, all others who have given their might to this noble cause of changing diabetes in children. Special mention is due to the NN India management team, medical team, CDB team and the CDiC India team for putting in that extra effort to coordinate and compile this useful booklet on, "Diabetes in Children"*

## Message from the Managing Trustee's Desk

*"Smiles on the faces of the little ones afflicted by diabetes makes our efforts worthwhile"*



**Melvin D'souza**

Managing Director, Novo Nordisk India Private Limited.  
Managing Trustee, Novo Nordisk Education Foundation.

Changing Diabetes in Children (CDiC) is yet again a testimony to the commitment we at Novo Nordisk Education Foundation have, to help people with diabetes, live a healthy and normal life.

Although studies on the incidence of T1DM in India are scarce, with documented statistics available only in three places, it is estimated that there are over 100,000 cases of T1DM in India with a 3-5% annual rate of increase in the incidence. T1DM is a special situation and requires special attention across all levels of healthcare. It is a well-known fact that socioeconomic factors and poverty are the most important barriers impeding access to quality healthcare. Outcomes for a child with type 1 diabetes can vary due to multiple reasons, but majority of the children with T1DM, who belong to the poorer sections of the society show far worse outcomes in India than in developed nations. We need to make sure that every child with diabetes gets timely and the best possible treatment.

CDiC program has made a strong impression on its relevance and impact. Many more milestones still need to be achieved and I am sure with our combined efforts we will be able to create a standard system to treat every child with type 1 diabetes. There is a dire need today to raise awareness about this challenge not only among the medical fraternity but also among policy makers and other government bodies. This 1<sup>st</sup> CDiC international consensus meet on Diabetes in Children, is a first major effort which, in addition to raising awareness will aim at identifying trend-oriented sustainable solutions for diabetes management in children passing through various stages of life. This consensus statement is yet another step in this direction. The smiles on the faces of the little ones afflicted by diabetes make our efforts worthwhile. We all need to focus our thoughts to achieve the ultimate goal of "No child should die of diabetes." My sincere thanks to each one of you, for your commitment and passion to changing diabetes in children in India. I hope this consensus statement will act as a stepping stone to move ahead with our mission.





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## **Abbreviations**

<b>APS-1</b>	Autoimmune polyendocrine syndrome type-1
<b>BCM</b>	Beta-casomorphin
<b>BMI</b>	Body mass index
<b>CDB</b>	Changing diabetes barometer
<b>CDiC</b>	Changing diabetes in children
<b>CGM</b>	Continuous glucose monitoring
<b>CHCs</b>	Community healthcare centers
<b>CME</b>	Continuing medical education
<b>DKA</b>	Diabetic ketoacidosis
<b>HbA1c</b>	Glycated haemoglobin
<b>HCPs</b>	Healthcare professionals
<b>HLA</b>	Human leukocyte antigen
<b>HMBG</b>	Home monitoring of blood glucose
<b>ISPAD</b>	International society for paediatric and adolescent diabetes
<b>ISPAE</b>	Indian society for paediatric and adolescent endocrinology
<b>MAU</b>	Microalbuminuria
<b>NCDs</b>	Non-communicable diseases
<b>ODD</b>	Oppositional defiant disorder
<b>PHCs</b>	Primary healthcare centers
<b>PPP</b>	Public private partnership
<b>SMBG</b>	Self monitoring of blood glucose
<b>T1DM</b>	Type 1 diabetes mellitus
<b>T2DM</b>	Type 2 diabetes mellitus





Session 1

# **Current Scenario, Overview and Insights**

## *2 Diabetes in Children*

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## Type 1 Diabetes in India - Overall Insights

**Prof. Ashok Kumar Das**

Medical Superintendent & Senior Professor of Medicine, JIPMER, Puducherry.

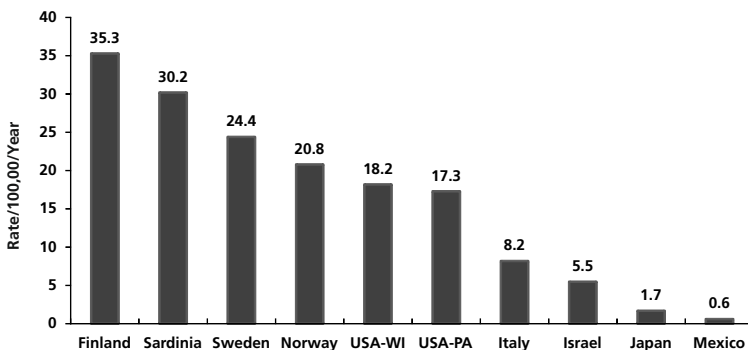


*Prof. Das is an internationally acclaimed clinician with over three decades of experience in the field of endocrinology. He has more than 80 publications in leading international journals to his credit. He has been the National President for the Association of Physicians of India and the Research Society for the Study of Diabetes in India (RSSDI). He is the Executive Patron at the RSSDI & national convener for the Indian National Consensus Group for development of insulin guidelines.*

Diabetes mellitus is a metabolic disorder of multiple aetiologies characterised by chronic hyperglycaemia with disturbances of carbohydrate, lipid and protein metabolism resulting from defects in insulin secretion, insulin action, or both. Type 1 diabetes mellitus (T1DM) is a chronic T cell-mediated autoimmune disease in which the body destroys insulin-producing beta-cells in the pancreas, resulting in progressive and irreversible failure of insulin secretion. This leads to hyperglycemia, ketoacidosis<sup>1</sup> and potentially death, if not treated with insulin. An understanding of the pathophysiology of diabetes rests upon the knowledge of carbohydrate metabolism and insulin action.

The incidence of T1DM increases with age and peaks at puberty. There are clear indications of geographic differences in trends, but the overall annual increase is estimated to be around 3%. T1DM accounts for 10% of all diabetes mellitus cases.<sup>2</sup> Countries with the higher incidence of T1DM include Finland, Sardinia, and the Scandinavian countries (Figure).

These dramatic differences, in the worldwide incidence of T1DM, are likely related to variations in the prevalence of the genetic and environmental risk factors for the disease. Several epidemiologic patterns suggest that environmental factors are important in the etiology of T1DM. In addition, when children from countries with a low T1DM incidence rate migrate to countries with a higher rate of incidence, their risk increases and becomes similar to that of the host country. This difference is much less dramatic for individuals who migrate during their adult years, indicating that the



childhood exposures are probably most diabetogenic. A number of viral infections have also been associated with T1DM. These include those that occur in uterus during pregnancy, as well as those that typically occur during childhood (e.g. enteroviruses). Because the peak onset of T1DM is at puberty, it is thought that changing levels of hormones may also precipitate the disease.

Predisposition to T1DM is better determined by haplotypes DRB1-DQB1. DQB1 is the best single genetic marker for T1DM and often used to identify individuals at a high risk of developing disease.<sup>3</sup> However, risk estimates based on DQB1 alone are less precise than those based on the combination of alleles at both the DQA1 and DQB1 loci. These combinations are called haplotypes. The two DQA1-DQB1 haplotypes that are most strongly associated with T1DM are DQA1\*0501-DQB1\*0201 and DQA1\*0301-DQB1\*0302. Caucasians with one and two high risk haplotypes have a 4 fold and 16 fold higher risk of developing T1DM respectively, than those with no such haplotypes. Therefore, the absolute risk (or actual likelihood) of developing T1DM depends on the number of high risk haplotypes an individual carries. Caucasians and African Americans with two high risk haplotypes have about a 3% chance of developing the disease before 30 years of age, depending on the population. The risk for Asians with two high risk haplotypes is much lower (<1 %). Therefore, even if a person carries high risk haplotypes, their chances of developing T1DM are quite low irrespective of their ethnicity. This likely indicates that the involvement of other genes and/or environmental factors that influence T1DM risk across various ethnic groups. However, in families where there is already one person with T1DM, the risk to unaffected relatives is much higher than that for the general population. For example, in Caucasian families, siblings of an individual with T1DM are about 15 times more likely to develop the disease than a person without a positive family history. The T1DM risk for a sibling who has the same two HLA haplotypes as their T1DM sibling is quite high (about 25%). If they share one or zero HLA haplotypes with their affected sibling, their risk is much lower, about 8% and 1%, respectively. The fact that the risk for individuals who have no shared HLA haplotype is still greater than the general population, suggests that genes other than those in the HLA region may also increase susceptibility for the disease.

There are three natural history studies for T1DM that are ongoing in the United States, viz DAISY (Diabetes Autoimmunity in the Young Study) in Colorado, PANDA (Prospective Assessment in Newborn of Diabetes Autoimmunity) in Florida, and DEW-IT (the Diabetes Evaluation in Washington). All are based on newborn genetic screening in the general population, and therefore, concerns have been raised about proper informed consent. Parents of babies who carry high risk DQB1 alleles receive a letter informing them that their infant is at 'high' or 'moderate' risk of developing the disease. The likelihood that these children will develop T1DM before they are 35 years of age is actually only about 6%.

Although a cure for T1DM is currently unavailable, several large international studies have been designed to evaluate a number of primary and secondary disease interventions. For the Trial to Reduce T1DM in Genetically at-Risk (TRIGR) and the Type 1 Diabetes Prediction and Prevention (DIPP) Project, genetic testing was performed as a part of newborn screening. For TRIGR, newborns were randomised to receive either regular cow's milk formula or one with hydrolyzed proteins. For DIPP, newborns with high risk DQB1 alleles from the general Finnish population were followed until they developed beta cell antibodies. New interventions will be tested in the future through T1D TrialNet; a collaborative network of clinical centers and experts in diabetes and immunology.

T1DM cannot be prevented. However, careful management of the disease can reduce the risk of long-term macrovascular complications.<sup>4</sup> Education programs are needed for parents who agree to enroll their children in such studies. Risk estimation is dependent on genes/auto-antibodies used for assessment and it is not sensitive or specific. Worldwide 317 million people are living with diabetes with a prevalence of 8.3%. According to the 'rule of halves', only around half of them have been diagnosed. Out of 317 million, 70 million people are living with diabetes in South East Asia with a prevalence of 8.7% and only 48.9% have been diagnosed. One in four deaths due to diabetes occurred in South East Asia and it is estimated that by the end of 2012, 1.1 million people would die from the disease. Unlike many other autoimmune diseases, where females are more at risk, boys and girls under 14 years of age are diagnosed with T1DM at relatively equal rates. A very high incidence was found in Finland, and Sardinia. The lowest incidence rate was found in the populations from China and Hong Kong. Evidence suggest that incidence of T1DM is rising 3-5% per year in children between 0-14 years globally, with highest incidence in Finland followed by Sweden, Colorado, and Germany. Thus, diabetes management involving diet, exercise and medicine can help achieve glycaemic control.

Around 78,000 children under 15 years are estimated to develop T1DM annually worldwide. Of the estimated 490,000 children living with the disorder, 24% come from European region and 23% from South-East Asian region. The South-East Asian region has one of the highest prevalence rates of T1DM in children. In 2011, an estimated 18,000 children under the age of 15 in this region developed T1DM. Of these, India accounts for most of the cases in the region despite variable prevalence reports. At Karnal, Haryana the prevalence of T1DM is 10.2 cases per 100,000 population. Karnataka has listed an incidence of 17.93/100,000 cases and Chennai has reported an incidence of 3.2/100,000. There are a lot of challenges in the management of T1DM. Current challenges include (1) Optimising the use of currently available therapies to ensure adequate glycaemic control (2) Educating patients on diabetes self-management (3) Improving patient adherence to a particular insulin/treatment regimen (4) Reducing barriers to the early use of insulin (5) Improving patients and physicians concern about hypoglycaemia.

## 6 *Diabetes in Children*

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## Type 1 Diabetes Mellitus–Awareness, Management and Challenges



**Prof. K. M. Prasanna Kumar**

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*Prof. Prasanna Kumar has vast experience in the field of Endocrinology and Diabetes over the last three decades. He has actively pursued research and teaching in this field at M. S. Ramaiah Medical College. He has published 75 papers in national and international medical journals as well as authored chapters in text books. A leading clinical research investigator in the country, he has amassed a large number of awards.*

The prevalence of diabetes is rising all over the world due to population growth, aging, urbanisation, physical inactivity and an increase of obesity. According to recent estimates, approximately 285 million people worldwide (6.6%) in the 20–79 year age group had diabetes in 2010 and by 2030, 438 million people (7.8%) of the adult population, is expected to be inflicted with diabetes. The largest increase will take place in the regions dominated by developing economies. T1DM is one of the most common pediatric endocrine illnesses caused by destruction of beta-cells in the pancreas.<sup>1</sup> It accounts for only about 5–10% of all cases of diabetes. The incidence of T1DM continues to increase worldwide and it has serious short-term and long-term implications. Wide geographic variations exist in the risk of T1DM across various countries. T1DM affects nearly 500,000 children below the age of 15 years. Of these, over half live in developing countries, with India being home to an estimated 100,000 children. The annual increase in the incidence of T1DM was found to be 3%. As there is currently no cure for T1DM, this increase in incidence along with enhanced access to insulin and better survival rates will lead to a higher prevalence in the near future. India lacks a diabetes registry but few studies have reported the prevalence of T1DM in India. Chennai has reported an urban incidence of 10.5/100,000 population in 1996. At Karnal in Haryana, the average prevalence of T1DM was found to be 10.2/100,000 population. The Karnataka state T1DM registry listed an incidence of 3.7/100,000 in boys and 4.0/100,000 in girls, over 13 years of data collection. Management of diabetes is crucial as patients with diabetes are at a higher risk of developing kidney failure, heart disease, stroke, blindness etc.

Management of T1DM is best undertaken by a multi-disciplinary healthcare team and requires continuous attention on many aspects, including insulin administration, blood glucose monitoring, meal planning and screening for comorbid conditions and diabetes-related complications. As per American Diabetes Association, every child newly diagnosed with T1DM should be evaluated by a team consisting of a paediatric endocrinologist, a nurse educator, a dietician and a mental health professional, to provide up-to-date paediatric-specific education and support.<sup>2</sup>

In the current Changing Diabetes in Children (CDiC) program, the data collected from various centres including Bengaluru, Mumbai, Kanpur, Delhi, Hyderabad, Ahmedabad and Indore revealed that the gender distribution of the study population was almost equal at all centres (50.9% males and 49.1%



females, respectively). When glycated haemoglobin (HbA1c) was compared with standard levels, at visit 1 only 8.3% had HbA1c level <7.9%, but majority i.e., 63.5% had HbA1c level >10%. But when the distribution was recorded at visit 4, 18.3% had HbA1c <7.9%, indicating a positive outcome of T1DM treatment (Figure). Improvement was also seen for urinary micro-albuminuria. 50% of the study population had urinary albumin <20.0 mg/mmol and 75.4% had normal thyroid stimulating hormone levels.

However, major challenges in the management of T1DM remain at the level of diagnosis, healthcare delivery, availability of trained physicians, infrastructure, availability of insulin, monitoring, and providing psycho-social support. So, a concerted effort needs to be made to sensitize diabetes care professionals, including nurses, dieticians and doctors for the management of T1DM in children. Child with T1DM requires frequent monitoring for glycaemia and ketonuria. Emphasis on diet, calorie counting, regular physical activity, injection technique and sick day management is essential.<sup>3</sup> The unique psychological needs and challenges of growing children needs to be addressed. What may be an optional management issue for patients with T2DM, may become essential in T1DM. All these, and other factors, underline the need for a structured diabetes education program for both patients and providers, better treatment approaches, trained doctors and initiation of diabetes registries which focus on T1DM management, so that there is no death due to diabetes.

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Session 2

# **Other Developing and Underdeveloped Countries - Insights on T1DM Management**



## Changing Diabetes in Children - Tanzania

**Dr. Kandi Catherine Muze**

*Paediatric Endocrinologist, Muhimbili National Hospital, Tanzania*



Tanzania has a total population of 44.9 million, out of which 44.72% are children <14 years of age.<sup>1</sup> Being a low income country, the gross domestic product (GDP) is US\$ 22915 million while, the GDP per capita is US\$ 526.56.<sup>1</sup> The expenditure for education is quite low, which accounts for 6.18% of the GDP.

The adult literacy rate (aged >14 years) is 72.9%. National survey revealed that there are 138,000 patients per doctor indicating a very huge work load on physicians. There are approximately 67,000 and 14,000 patients per assistant medical officers and clinical officers respectively. In addition, there are 5000 patients per trained nurse. The total health expenditure is 6.01% with private health expenditure of 1.96% and public health expenditure of 4.05%. Communicable diseases like malaria, HIV/AIDS and TB form a major threat to the healthcare system and diabetes was not given much priority and thus received less funding. Healthcare workers were more interested in HIV/AIDS, as it received more funding from various other sources. There are 120 paediatricians, 5 paediatric endocrinologists, 25 nurses and 5 dieticians; but no psychologist, counselor and social workers for diabetes management in Tanzania. Insulin is available as Regular; NovoRapid, Mixtard 30/70, and NPH costing around US\$ 25-30 per vial. Glucometers available are Accu-chek, Ascensia and Glucoplus costing around US\$ 60-75, which may not be affordable in a low income country like Tanzania.

