



# DPT

## DEVELOPMENTAL PEDIATRICS TODAY



March 2022

### Monthly e-Newsletter of IAP Chapter of Neurodevelopmental Pediatrics

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## Inside

Editorial.....	2
Chairpersons Message.....	3
Snippets from the Secretary .....	4
Journal Scan .....	5
Poems on Downs Syndrome.....	8
Glimpses from Pedicon 2022 Noida .....	11
Month in pics .....	17





## Editorial

Respected Seniors and dear Friends,

Warm greetings from Neurodevelopmental chapter of IAP!

Covid cases have started rising again especially because all schools and colleges have opened and so have other public places like cinema halls, gyms, swimming pools etc. So we all must again follow Covid appropriate behavior.



Pedicon was conducted in Greater NOIDA after being postponed at for last 2 years from this venue due to Covid Pandemic. It was conducted in a world class facility, probably the best facility in India with latest infrastructure. It was not only an academic feast, but also had great ambience and entertainment .Autism workshop which was a preconference workshop , had registrations to full capacity .It was conducted in a silent zone which was first time experience for all of us .It was one of the best attended workshops .

Nurturing care Early childhood development workshops have been rolled out. The IAP has a very ambitious plan of conducting 200 workshops in each zone in a year plus 5 TOTs per zone.

21st March is International Downs syndrome day. There was a walk organized for the same during Pedicon.

Here I would also like to share an interesting story. A 7 year old boy with Down syndrome named Avnish , has made Indore city proud as he has climbed the mount Everest , creating a world record .The child , who left for the Mount Everest base camp along with his father Aditya Tiwari earlier on April 14 , reached the summit on April 19. The base camp of Mount Everest is at a height of 5,364 meters. Aditya Tiwari adopted Avnish in January 2016 , when he was 26 years old and unmarried. Avnish was 2 years old at that time . Aditya had to fight the system to adopt him. First hurdle was that the age of adoption for a single parent was 30 years at that time . He wrote letters to the concerned people, politicians and Bollywood stars and got the age of adoption reduced to 25 years. Mr. Aditya Tiwari has been awarded the world's best mom award.

Long live IAP and our Chapter!

**Dr. Lata Bhat**

Chief Editor





## Chairperson's Message

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Dear Readers,

Greetings for the colourful season's celebrations !

Holi ushered in the colours of life, augmented by the Pedicon in Noida with renewed vigour. I am sure all of you are back to your work.

This month marks awareness day of Downs' Syndrome. Pedicon very aptly highlighted these unique children's desires, and their talents

have been very well highlighted, with chromosome 21 showcasing the uniformity of humanity beyond the borders of nationality, ethnicity, economic status and more. All the members of the Neurodevelopmental Chapter thank the organisers of the conference for highlighting this issue, and I trust each one of us are extending support to this awareness day.

This issue takes you through the emotional journey of a parent, looks into the riddle of infantile spasm while our photo gallery will give you an idea of the extent of nationwide activities.

Happy reading !

**Dr. Shabina Ahmed MD, FIAP**

National Chairperson

Neurodevelopmental Pediatrics Chapter of IAP







## Snippets from the Secretary

Respected Seniors and dear friends,

Seasons greetings from the IAP Chapter of Neurodevelopmental Pediatrics.

With the arrival of spring came the good news of Pedicon 2022 being held at Noida from 19-23 March. A full scale was being held after two years and everyone was looking forward to an academic and cultural feast. Noida event lived up to reputation with a great venue and excellent academic and non-academic events.

Pre-conference workshop on Autism was a huge success and covered the topic comprehensively. IAP Handbook on Developmental & Behavioral Pediatrics release was a key highlight and is available in Jaypee and Amazon websites. The Chapter has won the third best chapter prize and I take this opportunity to congratulate all the chapter members for their contribution and thank all seniors for their blessings and guidance. Chapter symposium was held on 21 Mar and was followed by Chapter general body meeting (GBM). The minutes of the GBM will be circulated soon by email.



