

## Reaching Out Dashboard

No. of Children 4063

No. of HCPs Trained 3502

No. of Children Camps 356

## CDiC - INDIA Newsletter

Issue: 11 / September / 2015



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Editorial Committee: Prof. P. Raghupathy, P. Dinakaran, Dr. Shuchy Chugh, Anupama Rau Attawar, Dr. Neera Gupta



## Editorial Desk



### Dear Friends / Colleagues,

"Changing Diabetes in Children" program always had a vision of bringing better outcomes for children with type 1 diabetes through comprehensive care. It also focused on bringing awareness in society & improved diagnosis plus management through capacity building. To continue with our vision, it will be a good idea to review our understanding on the key aspects of type 1 diabetes in children. It is heartening to note that we could capture >80% of data in the CDiC registry on type 1 diabetes. I will request you to keep on doing this on a continuous basis. After World Diabetes Day, we can take a decision on including non CDiC children with type 1 diabetes in the registry. We hope to bring more scientific literature and further increase our understanding on type 1 diabetes through this initiative.

I will like to congratulate all of you for successfully distributing scholarships to all the selected children. I would request each one of you to please take some time and present unique CDiC stories, which present in the psychosocial environment while we are treating these children with diabetes. These stories as you will agree will go a long way in improving the confidence and motivation among these children and their caregivers.

Please join the movement of creating awareness about type 1 diabetes by doing events on World Diabetes Day - 2015.

Wishing everyone a healthy and successful life.

**With Regards,  
Prof. P. Raghupathy  
Chairperson, CDiC.**



### Dear Colleagues

I always feel that CDiC program is a God sent opportunity for all of us. CDiC was strongly represented at the Madhya Pradesh, Bihar, Gujarat, Puducherry and Odisha state roundtable meetings. These meetings play an important role in communicating the issue of diabetes in children to state bureaucrats. One positive initiative has come into my notice. The "Standing committee on social justice and empowerment" has proposed in its report submitted on 7<sup>th</sup> May 2015, that type 1 diabetes may be considered as a disability. I would request each one of you to do a little bit from your part so that these children with type 1 diabetes can get their due rights and benefits.

With age and experience comes wisdom. Let us pool our collective knowledge and some key pieces of advice in our book on type 1 diabetes for Health care professionals.

Looking forward for your whole hearted support. Wishing you all and all the children a very happy Diwali.

**With Best Wishes  
Prof. Ashok Kumar Das**



### Dear Friends

I will like to thank each one of you once again, for your support in running the, "Changing Diabetes in Children", program successfully for the last four years. The smiles on the faces of children have strengthened our vision and mission of Changing Diabetes.

We are grateful for your backing in implementing the "Educational Scholarship Program", for the eligible children who are managing their diabetes & performing well in their studies. In keeping with our commitment on supporting, glucose monitoring for these children, we are now replacing the old meters with new meters. This will help them to check blood sugar regularly & keep their diabetes well under control.

I take this opportunity to wish you, your family, your support staff & all the children under your care a "Happy Diwali & Season's Greetings".

**Thank you  
Melvin D'Souza  
Managing Trustee NNEF  
VP & GM Novo Nordisk India Pvt. Ltd.**



## Changing Diabetes® in Children (CDiC)- on-going journey of care & commitment for children with type 1 diabetes

Changing Diabetes in Children program was unveiled in India, in September 2011 by our former President (Late) Dr. APJ Abdul Kalam. As a homage to the visionary, one will find CDiC moments with Dr. APJ Abdul Kalam in the photographs on every page.

### Quarterly Update

#### Infrastructure & Equipment

- Centre wise "lost to follow up" children in CDiC program can be replaced by children registered in respective centres under Novo Aid. The process discussed during advisory board meeting is being implemented.
- Pilot projects are being worked out for identifying the best way to improve compliance to prescription and reducing lost to follow-up children.

#### Insulin & Supplies

- The program continues with same dedication and momentum to seamlessly support access to insulin.
- New glucometers, strips and lancets are being sent to all the centres for children.

#### Capacity Building and Raising Awareness

- Planning to conduct 8 accredited HCP training programs across centres in the last quarter to further reach out to more HCPs.
- "Talking Diabetes in school", an e-mailer campaign to create awareness on type 1 diabetes among school teachers had reached around 2000 school teachers in the last 2 months.