CDiC was launched by Novo Nordisk, on 21<sup>st</sup> September 2010, with an objective of providing improved treatment and better quality of life in children with T1DM and strengthening the capacity of healthcare system. These approaches were implemented in partnership with the National Ministry of Health, key local stakeholders and support from external industry partner. This programme builds on the UN-defined cornerstones in the right to health and works to contribute to the achievement of the UN Millennium Development Goals (MDGs). Factors like extreme poverty, inadequate support from parents, inaccurate diagnosis, lack of public awareness, lack of access to insulin and inadequately trained healthcare



Participants at a public awareness campaign

workers were some of the challenges that were to be managed by these programmes. Under the CDiC program, (44.72%) children diagnosed with diabetes have been registered. Diabetes clinics were established at each of the 21 regional hospitals, and 4 referral hospitals in Tanzania were provided with infrastructure to manage children with diabetes. Frequent Continuing Medical Education (CME) programs regarding diabetes in children help in creating awareness (Figure). Diabetes treatment guidelines were also developed and adapted to suit different levels of healthcare providers (HCPs). Some approaches were made to provide special training to paediatricians and endocrinologists. The CDiC program trained health workers in dealing with diabetic children. Efforts were made to establish a telemedicine network and e-diabetes programs for CMEs; and to have at least one trained paediatric endocrinologist in each centre.

Efforts of non-governmental organisations which focuses on children at both local and international levels and awareness programs in public place and schools would help in managing diabetes. The CDiC program should aim to train more healthcare workers and reach out to more children to provide improvement in diabetes care, specifically in paediatrics and adolescents.

**Reference:**

1.<https://www.cia.gov/library/publications/the-world-factbook/geos/tz.html>

## Changing Diabetes in Children - Cameroon



**Dr. Mesmin Dehayem Yefou**

*Consultant Internist, Endocrine and Diabetologist, National Obesity Centre, Yaoundé Central Hospital, Cameroon.*

According to 2010 statistics, Cameroon has a total population of 19,406 million<sup>1</sup> with 43.6% of children below 15 years of age<sup>1</sup> indicating a burden of 13,468 patients per doctor. Cameroon is a resource-limited country with only two reference centres, eight diabetic clinics, ten endocrinologists and two paediatric endocrinologists. The prevalence of diabetes, according to 2010 diabetes atlas was 4.4% of which 6-8% were diagnosed with T1DM. A study conducted in 302 patients below 40 years of age with newly diagnosed diabetes showed that 9% of the patients presented with T1DM. Prior to 2010, although fragmented unreliable information was available, there was no national registry for children with T1DM in Cameroon. The available data from HCPs suggest that there are less than 150 children diagnosed with diabetes in the whole country with high death rates and limited access to healthcare.

CDiC was launched by the Minister of Health on June 18<sup>th</sup> 2010 in partnership with Novo Nordisk, World Diabetes Foundation, Roche Diagnostics, ISPAD and HoPiT (Heath of population in Transition). The project was started by recruiting project staff, which was involved in creating educational material for both administration and patients that include, project manual, investigators manual, letter of commitment from the host hospital, letter of consent from parents or guardians, patient's medical record and patient booklet. Under CDiC, 228 patients were included in the study with mean age



A participants at a diabetes clinic for children

of 15.6 years and mean duration of diabetes of 3 years. The HbA1c level at the initial visit was 5.4-14%. The patients were provided with free insulin and the mean HbA1c level decreased from 11.6 to 9.4% in the first 3 months and later to 8.1% at the end of 12 months. The impact of ketoacidosis, hypoglycaemia and quality of life in children with diabetes were not analysed. There was a significant improvement in quality of care offered to children living with diabetes.

In addition to these programs, CDiC provided the infrastructure for diabetes clinics, apart from one week training program for 41 doctors and 37 nurses working at central and intermediate levels. Ten training sessions were conducted in 10 regions with 651 trained HCPs. Children and adolescents enrolled in the programme were provided with free insulin, syringes and blood glucose monitoring kits. Such initiatives would improve the healthcare systems in developing countries like Cameroon.

**Reference:**

1. <https://www.cia.gov/library/publications/the-world-factbook/geos/cm.html>

## Diabetes in Children - Bangladesh

**Dr. Bedowra Zabeen**

*Paediatric Diabetologist & Coordinator, CDiC, BIRDEM, Dhaka, Bangladesh.*



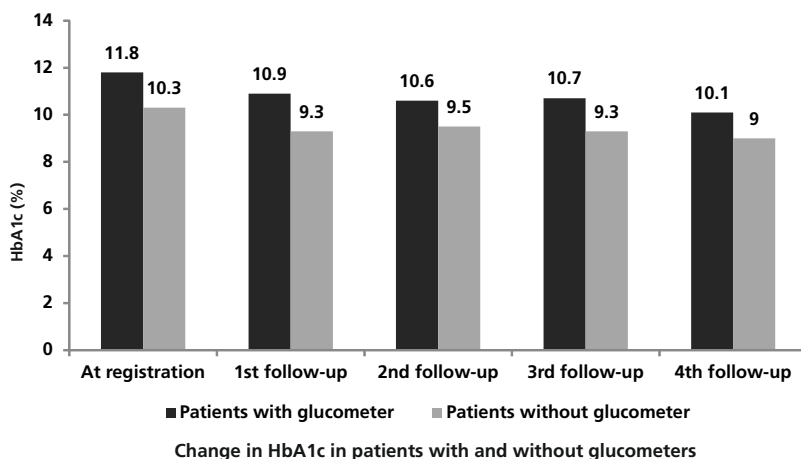
Bangladesh is a developing country, with a population of 152 million where most of the people cannot afford basic medical care. According to 2011 statistics, total population of children in the age group of 0-14 years was 1.9 million.<sup>1</sup> There are 490,100 children with T1DM in the 0-14 year age-group, and the annual increase in the incidence of T1DM is 3.0%. Currently, Bangladesh is in 8th place with 8.4 million diabetics, and it is expected that by 2030, it would reach 5<sup>th</sup> position with a diabetic population of 16.8 million. Diabetic Association of Bangladesh (BADAS) founded by Dr. Ibrahim on 28<sup>th</sup> February 1956, along with its 59 affiliate association across the country coordinated for better management of diabetes. Children with diabetes were managed in general clinics in all hospitals, except in the Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders (BIRDEM). BIRDEM, the biggest hospital of BADAS, has been treating children since 1997 and serves 4000 outpatients every day. It is also a World Health Organization (WHO) collaborative research centre for prevention and control of diabetes.

CDiC is an integrated approach for providing comprehensive and sustainable healthcare to children with T1DM. It was started in Bangladesh by a joint initiative of BADAS, Novo Nordisk and World Diabetes Federation (WDF). More than 1500 diabetic children and adolescents received free diabetes care in three centers viz., Dhaka, Faridpur and Chittagong. CDiC has been providing outpatient services, since 2010, to all diabetic children and adolescents in Bangladesh referred to these centres. The multidisciplinary team of CDiC consists of paediatric diabetologists, diabetes educators, psychologists/counselors and a dietitian. Activities of CDiC include monthly consultation by doctors, diabetes education, psychological screening and counseling, dietary advice by nutritionist, yearly review and screening for complications. Investigations such as blood glucose, triglyceride, cholesterol, serum creatinine, HbA1c and urine for microalbumin are also carried out by CDiC. Insulin with syringe and glucometer with strips are supplied to patients. Other features of CDiC are to provide transport cost to poor patients, home visit, school programs and annual camps. At consultation, a detailed history of patients is recorded, clinical examination is carried out and treatment is initiated. Education on diabetes is provided in group as well as individual sessions, and includes pre-assessment of knowledge through a structured questionnaire, individual session along with care-taker/parents based on pre-assessment of diabetes knowledge, practical demonstration of insulin administration and glucometer use and awareness of maintaining a record of blood sugar test results in a home monitoring of blood glucose (HMBG) book.

CDiC developed education materials, including audio-visual aids, for children



with diabetes and their care-takers. Primary education incorporated survival skills at diagnosis, reasons for symptoms, diagnosis procedure, and hyperglycaemia due to relative or absolute lack of insulin. Use of insulin at home and school, awareness of hypoglycaemia, psychological adjustment to the diagnosis and details of emergency telephone contacts are made known to children with diabetes. Educational holidays and camps for children with T1DM are a key feature of the program. Structured medical-cum-recreational experience is provided to children with diabetes and their families through a diabetes camp in a non-hospital setting. Aim of the diabetes camp is to provide enjoyable holidays while helping children with T1DM gain self-confidence and independence by sharing experiences with each other.



Patient education involves education on a) Insulin secretion, action, and physiology b) Insulin injections, types, absorption, action profiles, variability, and adjustments, and c) Nutrition monitoring; importance of HbA1c; d) Prevention, recognition and management of hypoglycemia. Further, education on concomitant illnesses, hyperglycaemia, ketosis and prevention of ketoacidosis, problem solving, adjustments to treatment, goal setting, microvascular and macrovascular complications and their prevention and exercise was provided. Psychological management consists of psychological assessment and screening, followed by psychosocial counseling for the family, parent and individual with diabetes, through both single and group counseling. In group counseling, dietary advice was given according to individual's taste. Patients receive a wide variety of benefits including blood glucose monitoring tools, medication and traveling expenses to the hospital. As many as 700 patients received glucometers and transport cost was provided to 517 patients. Personalized support at the doorstep is made available through an educator who visits a patient's home with a structured questionnaire and observes insulin storage, self-monitoring blood glucose book and provides counseling to family members. Rehabilitation programs

have been developed and include educational scholarship, training program and centre visits. Another key aspect of CDiC is to upgrade skills of healthcare professionals (HCPs). Training of HCPs included educational sessions by renowned international faculty like Dr. Stuart Brink, Dr. Warren Lee, Dr. Angela Middlehurst, Dr. Peter Swift and Dr. Sheridan Waldron. An important initiative of CDiC in Bangladesh was the establishment of the Kailakuri healthcare project (KHCP) which is meant to cater to the healthcare of the poor by the poor.

A total of 37 rallies took place across the country on 'World Diabetes Day' 2012. Rallies were organized in each city of Bangladesh and were led by the local directors of CDiC centers and leading endocrinologists or diabetologists with participation of Novo Nordisk field colleagues with posters, banners and education materials. In Dhaka, over 1000 people participated in a grand walkathon with the BADAS team. CDiC organized a motivational discussion for children with diabetes which involved eminent professionals in the field.

Glycaemia status of children under CDiC program has improved from onset of disease to 5th follow-up; 29.6% patients achieved HbA1c level of <7.5% and 31.7% patients achieved HbA1c level of 7.5-9.0%. Patients with access to glucometers demonstrated a robust decrease of HbA1c levels (Figure) and regular follow-up was seen in 96% patients. Through counseling children with diabetes were able to accept diabetes, share their experiences to others, show increased intimacy with peer group, be more attentive than before, control their emotions, take self-care, and improve their self-esteem. CDiC emphasized on diabetes education combined with appropriate motivation of the patients and care-takers, to improve glycaemic control and quality of life of these children and adolescents and is a model of healthcare management of diabetes in children worth emulating.

**Reference:**

1. <https://www.cia.gov/library/publications/the-world-factbook/geos/bg.html>

## Type 1 Diabetes Mellitus in National Hospital of Paediatrics - Vietnam

*Dr. Bui Phuong Thao*

*National Hospital of Paediatrics, Hanoi, Vietnam..*



Amongst endocrine diseases in Vietnam, hypothyroidism occurs most commonly, while diabetes stands in fifth position by occurrence.<sup>1</sup> Previous data obtained from the National Hospital of Pediatrics (NHP) showed 270 patients to be diagnosed with T1DM, of which 20-30 were newly-diagnosed cases. Previous figures showed that the incidence of T1DM, from 2002 to 2010, increased from 10-22 while in 2012 the number increased to 37. In Vietnam, there are approximately 600 patients detected with T1DM.

After the diagnosis in NHP, the patients were consulted by paediatric endocrinologists, diabetes educators/ nurses and the family was provided with diabetes education material (Figure). A regular follow up for every 3 months, with two or four injection regimes, was advised to patients. Patients were screened for complications and an annual diabetic meeting was organized. There were no paediatric endocrinologists in the district hospitals and in a majority of the provincial hospitals. Patient's family did not have glucometers and were not educated about insulin dose adjustments, diet and exercise, leading to a weak self-glucose monitoring.

A survey conducted on HbA1c levels showed that there were 9 patients in 2005 with HbA1c levels between 7.1 to 9%, which increased to 16 patients in 2008; whereas there were 44 patients with HbA1c >9% in 2003, which decreased to 39 patients in 2008. A cross-sectional study, with an aim to evaluate the risk factors associated with eye complication in children with T1DM, conducted in the NHP found that, T1DM children with eye complications were at increased risk of blindness. Retinopathy deteriorates to 5% in 5 years which degrades to about 100% in 25 years. Patients diagnosed with T1DM in NHP, from 1974-2007, were included in the study whereas patients with no eye tests and eye disease not related to diabetes were excluded from the study. During the study HbA1c was monitored, followed by complete eye check-up, of all the patients by ophthalmologists. Of the sixty patients included in the study, 27 (45%) were male and 33 (55%) were female. The age at diagnosis of T1DM was  $9.4 \pm 3.9$  years. Twenty nine (48.3%) patients had eye complications and sixteen (26.7%) had retinopathy, twenty (33.3%) had cataract and six (10%) had both retinopathy and cataract. Mean duration of T1DM was  $5.1 \pm 4.4$  years whereas duration until detection of eye complication was  $6.6 \pm 5.2$  years.

In the first five years of diabetes, 18.24% (n=38) patients had retinopathy. Within a decade, this proportion increased to 31.25% (n=16) and in >15 years of diabetes it increased to 100%, which indicates that retinopathy increases if

diabetes is not maintained properly. One patient was with HbA1c <7%; 10 patients had HbA1c between 7-9%, of which 6 had eye complications and 4 were without eye complications. There were 49 patients with HbA1c >9%, amongst which 24 had eye complications and 25 did not. The mean age at diagnosis of T1DM was  $9.4 \pm 3.9$  years. Of the total study population, 48.3% cases had eye complications, whereas 26.7% cases had retinopathy. Around 30% of patients developed early cataract in the first 5 years of T1DM. Prolonged polyuria and poor glycaemic control could result in cataract long before diagnosis of T1DM is done. Non-compliance were mainly due to socio-economic conditions (52.5%), forgetting insulin doses (27.5%) and use of traditional medicines (15%).



**Patient education at a diabetes clinic in Vietnam**

**Reference:**

1. Hirohide Yokokawa, Nguyen Thy Khue, Aya Goto, Tran Quang Nam, Tran The Trung, Vo Tuan Khoa, et al. Diabetes Control among Vietnamese Patients in Ho Chi Minh City: An Observational Cross-Sectional Study. *International Electronic Journal of Health Education*. 2010;13:1-13.

## Changing Diabetes in Children - Sri Lanka

**Dr. Navoda Atapattu**

*Paediatric Endocrinologist, Lady Ridgeway Hospital, Colombo, Sri Lanka.*



The total population of Sri Lanka is 20 million out of which 24.9% comprises paediatric population (Age group 1-14 years).<sup>1</sup> All the citizens of Sri Lanka are provided with free healthcare and the burden of total healthcare expenditure is 74.5 billion. University paediatric units are located at Jaffna, Kandy, Anuradhapura, Colombo, South Colombo, North Colombo, and Galle in Sri Lanka. Current- ly there are mainly two types of hospitals in Sri

Lanka for the treatment of children with T1DM. They are teaching hospitals and base hospitals with 107 paediatricians. A child with T1DM is primarily admitted in a hospital as an inpatient under a supervision of a paediatrician and started with initial therapy of insulin. Patients are given education on diet, exercise, hypoglycaemia management, injection techniques, and complications of the disease. In addition, diabetes education and nursing care facilities are provided to the patients and regular follow up is scheduled with pediatrician. Diabetic educator nursing officers play an important role in diabetic care and 279 nursing officers are scattered throughout the country

who are trained under Nirogi Lanka project funded by World Diabetes Federation.

Majority of patients with diabetes were initially started with premixed insulin therapy twice daily. However, in some patients the treatment was initiated on multiple doses of insulin based on the severity of the disease. Monitoring of capillary glucose profiles was conducted either as an inpatient or once a month for 3 days and frequency of capillary glucose monitoring was based on affordability along with the daily urine sugar monitoring. Monitoring



**Patient education at a diabetes clinic in Vietnam**

of HbA1c, was done for every 3-6 months. Screening of complications associated with diabetes was scheduled on annual basis at Diabetes Center, Colombo. Dietary advice on judicious use of carbohydrates was given by trained healthcare professionals as it plays an important role in the management of T1DM in children. Required carbohydrate proportion of the diet was calculated based on child's age and weight and based on carbohydrate proportion, required CHO exchanges was calculated. Further, a diet sheet containing carbohydrate exchanges was provided to each family. For example, a 20 kg child's total calorie requirement would be 1800 calories. The

amount of calorie needed from the carbohydrates (CHO) will be calculated as  $(1800 \times 55)/100=990$  calories, while the carbohydrate exchanges for the child will be calculated as  $990/(4 \times 15)=16.5$  carbohydrate units.