The chapter has started online teaching activities on every tuesday of the month as part of its fellowship program from the month of February and the activities of February received a good response from all the fellowship centers. These activities are open to all chapter members for viewing. Interested members can send a request for link to the chapter email at [cdgiap@gmail.com](mailto:cdgiap@gmail.com)/whatsapp message at 8472087960.

March month has many important health days - World Hearing Day, International Women's Day, Down Syndrome Awareness day to name a few. We have some interesting articles and journal scan related to these topics. Let us spread the knowledge and awareness of importance of early childhood development to all.

Jai Hind! Jai IAP !

Long live IAP!

**Wg Cdr (Dr) KS Multani**

National Secretary

IAP Chapter of Neurodevelopmental Paediatrics





## Journal Scan

### **Inequities in quality and safety outcomes for hospitalized children with intellectual disability**

**LAUREL MIMMO, REEMA HARRISON, JOANNE TRAVAGLIA, NAN HU, SUSAN  
WOOLFENDEN**

**Developmental Medicine & Child Neurology 2021**

**Accepted for publication 1st September 2021.**

**Published online**

#### **Abstract**

**AIM** To investigate if there are inequities in quality and safety outcomes for children with intellectual disability admitted to two tertiary paediatric hospitals.

**METHOD** A cross-sectional study of 1367 admissions for 1018 randomly selected patients admitted for more than 23 hours to one of two tertiary children's hospitals in Sydney, Australia (1st January–31st December 2017). Electronic medical records were manually interrogated to identify children with intellectual disability (including developmental delay). Data extracted included patient demographics, length of stay, number of admissions, and reported clinical incidents.

**RESULTS** In total, 12.3% (n=125) of children admitted during the study period had intellectual disability, which represented 13.9% (n=190) of admissions. Sex and age at admission in children with and without intellectual disability were similar: 83 (43.7%) vs 507 (43.1%) females and 107 (56.3%) vs 670 (56.9%) males,  $p=0.875$ ; median age 3 years (0–18y) vs 4 years (0–18y),  $p=0.122$ . Children with intellectual disability had significantly greater median length of stay (100.5h vs 79h,  $p<0.001$ ) and cost of admission (A\$11 596.38 vs A\$8497.96) than their peers ( $p=0.001$ ). Children with intellectual disability had more admissions with at least one incident compared to children without intellectual disability (14.7% vs 9.7%); this was not statistically significant ( $p=0.06$ ).

**INTERPRETATION** Children with intellectual disability experience inequitable quality and safety outcomes in hospital. Engaging children and families in clinical incident reporting may enhance understanding of safety risks for children with intellectual disability in hospital.





## Journal Scan

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### Response to treatment and outcomes of infantile spasms in Down syndrome

Susan Harvey, Sally A. Lynch, David Webb, Nicholas M. Allen, Mary D. King, Bryan Lynch, Mary O'Regan, Declan O'Rourke, Amre Shahwan, Kathleen M. Gorman, Irish Paediatric Neurology Group; *Dev Med Child Neurol.* 2022;00:1–9.

#### Abstract

**Aim:** To estimate the prevalence, and evaluate presentation, treatment response, treatment side effects, and long-term seizure outcomes in all known cases of children with Down syndrome and infantile spasms on the island of Ireland.

**Method:** This was a 10-year retrospective multicentre review of clinical records and investigations, focusing on treatment response, side effects, and long-term outcomes. **Results:** The prevalence of infantile spasms in Down syndrome was 3.0% during the study period. Fifty-four infants were identified with median age of spasm onset at 201 days (interquartile range [IQR] 156–242). Spasm cessation was achieved in 88% (n=46) at a median of 110 days (IQR 5–66). The most common first-line medications were prednisolone (n=20, 37%), vigabatrin (n=18, 33.3%), and sodium valproate (n=9, 16.7%). At follow-up (median age 23.7mo; IQR 13.4–40.6), 25% had ongoing seizures and 85% had developmental concerns. Treatment within 60 days did not correlate with spasm cessation. Seventeen children (31%) experienced medication side effects, with vigabatrin accounting for 52%.