#### Patient Education

- 45 children camps have been conducted since Jan 2015. This year focus is on practical topics like examination and diabetes, holidays and diabetes, etc.
- 2<sup>nd</sup> issue of Mishti Guardian for care givers for type 1 diabetes released.
- Educational scholarships distribution completed to the identified eligible children in almost all centres.

#### Advocacy

- Participation in Gujarat, Puducherry and Odisha State Roundtable meetings to bring the attention of the Government on the specific issues of children with type 1 diabetes.
- Working on adding type 1 diabetes in the disability list for getting benefits for these children.

The CDiC Centre Directors, viz., Dr. Banshi Saboo at Ahmedabad, Dr. Vijay Vishwanathan in Puducherry and Dr. Alok Kanungo at Bhubhaneswar, presented the situation and needs of children with type 1 diabetes to state bureaucrats in these meetings.

Going forward the key objectives of the program is to ensure better understanding, improved awareness and good outcomes for children with type 1 diabetes. There are plans for series of publications, best practices sharing and creating forums for discussing sustainable actions for these children from poor families suffering from type 1 diabetes.

#### Learning

- 8<sup>th</sup> Advisory board meeting was conducted on 23<sup>rd</sup> Aug 2015.
- 10<sup>th</sup> issue of CDiC newsletter released among caregivers and general public.

Going forward the key objectives of the program is to continue ensuring better understanding among HCPs, improved awareness among caregivers and general public and good outcomes for children with type 1 diabetes. Primary focus shall be to share the key learnings focused at reaching out to the medical fraternity, policy makers and Government stakeholders with the help of the scientific committee through periodic publications. There are plans for series of publications, best practices sharing and creating forums for discussing sustainable actions for the care of children from poor families suffering from type 1 diabetes.

#### Key Achievements so far

- 21 centres and 27 Satellite centres across India taking care of 4,063 children.
- Free insulin, monitoring, diagnostic, doctor consultation and diabetes education for improved type 1 diabetes management.
- 2302 doctors and 1068 Paramedical staff trained through type 1 diabetes workshops.
- More than 2000 books named "Diabetes in children and adolescents" from ISPAD were distributed among HCPs. Along with it, "Handbook for Diabetes Educators" and "Mishti Guardian", journal for parents and educators made and distributed.
- 23 Advertorials contributed by our centre directors published in the week and smart life magazine.
- More than 356 children camps conducted, reaching out to more than 10000 children.
- Innovative patients educator materials like NOTTI doll, Mishti books & video, Snakes & Ladders, make a healthy change, make your own plate, HbA1c calculator, Hypo kit are made and distributed to all the participating children. Most of the inputs are made available in 10 Indian languages.
- Two national level advocacy programs and participation in five state roundtable to get the attention of the Government & policymakers on type 1 diabetes.
- To review the implementation status and direction for the way forward plan, 8 advisory board meeting were conducted with the participation of the centre directors.





## CDiC Educational Scholarships for Needy Eligible Children

Each registered child gets free insulin, syringes, glucometer, glucose-strips, key diagnostic tests & Dr. Consultation. Along with this, the CDiC program also works for increasing their understanding on better self-management of diabetes through diabetes education camps and child friendly games, innovative educational tools and toys. Currently, CDiC has launched educational scholarships for the eligible children participating in the program to support their education. This special education scholarships will cover 10% ( around 400) of the registered CDiC children, supporting their academic or other skill development expenses, with a view to help them for their future and making them self-reliant.

### Selection Criteria

These children are selected on the basis of the following set criteria, viz.,

1. Economic status within the poor group
2. Academic Performance
3. Purpose: Need for education - Basic, Higher or Vocational
4. Good control of diabetes: Based on regular visit to centre and adherence to treatment recommendations

Each of these children have been given Rs: 10,000/- scholarship. Until now 337 scholarships in various CDiC centres have been distributed.