Hypoglycaemia was managed based on symptoms, signs and capillary glucose. Patients were advised to take 1 teaspoon of sugar or glucose/ half a carton of fruit juice, followed by a snack. In addition to this, patients were advised to take a snack if they exercised for 30 mins or more. School teachers and care-takers were trained on hypoglycaemia management. Patients with poor control were admitted and psychological support was provided to patients. When admitting a child with diabetic ketoacidosis (DKA), care was taken in teaching and majority of the doctors followed the BSPED protocol/local paediatric guideline adopted from the UK guidelines. Future steps for the treatment of T1DM was done in paediatric diabetic clinics in each teaching hospital with trained paediatric dieticians. As a part of the program the facilities for frequent capillary glucose monitoring were made available and a telephonic system for patients to discuss day-to-day concerns with a healthcare professional was put into place. The goals of the overall program was to provide children with diabetes an enjoyable childhood, minimized complications and hand over to adult services in good spirit.

**Reference:**

1. <http://www.statistics.gov.lk/page.asp?page=Population and Housing>

## Diabetes in Children, Yangon - Myanmar

**Dr. Kyaw Myo**

*Lecturer (Paediatrics) at Department of Paediatrics, University of Medicine, Magway, Myanmar.*



Yangon population is about 11% (69,21,000) of the total Myanmar population (59,264,000)<sup>1</sup>, with more than 2 million below 15 years of age. As per the 2012 hospital statistics, the incidence of diabetes was found to be 0.7/100,000, with an increase of 15 new admissions in 2012. The prevalence rate was estimated to be 2.1/100,000 and a male: female ratio of 1.75:1, indicating a higher prevalence among males. Most of the patients were within the age group of 3-12 years (median age - 8.5 years), with no family history of diabetes. More than half of the patients were Burmese, while remaining being ethnic minorities, Indians and Chinese. Clinical diagnosis of T1DM was made with patients presenting with diabetic ketoacidosis, nephropathy and diabetic foot (infection and gangrene).

Associated complications included thalassemia, obesity, hypertension or any autoimmune disorder. Twice-daily regimen with Human Mixtard (30/70) and multiple daily injections of soluble insulin were administered to these patients with the help of conventional syringes, pen devices and continuous subcutaneous insulin infusion (CSII) pumps. Patients were monitored for urine sugar level, urine ketone levels, capillary blood glucose and HbA1c with a continuous glucose monitoring system. However, adherence and follow up of the patients were irregular and poor. Two patients were lost in the last three years, one patient was shifted to another area, two more were shifted to the adult care and six patients did not follow-up.

Programs such as CDiC would benefit children with diabetes in developing countries like Africa and India. For Yangon, a multidisciplinary team including general paediatricians, paediatric endocrinologist, dietitian and nurse would help in improving the existing diabetes care for children.

### Reference:

1. <https://www.cia.gov/library/publications/the-world-factbook/geos/bm.html>

Session 3

# **CDiC in India: Journey so Far and the Way Forward**





# Changing Diabetes in Children in India - Key Achievements

**Dr. Archana Sarda**

*Chairperson, Sarda Center for Diabetes and Self Care, Aurangabad.*



*Dr. Archana started Sarda Centre for Diabetes and Self Care in 1999. In the year 2005, she launched "Udaan"- NGO which provided comprehensive care for underprivileged children with T1DM with more than 150 children being cared for, currently. She conducted several diabetes awareness workshops and attended national and international diabetes conferences. For the past 11 years she has dedicated herself to patient care, created awareness for prevention of diabetes at a grass root level through street plays, jingles, movies and magazines for patients in local language, etc.*

CDiC has provided infrastructure to 19 CDiC centers and 18 satellite centers (11 in Bengaluru, 3 in Gujarat, 3 in Aurangabad and 1 in Hyderabad) across India. More than 600 HCPs were trained to treat T1DM. In addition, 7 workshops and 2 large CME programs were conducted in coordination with the ISPAD (International Society for Pediatric and Adolescent Diabetes), ISPAE (Indian Society for Pediatric and Adolescent Endocrinology) and All India Institute of Medical Sciences (AIIMS).

About 3,800 kitbags, more than 145,000 insulin vials, approximately 6,00,000 syringes, 3,800 glucometers and 5,25,000 glucose monitoring strips were provided to children with diabetes. Furthermore, 8,000 HbA1c, 4,000 microalbuminuria, complete blood picture, thyroid stimulating hormone and fundus tests were conducted in children with diabetes which helped in better treatment of the patients. As a part of a structured patient education program, 75 children camps have been conducted which included 3 basic components, viz education on diabetes, sharing the experience and fun

activities. In the CDiC program, children were educated on diabetes using creative approaches such as providing story books (MISHTI), dolls and toys (NOTTI doll and snake ladder game) which created awareness on diabetes. In addition, hypo-kits and HbA1c converters were also provided which helped children and their parents to manage the disease.



Supporting children with key supplies

Data on age, sex and economic status was documented for all the enrolled children. This initiative was a step towards better care of a child with diabetes. Data on

HbA1c and other important tests was documented and stored in individual centres. Learning forums included 3 advisory board meetings with all centre directors involved in sharing the problems, challenges and utility of inputs. This shared approach would ultimately lead to a focussed way of ensuring the best practices for the overall development of children with diabetes.

The outcomes of the program included significant reduction in HbA1c levels in

majority of the children with diabetes in one year, along with a dramatic reduction in hospitalisation rates. Improved standards of care, monitoring and investigation delivered by centres of excellence for diabetes care would help set a standard for all the other practicing doctors in neighboring areas. In addition to the measurable outcomes, CDiC has enabled 3,800 children to live happily by managing diabetes. However, helping these children after completion of the duration of program in a sustainable manner still needs to be answered.



Key achievements of CDiC in diabetes management in children

## Changing Diabetes in Children in India - Challenges



**Dr. P. V. Rao**

*Professor and Head, Department of Endocrinology, NIMS, Hyderabad.*

*Dr. Rao is currently the Professor and Head, Department of Endocrinology at Nizam's Institute of Medical Sciences, Hyderabad. His main research interests include diabetes and other endocrine disorders. He has been involved in several global research projects including the LEAD (liraglutide effect and action in diabetes) study and trials on degludec. He has several publications to his credit. He is also well known for his research on metabolic disorders and the genetics of diabetes.*

Existing challenges in the successful management of diabetes in children include achieving HbA1c levels <8%, zero mortality rate, diabetes without complications, changing patient's and physician's mindset to achieve targets and management of psychosocial aspects. India, being a multi-climate, multi-linguistic and multi-cultural country, it is difficult to provide infrastructure based on region. Lack of awareness on T1DM among HCPs, general practitioners and parents of children with T1DM, inadequately trained staff and lack of infrastructure, lack of appropriate treatment protocols and structures highlight the need for the development of uniform methodology for managing diabetes. Moreover, financial burden related to the use of insulin, strips, and medication, transport expenses, providing nutritional food and coping with trauma, add on to existing problems in the management of diabetes in children.<sup>1</sup> Supply and right use of insulin appears to be a major problem in dealing with diabetes in children in India.

Misperception about diabetes, and its management, among general practitioners and parents of children with diabetes is a challenging situation that can be addressed by patient education. Successful management of diabetes depends on education of diabetes management, support from family, school and society.<sup>2</sup> In addition, the process of data collection and report submission should be strengthened to create a standard procedure for the treatment of T1DM. A close follow-up of the participated children is required for the reliability of the varied results. Standardization of care in relation to supplies and outcomes, is also needed. Implementation of training and education for HCPs also dictates acceptance, understanding and diabetes education among parents and children. However, treatment of diabetes mellitus remains suboptimal inspite of continuous management and presents with unsatisfactory results, a feeling of failure for children, parents, educators and even physicians. In this regards, CDiC initiated by Novo Nordisk has the potential to become a role model for government and non-government organizations by developing diabetes centres in India, thus helping diabetic children by providing support in disease management.

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## Changing Diabetes in Children - Best Practices

**Dr. Alok Kanungo**

*Chief Consultant Diabetologist and Chairman-Cum-Managing Director, Kanungo Institute of Diabetes Specialities (KIDS), Dumduma, Bhubaneswar.*



*Dr. Kanungo is a noted physician and also known for his research in the field of diabetes. He has more than 50 publications on different aspects of diabetes to his credit. He is presently the Principal Investigator for Type-1 Diabetes Genetics Studies in India and member of Consultative Committee of World Health Organisation for Management on Type-2 Diabetes in India. He is a scientific committee member of European Association for Study of Diabetes, Research Society for Study of Diabetes in India and International Committee for Diabetes and Immunology.*

Diabetes is a killer disease in many parts of the world, especially when it strikes in childhood or adolescence. The relative rarity of the disease makes it difficult for parents and family members to recognise its subtle beginning symptoms. As the global diabetes pandemic gathers speed, adding millions of newly diagnosed patients each year, the need for radical and immediate action becomes more imperative to create a brighter tomorrow. The following actions should be taken for better management of diabetes in



Physical exercise for managing diabetes in children

children:

1. Improving infrastructure facilities for T1DM in small towns and villages and creating multi disciplinary paediatric and adolescent diabetes team care for better acceptance/learning in children with T1DM; and promoting diabetes awareness programs through multilingual banners and posters.
2. Increasing the quality of care by conducting decentralised training workshops for patients and providers in metros and smaller towns attached to CDiC centers to detect more children with T1DM and make the reach more substantial. Besides this, working along with experts from ISPAE, ISPAD and organizing question and answer sessions for the participants would be beneficial.
3. Increasing awareness on diabetes through structured education programs. Considering the complexities of the subject, training manuals should be

prepared on diabetes management and distributed to healthcare professionals and patients.

4. Introducing innovative and novel ways of diabetes education like experience sharing, conducting fun activities in camps etc. and encouraging family members to participate in these camps for managing T1DM in children. Considerable emphasis should also be given for continued follow-up through periodic children camps.
5. Improving accessibility, availability and affordability of insulin and setting diabetes registries in children.
6. Establishing a standard of care to enhance health and safety.

So we look forward to training HCPs, ensure continuous supply of insulin, educate children and their parents about diabetes and explain different aspects in its management, establishing a public private partnership (PPP) model beyond the CDiC program and setting up a diabetes registry to ensure that no child dies of T1DM.



Session 4

# **Public Private Partnership Initiatives - Role of Policymakers**





## Changing Diabetes in Children - Karnataka



**Dr. N. Prabhu Dev**

*Chairman, Karnataka Health Commission and Vice-chancellor, Bangalore University, Bengaluru.*

*Dr. Dev is the Vice-chancellor of Bangalore University, Bengaluru since 2009 and was former Director of Sri Jayadeva Institute of Cardiology, Bengaluru. He has contributed to healthcare services as the Professor & Head of the Department of Cardio-thoracic surgery for the past two decades. He was the organising secretary of the 41<sup>st</sup> annual conference of Indian Association of Cardiovascular and Thoracic Surgeons (IACS)– 1995, President of Indian College of Cardiology and the Honorary Secretary of the IACTS.*

India, until very recently, was considered the diabetes capital of the world. Bengaluru is considered as the diabetes capital of India. Since diabetes is a silent killer, govt. of India has taken the initiative to promulgate efforts aimed at the management of diabetes. The Karnataka government has approved a budget of Rs. 1 lakh crore on healthcare and universal coverage benefits for people with diabetes. Out of the five million population of Bengaluru, more than 5 lakh people diagnosed with diabetes are expected to receive universal coverage of health benefits. Globally, it was estimated that diabetes accounted for 12% of health expenditures in 2010, or at least US\$376 billion- a figure expected to hit US\$490 billion in 2030.<sup>1</sup>

Although the magnitude of T2DM is huge, with 95% of the total diabetic population affected, T1DM appears to be equally important. An interaction between westernized diet and lifestyle modifications poses a direct impact on economic progress in India.<sup>2</sup> As a precautionary measure, the government of India has planned to invest Rs. 5 crore on diabetes programs that will offer free diabetes screening in urban areas, slums and rural districts. Two projects in 100 districts each will be launched soon by the government. The government has also planned to provide free check-up, glucometers, strict diet plans and BP check across 33 cities of India which are not close to the state capital. Targets are made to treat 7 crore adults below the age of 30 years. Recommendations have been made to the government to launch a policy exclusively for patients with diabetes, regardless of their income level, social status, caste or gender to offer affordable, accountable, appropriate care and ensure a system which encompasses the whole range of diabetes care.

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## Changing Diabetes Barometer - Puducherry

**Dr. K. V. Raman**

*Director, Department of Health and Family Welfare Services, Government of Puducherry.*



*Dr. Raman has been an active participant in research and teaching activities and has worked in various administrative capacities in the government of the union territory of Puducherry and has over 20 years of experience as a medical practitioner. He has administrative experience as TB Control Officer, Government of Puducherry, Deputy Director In-Charge, Government Hospital, Mahe and as Dean, Mother Theresa PG&RIHS. He has teaching experience as Senior Resident in JIPMER and as guest lecturer in Physiotherapy at Mother Theresa PG&RIHS, Puducherry besides numerous other positions.*

The geographical locations of the union territory of Puducherry are distributed in four districts in three southern states of India. With a total population of 12.44 lakhs,<sup>1</sup> Puducherry has 8 hospitals, 4 CHCs, 39 PHCs and 9



**A) Inauguration of the Changing Diabetes Barometer program in Puducherry and b) Launch of the diabetes awareness van by honourable CM - Puducherry**

medical colleges. According to 2011-2012 estimates of Puducherry, the live birth-rate and death rate are 16.7 and 7.4 per 1000 population, respectively. The reported number of cases with diabetes in Puducherry increased from 2009 to 2012. Despite the increase in the number of cases, deaths due to diabetes showed a decreasing trend. Of the total 36,816 cases of diabetes reported in 2009, there were 291 deaths. In 2012, despite the fact that there was an increase in number of patients diagnosed with diabetes i.e. 56,375 patients, mortality rate was low (approximately 102 cases using oral agents).

With the aim of improving awareness and care towards diabetes care in Puducherry, the government of Puducherry launched the 'Changing Diabetes Barometer' project in collaboration with Novo Nordisk Education Foundation (NNEF). Dr. A.K. Das, the Medical Superintendent of JIPMER, Puducherry and Mr. Melvin D'Souza from Novo Nordisk signed a memorandum of understanding (MoU). As part of the various activities, the honourable Chief Minister of Puducherry, Thiru N. Rangaswamy, launched the diabetes awareness van. In addition, diabetes screening camps were organized at PHCs and CHCs to screen the general population at risk of developing diabetes. Diabetes exhibition programs were conducted to spread awareness on causes and risk of diabetes as well as explain the importance of healthy diet and

Vital Statistics of Union Territory of Puducherry (2007-2011)					
Parameter (per 100,00 population)	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012
Live Birth Rate	16.4	16.4	16.4	16.5	16.7
Death Rate	7.5	7.5	7.5	7.0	7.4
Still Birth Rate	0.95	0.95	1.19	0.78	NA
Infant Mortality Rate	25.0	25.0	25.0	22.0	22

Total No. of Reported Cases & Deaths						
	Cases			Deaths		
	Male	Female	Total	Male	Female	Total
Insulin	1853	1572	3425	0	0	0
Oral Hypoglycaemic Agents	24365	28585	52950	70	32	102

lifestyle modifications for people with diabetes.

**Reference:**

1. <http://www.census2011.co.in/census/state/puducherry.html>

## Public Private Partnership in the Management of Diabetes in Goa



**Dr. Rajnanda Desai**

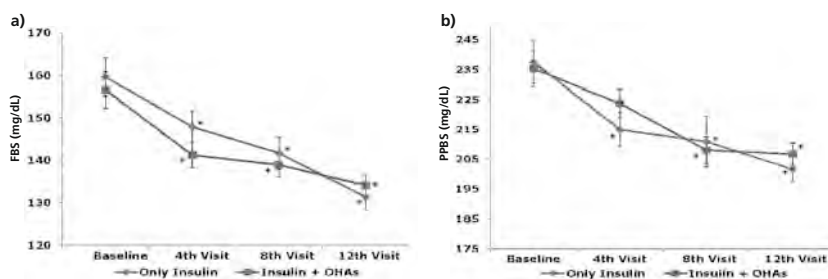
*Chief Medical Officer, Goa.*

*Dr. Desai is the Project Director, Goa State AIDS Control Society and was the Director of Health Services for 5 years. During her tenure as Director, projects like EMRI-108, newborn screening for internal errors of metabolism, Diabetes Control Program and Cancer Registry were launched. Diabetes registry, the first of its kind was launched. Infant and maternal death audit was introduced for the first time resulting in an IMR of 10, lowest in the country. Immunization coverage touched 93.8% which is highest in the country. She was key to the successful implementation of National Vector Borne Disease Control Program and to bring down the case load by 50% every year.*

Diabetes management is a complex issue needing comprehensive healthcare efforts. Health seeking behaviour is at its best in Goa. Despite sustained efforts in starting a diabetes management program, the Goa government could not provide adequate funds for the same. At this juncture, Novo Nordisk Education Foundation approached the government of Goa, which led to the initiation of the Changing Diabetes Barometer (CDB) program in the state. It was the first PPP in health sector throughout the country. Although there was a lack of a structured program initially, the management of diabetes in Goa started with awareness of the disease and a screening program.