**Interpretation:** Prednisolone is an effective and well-tolerated medication for treating infantile spasms in Down syndrome. Despite the high percentage of spasm cessation, developmental concerns and ongoing seizures were common.





## Journal Scan

### **Mini-EDACS: Development of the Eating and Drinking Ability Classification System for young children with cerebral palsy**

**Diane Sellers, Lindsay Pennington, Elizabeth Bryant, Katherine Benfer, Kelly Weir, Sonia Aboagye, Christopher Morris**

**Developmental Medicine & Child Neurology First published online January 29, 2022**

#### **Abstract**

##### **Aim**

To develop and test Mini-EDACS to describe developing eating and drinking abilities of children with cerebral palsy (CP) aged between 18 and 36 months.

##### **Method**

The existing Eating and Drinking Ability Classification System (EDACS) was modified to define Mini-EDACS content. Mini-EDACS was developed in three stages: (1) EDACS was modified after application to videos of standardized feeding evaluations of children with CP aged 18 to 36 months ( $n = 130$ ); (2) refined content and validity of Mini-EDACS was established through an international Delphi survey; (3) interobserver reliability was assessed by comparing Mini-EDACS levels assigned by speech and language therapists (SaLTs) from video data and parent report.

##### **Results**

Mini-EDACS provides age-appropriate descriptions for children aged 18 to 36 months with CP. Eighty-nine stakeholders participated in the Delphi survey; required levels of agreement were met after one round (i.e.  $>80\%$  agreement). Thirteen SaLTs completed paired ratings from 43 video recordings: absolute agreement was  $58\%$  ( $\kappa = 0.43$ ; intraclass correlation coefficient  $0.78$ ;  $95\%$  confidence interval  $0.63-0.87$ ).

##### **Interpretation**

Mini-EDACS provides a valid system for classifying eating and drinking performance of children with CP under 3 years old. Results suggest moderate agreement and good reliability when rating Mini-EDACS levels from video recordings of young children with CP.



**Dr. Smita Misra**  
Senior consultant, Paediatric Cardiology  
Manipal Hospital, Dwarka, Delhi

## "Dear Mother"

### Prayer By a Baby

#### EDUCATIONAL POEM

**My Dear Mom, Stay little calm,**  
Because as I grow,  
You will need to know,  
what are the things you must do?  
and the things, you must stay away from!  
**When I am just born,**  
Don't bottle feed me,  
But offer me breast feed,  
Let me enjoy efforts to feed on breast,  
Safely nestled in the warmth of your lap;  
**I grow-up as the infant 7<sup>th</sup> months onwards,**  
Don't spoon feed me Maa all the time,  
If I can hold the food by hands,  
Let me be messy and sporty,  
Relishing my coos, giggles and squeals;  
**If I am ready to move on,**  
Please Don't offer me a walker,  
If I can crawl on my tummy or knees,  
Let me enjoy the discoveries,  
I am about to make!  
**If I am ready to be on my feet,**  
Don't try to walk me on your lap,  
even if I would walk with unsteady gait,  
Let me learn to fall, have little bruise, and cry,  
So, I can learn the art of getting up after a failed try!



**When I would be three years old,**  
I will play with my friends,  
And would fight while taking the turns,  
Please, don't take my side,  
Instead Let me negotiate my way-out!  
**When I go to school,**  
Dear Mom, don't get upset  
If my teacher complaints,  
Just try to help me in getting over,  
Of my tendency to lie or  
running away from homework again!  
  