S. No	Name of Centre	No. of Scholarships Distributed
1	BDH	60
2	Samatuvam	17
3	Diabetomics	44
4	Tapadia	20
5	MVDRC	15
6	TOTAL	17
7	JEHANGIR	5
8	SARDA	14
9	DDRC	5
10	Wadia	5
11	AIIMS	5
12	PMCH	5
13	IGICH	13
14	KEM - Mumbai	19
15	Barati	20
16	Diacare	49
17	SPAD	14
18	KIDS	4
19	IID	6
	Total	337

The scholarship distribution programs conducted in most of the centres were emotionally charged. Many children and centre directors spoke during these programs and extended their thanks to NNEF. One of the child who received the scholarship told, "when I was diagnosed with type 1 diabetes, my mother used to cry every day. But now, she feels proud of me as I am a topper in my school & she understood that diabetes can be managed and I can live a healthy and good life". She also added, "This scholarship is a motivation for me to study well and serve society when I grow". As part of the advocacy programs in the states of Bihar and Gujarat, the scholarships were distributed during the state roundtable meetings. These meetings had the participation of government officials, policy makers, doctors, patient groups and media. The government representatives present lauded the effort of NNEF on scholarship program.

**A SPECIAL INITIATIVE  
ENCOURAGING LONG  
TERM SELF-RELIANCE**







## Advisory Board Meeting

The 8<sup>th</sup> Advisory Board Meeting of the CDiC Centre Directors was held on 23<sup>rd</sup> August in Bangalore. The primary objective of the meeting was to review the program implementation & challenges; as well as to discuss direction and way forward action plans. Dr. AK Das, Convenor CDiC program co-ordinated the meeting. The key areas for discussion included

- Current status of care in the program and key challenges
- Capacity building efforts for better type 1 care in the healthcare system
- CDiC Registry initiative to capture prevalence and other important information
- Publication plan of the scientific committee of the learnings and guidelines for care going forward .
- Book on type 1 diabetes for doctors
- New SMBG partnership from 2015 and action plan for implementation,
- WDD 2015 key activity plans

The program also held an open house for Centre Directors inputs and suggestions. The meeting went on very well with all participants keenly discussing various plan and thoughts on how to ensure good quality of life for these children. It was also decided that we need to put special efforts to reduce lost to follow-up & drop-outs among the registered CDiC children. Pilot projects to help support the follow up efforts will be initiated soon. The three main plans suggested are, 1. Social worker, 2. Peer group and 3. Parent of type 1 child or elder type 1 children from the CDiC group. The three options were suggested by the participants for trying out activities to stem the loss to follow-up and improve outcomes among the participating children.

For long term sustainability and care of children with type 1 diabetes, special focus will be towards capacity building in the healthcare system in the management of children with type 1 diabetes & get the needed attention of the policy makers, public officials and the Government on the specific needs of these children with type 1 diabetes.





## Children Camps

"Self-help is the best help", this note is more true when it comes to managing type 1 diabetes. It is very essential to learn about diabetes and its management. People with diabetes need to learn every day so that they can adapt their diabetes to their life. Keeping in mind the importance of diabetes education, CDiC centres focus on imparting diabetes education to the registered children on a regular basis. It is done both during the child visit to the centre and also through periodic children diabetes education camps. In these camps parents and siblings are also involved. More than 40 camps

have been conducted till now in 2015 reaching to more than 1800 registered children. Along with education on basic topics like diet and diabetes, importance of exercise and monitoring, other topics of importance like Examination and Diabetes, Hypoglycaemia and Hyperglycaemia – prevention and management and prevention of complications were discussed in these camps. These camps along with education also work on motivating children to lead their life independently and take control over their diabetes. It also gives a lot of psychosocial support to the children and their families.







## HCP Training

As part of the CDiC program in collaboration with the International Society for Paediatric and Adolescent Diabetes (ISPAD), the program focuses on capacity building among the HCPs in support of the healthcare system to manage children with type 1 diabetes. Along with the primary objective of improving access to proper medication, the CDiC program also focuses on training of healthcare professionals to enhance their capabilities in diagnosis and treatment of children with type 1 diabetes. The changing diabetes in children (CDiC)

program along with 21 centre directors is helping in overcoming the challenges or barriers faced by HCPs by providing continuous training to HCPs through focused healthcare programs on management of children with type 1 diabetes.

CMEs have a standardized agenda which covers.