According to the 2011 statistics, Goa had a population of around 14.57 lakhs.<sup>1</sup> Sex ratio was on par with national statistics; life expectancy was 68 years for males and 72 years for females with a mean marriageable age of 25 years. There were 42 government hospitals with 2,884 beds and 129 private hospitals with 2760 beds, indicating that the public and the private sector share equal responsibilities towards healthcare. Doctor to patient population ratio in Goa was 1:636. There were 64 wards, 1,772 sub-centers, 29 rural dispensaries, 13 primary healthcare centers (PHCs) with hospitals, 6 PHCs without hospitals, 5 community healthcare centers (CHCs), 2 district hospitals and 1 medical college and hospital. The CDB program in partnership with the private sector was launched on 28<sup>th</sup> August, 2008 with 105 diabetic camps which screened 13,000 people. 2,341 cases were detected positive for diabetes, with more than 79% of this population having HbA1c > 6.5%, indicating that diabetes was not well controlled in Goa, indicating the need for a structured program for diabetes management. With an aim to educate patients, physicians and general public about diabetes, education material for diabetes management was developed. In addition to distribution of these education materials, training programs were conducted for medical officers and specialists where several aspects of diabetes management were dealt with. Continuous Medical Education (CME) programs and workshops were also conducted to create awareness. Anganwadi workers were involved in these programs, so that as members of their respective communities they could help patients overcome fear and anxiety related with diabetes and insulin.. House surveys were also undertaken by PHCs, where 18,000 people had been screened and 857 people tested positive for diabetes.

Though children in Goa do not have separate clinics for diabetes management, a total of 110 diabetic children, who were a part of the central registry, were given free treatment and insurance through this program. Government of Goa has decided to supply free insulin to the patients with diabetes. All these measures, taken by the public and private sectors, have yielded good results. An article published by the Head of the Department of Health in Goa, indicated lower HbA1c levels and reduced hospital stay in patients treated for diabetes. Government has also supplied HbA1c kits for diabetic patients. Training for medical officers has resulted in very good monitoring of diabetic patients. The outcome of the CDB program established that the partnership of the public and private sectors would yield better results, providing good glycaemic control for diabetic patients.



Change in a) Fasting blood sugar and b) Post prandial blood sugar from baseline to endpoint during the Changing Diabetes Barometer program in Goa

#### Reference:

1. <http://www.census2011.co.in/census/state/goa.html>

## Risk Factor Surveillance Among School Children in Andhra Pradesh

**Dr. T. Geetha Prasadini**

*Additional Director (DCP), State Surveillance Officer (IDSP) & State Nodal Officer (NCDs), Directorate of Public Health and Family Welfare, Government of Andhra Pradesh, Hyderabad.*



*Dr. Prasadini is the head of State Epidemic cell, C4D cell, Industrial Health and is responsible for monitoring, collecting, reviewing and reporting the disease burden of water borne diseases and other communicable diseases in the entire state of Andhra Pradesh. She is involved in planning and initiating actions in preventive measures for reported outbreaks. In addition, she is in charge of State Surveillance Unit which coordinates activities of RRTs, monitors and reviews the activities of DSUs, coordinate with state public health laboratories and medical colleges. She is the head of all programs that are under the NCD category like NPCDCS, NPHCE, NIDDCP, NPPCF.*

The burden of non-communicable diseases (NCDs) is rising in India, accounting for over 42% of the mortality burden and considerable economic loss. The prevalence of diabetes in India (62.47 million) is increasing including that in children (1 in every 400-600 children).<sup>1</sup> Disturbingly, among the newly diagnosed cases of T1DM, around 75% are younger than 18 years of age. In addition, the number of children and adolescents who are overweight or obese, are insulin resistant, have a family history or diagnosis of T2DM is increasing. Further, undiagnosed diabetes may place these young people at early risk for cardiovascular disease although no data is available to define the extent of this problem. With a majority of these children attending school, preschool and/or daycare, parents and healthcare providers must work together to make sure that schools and day care providers have knowledgeable and trained staff to allow these children to participate fully and safely while attending school.<sup>2</sup> T1DM can develop at any age during childhood or adolescence and has no link with family history of diabetes. Children with T1DM are at risk for long-term complications (damage to cardiovascular system, kidneys, eyes, nerves, blood vessels, gums, and teeth). Frequent urination and extreme thirst are usually the first apparent signs of diabetes, though other symptoms like excessive hunger, fatigue and blurred vision can be observed. Symptoms of T1DM develop over a short period of time and the intense onset is usually identified in children and adolescents.

Different states of India have initiated activities for prevention and control of NCDs with technical and financial support from the Government of India through the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS). In the state of Andhra Pradesh, NPCDCS was implemented in eight districts, with Vizianagaram and Nellore in 1<sup>st</sup> Phase and Srikakulam, Krishna, Prakasam, Chittoor, Kadapa and Kurnool in 2<sup>nd</sup> Phase. In this program, early diagnosis of NCDs (opportunistic screening in people >30 years of age) involving clinical examination and physical measurements (blood glucose, blood pressure etc.,) was carried out. Among the 17,03,512 people screened in eight districts, prevalence of diabetes and hypertension observed was 7.23% and 7.84%, respectively.

As part of the pilot project, school-based diabetes screening program was started by the Government of India in six districts across the country. 752 children from urban (268) and rural (484) localities of Nellore district were screened. Out of the 752 children, 6 students had random blood sugar >160 mg/dL; 488 (urban - 131, rural - 357) children were under weight (BMI <18 kg/m<sup>2</sup>), 32 (urban - 20, rural - 12) were overweight (BMI = 23.1-25 kg/m<sup>2</sup>) and 22 (urban - 16, rural - 6) were obese (BMI >25 kg/m<sup>2</sup>). The incessant increase of T1DM and the observed prevalence of overweight/obese children warrant vigorous efforts to successfully manage this condition in children.

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Session 5

# **Managing Type 1 Diabetes 'As Complex as Bringing Up Children'**



# Maternal and Early Childhood Risk Factors for Type 1 Diabetes Mellitus



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In this era of modern science, the field of endocrinology has advanced to an extent where today's endocrinologists are capable of performing prenatal manipulations and postnatal corrections. The concept of prenatal programming using steroids has been extensively studied, where the sex of the new born infants can be controlled. Similar concepts may have applicability in controlling chronic diseases, such as diabetes, where maternal glycaemic control and thyroid control can have favorable effects on foetus in the womb. It has been shown that by decreasing the thyroid stimulating hormone (TSH) levels in mother during pregnancy, the offspring's IQ can be increased by 7 points. Several hypotheses such as thrifty phenotype, thrifty genotype and intrauterine programming have been put forward for management and perhaps prevention of type 2 diabetes.

Earlier T1DM was thought to be purely genetic, monogenic, easy to explain and simple to treat. However several factors have been attributed to its increasing prevalence, including genetic and environmental factors. Environmental influences in T1DM can be classified in feto-maternal, infancy and early childhood stages.

## Feto-maternal influences on T1DM

Factors such as maternal age, increasing birth order, maternal education and pre-eclampsia have been associated with T1DM. The risk of T1DM in infants increases by 5-10% with every 5 year increase in maternal age, due to increased maternal micro-chimerism, weight and accumulated toxins. Less breast feeding and intrauterine infections particularly with rubella and Coxsackie B virus have also been associated with increased risk of T1DM in infants. Reports from earlier studies suggest that feto-maternal vitamin D or maternal cod liver oil has beneficial effects in preventing T1DM in children. Vitamin D is involved in suppression of T-helper cells, which in turn aids in reducing infections and enhances insulin secretion from beta cells. It also acts as a free radical scavenger and is useful in prevention of post-insulinitis. On the other hand, although earlier reports on the effects feto-maternal omega-3 fatty acids on T1DM have been shown to be beneficial, latest reports found no association with T1DM risk. Another study showed that the fetus develops a liking for food odours that reach amniotic fluid through maternal diet flavours. Another aspect that can have profound influence on T1DM is prenatal stress/bereavement. Evidence suggests that pregnant women exposed to severe stress, prior to 20-24 weeks gestation, show overall risk ratio of T1DM to 2.03; while for girls the risk ratio increases by 2.91, indicating that girls are at higher risk of developing T1DM when exposed to stress.

Neonatal complications such as prematurity and neonatal illnesses, particularly neonatal jaundice caused by blood group incompatibility, are also associated with increased risk of T1DM in children. ABO and Rh incompatibilities, which are gene modulated, increase the risk of beta cell toxicity and cause haemolysis increasing the risk of T1DM in young infants.

### **Influences on T1DM during infancy**

Several factors such as breast feeding, weaning, types of weaning foods, vitamin D, infections and immunisation have been shown to be associated with T1DM in infants. Exclusive breast feeding and late weaning are associated with low risk of T1DM while early initiation of cow milk, which may or may not cause weight gain, is linked to a high risk of T1DM in children.

**Cow's milk A1/A2 hypothesis:** Bovine beta casein is a protein found in cow's milk which contains two variants, A1 and A2. A2 variant is found in Zebu (desi) cows while A1 type variant is found in American cows. Studies suggest that



infants feeding on American cow milk, which has the A1 variant present in it, produce bioactive peptide Beta-casomorphine-7 (BCM-7) upon GI proteolysis. The BCM-7 easily gets absorbed by immature guts of infants, binds to opioid receptors and oxidises low density lipoproteins (LDL), which does not happen with Zebu cows. It is hypothesized that the higher prevalence of T1DM in the west may be attributed to increased intake of milk with A1

variant that increases the levels of BMC-7 in infants resulting in higher oxidation of LDL. On the other hand it has been shown that infants elicit a higher insulin response to feeding with cow's milk and are more susceptible to cytotoxic effects of cytokines when compared to feeding with human milk. Increased amino-acid induced insulin secretion promotes growth in infants.

It was also hypothesised that gut microbes and helminthes may have some influence on T1DM in infants. Disturbing the microbial flora in gut may increase gut permeability and increase the production of toxins, while gut helminthes secrete glycan that has anti-inflammatory effect on islet cells of pancreas and may have beneficial effects against T1DM in children. Weaning of infants with processed foods, than with home-made foods, increases the risk of T1DM. Early use of potato in infants increases the risk of T1DM as it contains *Streptomyces* toxin bafilomycin A1. Similar to feto-maternal influence, Vitamin D and cod-liver oil had similar beneficial effects in infants, while omega 3 fatty acid showed no benefit.

### **Influences on T1DM during early childhood**

High meat intake was associated with an increased risk of T1DM in children. In

addition, air pollution, organic pollutants and viral diseases have been linked to a high risk of T1DM. Although vaccinations may promote T1DM, it has been shown that BCG vaccine may reverse T1DM in children. It may be hypothesised that malnutrition related diabetes mellitus may be associated with vitamin D deficiency. Increasing calciferol levels in children reduces insulin dosage in the short term. In conclusion, T1DM is a multifactorial disease in which environmental components play a major role. A multipronged research is needed to understand these environmental modulators that can influence T1DM in children.

## Preventing and Managing Complications in Type 1 Diabetes Mellitus

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T1DM is the most common type of diabetes in children and adolescents. This group of patients are most often insulinopenic and prone to diabetic ketoacidosis. T1DM is associated with an increased risk of hypoglycaemia, chronic complications and co-morbidities which place a heavy economic and psychological burden and hamper the affected child's ongoing growth and development. Moreover, clinical management of diabetes in children is often more challenging, as they rely solely on their parents as proxy decision-makers.

Neonatal diabetes mellitus which usually manifests in the first six months of life is characterized by polyuria, excessive thirst, increased appetite, weight loss and, episodic ketoacidosis with an increased risk of cerebral oedema. HbA1c, random blood sugar, fasting blood sugar, post carbohydrate blood sugar, C-peptide and auto antibody testing are some of the pathological tests useful in diagnosing T1DM in children. There is no single recipe to manage diabetes, which fits all children. Hospital-based management of diabetes, particularly DKA, should include fluid replacement for 48 hours, electrolyte homeostasis and insulin infusion until acidosis is resolved; whereas, ambulatory management of diabetes should include proper insulin therapy and self-monitoring of blood glucose, coupled with appropriate meal plan. It is also important to focus on comorbidities, growth and development surveillance, adjustment for sick days and, detection, treatment and prevention of hypoglycaemia. The insulin therapy should aim at adequate metabolic control, prevention of complications, normal growth and development, and better quality of life while providing ample flexibility. Although, a variety of insulin regimens (like split mix and premixed insulin regimens) are available for the treatment of diabetes in children, basal bolus regimens are best suited for the same.

Levemir or glargine, in combination with rapid acting insulins, is shown to be clinically effective in treating diabetes. However, considering the socio-economic status of people in India, neither these regimens nor insulin pumps (which are expensive) are a favourable option. Alternatively, cheaper regimens such as combination of Neutral Protamine Hagedorn insulin, with regular insulin may be selected, as they may have better efficacy in children when planned according to the intake of pre-meal sugars, carbohydrate

counting, insulin sensitive factors and physical activity. It is important to formulate a prudent meal plan with a healthy glycaemic index, to ensure normal growth and development while providing good glycaemic control. Diet should mainly consist of 70% carbohydrate and mono-unsaturated fatty acid content and supply age-appropriate calories and nutrients. Sucrose should be replaced with fructose and galactose to avoid sucrose abuse.

Home monitoring of blood glucose (HMBG), periodic height and weight check is essential in children with diabetes for proper insulin management. In addition to HbA1c, microproteinuria, thyroid function, serum creatinine levels and blood pressure monitoring, a comprehensive foot and retinal examination should be conducted on a regular basis. Celiac workup, cardiac function and fluorocein angiography should be performed periodically, while serum lipids should be examined in patients with a family history of hyperlipidaemia. It is essential that family, friends and school authorities be aware of this situation and act appropriately in case of an emergency.

**Salient points:**

- Basal-bolus regime is most suitable even in the most resource limited settings.
- Insulin therapy, in conjunction with self-monitoring of blood glucose, is absolutely essential in children, for effective glycaemic control.
- Both hyperglycaemia and hypoglycaemia should be avoided.
- Although insulin pumps provide greater flexibility in toddlers, they are expensive.



## Type 1 Diabetes Mellitus: Managing the Transition to Adulthood

**Dr. Archana Sarda**

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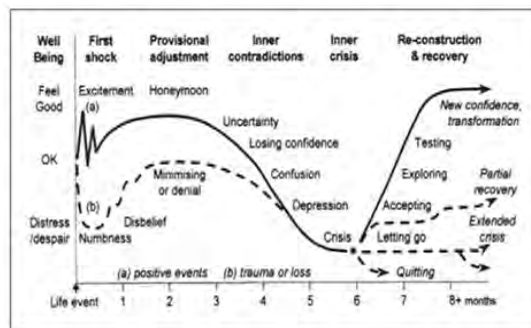
*Dr. Archana started Sarda Centre for Diabetes and Self Care in 1999. In the year 2005, she launched "Udaan"- NGO which provided comprehensive care for underprivileged children with T1DM with more than 150 children being cared for, currently. She conducted several diabetes awareness workshops and attended national and international diabetes conferences. For the past 11 years she has dedicated herself to patient care, created awareness for prevention of diabetes at a grass root level through street plays, jingles, movies and magazines for patients in local language, etc with a special passion for type 1 diabetes.*

The management of T1DM in adolescence is characterized by special challenges related to hormonal, emotional and social changes. During childhood and adolescence, diabetes care gradually shifts from being supervised by parents and guardians to self-care management. Thus, it is a period of transition from physical and mental immaturity to maturity. With the increasing incidence of both T1DM and T2DM, there is an increase in the absolute number of individuals with diabetes during this transition period.<sup>1</sup> The Transition Theory, proposed by Hopson and Adams in 1976, describes how individuals respond to change, either in their own lives or in environmental development (Figure).<sup>2</sup> Diabetes care for patients transitioning to adulthood is challenging with significant gaps that include lack of empirical evidence, difference between paediatric and adult healthcare providers (HCPs), social and demographic changes, health insurance gaps, unique learning style of emerging adults and lack of HCP training regarding emerging adults.

The incidence of T1DM in the paediatric population has increased in the last 50 years and it can be expected that each year, there will be a significant increase in the number of emerging young adults with T1DM or T2DM, who will be transitioning from paediatric to adult care. Competing academic, economic and social priorities often distract from a focused commitment to chronic disease management. With the increasing occurrence of T1DM in childhood and adolescence, more young people with diabetes will require a framework of care and education that prepares teenagers and emerging adults for successful self-management of diabetes. Additional tasks associated with self-care such as, scheduling follow-up diabetes appointments, obtaining diabetes prescriptions, and picking up supplies need to be shifted to emerging adults. During adolescent development, there is a need for families to remain involved in their child's diabetes management in order to reduce the risk of deteriorating glycaemic control. Although problems associated with the transition of paediatric patients to adult care providers have been addressed in several studies, the challenges of optimizing transition to adult care are formidable due to decline in clinical attendance. Considerable gap exists between recommended HbA1c levels and the levels actually achieved in clinical practice, especially for older teenagers and young adults. Studies in the U.S. have shown that only 32% of youth with T1DM aged 13-18 years and 18%

of those aged  $\geq 19$  years achieve ADA-recommended HbA1c target of  $<7\%$ , indicating an urgent need for effective treatment strategies to improve metabolic status in youth with diabetes.<sup>3</sup>

Currently, there are no proven strategies that ensure the best transition in order to prevent short- and long-term complications and maximize lifelong functioning. Motivation, which will lead to an increase in compliance to treatment is one of the most important aspects of T1DM management in adolescents. Several promising multi-disciplinary approaches, including patient self-care education and training skills, provision of speciality transition clinics with flexible evening clinic hours and after-hours phone support may help with the transition process. Continuity of diabetes care during adolescence and avoiding loss-to-follow-up care remains critical as it helps in reducing the need for acute hospitalisations, which proves to be expensive, and assures good glycaemic control with long term benefits. At the time of transferring from paediatric patient care to an adult facility, it is the responsibility of the paediatric team to provide written summaries of care issues along with medication lists. Special attention should be paid to screening, at this time, for diabetes complications such as disordered eating behaviours, psychological and mental health issues.<sup>4</sup> Healthcare providers should have open discussions with emerging adults regarding birth control, drug and alcohol use, smoking, sexually transmitted diseases, and planning for pregnancy as these issues are linked closely to healthy living with



The Transition Theory, by Hopson and Adams in 1976

diabetes.<sup>5,6</sup>

On-going and expanding research initiatives are needed, including efforts to identify and train adult providers who are well versed with medical care and psycho-social needs of emerging young adults with diabetes. Programs such as "Let's Empower And Prepare", designed to assist young adults with T1DM as they transition from paediatric to adult care, should be encouraged. They provide patients with a review of diabetes education and group classes to

help with carbohydrate counting, decision making regarding relationships, substance use and figuring out how to apply for low cost healthcare programs or maintain adult health insurance once paediatric coverage ends.<sup>7</sup>

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Session 6

# **Living with Type 1 Diabetes: Prevention and Management of Complications**



# Diabetes Mellitus in Children: Exploring the Psycho-social Domain

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Diabetes being an ecosensitive disease, children with T1DM are highly ecosensitive to biological or psychological environment. Management of diabetes in children is much more than just providing tight glycaemic control. It is related to various physical aspects such as availability of, accessibility to, and affordability of various therapeutic regimes in addition to diet, physical activity and healthcare. It also involves various social aspects related to availability of support by family and friends, and attitude and acceptance of society towards children with diabetes. Thus, psychosocial aspects would play an important role in management of diabetes. This psychosocial domain can be broadly categorized into general, psychological, psychiatric and social issues.

