

CDiC - INDIA

Newsletter



Issue 19, September 2018

Outreach Dashboard

No. of children 4063

No. of HCPs trained 6975

No. of children's camps 630

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Prof. P. Raghupathy

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Dr. Shuchy Chugh

"I want to earn well and make my parents and doctors feel proud of me."

Srinivasan

Story on last page

Srinivasan R,
Bengaluru



Insights

"What you consider as an obstacle is sometimes a stepping stone in your journey."



Editorial Desk



Dear Colleagues,

There is a special place in our hearts for the CDiC programme and the children who are part of it. We are proud of what we have been able to achieve through this programme, but we still have a long way to go. I am finding an increase in the number of children who have been newly diagnosed with type 1 diabetes. Just at our hospital alone, 40 new children have joined us over the last six months. At the same time there is also an increase of psychosocial issues associated with type 1 diabetes. So there is still much work we need to do.

To ensure that all these children succeed in their aspirations for life, we need to focus on advocacy and on strengthening the scientific data around type 1 diabetes. We need to ensure that the lessons from their lives are shared among the medical community for the betterment of all children with diabetes.

I look forward to hearing from you, and to your invaluable ideas and thoughts concerning this programme and ways to improve our care. I once again thank you for your passion and commitment.

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



Dear Colleagues,

The “Changing Diabetes® in Children” programme always had the vision of better outcomes and a healthier future for children with type 1 diabetes through comprehensive care. Together over the last seven years, we have been able to contribute significantly towards the cause and will continue to do so until 2020. Through our commitment for this cause, we have gathered immense learning and understanding on the management of children with type 1 diabetes in India. It is our responsibility to collate our learnings and to create scientific publications for the benefit of our fraternity. This will also go a long way towards sensitizing the health authorities and the government on the burden and complex nature of type 1 diabetes.

**Best Wishes
Prof. Ashok Kumar Das**



Dear Friends,

CDiC has been addressing the multiple needs of children with type 1 diabetes from poor socio-economic families since 2011 in India. It is very close to our hearts and we are committed to our mission to ensuring every child with type 1 diabetes lives a healthy life. And for this, we need to work collectively with all stakeholders including the government to ensure that these children get timely access to care. Our CDiC programme is currently helping over 4,000 children in India by providing them free medication, glucometers, strips and medical check-ups. This is our commitment towards building a healthier future for India.

Thank you for your guidance.

**Melvin D'souza
Managing Trustee, NNEF
Managing Director, Novo Nordisk India Pvt Ltd**



CDiC Update

Children First, Diabetes Second: CDiC Continues to Keep its Commitment

The Changing Diabetes® in Children (CDiC) is a unique global programme that has been improving access to care for children with type 1 diabetes from marginalized socio-economic families since 2009. Currently offering care to around 16,000 children in 13 countries, the programme's India chapter was launched in 2011. Since its launch, the programme has brought about a big difference to over 4,000 children.

The programme is truly one-of-its-kind program as it addresses the specific needs of these children in a holistic manner, taking care of the insulin, monitoring, diagnostics, and doctor consultations apart from the psychosocial needs. The programme's extension will ensure that it will support the children till 2020. The following activities were undertaken during the last 4 months.

- On 1st June the International Parents' Day, we released a special video to create awareness about type 1 diabetes featuring Changing Diabetes® ambassador Anil Kumble. The video was created both in English and Hindi and featured the difficulties of parents of children with type 1 diabetes. Both these videos were released exclusively on Quint, one of India's leading new-age online publications and reached over 6 million readers.
- The 10th CDiC Advisory Board was conducted in Bengaluru. The new glucometers and syringes options were been shared with the assembled KOLs for their approval to be introduced to the children and was accepted. A new parents' FAQs booklet and new educational materials with Changing Diabetes® ambassador Anil Kumble was released. The success of the programme has led to proactive requests for new centres from four additional states: Jammu and Kashmir, Punjab, Rajasthan and Chhattisgarh. We are delighted to share that all four requests were approved by the advisory board.
- To mark Insulin Day, a run was organized on 28 July at Bengaluru. It was attended by over 150 children and their parents. The run was led by Anil Kumble and Dr K.M. Prasanna Kumar, Director, Primer Academy of Medical Sciences (PAMS). The Insulin Day Run was organized to bring the attention of government stakeholders to the need for providing children with type 1 diabetes care and support.
- 11 children's camps were conducted, covering more than 350 children.
- Methodology paper on CDiC functioning has been initiated as part of best practices sharing.