- Epidemiology of diabetes in Children-Global / Indian scenario
- Clinical Features & Diagnosis of type 1 DM
- Management of type 1 DM in children - Insulin
- Type 1 Emergencies - Management of DKA
- Living with Diabetes - Meals Planning and Exercise in T1DM
- Psychosocial aspects of type 1 DM
- Chronic complications & prevention
- Discussion of practical problems and cases

By this approach of training HCPs and educators are conducting it more in a form of practical learning and workshop. CDiC hopes to change the paradigm of management of T1DM in India in coming years. In 2013, two and in 2014, eight T1DM workshops have been accredited by the respective State Councils. In 2015, two workshops have been conducted and both are accredited. With the help of centre directors, we would like to train more doctors, paramedics and educators on management of type 1 diabetes.

### Till now we have

- 2,434 doctors and 1,068 Paramedical staff trained CMEs workshops on type 1 diabetes
- 12 out of 45 CMEs conducted so far have been accredited by the local medical council
- 2000 books and 2000 CD's of ISPAD book on type 1 management distributed
- Unique, "Handbook for Diabetes Educators and Nurse Educators", created with the support of all CDiC centre heads distributed during these programs
- Handbook on type 1 diabetes, animated video on type 1 diabetes, literature on management of DKA, makes your own plate & HBA1C calculator also distributed.





## Plan - World Diabetes Day 2015

Each year 14<sup>th</sup> November is marked as World Diabetes Day (WDD). To create awareness about Diabetes & its Complications, we organise various activities on WDD, which is the birth anniversary of Frederick Banting (the famous discoverer of insulin along with Charles Best in October 1921). In India, we celebrate 14<sup>th</sup> November as children's day also. On this WDD, Lets together make an effort to reflect the realities of dealing with this chronic condition for children with type 1 diabetes. This effort should aim towards providing sustainable comprehensive care for all children with diabetes till an ideal cure is found.

Last year CDiC India had a great WDD at more than 28 places across India reaching to around 4500 people. This year let us all come together and have an even better and more effective World Diabetes Day, so that every child with diabetes is more motivated to accept and control diabetes and have a better world to live in. The World Diabetes Day theme for 2014-2016 is, Healthy Living and Diabetes, this year the campaign focus is on "Healthy Diet and Diabetes".

In line with the objective of WDD and theme of this WDD, we will all together do events to create awareness and promote better management and healthy life for children with type 1 diabetes.

- Oath taking by children - Children will take an oath to take care of their diabetes well as diabetes management involves 24x7 care. The format of the oath is attached in the newsletter.
- 4 Promises - Oath taking is like their goal for diabetes management and the 4 promises is like their action plan to achieve the goal. Children will also make their own 4 promises.

We will send both these inputs in hard copies along with other WDD inputs.

- We will send you a presentation on diet and diabetes, along with diet quiz which contains practical situations and probable answers. We request you to add this as a part of the WDD camp.
- We will also be sending you painting sheets and colours and would request you to conduct painting completions also on theme of diet. Children can be asked to draw food items which they need to avoid, which they can have in moderation and which they can have in plenty. The theme of competition can be, "Understanding Diet - Red, Yellow and Green way"

We would request you to plan WDD 2015 activities on 8<sup>th</sup> Nov, as discussed during the advisory board meeting to have a national level impact.

Some of the other activities which can be conducted

- Walks
- Diabetes education activities at schools (including painting competition)
- Blue circles - with many pictures as possible with people forming blue circles with blue balloons in their hands
- Talent search competition
- Living with diabetes - Essay competition

Let us make this year's World Diabetes Day - 2015 a great one and reach to all our CDiC children and also create awareness so that we can create a better and supportive world for our children with type 1 diabetes.