Child development is a dynamic process where they undergo rapid physical, cognitive and behavioral changes with time. It can be best explained by Piaget's theory which states that children in age group of 0-2 years will be in a sensorimotor stage where causality is not thinkable. Children in the age group of 3-8 years enter pre-operational/pre-logic stage where object permanence plays a major role in acceptance of regimen, e.g. play therapy with NOTTI dolls. In the concrete operational stage (8-11 years), children start comparing things with siblings or within their same age group where they require a logical answer to get convinced; while for children in the formal operational stage ( $\geq 12$  years), thoughts are complex/abstract and require abstract and logical answers to get convinced.

A 360 degree assessment of the child's behaviour is required before taking a major decision on treatment regimen. The behavioural assessment can be done by asking the child more than once in different ways, in different contexts and in different environments. Opinion of different stakeholders also helps physicians to understand child behaviour. Communication among HCPs, family members, the affected child and his/her school is absolutely essential to identify and resolve psychosocial issues.

Psychological assessment and modulation is another major aspect in this domain. Psychometric instruments, either self-rated (Beck Depression Inventory) or clinician rated (Children Depression Rating Scale-Revised and State Anxiety Scale-Children) can be used for assessment. However, most of

these instruments are either expensive or less validated in hospital settings and require professionals to evaluate. Alternatively, tools such as “DAWN Youth” by Novo Nordisk, can be employed at zero cost. In addition, psychological assessment of parents should also be performed and they should be explained about the link between glycaemia and psychological issues. Depending on the severity of the psychosocial problem, other management strategies such as cognitive behavioural therapy, interpersonal therapy, family therapy, play therapy (using NOTTI dolls), dancing and creative expression (such as painting) can be employed under the guidance of trained professionals. On the other hand, physicians handling children with diabetes need to be focused by listening and talking to them and explaining in simple language instead of using complex terminology. Infantilizing, depersonalization and stereotyping are often not appreciated by children and hence should be avoided.



**Soft toy “NOTTI” for demonstrating  
injection sites on the body**

Assessment and modulation of psychiatric disorders among children with diabetes is essential. About 3-7% of school children were observed with attention-deficit hyperactivity disorder where the child is inattentive or in defying mode towards treatment. Oppositional defiant disorder (ODD), observed among 2-16% of children, is another psychiatric disorder, where child is disobedient, and may not cooperate, opposing the authority. Conduct disorder is an advanced stage of ODD observed in 1-10%, where the child/adolescent may involve in violation of basic rights of others and age appropriate societal norms such as stealing things. Depression in children is usually characterised by irritability unlike loss of interest and loss of enjoyment (anhedonia) as seen in adults. In addition, eating disorders such as anorexia nervosa and bulimia nervosa can be observed among children with diabetes. Combining both psychological and psychiatric issues, a new concept of “Problem child” was developed. However, one should carefully assess if the problem is with the child or family or physician himself before labeling the child as a “Problem child”. Timely diagnosis by the physician or psychiatrist

and judicious treatment can help resolve such problems.

Children with diabetes are subjected to multiple pressures in a society. Abundant lay information on diabetes may result in cross talk of T1DM with T2DM consequently confusing patients. Parents should also understand that a child developing diabetes is not a sign of imperfect parenting and should come out of such myths. It should be understood that diabetes can occur at any time irrespective of age, sex, location and socio-economic status. Parents should educate and train their children about different coping mechanisms and how they can handle peer pressure. Patients should be taught that every window of vulnerability can be converted into an opportunity, which is only possible through effective learning and sharing responsibility of healthcare among patient, family and physician based on the ability and practicability. In conclusion, a physician should strengthen himself, the patient and his/her family to achieve the psychosocial wellness of that patient, which ultimately helps in attaining optimum glycaemic control in such children with diabetes.



## Preventing and Managing Complications in Type 1 Diabetes

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Diabetes is a chronic, life-long condition that requires careful monitoring and control. Without proper management it can put a patient at risk for a host of complications that can affect nearly every organ in the body, including damage to large and small blood vessels. Some common risk factors like poor glycaemic control, dyslipidaemia, hypertension, smoking and genetic predisposition can increase the risk of complications. In addition to vascular disease, diabetes accounts for approximately 233,000 deaths annually in the US alone. A meta-analysis of 97 studies has reported the hazard ratio (HR) for death among patients with diabetes compared to those without diabetes. HR was 1.80 for death from any cause, 1.25 for cancer-related deaths, 2.32 for death from vascular causes, 1.73 for death from non-vascular causes, and 1.88 for deaths from unknown and ill-defined causes.<sup>1</sup> As evident from the Diabetes Control and Complications Trial data, long-term complications of diabetes such as diabetic retinopathy, nephropathy, neuropathy, and microalbuminuria are associated with high levels of HbA1c.<sup>2</sup>

However, the risk of diabetes-related complications can be reduced with good glycaemic control. In view of this, the need for tight glycaemic control has been emphasized in several guidelines including the American Diabetes Association (ADA)<sup>3</sup> which recommends a target HbA1c of <7%, while the American Association of Clinical Endocrinologists (AACE) recommends a target HbA1c value of <6.5%. The Epidemiology of Diabetes Interventions and Complications follow-up study showed that intensive glycaemic control has a long-term, sustained effect on the subsequent risk of late microvascular and macrovascular complications. These observations suggest that either there is an influence of the concept of 'metabolic memory' or that once the processes leading to microvascular complications are initiated, they are self-perpetuating. Thus, intensive glycaemic control early in the course of the disease is highly recommended in patients with diabetes. Insulin is the most effective therapy for lowering of blood glucose, although it is associated with adverse effects of weight gain and hypoglycaemia. Accordingly, insulin kinetics have been modified by introducing insulin analogues and new therapeutic devices like, user friendly devices/syringes, pens and pumps to allow a rational approach to the treatment of diabetes.

Complications of diabetes can be avoided by aiming to achieve HbA1c levels

<7%, total cholesterol <200 mg/dL, triglycerides <150 mg/dL, high density lipoprotein (>40 mg/dL in men, >50 mg/dL in women), low density lipoprotein <100mg/dL, and blood pressure <130/80 mm Hg. The other ways of monitoring diabetes complications are by primary prevention and secondary prevention, prognostication and offering advanced care. Tempering of glycaemic control, using lipid lowering agents and anti-platelet drugs, in addition to other complication-specific measures like photocoagulation and intra-vitreous injections for retinopathy; calcium, activated vitamin D, iron, erythropoietin, vaccines and renal replacement therapy for nephropathy; foot protection and pain relief for neuropathy were found to be effective management strategies for diabetes in children.

Other management criteria includes adherence to disease specific recommendations by ISPAD.<sup>4</sup> For hypertension, ISPAD recommends monitoring BP, at least annually, and should be maintained at <95<sup>th</sup> percentile for age or 130/80 mmHg for young adults to decrease cardiovascular morbidity and mortality. For lipids, ISPAD recommends screening for fasting blood lipids in children over 12 years of age.<sup>4</sup> In case of a family history of hypercholesterolaemia or early cardiovascular disease, or if the family history is unknown, screening at 2 years of age is recommended and should be repeated every 5 years when results appear normal. ACE-inhibitors are recommended in patients with nephropathy as they tend to reduce progression to proteinuria. ISPAD recommends screening from 11 years of age and after 2 years of diabetes duration for retinopathy. However, the frequency of retinopathy screening should occur annually and frequently if there are high risk features for visual loss. For neuropathy, ISPAD recommends assessment of peripheral and autonomic neuropathy from 11 years of age, with two years diabetes duration, annual examination of feet; infections and ulcers after two years duration, and annually thereafter.<sup>4</sup>

Therefore, recognising the complexity of diabetes management, team approach is endorsed as an ideal model for diabetes care. The diabetes treatment team should include a physician, dietitian, nurse and behavioural therapist trained in diabetes management who would be responsible in providing medication, nutrition, and monitoring support to children with diabetes. In future, novel therapies like closed loop delivery, islet cell transplant and prevention strategies may mitigate diabetes associated complications in children and adolescents.

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# Managing Comorbidities in Type 1 Diabetes Mellitus

**Dr. Vijay Viswanathan**

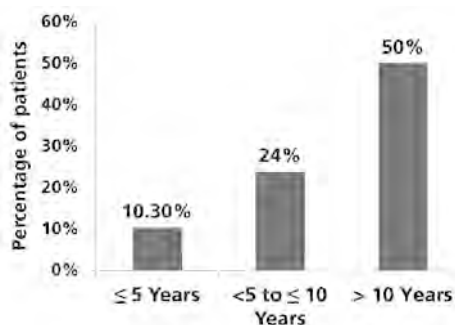
Head & Chief Diabetologist, M.V. Hospital & Prof. M. Viswanathan Diabetes Research Centre, Chennai.



Dr. Vijay Viswanathan completed his MD in Internal Medicine and was awarded Ph.D. in Medicine for his study on Diabetic Nephropathy in Type 2 Diabetes. He has published over 150 original articles in peer reviewed journals on diabetic kidney diseases and prevention of foot amputation in diabetes. He has organized 5 international conferences on diabetic foot and trained over 2,000 physicians in preventing foot amputation related to diabetes. He is currently Head of the WHO Collaborating Centre for Research, Education and Training in Diabetes and Secretary of the Diabetic Foot Society of India (DFSI).

The management of T1DM in children is complicated by several comorbid conditions that need regular screening, evaluation, and treatment. T1DM is associated with both autoimmune and non-autoimmune conditions which affect the physical and mental well-being of the child. The economic burden of diabetes management from an Indian study estimates an annual cost of INR1541.4 billion (US\$31.9 billion)<sup>1</sup> which is beyond the reach of those with limited family income. Premarital and preconception fear was observed among majority of youth with T1DM. Evidence suggests that more than 80% of patients either hide from their partners or feel difficult to take over family responsibilities. Majority of either sex are with the opinion that they will not have healthy children or their child may also develop diabetes in future.<sup>2</sup>

Reports suggest that several comorbidities such as microalbuminuria (MAU), thyroiditis, celiac disease, addison's disease, vitiligo and impaired growth are associated with T1DM in children. In a study by Vishwanathan et al. 2002, which assessed the prevalence of MAU in Indian subjects with diabetes, observed that MAU occurs in T1DM after the age of 20 years and increases with the duration of diabetes.<sup>3</sup> The incidence of thyroiditis in children with T1DM was 4 to 50% which is higher than children without diabetes. It was found that 70-80% of children with thyroid autoimmunity develop clinical disease over time which increases with age and duration of diabetes.<sup>4</sup>



Prevalence of Microalbuminuria

Hypothyroidism, a most common comorbidity that occurs with T1DM, increases the risk of hypoglycaemia resulting in growth failure. Hyperthyroidism on the other hand causes wider fluctuations in blood glucose levels and increases insulin needs.

Celiac disease is an immune-mediated enteropathy caused by a permanent sensitivity to gluten in genetically susceptible individuals. It is

characterized by modest/atypical symptoms. Reports suggest that there is increased prevalence in T1DM, reaching up to 10-20%. Incidence is also higher in children with positive family history, younger age and associated thyroid autoimmunity. A 3-fold increase in risk of developing celiac disease was observed in children with diabetes diagnosed at age under four compared to age over nine. Initial screening of all children with T1DM, periodic screening for every 2-3 years and an annual follow-up of antibody levels is recommended for diagnosis of celiac disease.<sup>5</sup>

Addison's disease is an autoimmune process identified by the detection of autoantibodies against the adrenal cortex. Up to 2% of patients with T1DM have been identified with presence of antiadrenal autoantibodies. Addison's disease is occasionally associated with T1DM in the Autoimmune Polyglandular Syndromes (APS I and II) and approximately 20% of subjects with APS-I develop T1DM. The condition is suspected by the clinical picture of frequent hypoglycaemia, unexplained decrease in insulin requirements, increased skin pigmentation, lassitude, weight loss, hyponatraemia and hyperkalaemia. Positive adrenal antibodies indicate a failed adrenal cortex and the development of primary adrenal insufficiency necessitating urgent treatment with a glucocorticoid. In some cases the therapy has to be supplemented with a mineralocorticoid.<sup>6</sup> Vitiligo is an acquired pigmentary disorder characterised by loss of melanocytes resulting in white spots or leukoderma. It is a common autoimmune condition associated with T1DM and is present in about 6% of diabetic children. Treatment is difficult and multiple therapies have been tried with little success.<sup>7</sup>

Poor gain of height and weight, hepatomegaly, and late pubertal development might be seen in children with poorly controlled diabetes. Pubertal phase is associated with reduction in insulin sensitivity, which is more severe in T1DM patients. Initiating intensive insulin regimen since the onset might help physiological growth in children and adolescents with T1DM.<sup>8</sup> In addition children with inadequate coping skills and family support may be more prone to psychological problems that include eating disorders, depression and anxiety.<sup>9</sup>

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# Growth Disorders in Type 1 Diabetes

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*Dr. Shaila Bhattacharyya has been actively involved in treating and educating patients on management of T1DM in children. Her area of research interests include growth disorders in diabetes and other endocrine disorders. She was also involved in developing nutrition guide for children covering various aspects involving good nutrition for your baby, kids nutrize, managing your diabetes - the carbohydrate counting way and creating awareness on the significance of paediatric nutrition.*

T1DM is a chronic disorder that may alter linear growth and pubertal development. Mauriac syndrome is a rare cause of severe growth failure in T1DM. Available data on growth of children suffering from T1DM, published over the last 20 years, are conflicting. Several studies have reported differential data on height at diagnosis. Some authors state that children with T1DM are taller at diagnosis;<sup>1</sup> while some report that they are shorter; whereas yet others do not observe any difference in height when compared to the control group.<sup>2</sup> T1DM can delay the onset of puberty in children, which can have adverse effects on growth velocity. Studies that observed the relation of height with time of onset of diabetes indicate that the children with onset of disease before puberty are taller than those with onset at puberty, when compared with the control group.<sup>3</sup> This can be attributed to the fact that neither puberty begins at the same time in all children nor it develops at the same rate.

Studies relating to growth retardation with metabolic control are also in line with the above studies. Additional data suggests that patients with T1DM manifest growth retardation irrespective of the degree of metabolic control.<sup>4</sup> In a five-year observational study by Stipancic et al. growth retardation was found to be more significant in pre-puberty and insignificant at puberty, while other studies demonstrated satisfactory growth with good metabolic control.<sup>5</sup>

**1**

- Whether the height weight and body mass index of children suffering with T1DM differ?

**2**

- Whether the possible differences depend on the stage of pubertal development as onset of disease?

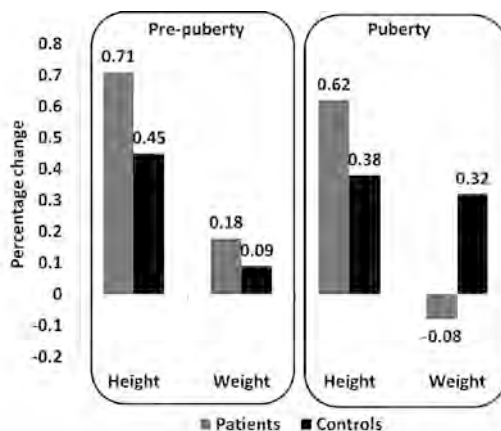
**3**

- Whether the course of disease effect height and weight and whether possible changes depend on metabolic control?

In this context, certain questions need to be answered for assured benefits in terms of growth in children with T1DM (Figure). Growth retardation was also found to be associated with difference in height of the patients with T1DM, which was dependent upon the age of onset of disease. Furthermore, the accelerated growth in young children was not compromised by the period of retarded growth. On the other hand, the onset of disease at puberty resulted in either same or shorter height, when compared to the control group. The growth retardation was more dramatic during the period of growth spurt.