Thanks to each one of you for your support and commitment





Ad Board Meeting

The CDiC India programme recently concluded a review of its key achievements and the action steps for the year 2018 and beyond, at the 10th Advisory Board meeting in Bengaluru.

The most important update from the review was the graduation of nearly a third of the enrolled children. With 1700+ children having grown into healthy young adults, the programme is now ready to accept new children who need help. The young adult group will continue to receive free insulin till the age of 22.

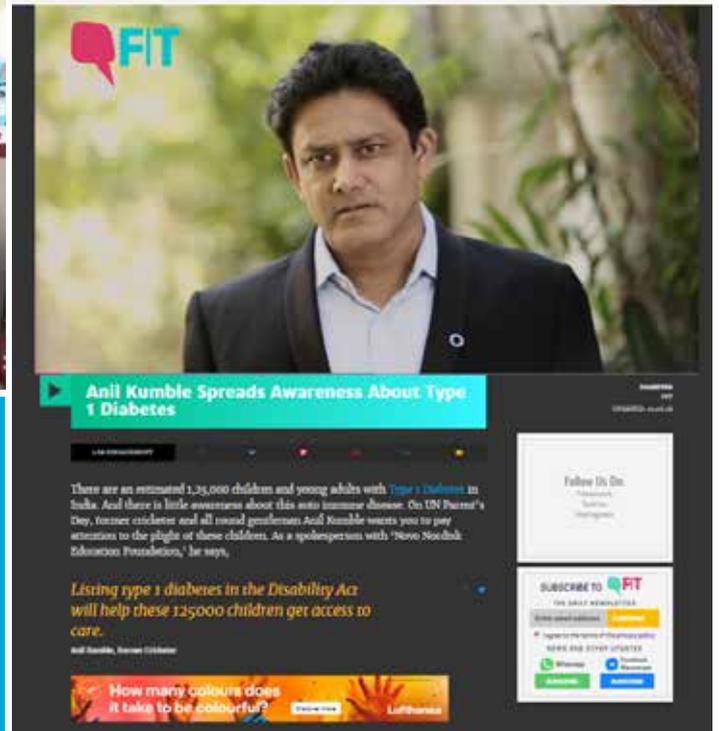
As part of the programme's efforts to continually improve the support given to the children, new glucometers and syringes are being introduced. These were shown for taking their comments & approval for introduction to the children with the assembled KOLs along with a new parents' FAQs booklet and new educational materials featuring Changing Diabetes® ambassador Anil Kumble.

Being a unique programme, there is much learning from the experience of the past several years.

Dr K M Prasanna Kumar shared the outline of a paper whose abstract will be announced at the upcoming ISPAD Conference in October. The other assembled doctors suggested adding a methodology paper that could be published in an indexed journal.

From an advocacy viewpoint, the doctors expressed their willingness to support an initiative to have type 1 diabetes included in the Disability Act which would help all at-risk children receive care from their respective state governments.

Dr P Raghupathy, CDiC Chairperson, said, "We are very proud of what we have achieved through this programme. We are also very happy that the medical community recognises this which has led to proactive requests for new centres from four additional states: Jammu and Kashmir, Punjab, Rajasthan and Chhattisgarh."