**Dear mom,** you are the guardian angel sent by God,  
to see, me grow to become independent,  
and to learn to take decision, time management;  
Also Let me handle my anger, zest, disappointments;  
If I won't learn to use my own hand feet and brain,  
I would walk through life on crutches and restrains;  
  
**But Mom you need to ask me**  
If I am unhappy and sad,  
If I am fearing the school and running away;  
There may be bullies and monsters,  
Hunting for smaller kids,  
I must know about good touch, bad touch|  
and must have faith to confide it to you;  
**Now its my time to cry and let you soothe me,**  
**Mom, I am your little baby and you are world to me.**

*Smita Misra*





## A poem On Downs Syndrome Day!

♥ मासूम जज़्बात ♥

**Dr. Smita Misra**

Senior consultant, Paediatric Cardiology  
Manipal Hospital, Dwarka, Delhi

मैं मासूम हूँ पर जानता हूँ मैं,  
अपनी सीमाओं को पहचानता हूँ मैं;  
तो देखता हूँ सबको दौड़ते हुए,  
खुद चलता हूँ अपने मज़े के लिए;

टिंकू था मेरे साथ पैदा हुआ  
चढ़ रहा है आराम से सीढियाँ,  
मैं हूँ पकड़े माँ की उंगलियां  
ये नहीं कि है मुझे ईर्ष्या नहीं  
पर माँ तो मेरे पास है खड़ी;

उसने मुझसे कहा बेटा, तू है बड़ा,  
बहादुर और कुछ है अलग छोकरा;  
तू भी चढ़ेगा सीढ़ियां पर कुछ बाद में  
सब एक हैं पर अलग हैं कुछ बात में;

जैसे कागा उड़ता तो है, पर दौड़े नहीं,  
गैया माँ, कभी खरगोश से जीते नहीं;  
तू तू है, और न ये कभी भूलना तुम,  
अलग हो तुम पर ज़िंदगी कबूलना तुम;

हर इंसान जकी होती अलग पहचान है,  
मासूम कोर्ड और कोर्ड मेहरबान है.

जैसे कागा उड़ता तो है, पर दौड़े नहीं,  
गैया माँ, कभी खरगोश से जीते नहीं;  
तू तू है, और न ये कभी भूलना तुम,  
अलग हो तुम पर ज़िंदगी कबूलना तुम;

हर इंसान जकी होती अलग पहचान है,  
मासूम कोई और कोई मेहरबान है;  
जियेंगे हम हमेशा अभिमान सहित;  
कमी नहीं पर क्रोमोजोम है जो अधिक;

दिल दिमाग, कान जोड़, दांत भी,  
मांगते हैं देखभाल और ध्यान भी;  
दिल के दरवाजो और दीवारों को भी,  
होती है ज़रूरत ऑपरेशन की भी कभी;

गर्भ में रह कर भी मेरी पहचान हो,  
तो शायद अलग सी मेरी राह हो;  
एक लड़ाई थी जीती मेरे पिता माँ ने  
मुझको पाला है उनकी उम्मीदों ने;

देखो मुझे तो सम्मान और प्यार से;  
मैं दिखा दूंगा सबको एक दिन यही,  
मैं खुशियों को देने में पीछे नहीं!

स्मिता

10:46 pm





*Down's Syndrome is a chromosomal disorder. Today world says,  
Pl Do not discard them because they are beautiful creature  
who need right kind of nurturing. They have different way of  
assessment and a good grooming makes them happy.*

## EDUCATIONAL POEM DOWN'S BABY-UP ON ROAD

**Dr. Smita Misra**  
Senior consultant, Paediatric Cardiology  
Manipal Hospital, Dwarka, Delhi

'Mom, with you, i am here,  
With my upslanted eyes, large tongue  
short limbs, and curved finger!  
I am sure I am not what you thought,  
As I will walk in a different growth chart!

You may think, in 12 weeks' scan,  
why did they miss, nuchal fold as thick it was,  
And a short nasal bone,  
Also, a common AV valve, in my heart!

It's true,  
I will hold my neck and roll-on tummy late,  
As I am a lazy guy;  
Yet I will learn talk, walk and play,  
To bring you immense happiness and joy;  
So, we will enjoy our journey,  
with compassion and love;  
Though I would hold your finger, longer for sure!