The change in weight was observed in several stages of growth, pre-puberty and puberty. However, the available studies are confined to weight variations in patients at puberty. Stipancic et al. found that in children diagnosed at pre-puberty, BMI was not significantly decreased than those diagnosed at puberty, compared to the controls. The influence of BMI in relation to age and sex did not show any difference. Data from the study indicates that there is no difference in BMI and height between the patient group and the control group, though younger patients were heavier than controls. BMI was significantly reduced in older patients at diagnosis when compared to controls.<sup>5</sup>

Quality of metabolic control is crucial for normal growth of children with diabetes.<sup>6</sup> Evidence suggests that children in the pubertal stage are strongly affected by metabolic control, however in pre-puberty, children with good metabolic control demonstrated significant growth retardation.<sup>5</sup> Some other authors consider metabolic control as an important aspect in the duration of the disease<sup>7</sup> and age of onset of disease.<sup>4</sup> In contrary to this, others indicated that growth does not depend on metabolic control<sup>8</sup> indicating split opinions on this issue among researchers. Another study by Bonfig et al. showed that even with a combination of intensive insulin therapy and acceptable



Change in height and weight of patients with T1DM during pre-puberty and puberty

metabolic control, height was negatively correlated with duration of diabetes and mean HbA1c levels.<sup>9</sup>

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Session 7

# **Special Situations and Improving Long-term Outcomes in Type 1 Diabetes**



# Management of Type 1 Diabetes During Pregnancy

**Prof. Subhankar Chowdhury**

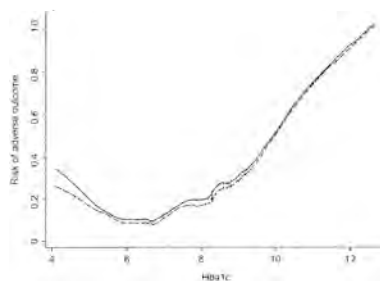
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Prof. Subhankar Chowdhury is the President Elect of Endocrine Society of India and has served at various positions in Diabetic Association of India, West Bengal, Endocrine Society of Bengal and Research Society for the Study of Diabetes in India. Dr. Chowdhury has worked on "Thyroid Peroxide gene polymorphism and its relation with thyroid dysfunction" funded by Department of Biotechnology, Government of India and "Genetic study of young onset diabetes mellitus in Eastern India" funded by Department of Science and Technology, Government of India.

Diabetes during pregnancy affects both maternal and foetal metabolism and even non-diabetic women exert a diabetogenic effect on the foetus. Adverse pregnancy outcomes associated with T1DM include abortions, fetal death, preeclampsia, pre-term delivery, neonatal death (death occurring between 22 gestational weeks and 28 days after delivery), congenital malformations, macrosomia and maternal morbidity and mortality. Children born to mother with diabetes mellitus have been observed with one or more of several anomalies which affect almost every system of the body and mainly occur before the 7<sup>th</sup> week of gestation. They include caudal regression, anencephalus, heart and renal anomalies, central nervous system congenital abnormalities etc.<sup>1</sup> During the 1<sup>st</sup> trimester of pregnancy, risk of adverse pregnancy outcomes increases with rising HbA1c levels.<sup>2</sup> Presence of nephropathy and MAU increase the risk of pre-term delivery; mainly caused by pre-eclampsia which occurs in 11–20% of women with T1DM. Infants with exposure to angiotensin-converting-enzyme inhibitors in first-trimester had an increased risk of major congenital malformations.<sup>3</sup> Diabetic nephropathy with macroalbuminuria results in significant loss of kidney function and may lead to end-stage renal failure while increased risk of hypertension and pre-eclampsia occurs with MAU during pregnancy. Pregnancy-induced deterioration of retinopathy may occur in T1DM.<sup>4</sup> Evidence suggest that improvement in glycaemic control in pregnant women has been associated with temporary worsening of retinopathy.<sup>4,5</sup> Moreover, women with moderate or severe retinopathy have the higher risk of progression to sight threatening retinopathy. However, supplementation with folic acid before pregnancy and up to 12 gestational weeks may reduce the incidence of complications and malformations in pregnant women with diabetes.

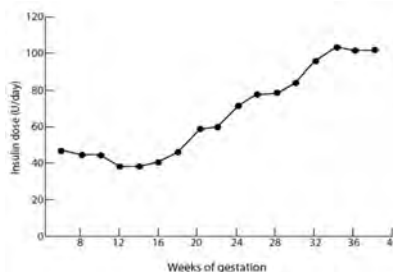
Evidence suggests that the risk of adverse pregnancy outcomes is halved with each percentage point reduction in HbA1c achieved before pregnancy (Figure). National Institute for Clinical



Risk of adverse pregnancy outcomes increases with rising HbA1c levels during pregnancy

Excellence (NICE) guidelines 2008 recommends a preconception HbA1c goal of <6.0%, if it can be attained without the risk of severe hypoglycaemia. The ADA recommends a target HbA1c of <6% in pregnancy. Moderate physical activity for 30 mins or more is also recommended for pregnant women, unless contraindicated. Urine ketone measurements at times of illness or when the blood glucose exceeds 200 mg/dl should be performed.<sup>6</sup>

Insulin requirements decrease during the first trimester of pregnancy, while insulin resistance increases progressively from middle of second trimester which often levels off or decreases after 35 weeks (Figure). Hypoglycaemia frequently occurs in the first trimester, where the peak of severe hypoglycaemic events persist between 8 and 16 gestational weeks.<sup>5</sup> Major risk factors for hypoglycaemia in pregnant women includes history of severe hypoglycaemia before pregnancy, impaired hypoglycaemia awareness, longer duration of diabetes, HbA1c <6.5% at first pregnancy visit and higher total daily insulin dose.<sup>7,8</sup> CSII may improve overall control, with a decrease in glycaemic fluctuations and events of hypoglycaemia, particularly nocturnal hypoglycaemia in pregnant women. Artificial sweeteners like aspartame and sucralose can be used in pregnancy.<sup>9</sup>



Insulin requirements decrease during the first trimester of pregnancy

Self-monitoring of blood glucose levels, before meals, along with postprandial capillary glucose measured 1-hour post meal is important. Short-acting insulin analogues (lispro and aspart) and a long-acting insulin (detemir) have been approved by the Food and Drug Administration (FDA), for use in pregnancy.<sup>10</sup> Proper preconception counseling should be given to diabetic women involving information on glycaemic status, folic acid supplements, diabetic complications, hypertension and thyroid dysfunction.

Optimizing glycaemic management in the 1<sup>st</sup> and retinal screening in the 2<sup>nd</sup> and 3<sup>rd</sup> trimester should be considered. Mode of delivery in mothers with ultrasound diagnosed macrosomic fetus should be discussed and mothers should be informed about the risks and benefits of vaginal birth, induction of labor and caesarean section. Insulin requirements drop to 60% of preconception dose immediately after delivery, which may further reduce by 10% when breast feeding. Thyroid function test and retinal examination should be done in the mother, while blood glucose test should be examined for every 1-2 hours in the newborn and the baby should be breast fed within 1 hour of caesarian section and 30 minutes of vaginal delivery. Tests for polycythaemia, hypocalcaemia, hypomagnesaemia and hyperbilirubinaemia should also be done and monitored for at least 24 hours. In conclusion, improved pregnancy outcomes in diabetic women can be achieved through

proper management of diabetes at all stages of pregnancy.

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## Diabetes in the Young: Guidance of Care

**Dr. Stephen Greene**

*President, ISPAD (International Society for Paediatric and Adolescent Diabetes) and Professor in Child and Adolescent Health, University of Dundee.*



*Dr. Stephen Greene qualified from University College Hospital Medical School, London and then pursued career in Paediatrics and Child Health with positions in Oxford, London, The Kinderspital Hospital, Zurich and Guy's Hospital, London. He was Secretary and then Chairman to the Scottish Study Group for the Care of the Young Diabetic, and has continued to direct the DIABAUD Programme. His research interests include diabetes technology and their effect on glycaemic variability and impact on angiogenesis, mobile - health support for diabetes and emotional and cultural impact on health and chronic illness of the young. He was Secretary to the Academic Board of the Royal College of Paediatrics and Child Health. In 2012 he became the President of ISPAD.*

Globally, diabetes is a disease in evolution, affecting more and more children and adolescents. Approximately 4,90,000 children around the world have been detected with T1DM; 2,50,000 of whom live in developing countries like India. Globally around 78,000 new cases are diagnosed each year with an annual increase in incidence reaching to 3%. In developing countries, the mortality rate for children with T1DM is critical with life expectancy less than one year. Despite the fact that this very large number of children need insulin, to survive without restrictions or disabling complications, the most common cause of death from a global perspective is lack of access to insulin. Furthermore in developing countries, when child is diagnosed with diabetes, it can be an immense burden and dilemma for the family.

ISPAD is a professional organization which aims to promote clinical and basic science, research, education and advocacy in childhood and adolescent diabetes.<sup>1</sup> The strength of ISPAD lies in the scientific and clinical expertise in childhood and adolescent diabetes provided by its members, majority being paediatricians and adult physicians involved in the care of children with diabetes. Other non-physician members are generally other healthcare professionals such as psychologists, nurses, dieticians, and social workers working for children with diabetes.

In 1993, members of ISPAD formulated the Declaration of Kos, proclaiming their commitment to “promote optimal health, social welfare and quality of



Management of children with diabetes

life for all children with diabetes around the world by the year 2000”. ISPAD published its first set of guidelines in 1995 and its latest in 2011.<sup>2</sup> Since then, the acceptance of intensive therapy using insulin and insulin pumps, for very young children, has increased around the world. The ISPAD 2000 consensus guidelines has been translated in to 11 languages, indicating the need for a truly international document. The 3rd edition of ISPAD's consensus guidelines, now called “Clinical Practice Consensus Guidelines”

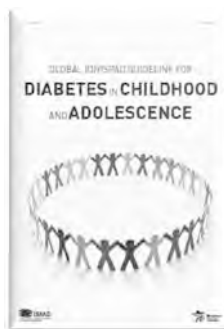
was released in 2009. In association with ISPAD, CDiC has developed a basic training manual, titled 'Diabetes in Childhood and Adolescence' (Figure), for healthcare professionals in developing countries. It deals with diabetes care in children involving diagnosis, treatment and care, patient education programs and training programs for health professionals.

Education on diabetes and encouragement from the society in combating the disease would provide moral support to T1DM patients. Diabetes healthcare strategies should focus primarily on diabetes health service and individual need of patients, supported by a structured education program and proper monitoring. T1DM patients should be given adequate counseling and support to manage the disease. Supply of insulin, blood glucose monitoring equipment and emergency facilities should be provided by healthcare professionals. Evidence based diabetes practice will eventually improve patient outcomes.

In conclusion, ISPAD is committed to improving the standards of care for children with diabetes (Figure), by implementing several programs such as preparing and disseminating written guidelines. It seeks to establish standards for practical and realistic care. Some of the key elements of care advocated by ISPAD include blood glucose testing of sick children, service through a multi-disciplinary team, resource-led intensive therapy, culturally appropriate patient education by a trained educator including a dietitian, establishing local guidelines for the acute metabolic complications of diabetes, supporting self-management and culturally appropriate counseling. At the institutional level it essential to focus on research and audit of clinical practice and take up advocacy for diabetes.

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Global IDF/ISPAD guidelines for diabetes in children and adolescents



# Type 1 Diabetes Care in Resource-limited Settings: An Indian Experience

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Dr. Srikanta is a Post Graduate MD [Internal Medicine] from All India Institute of Medical Sciences (AIIMS), New Delhi, India and Fellow in Endocrinology, Diabetes and Metabolism from Duke University Medical Center, USA. He is fellow in Joslin Diabetes Center, Brigham & Women's Hospital, Harvard Medical School, Boston, MA, USA. He has served as Assistant Director, Endocrinology, Diabetes and Metabolism at AIIMS and is also a Senior Consultant / Faculty at National Institute of Mental Health and Neurological Sciences, Bengaluru. Over the last 3 decades, the 3 major and innovative community service projects of Samatvam Trust, namely DISHA, DOSTI and DEEPA, have tried to enrich diabetes care in India, especially to the economically underprivileged.

A linear relation between the technological progress in the field of diabetes and the care process for patients with T1DM has been observed in the past two decades. However, for patients in resource-limited setting, the care process has changed only in the recent past. Experiences of care for T1DM in resource-limited setting, from the Indian scenario have been discussed.

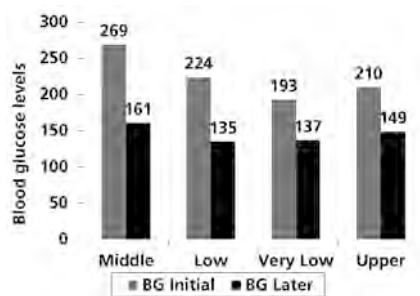
1974: During routine bedside teaching to medical students, Prof. Benakappa identified an 8-year old subject with juvenile diabetes at Vani Vilas Hospital, Bengaluru, India and kept him as a 'museum specimen' at that medical hospital. However, the boy was left untreated and a few months later he succumbed to the disease.

1978: Dr. Srikanta started research on 'Type 1 diabetes in India: Autoimmunity and genetics' with Prof. Man Mohan Singh Ahuja from AIIMS, India. A large number of patients with T1DM were screened for HLA typing (detection of HLA-A and B loci) and auto- immunity for islet cell antibodies.<sup>1</sup> The study established that the characteristics of patients with T1DM in India are similar to that of the western world including islet cell antibody, the first assay developed from India.

1981: He discovered two important phenomena in the pathogenesis of diabetes<sup>2</sup>:

- Autoimmune destruction starts 5-10 years before the clinical onset of T1DM patients.
- Selective destruction of beta-cells occurs 20-30 years after the disease onset, in T2DM patients.

A series of islet cell antibodies were identified, purified and characterised<sup>3</sup> in the process of developing a vaccine, specific to islet cell antigens, for patients with T1DM.



Blood glucose levels in different socio-economic status groups taking self monitoring blood glucose meters

1987: Dr. Srikanta, from his experience of molecular biology, initiated molecular sociology for the care of patients with T1DM. Two organisations: Jnana Sanjeevani, a medical centre and Samatvam, an endocrinology and diabetes centre were started for diabetes care.

The Jnana Sanjeevani centre offers healthcare, education, research, charity and spirituality for the cause of diabetes. The centre provides healthcare to inpatients and outpatients, free education and 24-hour diabetes helpline. The center supports programs such as 'Disha' for children and young adults with T1DM, 'Dosti' for adults with T2DM and 'Deepa' for diabetes care professionals.

Through project Disha, 30,000 children with T1DM from the state of Karnataka, India were screened and free insulin was supplied to around 3,000 underprivileged children. Insulin supplied was through bulk purchases, collection of leftovers from hospitals, short expiry from industry and gifts. Due to scarcity faced in the 2 decades of project, insulin rationing and reservation was undertaken to provide free insulin to children with limited resources. However, during the self-audit in 2008 when it was understood that overall healthcare was substandard, the 'Insulin plus Education' program was planned to encourage self-support in patients taking insulin.

2006: Another program, 'Rationed SHBGM' (self-home blood glucose monitoring), was started to supply free blood and urine glucose meters with strips to economically disadvantaged children with T1DM in India for improvement in metabolic control. A 7-point blood glucose profile of patients with T1DM from very low, low and middle socio-economic status groups taking rationed SHBGM, and upper socio-economic status group taking unlimited SHBGM were recorded over 4-6 weeks with 4 doses of insulin/day. Patients from very low socio-economic status not only showed excellent logs of profile with discipline but also achieved blood glucose profiles comparable to upper socio-economic status group after 6 weeks (Figure). The 'Rationed SHBGM' program is an example of rewards to intense discipline, sacrificing flexibility and enjoyment by children in resource-limited settings to achieve euglycaemia. A similar observation was made in a study, where children with T1DM from New Delhi (Indian cohort) achieved improvement in HbA1c values comparable to their western counterparts.

2011: The 'Changing Diabetes in Children program was introduced by Novo Nordisk for comprehensive care of diabetes for children in India. The program aims to enroll 4,000 children with T1DM, to improve access to needed medication and other elements for proper diabetes care. The program also aims to train diabetes care professionals and conduct awareness camps for children. In conclusion, the future of T1DM care in countries with resource-limited settings like India is a challenge with more political and individual will and honesty being required.