Parents' Day Video on Quint Reaches Over 6 million people

1 June is the UN's International Day of Parents. To mark the occasion, Novo Nordisk Education Foundation released a special video featuring changing diabetes® ambassador Anil Kumble. The video was created both in English and Hindi and featured the difficulties of parents of children with type 1 diabetes. The Hindi video featured story of Pihu – a girl with type 1 diabetes living in Patna and English video featured story of Sumith- a boy with type 1 diabetes living in Bangalore.

Both videos were released exclusively on Quint, one of India's leading new-age online publications and reached over 6 million readers.





Insulin Day Run

Anil Kumble leads 150 CDiC kids in Insulin Day Run

Since the first successful insulin injection was given on 30 July, 1921, insulin has been saving lives the world over. To mark the anniversary of this momentous day, Insulin Day was commemorated with a special run at Bengaluru's Cubbon Park. The run was attended by over 150 children and their parents led by Anil Kumble, Changing Diabetes® ambassador. Dr K.M. Prasanna Kumar, Director, Primer Academy of Medical Sciences (PAMS), Joint Director & Deputy Director, NCDs Ministry of Health & Family Welfare, Government of Karnataka attended the program.

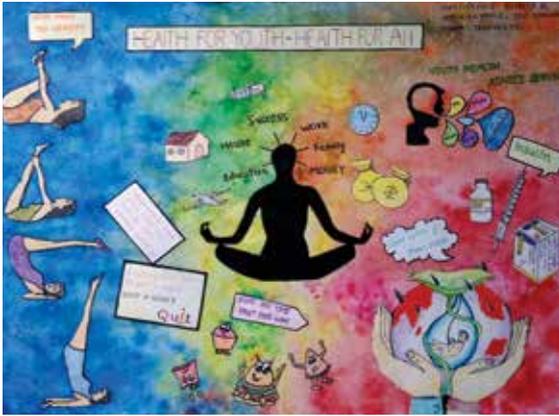
The Insulin Day Run was organized to bring the attention of government stakeholders to the need for supporting children with type 1 diabetes. Anil Kumble called the children "champions" and said: "I am glad that I had the opportunity to interact with these talented children. I was happy to see their positivity and optimism. As changing diabetes® ambassador, I appeal to government stakeholders to extend full support to them."

The highlight of the event was the successful completion of the run with no incidences of hypoglycaemia in the participating children. Immense enthusiasm & happiness was seen on the faces of the participating children.



changing diabetes® in children





NCD Child Global Art Contest

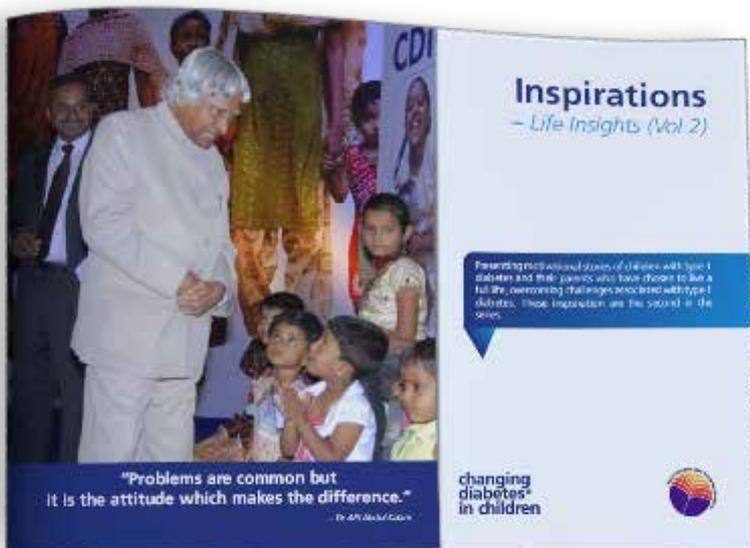
NCD Child launched a global art and video contest for adolescents to visually highlight the importance of non-communicable disease prevention and control for young people and their communities. The theme for the contest was "Health For Youth = Health For All". It was done in recognition of World Health Day, 2018. Artists between the ages of 12 and 21 were invited to submit original drawings, paintings or videos.