But you need to correct  
my heart defect early,  
So, I remain fit to learn all stories, poetries;

Though I am fragile and seek more care,  
For my muscles, teeth, eyes and ears;  
I promise to do all what can I do.  
To earn my wages and live for you;

Mom, I would be stay under  
your wings longer, than any other kid;  
But rest assured, I would be best baby,  
Learning all the skills!

Let them name me a Down's baby  
But I will be aiming for uphill road,  
Only if you trust me and yourself,  
Then we will happily travel  
roller coaster ride of life together!'

Mother:  
' It is fine my son, you have  
an extra chromosome,  
I will work with you to make  
A happy living and life awesome!  
I love you as much as you do,  
We both would enjoy new learnings too!'





## Glimpses from PEDICON 2022 Noida



Faculty at Autism workshop which was Preconference workshop of Pedicon 2022.

Dr. Samir Dalwai and Dr. Zafar Mannai were national conveners.

Dr. Lata Bhat and Dr. Jyoti Bhatia were local Conveners for the same



IAP Handbook of Developmental Pediatrics was released during Pedicon 2022





## Glimpses from PEDICON 2022 Noida



Chapter symposium of Neurodevelopmental Chapter of IAP



Smriti Irani was the chief guest at the inaugural ceremony of Pedicon 2022





## Glimpses from PEDICON 2022 Noida



Ladies in Organising committee of Pedicon 2022.



Dr. Lata Bhat and Dr. Subhash Chandra managed all the abstracts, editing, Oral / e posters presentation, publishing the Souvenir and hall management of the free papers. It was a herculean task but enjoyed every bit.





## Glimpses from PEDICON 2022 Noida



As judge for ePoster



Dr. Lata Bhat being felicitated for her contribution to Pedicon 2022 organizing committee as chairperson of Abstract committee and Souvenir committee





## Glimpses from PEDICON 2022 Noida



Sonu Nigam night at Pedicon



Downs syndrome kids being felicitated at Pedicon





## Glimpses from PEDICON 2022 Noida



Autism.workshop



Dr. Lata Bhat with organizing secretary of Pedicon 2022 Dr.Ruchira Gupta and IAP HSG Dr.Vineet Saxena





## Month in pics



Avneesh (7) and his father Aditya Tiwari holding national flag | File Photo

Avneesh, a 7 year old kid with Down Syndrome created a world record by climbing upto Mount Everest base camp (Height 5364 meters) along with his dad Mr Aditya Tiwari. Mr. Aditya Tiwari adopted him when he was 26 years old and Avneesh was 2 years old. Aditya has been awarded world's youngest dad award.





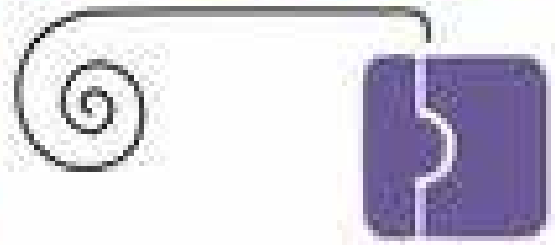
## Month in pics

### How To Improve Your Dental Health 4 Easy Tips



1

Brush your teeth 2x a day with fluoride toothpaste and replace your toothbrush every 3-4 months.



2

Floss Daily to remove food particles that get caught in teeth.



3

Eat a balanced diet and avoid in-between meal snacks.



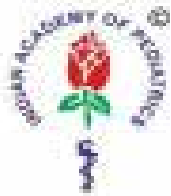
4

Schedule regular dental checkups for professional cleaning and oral exams.