## 74 *Diabetes in Children*

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# Diabetes Technology and Their Effect on Blood Glucose Variability

**Dr. Santosh Olety Sathyanarayana**

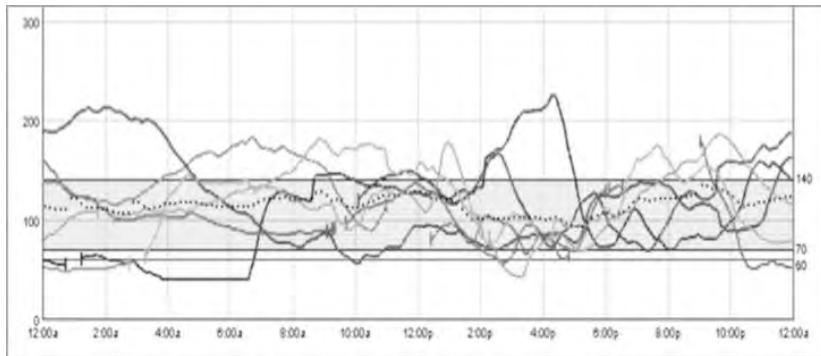
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To improve and make diabetes management more precise and easier, there has been significant advances in glucose monitoring techniques over the past few years. Blood glucose monitoring forms a core component of effective diabetes management in insulin treated patients. It helps to analyse the impact of lifestyle changes and effectiveness of insulin or other medications on blood glucose and prevent hyperglycaemic and hypoglycaemic episodes. Keeping blood glucose levels in a healthy range provides both short-term and long-term benefits with respect to health related quality of life. Although evidence from several landmark studies such as the Diabetes Control and Complication Trial (DCCT), Kumamoto and United Kingdom Prospective Diabetes Study (UKPDS) suggest that tight glycaemic control can significantly reduce long-term complications, it is often associated with increased episodes of hypoglycaemia. In addition to HbA1c and genetic factors, glucose variability may also result in hypoglycaemia. Thus, measuring glycaemic variability, in combination with HbA1c, may be a more reliable indicator to reduce long-term complications. Careful blood glucose monitoring is a more reliable way of detecting both glucose variability and hypoglycaemia.

Blood glucose monitoring can be performed either by continuous glucose monitoring (CGM) or by self-monitoring blood glucose systems.<sup>1</sup> However, conventional self-monitoring cannot detect the high variability of blood glucose levels and requires frequent testing in order to adjust insulin doses. Moreover, monitoring is limited to day time and nocturnal surveillance is not possible, which may have potentially serious consequences in patients with diabetes.<sup>2</sup> On the other hand, CGM provides the patient with real-time notification of blood glucose levels that identifies fluctuations in glucose levels. They come in both semi-invasive and non-invasive technologies and are particularly useful in patients with T1DM who are at greater risk of nocturnal hypoglycaemia, women with gestational diabetes<sup>3</sup> and for patients with hypoglycaemia unawareness.<sup>4</sup> CGM not only displays the real-time interstitial blood glucose values, but sounds auditory alerts for extreme changes in blood glucose values. These CGM systems are useful for children with T1DM,<sup>5</sup> patients with high glucose variability and poorly controlled diabetes.<sup>2</sup> Modern CGM systems use a needle-type disposable glucose sensor (at the end of needle) placed just under the skin that measures glucose levels in the interstitial fluid using glucose oxidase method. The information is sent to a



Real time system of monitoring blood glucose levels to detect hypoglycemia and hyperglycemia

non-implanted transmitter that displays glucose levels with continuous updates and monitors the rising and falling trends of glucose. The steady state difference in capillary blood glucose and interstitial fluid (~10 min) is compensated for by sensor calibration, using traditional blood glucose measurement.

CGM systems can identify four times as many serious blood glucose excursions, 60% more hypoglycaemic episodes,<sup>4</sup> and significantly reduces the HbA1c levels<sup>6</sup> than conventional self-monitoring. However, interference of certain chemicals (glutathione, ascorbic acid, uric acid, salicylates) with glucose readings and the 10 minute lag time in patients with rapid glucose variability can limit their use. Two types of CGM systems are available:

- Retrospective systems that measure glucose levels during a certain time span (usually 3-4 days), where the stored information can be downloaded in different graphical representations
- Real-time systems that continuously provide the actual glucose concentration on display, added with alarm for hypoglycaemia and hyperglycaemia (Figure).<sup>7</sup>

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**Continuous blood glucose  
monitoring kit**



Panel Discussion

# **“No Child Should Die of Diabetes”: Vision to Reality**





## Panel Discussion: “No Child Should Die of Diabetes”

*Dr. Manoj Chadha (Moderator), Prof. A.K. Das, Prof. K.M. Prasanna Kumar, Prof. Stephen Greene, and Prof. Subhankar Chowdhury*

Panel discussion on second day focused on identifying children with T1DM, delineating the extent of problem, focusing on acute, ongoing care with motto of optimum care for all, managing comorbidities, preventing acute and chronic complications, recognizing the importance of quality of life and scope of rehabilitation in children with T1DM. The following points were discussed during this session,

### **1. Is it important to establish registries for T1DM in India and what is the best way to do it?**

- The number of cases of T1DM in India is rising faster than the 3% rate of increase reported globally. In India, it is between 3-10% which is a cause of concern. Globally, we have minimum of 78,000 cases per year which will soon touch 100,000. In South-east Asia, India has the maximum number of cases. It is the 2<sup>nd</sup> most common childhood chronic disease. It is the need of the hour to make a structured effort of organising registries and try to capture all the cases.
- Comprehensive programs are necessary which include all aspects of care; e.g. when China started to prepare the registry to capture all data about patients with T1DM, the 3C study (coverage, cost and care) was initiated, which included all the leading universities and healthcare clinics.

### **2. How to identify these children with T1DM?**

- Any sick child should initially have blood glucose test as first step.
- Screening sick children initially for blood glucose values followed by more extensive screening programs.
- Creating awareness at all levels, especially HCPs, about the importance of blood glucose testing.

### **3. What would be the recommendations for the management of acute decompensation?**

- Every child diagnosed with diabetes for the first time should be admitted to hospital which has got facilities that can differentiate the type and analyze samples further. New diagnoses will enhance available data only when investigated properly and evaluated.
- Care for diabetic ketoacidosis: Guidelines for care have not been addressed in the previous protocols and they must be developed.
- Blood sugar above 250-280 mg/dL should be treated as an emergency

and the child should be immediately admitted to hospital and should be given acute intensive care.

- ♦ For children who cannot be admitted, guidelines have to be developed for minimal setup investigation, evaluation and treatment.
- ♦ There should be a structured education program for both child and parent about the importance of monitoring and tight glycaemic control, and then for subsequent care the child should be followed up.
- ♦ There is a need to develop Indian criteria for diagnosis of patients and data obtained from the standardised criteria must be used for advocacy with the government, so that certain amount of resources can be obtained for the same.

#### **4. What is the importance of non-pharmacological interventions like lifestyle modification in T1DM?**

- ♦ Non-pharmacological intervention for T1DM is of paramount importance and thus requisite resources must be made available to the patient. e.g. dietitians and nutritionists must be accessible, diet must be matched with insulin.
- ♦ Carbohydrate count of food is necessary as the Indian diet does not lend itself to easy carbohydrate counting.
- ♦ Nutrition and exercise must be balanced.
- ♦ Self-management and support must be encouraged.

#### **5. For monitoring what is the ideal setup and regular day-to-day setup?**

- ♦ Monitoring is central for management of T1DM thus monitoring tools must be made accessible by the government.
- ♦ Ideal frequency of blood glucose monitoring should be as frequent as possible to achieve good glycaemic control.
- ♦ Monitoring protocols must be situational, to be sensitive to conditions like pregnancy, sick children etc. and to suggest best possible therapy in the setting.
- ♦ Team approach with different responsibilities is fundamental and most effective for monitoring.

#### **6. Recommendations for monitoring of complications in T1DM**

- ♦ “Catch them young catch them early” is the notion.

#### **7. Co-morbidities in patients with T1DM that should be tested?**

- ♦ Thyroid and celiac function should be tested.
- ♦ Antibody test along with thyroid-stimulating hormone should be conducted.

### **8. How could we make use of technology in management of T1DM?**

- ♦ Gadgets used should be based on affordability, and acceptance of the patient; pen technology is the basic minimum that should be provided.
- ♦ Use of internet can be a powerful tool for enhancing the knowledge of the patients with diabetes and e-consultation.
- ♦ Non-invasive monitoring at zero maintenance cost and cheaper sticks for blood glucose monitoring must be developed.
- ♦ Mobile phones can be a useful tool to spread awareness due to their reach; sending SMS can be an easy and affordable way to connect the patient with the physician.
- ♦ Patient awareness of pens as basic minimum requirement.
- ♦ Pumps and CGMS and their advantage and limitations should be made available.

### **9. What can we do to encourage rehabilitation of the patients with T1DM?**

- ♦ Providing psychosocial support to the child and family.
- ♦ Government must pass suitable legislation and ensure its implementation such that children or adults with type1 diabetes are not discriminated in employment, education and marriage (A known and well controlled diabetic is better than a non-diabetic-WHO).
- ♦ The amount of insulin required by children with T1DM, is about 0.48% of the total insulin production. If concerted efforts are made by the government or industry it must be easy to take care of all children with type1 diabetes.
- ♦ The aim should be "No child should die of diabetes". It is also important that childhood doesn't get ruined and that children with T1DM grow up into healthy productive adults.



# **Consensus Statement on Diabetes in Children - Improving Access to Care**

**1<sup>st</sup> International Consensus Statement on  
Diabetes in Children**



## Consensus Statement on Diabetes in Children

*Prof. K.M. Prasanna Kumar (Chairperson), Dr. N. Prabhu Dev, Dr. K. V. Raman, Dr. Rajnanda Desai, Dr. T. Geetha Prasadini, Ms. Soraya Ramoul and Prof A. K. Das (Moderator) and a panel 294 eminent doctors*

*The first international consensus meet on diabetes in children was convened with the aim of providing a common platform to all the stakeholders in the management of T1DM, to discuss the academic, administrative and healthcare system related issues. The ultimate aim was to articulate the problems faced by children with diabetes in a way that centralised their position and focused on creating modalities of management sensitive to their needs and aspirations. It was conceptualised to raise a strong voice of advocacy for improving the management of T1DM and ensuring that "No child should die of diabetes".*

### **Background**

Worldwide, T1DM accounts for approximately 78,000 children, with 70,000 new cases diagnosed each year.<sup>1</sup> These individuals have an absolute deficiency of insulin secretion, primarily due to T-cell mediated pancreatic islet beta cell destruction, making them prone to ketoacidosis.<sup>2</sup> The number of children developing this form of diabetes is increasing rapidly every year, especially, amongst the youngest age groups.<sup>1</sup> While there are geographic differences in trends, the overall annual increase in the incidence of T1DM among children (especially <15 years) is estimated at around 3% worldwide. Increased incidence can be explained by an increased detection rate and autoimmunity among children.<sup>1</sup> However, unlike west, increasing trends in T1DM with a non-autoimmunological etiology might be responsible for increased incidence in India; of the cases diagnosed with T1DM, 23% did not show much correlation with autoimmunity in physician-reported clinical experience, showing high levels of C-peptide (>0.8%) and presence of glutamate decarboxylase and IL-2 antibodies. Many factors such as environmental pollution, toxins in food, chemical-intensive cultivation practices, sanitation, stress factors and viral infections have been implicated in the increased incidence of T1DM in children, apart from conventional risk factors such as history of T2DM and genetic predisposition.

### **Incidence and prevalence in India**

Globally, around 78,000 children under the age of 15 years are estimated to develop T1DM. Of the estimated 4,90,000 children living with the disorder, 24% come from the European Region and 23% from the South-east Asian Region, according the IDF 2011.<sup>1</sup> Although studies on the incidence of T1DM in India are scarce (with documented statistics available only from three studies), it is estimated that there are over 1,00,000 cases of T1DM in India with a 3-5% increase annually.<sup>1</sup> A study conducted in Karnal showed that the overall prevalence of T1DM is 10.20/1,00,000 population. The prevalence was higher in urban populations (26.6/1,00,000) and in men (11.56/1,00,000) as compared to rural areas (4.27/1,00,000) and women (8.6/1,00,000).<sup>3</sup> Two other previous studies, conducted in Chennai and Karnataka, showed the overall prevalence to be 10.5 and 3.8 cases per 100,000 population, respectively.<sup>4,5</sup> Currently data collection for the ICMR-led "Diabetes in Young" registry for T1DM is under progress at more than 70 centres across the country and efforts are underway to begin these registries in all the states. From the data



currently available, around 6,600 cases of T1DM have been identified and centre-wise variations in the prevalence were found, in certain cases. Though the incidence of T1DM in the population is low when compared to the west, the burden of diabetes is high in India due to a large population.<sup>6</sup>

Surprisingly, the prevalence of T2DM in children also showed a rising trend. Increasing sedentary lifestyle seen in all sections of the population, including people with diabetes, further amplify the incidence rate.<sup>7</sup> Irrespective of the socioeconomic status, this disease is equally prevalent among all sections of the society. It is a well-known fact that socioeconomic factors and poverty are the most important barriers impeding access to quality healthcare in India.<sup>8</sup> Thus, it is highly likely that a majority of the children with T1DM who belong to the poorer sections of the society, show far worse outcomes in India than in developed nations.

<b>Criteria for the Diagnosis of Diabetes Mellitus in Children &amp; Adolescents</b>	
Symptoms of diabetes plus casual plasma glucose concentration $\geq 11.1$ mmol/L (200 mg/dl). <sup>*</sup> (Casual is defined as any time of day without regard to time since last meal)	
OR	
Fasting plasma glucose $\geq 7.0$ mmol/L ( $\geq 126$ mg/dl) <sup>†</sup> (Fasting is defined as no caloric intake for at least 8 h)	
OR	
2-hour postload glucose $\geq 11.1$ mmol/L ( $\geq 200$ mg/dl) during an OGTT	

OGTT: Oral glucose tolerance test; The test should be performed as described by WHO,<sup>9</sup> using a glucose load containing the equivalent of 75 g anhydrous glucose dissolved in water or 1.75 g/kg of body weight to a maximum of 75 g. <sup>\*</sup>Corresponding values (mmol/L) are  $\geq 10.0$  for venous whole blood and  $\geq 11.1$  for capillary whole blood <sup>†</sup> $\geq 6.3$  for both venous and capillary whole blood

### **Challenges in management of T1DM in children**

A child with T1DM needs to follow a structured self-management plan including proper insulin use coupled with blood glucose monitoring, physical activity, and a healthy diet. In addition, awareness of diabetes and diabetes care is needed for successful disease management. However, in many parts of the world, especially in developing countries, access to self-care tools including self-management education and to insulin therapy is limited.<sup>1</sup> Low levels of awareness of diabetes and its complications and inadequate physician recommendation of insulin,<sup>10</sup> coupled with financial<sup>11</sup> and emotional burden of the cost of treatment and monitoring equipment, result in poor glycaemic control.<sup>12</sup> Poor glycaemic control in turn is associated with frequent

hyperglycaemia, diabetic ketoacidosis, dehydration, thrombosis and early death in children with diabetes.<sup>13</sup> Although insulin treatment is life-saving and lifelong, perceived non-flexibility of insulin regimens, in terms of administration and multiple doses, contribute to non-adherence to treatment.<sup>14</sup> The ease of administration and flexibility of use is an important factor affecting the acceptance of treatment recommendations<sup>15</sup> and numerous studies have shown low levels of compliance to therapy.<sup>16,17</sup> Children find using insulin therapy inconvenient due to its perceived interference with eating, exercise and daily routines. In addition, fear associated with hypoglycaemia, pain of injection, time required for administration and embarrassment hinder the use of insulin by children.<sup>18</sup> Regular monitoring of blood glucose through self-monitoring devices is insufficiently practised among children as they find it painful and cumbersome.

Diabetes can result in discrimination and may limit social relationships, particularly in children and adolescents, who may find it difficult to cope emotionally with their condition. Children with T1DM often show low levels of compliance to therapy, as they avoid/skip taking injections at school.<sup>16,17</sup> The burden of timely dosing of insulin, religious sensitivities about dietary taboos, and low awareness among teachers about the disease may adversely affect patients' ability to comply with medical advice.<sup>19</sup>

The problems facing successful T1DM management are further compounded by the benign neglect of T1DM in the public healthcare system. Due to the sheer number of patients with T2DM (i.e. more than 61 million cases in India),<sup>1</sup> T1DM often is relegated to being its "poor cousin" in the matter of receiving administrative attention and allocation of resources. The focus while teaching, managing and allocating resources is always on T2DM; doctors are poorly trained in managing T1DM cases resulting in several long-term implications. The quality of medical education for T1DM is low with an allocation of a maximum of three hours for undergraduate- quite generous when compared to the one hour that is deemed necessary as per MCI guidelines. This adds to the lack of knowledge about the management of T1DM among healthcare professionals.

Inadequately trained primary care providers (PCPs) fail to provide quality diabetes care and/or disseminate the information necessary for adequate diabetes awareness. The variable levels of awareness of diabetes amongst the general public and government is also manifested through the disparity in funding for diabetes seen amongst different state governments in India. The unique clinical presentations of T1DM coupled with ignorance on the part of the medical community and society in general results in outcomes that are far worse than that seen with T2DM. So there is a need to substantially improve training of HCPs at all levels on this neglected aspect of healthcare.