### Glimpses of WDD 2014





## MY PLEDGE

I \_\_\_\_\_ pledge to take care of my health  
I pledge to make my diabetes my strength in life through discipline & moderation  
I pledge to follow my Doctor's direction  
I pledge to pursue my education and be a responsible citizen of India  
I pledge to create awareness about healthy living & prevention of diabetes among everyone

## MY WISH

One wish for the future and what actions I will take to fulfill it

My Doctor		My Friend at Centre
My Father		My Friend at School
My Mother		My Friend at Home



**CDIC Children Oath for better health  
and improved quality of life**

We pay homage to **Dr APJ Abdul Kalam**  
who inaugurated this program by abiding to his values

## Making a difference for children with type 1 diabetes

**4 Years of care and commitment**



### 4 Promises

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- 4. \_\_\_\_\_

### 4 Outcomes

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_
- 4. \_\_\_\_\_



changing  
diabetes®  
in children



changing  
diabetes®  
in children



# Diabetes Education Material

## Knowing about Carbohydrate







## FAQ

### Q1 - Can my child outgrow the need of insulin injections? What is the life expectancy of child with type 1 diabetes?

Type 1 diabetes is an autoimmune disease, a condition in which the body's immune system destroys pancreatic  $\beta$ -cells which produces insulin. People with type 1 diabetes need insulin from the beginning. As of now, one can never outgrow insulin injections, but treatment options are improving all the time and people with type 1 diabetes can lead full and active lives.

A 30 year study by the University of Pittsburgh, published in 2012, noted that people with type 1 diabetes born after 1965 had a life expectancy of 69 years\*. New improvement in diabetes care every year brings a hope that people with type 1 diabetes can even live significantly longer than their siblings and friends because of following healthy and disciplined life style.

### Q2 - How is type 1 diabetes different from type 2 diabetes?

Although, both type 1 and type 2 diabetes are characterised by higher blood sugar levels, the cause and development of the conditions are different.

Type 1 diabetes is an autoimmune disorder (body's own immune system attacks and destroys the insulin-producing cells in the pancreas) that mostly affects children and young people. A person diagnosed with type 1 diabetes need to take insulin injections from the beginning and for life time. If the diagnosis or treatment is delayed because of any reason, the severe lack of insulin can result in life threatening condition called Diabetic Ketoacidosis (DKA). While the cause for type 1 diabetes is still not entirely understood, there is nothing one can do to prevent or get rid of it.

Type 2 diabetes is usually seen in older people, nowadays due to sedentary lifestyle and higher obesity, it is increasing in young people including children and adolescents. Most people with type 2 diabetes mellitus are overweight or obese and have family history of type 2 diabetes. In this form of diabetes, the pancreas still produces some insulin. Treatment includes diet control, exercise and in some cases oral drugs or insulin. It is a progressive disorder and treatment keeps on changing. Although we cannot change our family history but by adopting right life style which includes balanced diet, physically active life and keeping weight in normal range, one can definitely delay and to some extent prevent type 2 diabetes.

### Q - 3 If one is taking Insulin regularly; still his/ her diabetes is not under control. What is the reason for this?

The most common reasons for diabetes not being controlled are

- Excessive eating - more than required by the body, and advised by the doctor (portions may be large)

- No or limited physical activity
- Any illness or infection
- Mental or emotional stress
- Hormonal changes
- Presence of other associated conditions e.g., thyroid problem, celiac diseases etc.
- Influence of medicines used for other disease e.g. asthma, allergy, thyroid, heart diseases etc.
- Inadequate insulin - the insulin prescribed is either not taken regularly at the advised time or the quantity is not sufficient.

There could be many reasons when you feel insulin is not working.

- Check if it is the right strength, using the right syringe.
- Check to see whether it is being administered in the right way.
- If the insulin which is used is not past expiry.
- If the insulin bottle is rolled/ shaken in the right way, i.e. it is well suspended.
- Make sure that the insulin has been properly stored and not exposed to high temperature or frozen.

### Q4 - Can a child with diabetes have sweets containing artificial sweeteners , if yes in what quantity?

Artificial sweeteners are sugar substitutes that have fewer or zero calories and do not raise blood glucose levels through eating them. This makes them a preferable choice for people with diabetes. Before using any artificial sweetener, it is essential to know if they are medically safe for consumption by children and in what quantity

Moreover, it is worth being aware of what the food you are eating contains. Sugar free does not mean calorie free or carbohydrate free. It is advisable to keep a check on the calorie value of the food, before consuming it. This way the total calorie intake especially carbohydrate intake can be kept under control and this will help in keeping a check on the blood glucose levels. Research has shown that increase in blood glucose levels is largely determined by the total amount of carbohydrate one eats, not the source of the carbohydrates eaten. It is also agreed that one can substitute small amounts of sugar for other carbohydrates, but it has to be done judiciously.