More than 30 CDiC children from all over India participated in this contest. There entries were an eye opener as they gave a glimpse into the minds of the children. It was really heartening, when Spoothi's video entry was adjudged the 3rd prize winner among the videos.





New Publications from CDiC



The Insights book contains the life story of 5 young CDiC members and how they are winning over diabetes. In words of Maitry Pancholi, one of the CDiC beneficiaries, who is now an educator "There is an exciting life, despite living with diabetes. All one needs to do is to take insulin on time and eat healthy. If we lead a disciplined lifestyle, we also can fulfill our dreams and live and enjoy life."

Type 1 diabetes and Your Child deals with the top 10 questions which come to the mind of every parent whose child is diagnosed with type 1 diabetes. Like, Is it my fault that my child got diabetes. It also includes a diabetes dictionary and list of key things which parents need to learn.





Mishti enjoys her vacation



Mishti, along with her brother and mother has gone to her grandmother's home.



Hello Anu, it's great to see you after 2 years. Mishti and Chintu, how are you both? I missed you both.

Hello grandmother, we are fine and we missed you too.



You all must be tired. Come, lunch is ready.



Mishti and Chintu, wash your hands. Mishti check your blood sugar levels and take insulin.

Yes mom



Mishti your sugar levels are too high and this is not good for your health.



Don't worry mother, it's because she was sitting for a long time in the train. She'll take correction dose of insulin and it will be fine.



Is taking too much insulin, good? Haven't you asked her doctor about tablets?

We all need insulin grandmother. We make it internally and she takes it from outside.



In the evening

Mishti, do not eat Mangoes, your sugars are high.

Grandmother, that was in the afternoon. I checked it a while back and it's now normal. And this is my fruit eating time.



Next day

Mishti, do not play, you will fall sick, your sugar levels will come down.



Mishti, we will go but we will also take granny along with us. She also needs to understand about your diabetes.

Mom, this is not fair. Let's go back home.



Next day, in doctor's clinic

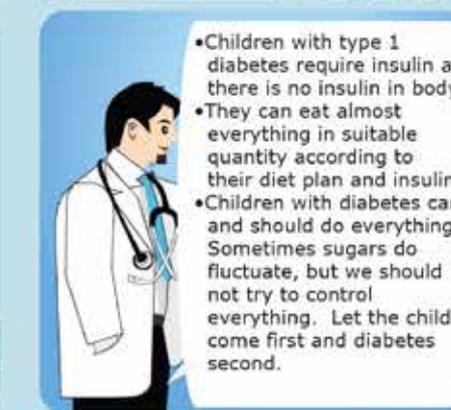
Good evening Mishti. How are you doing?

I am fine doctor uncle. Grandmother is confused about my diabetes and always gives me vague suggestions.



My sister had diabetes. She was diagnosed when she was 60 years old. I am only telling her what her doctor had told us then.

Let me explain. Mishti has type 1 diabetes.



- Children with type 1 diabetes require insulin as there is no insulin in body.
- They can eat almost everything in suitable quantity according to their diet plan and insulin.
- Children with diabetes can and should do everything. Sometimes sugars do fluctuate, but we should not try to control everything. Let the child come first and diabetes second.



Mishti is a responsible girl. I am sure, she'll be able to take care of herself and also enjoy her vacation.



FAQs

Q1. Should blood glucose levels be kept high to avoid low blood glucose or hypoglycaemic events?

No. It is harmful to your child if blood glucose levels remain high long-term. Prolonged high blood glucose can lead to life-threatening conditions.

Also, when there is a shortage of insulin in the blood, the body cannot use all the glucose available and instead breaks down fat for energy, producing harmful chemicals called ketones. High levels of ketones, a condition called diabetic ketoacidosis

(DKA) is toxic to the body and could lead to coma¹.

Although hypoglycaemia events can be scary, they are manageable². Eat on time and monitor blood sugar levels regularly to prevent hypoglycaemia. Also it is good if the child or parents carry a few hard candies to treat hypoglycaemia. Some children may experience severe hypoglycaemia. If severe hypoglycaemic events occur regularly, speak to your healthcare professional.