***Treatment approach for management of T1DM******Rationale and implementation***

Optimal use of insulin helps to redress the balance between hyperglycaemia and hypoglycaemia when administered in consideration to the continuous availability of insulin, and assuring access to tools for self-monitoring of blood glucose in order to enable titration of insulin doses based on carbohydrate intake. For ensuring effective T1DM management, it is important to focus on a multidimensional strategy which involves:

- Enabling access to insulin and providing tool for the optimal use of insulin in a convenient manner
- Tailoring the treatment according to the patient/family convenience
- Diabetes education of patient/family to empower them with appropriate information about insulin use
- Context-sensitive training and education of HCPs

***Evidence-base***

The strong relationship between HbA1c levels and long-term complications warrants good glycaemic control, early after diagnosis.<sup>20-24</sup> Novel options in insulin therapy are crucial necessity to address efficacy and safety concerns. The basal-bolus concept, as either multiple daily injections or continuous subcutaneous insulin infusion (CSII), has been shown to give the best results with regard to this aspect.<sup>25-28</sup> Evidence suggest that rapid-acting analogues given immediately before meals reduce postprandial hyperglycaemia as well as nocturnal hypoglycaemia.<sup>29</sup> Rapid-acting analogues are approved for paediatric use e.g. insulin aspart for children above 2 years, insulin lispro for those above 3 years and insulin glulisine for those above 4 years of age. They also offer the useful option of being given after food when needed (e.g. for infants and toddlers who are reluctant to eat). Insulin detemir is approved for children above 2 years of age and has shown lowest within-subject variability,<sup>30</sup> reduced hypoglycaemia rates, improved adherence and greater treatment satisfaction.<sup>23,28</sup>

With adequate education and support, use of external pumps (CSII) in young infants is successful.<sup>31-35</sup> Combining intensive insulin therapy and glucose sensors with real-time display is associated with a significant improvement of glycaemic control, when worn continuously compared to conventional self-monitoring of blood glucose.<sup>36</sup>

***Guideline on insulin dosage - At diabetes onset<sup>37</sup>***

- Day 1 (throughout the night): Give regular insulin every second hour until blood glucose is <11 mmol/l or (198mg/dL), then every fourth hour.
- Dose: <5 years - 0.1 U/kg, 5 years or older 0.2 U/kg. If hourly monitoring of blood glucose cannot be provided, begin with half the above doses.

- Day 2 (from morning/breakfast): 0.5-0.75 U/kg/day, distribution of insulin as below: adjust doses daily according to blood glucose levels. The morning (and 3 am) blood glucose is used for adjusting the bedtime basal dose, premeal levels to adjust the daytime basal insulin. Two-hour postprandial blood glucose is used to tailor the meal bolus doses. The breakfast premeal dose is usually the largest bolus dose, due to insulin resistance in the morning.

*Insulin need<sup>37</sup>*

- During the partial remission phase, the total daily insulin dose is often <0.5 IU/kg/day.
- Prepubertal children (outside partial remission phase) usually require 0.7-1.0 IU/kg/day.
- During puberty, requirements may rise substantially above 1 U/kg/day and even up to 2 U/kg/day.

*The "correct" dose of insulin<sup>37</sup>*

- Achieves the best attainable glycaemic control for an individual child or adolescent.
- Does not cause obvious hypoglycaemia problems.
- Leads to appropriate growth according to children's weight and height charts.

*Distribution of insulin dose*

- Children on twice daily regimens often require two-third of their daily insulin in the morning and one-third in the evening.
- On this regimen, approximately one-third of the insulin dose may be short-acting insulin and approximately two thirds may be intermediate-acting insulin.
- On basal-bolus regimens the night-time intermediate-acting insulin may represent between 30% (for regular insulin) and 50% (for rapid-acting insulin) of the total daily insulin dose. Approximately, 50% as rapid-acting or 70% as regular insulin is divided between three to four premeal boluses. When using rapid-acting insulin for premeal boluses, the proportion of basal insulin is usually higher, as regular insulin also provides some basal effect.
- Recently introduced rapid-acting analogues are safer and better because of shorter duration of action so higher percentage of basal insulin required as no basal coverage is provided by rapid-acting analogues.

### ***Addressing barriers in T1DM management***

#### ***Ambulatory diabetes care***

A team of specialists with expertise in diabetes and paediatrics should care for children with diabetes with an aim to provide:

- Specialised hospital care including the diagnosis and initial treatment using established protocols for diabetic ketoacidosis.
- Comprehensive ambulatory care of diabetes and associated complications and comorbid conditions, including advice on all aspects of the child's home/school care.
- Thoughtful introduction of new therapies and technologies; emergency access to advice for patients, 24 hours a day.

#### ***Insulin treatment***

Novel options in insulin therapy with better features, has been a crucial necessity to address the efficacy and safety concerns. Patients either skip doses or take less than the recommended dose due to concerns about the deficiencies in efficacy or safety profile of existing insulins. Independent factors like multiple injections, interference with daily activities, injection pain and embarrassment play a significant role in insulin omission. To avoid multiple dosing, a truly basal insulin must be designed which requires once daily administration, has a flat profile, which mimics the pharmacokinetic/ pharmacodynamic action of physiological insulin and ensures minimal intra-patient variability and longer duration of action.

#### ***Sick-day guidance***

Whenever the child is having a minor illness such as a cold, flu, an upset stomach, emotional stress or any surgical stress, these guidelines can be used;

- Test and record of blood sugar (glucose) and urine ketones every 2-4 hours.
- Check and record of temperature every 4 hours
  - If child has a fever (temperature greater than 99.5), drink some liquid at least once every half an hour.
  - Even if no fever, drink 120 ml of sugar-free, caffeine-free liquid every hour.
- Call the doctor for any of the following:
  - Rising urine ketone levels – if moderate to large.
  - Urine ketones present for more than 12 hours.
  - 2 blood sugar levels in a row higher than 250 mg/dL or lower than 60 mg/dL.
  - Vomiting or diarrhea that lasts longer than 6 hours.
  - High (101°F) or rising fever or fever for more than 24 hours.

## Recommendations for Insulin Use

There is no perfect insulin preparation, but good glycaemic control can be reached with insulin suitable to the patients' needs. The choice of suitable insulin should be individualized and based on the desired characteristics of the insulin as well as the availability and cost of the insulin.

- Insulin treatment must be started as soon as possible, after diagnosis in all children with hyperglycaemia to prevent metabolic decompensation and DKA.
- Multiple subcutaneous injection (MSI) of insulin, is feasible for a majority of patients that minimises the risk of hypos while offering the best control.
- The dynamic relationship between carbohydrate intake, physical activity and insulin should be properly communicated to the patient/family from the very first moment.
- The insulin selected should be as physiological as possible, but with consideration of the patient's and caregiver's preferences.
- Continuous glucose monitoring (CGM) should be made available and considered as an essential tool for adjusting insulin doses.
- Good technical skill with regard to handling syringes, insulin pens and pumps must be stressed upon to make insulin administration easier.
- Rapid- and long-acting insulin analogues should generally be available, alongside regular (soluble) and NPH insulin.
- Insulin storage
  - Insulin must never be frozen.
  - Direct sunlight or warming (in hot climates) damages insulin.
  - Patients should not use insulin that have changed in appearance (clumping, frosting, precipitation, or discolouration).
  - Unused insulin should be stored in a refrigerator (4-8°C).
  - After first usage, an insulin vial should be discarded after 3 months if kept at 2-8°C or 6 weeks if kept at room temperature.
- A basal bolus regimen with regular and NPH insulin is preferred over pre-mixed insulin preparations. NPH insulin should be given twice daily in most cases, in addition, regular insulin needs to be given 2-4 times daily to match carbohydrate intake.
- Pre-mixed insulin may be convenient (i.e. few injections), but they limit the customisation of the insulin regimen, and their use can be difficult in cases where regular food supply is not available.
- Insulin pump therapy should be made available and considered wherever suitable.
- Severe hyperglycaemia detected under conditions of acute infection, trauma, surgery, respiratory distress, circulatory or other stress may be transitory and may require treatment, but should not in itself be regarded as diagnostic of diabetes.
- Screening for diabetes associated antibodies may be useful in selected patients with severe hyperglycaemia.

*Addressing nutritional management*

A specialist paediatric dietician should be involved if possible in giving tailored advice to children and their families about the amount, type and distribution of carbohydrate to be included in regular balanced meals and snacks over the day, to promote optimal growth, development and blood glucose control. This advice should be regularly reviewed to accommodate changes in energy requirements, physical activity and insulin therapy.

*Managing diabetic ketoacidosis (DKA)*

Children and adolescents with DKA should be managed in centres with expertise in its treatment and where vital signs, neurological status and laboratory results can be monitored frequently.

*Patient-centric approach*

A patient-centric approach of diabetes care must be built, which is sensitive to the needs of patients and their ability to adhere to treatment recommendations.<sup>38,39</sup> Such an approach must respect socio-cultural factors (fasting, religious requirements etc.) that may play an important role in determining patient attitude to diabetes management.<sup>40</sup> India being a culturally diverse country, keeping the psychosocial factors in mind becomes all the more important. Socio-culturally responsive Indian national guidelines were evolved so that physicians can make treatment decisions accommodating Indian socio-cultural aspects. A greater degree of customization of therapy to individual needs can be achieved through a pool of well-informed and adequately trained paramedical personnel who facilitate better and easier adherence to therapy.<sup>41</sup>

*Diabetes education and awareness*

It is evident that in order to effectively manage diabetes, comprehensive education encompassing a variety of components of management such as blood glucose monitoring, insulin replacement, diet, exercise, and problem solving strategies must be delivered to the patient and family. People who are well educated often can manage their diabetes well. An effective diabetes awareness program needs to encompass:

- Strategies to reach out to the general population to spread awareness of the disease and its complications.
- Educate and reach out to diabetes patients and physicians to improve outcomes.
- Public health campaigns led by associations and policy makers to overcome social stigma of T1DM.

Educational programs to educate and sensitize concerned persons in diabetes management must be uniform with respect to content, especially with regard to insulin therapy.<sup>42</sup> There is a need to create space for specialised diabetes

educators who will satisfactorily educate patients and their families, and raise awareness of diabetes and insulin therapy.<sup>43</sup> Designing family-centric education programs using a team of HCPs, to address the immediate care environment i.e. the family, will help in encouraging insulin use by patients. Below are ten best practices for creating awareness of diabetes among public:

- Diabetes through media and public posters with catchy phrases like “Jaanch Kijiye Do Jaan Bachayiye” or “Ek Boond Jindagi ke Liye”.
- Display visual posters on T1DM in every clinic irrespective of the treatment area across the country.
- Inclusion of diabetes and its management as topics of instruction in school curriculum.
- Training teachers at school level about the management of diabetes in children.
- Launching diabetes oriented short films/movies.
- Special incentives to be provided by the government to people with T1DM.
- Developing specific websites for T1DM.
- Diabetes education through celebrity endorsements.
- Printing diabetes awareness messages on train/bus tickets.
- Celebration of world diabetes day especially for T1DM .

#### *Training of healthcare professionals*

T1DM is a special situation and requires special training of medical fraternity across all levels of healthcare, on a large scale, in all parts of the country. Integrating diabetes education and diabetes treatment protocols within a uniform framework across all levels of healthcare (HCPs, patients and community) will ensure effective care. There is an immediate need for special clinics for T1DM with specialized personnel such as nurses, doctors, and paediatricians for improved prognosis of children with T1DM.

#### *Documentation*

Documentation of non-communicable diseases on field, or through cost-effective means such as online registries, is a much needed initiative for obtaining undeniable, logically correct and accurate data. This will facilitate assessment of the current epidemiological status of the disease and the direction of progress of implemented programs. In addition, there is a need to delineate clear mechanisms to comprehensively capture clinical data which in turn is essential for effective advocacy for funding, which gains credibility through proper documentation. In rural areas, if any child is detected with diabetes, it should be made mandatory for schools, hospitals and pharmacies to report to the government for effective data collection. In case paediatric



of death in paediatric cases, a verbal autopsy of how the child died should also be undertaken to rule out/ascertain T1DM. All children with onset of diabetes below 14 years age should be categorised as T1DM and should be included in registry. Although, clinical manifestation characterised by presence of ketosis, atypical body mass index (BMI) of  $<23.5 \text{ kg/m}^2$  and high blood glucose levels are sufficient to confirm T1DM registry cases, there are many other criteria which can be made the basis of inclusion in the registry but may not be a mandated (e.g C-peptide, test and GAD test).<sup>44</sup> Borderline cases of C peptides should also be included for further diagnostic accuracy. In addition to epidemiological surveys to capture the true state of affairs, case findings beyond registries have to be highlighted for better understanding of the disease state in a country like India.

### ***Managing diabetes in children – the role of stakeholders***

Designing and implementing comprehensive strategies at a scale befitting the T1DM situation in the country requires collaboration and partnership between different constituents with an interest in diabetes care. Multiple partnerships between the government and the private sector in diabetes education should also be explored. There is a strong and unequivocal need for a paradigm shift in the management of T1DM by the medical community, government & society in general. NGOs, religious leaders and school teachers can also play an important role in creating awareness about diabetes as they influence the thought process of a vast majority of population. A multi-pronged approach is needed to tackle this situation. The roles and steps proposed to achieve this goal are discussed below:

#### ***Role of government and policy makers***

The government should support the collection and generation of countrywide epidemiologic data to capture the true state of the disease along with appropriate socio-economic criteria for proper disease management. Epidemiological surveys should be done, in at least one rural and one urban school, at 4 different geographical locations/population centres to know the true state of the disease in the country. If any child is detected with diabetes, it should be made mandatory for schools, hospitals and pharmacies to report to the government for effective data collection. The government should declare patients with T1DM as being metabolically-challenged and provide them with special privileges such as free admission to any hospital, in case of emergency. Insulin is a lifesaving drug for children with T1DM and thus the government should exempt tax on insulin and ensure its availability at a cost effective price. Diabetes should be specifically targeted by making provisions for insurance coverage to include patients with T1DM and facilitate equitable access to everyone, regardless of income. Government should be involved in developing comprehensive diabetes care programs and establish “centres of excellence” (e.g NDCDCS in Andhra Pradesh), which can provide education and support for preventing complications in children with T1DM.

### *Role of partnerships between various stakeholders*

Governments, in partnership with the industry and all other stakeholders, must consider supporting and augmenting the sustainability of programs such as CDiC to enable children with T1DM to have perfectly normal lives as their brethren in other countries. Public health campaigns must be designed to educate the lay public about this disease and its possible management with appropriate medicines, insulin, and education for achieving a normal life for the afflicted. Anganwadi programs like "Choti si asha" should be conducted in rural areas to identify and educate children with T1DM. Doctors, parents and school teachers should take onus for best optimal care. To ensure the delivery of quality care, specified private hospitals and clinics should be designated as centres for free disbursement of insulin, in addition to government hospitals. Furthermore, government along with the industry should encourage special courses for diabetes educators, to manage diabetes in children, and funding research for the development of low cost meters and non-invasive sticks for glucose measurements.

### *Role of industries*

Industries as a part of corporate-social responsibility should be involved in diabetes management programs in the public private partnership (PPP) mode. They should be encouraged to sponsor the treatment cost for children diagnosed with diabetes locally, apart from contributing towards education and awareness programs.

### *Role of physicians*

Physicians should offer free service and run holiday clinics for children with T1DM, particularly for those in the lower socio-economic strata. They should actively be involved in organizing camps for children with T1DM. They should form a link with school teachers and educate them about diabetes and its management in children. If possible, they should rope-in local pathological labs to perform free tests for T1DM as the number of patients is lower when compared to T2DM. Physicians should adopt "Learn globally and think locally approach" and substantially improve the quality of medical education with regards to T1DM considering the disproportionately poor clinical outcomes in this class of patients. Physicians should make use of training manuals from ISPAD and CDiC websites that are available free of cost. Training programs for paramedic's and healthcare professionals for diabetes specific situations such as diagnosis, treatment and management of children with T1DM should be undertaken by associations and government.

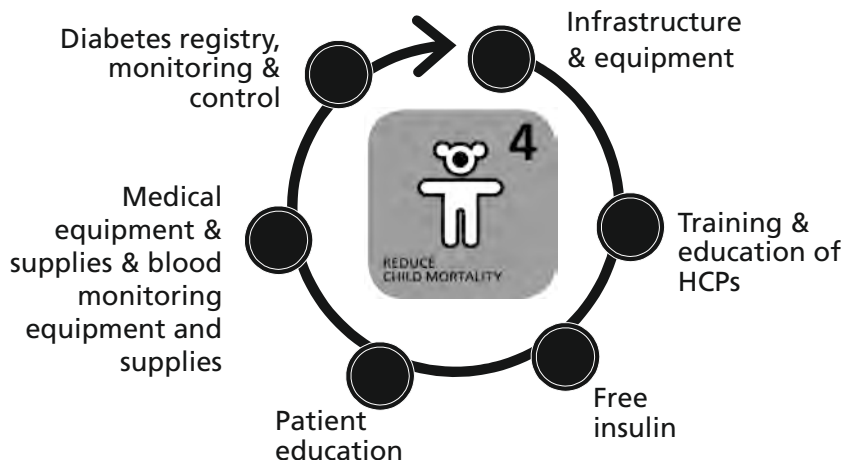
### **Conclusion**

While T1DM has been traditionally seen as a minor concern in the larger picture of paediatric ailments, new data reveals that the incidence of T1DM has assumed alarming proportions. It has long been clear that while the disease may be diagnosed at an early age, its impact is not isolated to afflicted

children. The direct impact of the disease on the patient is debilitating due to the nature of the disease and lack of proper access to treatment in India. But this impact is further compounded by the utter apathy and often times antipathy, which patients with T1DM have to face.

Lack of awareness of the issue in all stakeholders, low access to quality healthcare, patient, physician and system level barriers to the delivery of optimal diabetes care are some of the factors which hinder successful management of T1DM. With coordinated action by all the stakeholders, effective mechanisms to manage T1DM can be evolved. This must be a priority that should occupy our foremost thoughts to achieve the ultimate goal of “No child should die of diabetes”.

## Key Components of the Changing Diabetes in Children (CDiC)



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## CDiC India VISION

**"To initiate and strive for comprehensive diabetes care for the economically underprivileged children with diabetes"**

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