\* Dr. Orchard, Aaron M. Secrest, Ph.D.; Ravi K. Sharma, Ph.D.; and Thomas J. Songer, Ph.D., University of Pittsburgh: Life Expectancy Increasing for Type 1 Diabetics, According to Latest Pitt Research. August 10, 2012



## Diabetes Educator Column

### Tips for parents on healthy diet for children with type 1 diabetes

Having healthy eating habits is essential for every one of us including children with type 1 diabetes. When a child is diagnosed with type 1 diabetes and as they grow up, worry and confusion about following diet occupies most of the parents.

As educators, it is our duty to counsel parents repeatedly on healthy diet. Please find few important points. The fact is that most foods provide carbohydrates which gives us energy.

#### Understanding diabetes and its relationship to diet

The fact is that all foods provide carbohydrates which give us energy, It is not only the sugar that we buy from grocery shop. Basically there are two types of carbohydrates- simple like glucose, sugar, and jaggery. These also include fruit and milk. Complex carbohydrates (starches) include grains such as wheat, corn, oats, rice and vegetables like potatoes. If there is enough insulin present in the body naturally or provided by injections, it will utilize the carbohydrates and consequently the blood sugar will not rise. However, if body is producing less or no insulin, then blood sugar is bound to rise even if one eats healthy foods.

Following a "diabetes diet" means, choosing food that will work along with activities and insulin to keep blood sugar levels near normal. In fact diabetes underlines the need for a healthy and balanced way of eating which is good for everyone in the family.

#### Is diet of a child with type 1 diabetes different from other children?

The only difference is that the children with diabetes need to balance the quality, quantity and timing of their meals with the amount of insulin they take and their activity level or vice versa. If the insulin doses are fixed, the meals must also be fixed in time and quantity. Basal – bolus regimen (Multiple doses) with insulin dose adjustment is the best option, at is helps maintain good blood glucose control along with allowing flexibility for the child in meal quantity and the timing to some extent. Skipping meals and overeating both are harmful.

#### Planning the right meal for children with type 1 diabetes

##### Key points which can help you to plan the right diet for your child with type 1 diabetes are:

- A child can eat everything which is usually made in a normal house hold. Certain changes can make it healthy E.g. Avoiding foods that are high in sugar and oil, using whole grain products instead of refined grains. E.g. Whole wheat flour instead of Maida, Brown rice instead of white rice. Having plenty of vegetables and fruits - at least 5 a day. Truly speaking these practices are good for everyone.

- Almost all fruits and vegetables are good for people with type 1 diabetes if consumed in appropriate amounts as they are rich in fibre and other essential vitamins and minerals. Eating whole fruit is more beneficial as it has more fibre and juices need to be avoided.
- Eating a consistent amount of carbohydrate at each meal and snack will help to keep blood glucose levels more stable. Any carbohydrate E.g. Roti, rice or fruit can be exchanged with small amounts of sugar as part of a healthy eating pattern. Since most foods that are very high in sugar are empty calories with very less nutrients, it is better to limit them as an occasional treat.
- Most people think they can eat endless amounts of "sugar free" diabetic products foods because they don't contain sugar. They will still affect the blood sugar as they contain other carbohydrates. Having in moderation is best.
- Many people may suggest special foods for children with diabetes. This may be vegetables which are good for everyone as they are very low in calories and very rich in nutrients along with soluble fibre. These include non-starchy vegetables and fruits. In this group, foods like Bitter gourd (karela), Fenugreek (methi), Indian blackberry (jamun), Garlic, Flax seed, Cinnamon are mis-communicated as a treatment of diabetes. While, these are good for people with diabetes but they cannot be a substitute for insulin. It is also essential to consider the choice of the child for whom the food is made.

Education is essential. It would be great if dietary review is done at least once in a year for every child individually. Food portions, exchange lists and carbohydrate counting are all part of systems designed to learn how every variety of food can be included in the diet and maintain good blood sugar levels. You can teach according to the parent's ease of understanding.

**"We thank everyone for their kind efforts in implementation of the changing diabetes in children program. Please write to us about your views, stories and ideas which can add value to this program and to the newsletter at [CDICINDIA@novonordisk.com](mailto:CDICINDIA@novonordisk.com)."**