## Month in pics



### IAP COCHIN

INAUGURATION OF ACTION PLAN AND ORIENTATION  
CME FOR TEAM COORDINATORS AND PAEDIATRICIANS

IAP KERALA PRESIDENTIAL ACTION PLAN 2022

## HEARING FRIENDLY KERALA

Date: 05th February 2022 Saturday

Time: 7.00 PM - 8.30PM

### SPEAKERS



**Dr. Abraham K Paul**  
Head of Paediatrics  
Indra Gandhi Co-operative Hospital



**Dr. Febi Francis**  
Assistant Professor,  
GMC, Thrissur



<https://us02web.zoom.us/j/86341729692?pwd=aURGcGdVODhjaOE9XUI9Wa1trQkgyQT09>

Meeting ID: 863 4172 9692

Passcode: 448853

Dr Noushad,  
President, IAP Cochin

Dr VijayaKumar M,  
President, IAP Kerala

Dr Rekha Zacharias,  
Secretary, IAP Cochin

Dr Johnny Sebastian,  
Secretary, IAP Kerala





## Month in pics

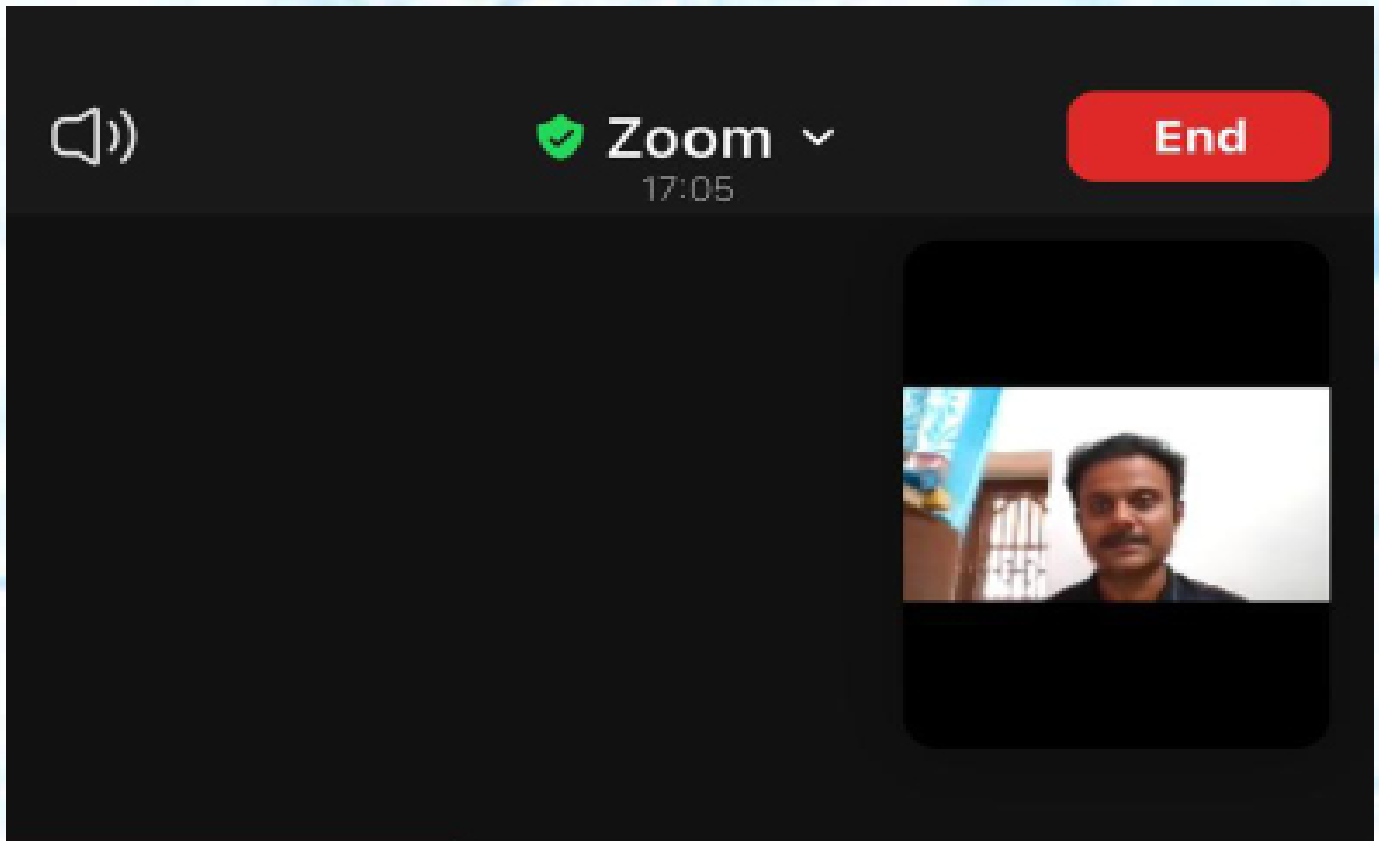


Cyclathon to spread awareness about Down Syndrome at PEDICON 2022 today. Theme - WE DECIDE





## Month in pics



### Journal Club Presentation. IAP NDP fellowship.

- Presentation-Dr Chaitanya Varma.  
IAP NDP fellow,  
SETHU, Centre for child development &  
Family Guidance, Goa.
- Senior Expert- Dr Praveen Suman.  
Sir Ganga Ram Hospital, New Delhi.
- 8<sup>th</sup> March 2022.

Journal club 08 March 2022 by Dr Chaitanya Varma





## Month in pics



Dr Chaitanya V



cdcmkc@gmail.comAD867011...







## Month in pics



Case Presentation - Down Syndrome





## Month in pics

Rinsy

Roopa Srinivasan

WE DECIDE

WORLD DOWN syndrome DAY MARCH 21

no discrimination

**SWOT**

	Helpful	Harmful
<b>Internal</b>	<p><b>STRENGTHS</b></p> <ul style="list-style-type: none"> <li>Very well innately</li> <li>No other major systemic involvement</li> <li>Good functional status</li> </ul>	<p><b>Weakness</b></p> <ul style="list-style-type: none"> <li>Extra chromosome</li> <li>Behavioral issues arising as</li> <li>Personality changes</li> <li>Motorized lag as for normal walking</li> <li>Speech abilities</li> </ul>