Q2 Can children with type 1 diabetes take over-the-counter medicines for cold, cough and fever?

In general, children or adolescents with diabetes with caution can take cold medications for any acute illness.

However it is very important like other child, it is essential to consult the doctor for

- Medicine quantity (dosage) for age
- Any specific allergy

Also, cold medicine that is given as syrup can contain glucose and the medications themselves can raise the blood glucose. So, it is essential to either use a sugar-free cough syrup or to use a correction dose by calculating extra carbs. Also, remember that during any sickness, it is very important to check blood glucose levels frequently and to take insulin as per the sick day plan, whether or not the child is taking any additional medications.

Q3 Which test is better - fasting plasma glucose (FPG) and postprandial plasma glucose (PPG) levels or HbA1C test?

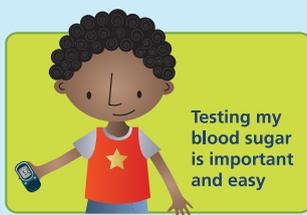
The important thing to understand is that no single test is perfect: each has its strengths and weaknesses. Fasting plasma glucose (FPG) and postprandial plasma glucose (PPG) levels are great ways to monitor short-term treatment changes as these indicate how well a person is doing at that point in the day. On the other hand, an HbA1c test will provide information that FPG and PPG can't, because it represents 2-3 months compliance. For living well with diabetes, a person needs to undergo a combination of all the tests.

1. NICE Clinical Guideline 15. Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults. July 2004. Available at: www.nice.org.uk/guidance/CG15 Accessed July 2012.

2. Diabetes UK. Children and diabetes. Available at: www.diabetes.org.uk/Information-for-parents/ Accessed July 2012.

How to use my glucometer

Take your glucometer along with you, wherever you go.



I must always remember to take my glucometer and diabetes diary with me to the clinic and give it to the nurse. This helps her help me!





Meet Srinivasan R.



Srinivasan was diagnosed with diabetes in 2006 when he was 12 years old. He was a happy-go-lucky child who loved to play; he was interested in sports but not in academics. His father worked as a daily wage worker and his mother as a homemaker. Both he and his younger brother were full of pranks and fun. In November 2006, he had a cough and fever. His parents tried to give home remedies, but he didn't improve. After a week, his parents took him to a local doctor who diagnosed that Srinivasan had pneumonia. Since the child didn't improve, the doctor prescribed a few blood tests.

Srinivasan's father got the tests done in the morning, but could not collect the reports because he did not want to lose the day's earnings. By night, Srinivasan was extremely unwell and was gasping for breath. He was taken to the hospital where he was diagnosed with diabetes and ketoacidosis.

Srinivasan's parents were initially very anxious about his future and the disease. The doctor at the hospital referred him to Dr P Raghupathy. The initial few months were tough and depressing. He says, "I felt like running away from high and low blood sugar levels and my parents and I felt clueless."

In April 2007, Srinivasan again visited Dr P Raghupathy and then started his journey of understanding diabetes. After that his whole life changed. He started focusing on his studies and taking care of himself. One thing which was troubling his parents was the cost of the treatment and they discussed it with the doctor.

In 2011, Srinivasan was enrolled in the CDiC programme. He says that his life changed after that. His parents and doctor motivated him to focus on his health and studies. He says, "If I didn't have diabetes, I might have wasted my life in wrong habits and drugs. I am living a healthy life because of diabetes."

Today Srinivasan is 24 years old, has finished his M.Com with flying colours and has found a job with the finance department of a multinational company.

Without doubt, this programme has impacted the lives of many children with type 1 diabetes.

We thank each one of you for your valuable contribution. Let's work together to the best of our ability for changing diabetes to support and help children with type 1 diabetes.

For more information:

you can visit us at: <http://cdicindia.org/> or write to us
diabeteseducatorindia@novonordisk.com