<b>External</b>	<p><b>OPPORTUNITIES</b></p> <ul style="list-style-type: none"> <li>Access to developmental centers</li> <li>Government facilities</li> <li>DQ is still holding on to and his</li> </ul>	<p><b>THREATS</b></p> <ul style="list-style-type: none"> <li>Responsible parents bring away</li> <li>Oppositional defiant behavior</li> <li>Psychotic group</li> <li>Further fall in DQ</li> <li>Setting in of Down Complications</li> </ul>

Examination of musculoskeletal system – GALS Screening

- Gait : clumps. Can't turn around briskly. No waddling or knee deformity
- Limbs and spine aligned
- Arms: Full Movements around shoulder
- Not hyperextended.
- Hand grip good >gr 4
- Legs: Full Movements around hip and knee
- Spine : ? Kyphosis noted.





## Month in pics

IDSD Logo



### World Down Syndrome Day Theme

#### International down syndrome day 2022 Theme

This year of 2021, The World Down Syndrome Day Theme is focuses on "We Decide". all people with Down syndrome should have full participation in decision making about matters relating to, or affecting, their lives.

# "We Decide"







## Month in pics



FIAP award to Dr S. sitaram and Dr. Sanjay KS at Pedicon 2022 Noida





## Month in pics



Chapter awarded 3rd best chapter at PEDICON NOIDA





GBM at Pedicon





## Month in pics



Dr Shymal Verma presenting a paper at Pedicon 2022





## Month in pics



**Downs syndrome day celebration with parents guidance program  
and kids fashion Show and drawing competition  
Dr. Kashmiri Badbade**





## Month in pics

Behaviour management in children - Online workshop





## Month in pics



Downs syndrome day celebration with parents guidance program and kids fashion Show and drawing competition  
Dr. Kashmiri Badbade

