DPT

DEVELOPMENTAL PEDIATRICS TODAY

October 2018

Monthly e-Newsletter of IAP Chapter of Neurodevelopmental Pediatrics

IAP CHAPTER OF NEURO DEVELOPMENTAL PEDIATRICS

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Editorial

Regulating Challenges

Regulations are meant to streamline and guide and not obfuscate. But sometimes the solution becomes worse than the problem. Our Chairperson has highlighted just such an issue in his article on government regulations on people with challenges taking exams. Exams are a challenge to everyone and the plight of the differently abled including children and young people with Specific Learning Disability is worthy of some serious empathy. The exam systems in our country have a strong bias in favour of the written word and that is not going to end anytime soon. Be that it may it is imperative that due concessions are given. Dr Jeeson has given critical suggestions on this and we hope that the authorities take note.

Initiation and withdrawal of life sustaining treatments in the face of expected bad prognosis and vegetative states have been without any formal regulation till recently. But the Supreme Court judgement on euthanasia is a landmark piece of judicial legislation if we can call it that ,without any negative connotation intended. The verdict in the so called Aruna Shanbaug case is a remarkable work which examines the issue from every possible angle. But the rights of the differently abled are not discussed in detail. I have penned an article on the issue in what is going to be my monthly column called The Right(s) Choice.

Happy reading.

Dr. Santhosh Rajagopal
Chief Editor

Chairperson's Message

Dear colleagues,

This is the 1st DPT post our National Conference at Hyderabad in association with PATSCON organised as a grand event by Dr Himabindhu Singh, Dr Sudharshan Reddy and the entire organising committee. I, on behalf of all members of IAP Neurodevelopment Chapter would like to, at the outset, record our profuse thanks to them and to IAP President Dr Santosh Soans, IAP HSG Dr Remesh Kumar and Dr Bakul Parekh for gracing the occassion.

The Executive Committee and our AGM decisions will be shared with you all in this issue.

World Cerebral Palsy Day is celebrated on Saturday 6th October 2018 and this month is the Cerebral Palsy Awareness month. Dyspraxia Awareness Week (7-13th October) needs also to be focused on.

We are thrilled to inform you all that at least 20-25 more IAP NDD Guideline workshops have been sanctioned with a funding of Rs.50,000 per workshop. Please send in requests for the same.

The Chapter Advocacy on various issues related to care of differently abled children of our country needs attention of all our members and through us and IAP to concerned authorities.

1. What is the status of the new PWD Act as far as facilities that children with Learning Disorders could access? In THE GAZETTE OF INDIA : EXTRAORDINARY [PART II—SEC. 3(ii)]; MINISTRY OF SOCIAL JUSTICE AND EMPOWERMENT [Department of Empowerment of Persons with Disabilities (Divyangjan)]; NOTIFICATION New Delhi, the 4th January, 2018 the only mention of Specific Learning Disability is a Figure 2. The suggested flow for identification and certification of Children with suspected Specific Learning Disability. Access at http://disabilityaffairs.gov.in/upload/uploadfiles/files/Guidelines%20notification_04_01_2018.pdf.

2. What is the position of the Govt regarding the No Detention Policy?

3. Issues relating to the Govt's revised guidelines for conducting examinations for differently abled children

We need to work on updating our IAP NDD Guidelines and add guidelines for management of 3 more conditions 1. Downs Syndromes 2. Cerebral Palsy 3. Intellectual impaired child

We also need to create Guidelines for developing a Neurodevelopmental Centre and develop amethod of validating tools..

There is lots to do and many miles to go.

Jai IAP, Jai IAP NDCP

Dr. Jeeson C. Unni
Chairperson
IAP Chapter of Neurodevelopmental Pediatrics

Snippets from the Secretary

Respected seniors and dear friends,

Back from the annual conference always has a nostalgic feel to it...The high of being immersed in the aura of academic updates about the field the whole day, the joy of meeting annual friends and exchanging notes both professional and personal...and the overwhelming feeling of returning after a successful NCDP is the best part!

Thanks to the entire organising team of NCDP 2018 at Hyderabad for the meticulous planning and execution and the excellent faculty from the Chapter and the state for the academic feast . Sincere thanks goes out to each and every one of you who attended and made the event possible with your enthusiasm, interest and response to the whole event. The enthused new members are welcome aboard this family of Neurodevelopmental Pediatrics and we hope to have active participation by you all in the academic exchange in the times to come.

Please keep sending in events with snaps and if anybody is interested in sharing/ writing on any topic pertinent to the field please write to us at cdgiap@gmail.com.

Happy learning friends...

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Journal Scan

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COMMON USE OF STIMULANTS AND ALPHA-2 AGONISTS TO TREAT PRESCHOOL ATTENTION-DEFICIT HYPERACTIVITY DISORDER: A DBPNETSTUDY

Blum, Nathan J., et al. Journal of Developmental & Behavioral Pediatrics: September 2018 - Volume 39 - Issue 7, p 531–537

Original Article

Objective: To describe the use of stimulants and alpha-2 agonists (A2As) for the treatment of preschool-aged children with attention-deficit hyperactivity disorder (ADHD) at 2 Developmental-Behavioral Pediatrics

Research Network sites

Methods: Demographic information, diagnoses, and medications prescribed by developmental-behavioral pediatricians (DBPs) were extracted from the electronic health record for all outpatient visits from January 1, 2010, to December 31, 2011. The subset of visits for children aged 2 to 5 years who had a diagnosis of ADHD was included in this analysis. Multivariable models were constructed to identify factors associated with prescribing stimulants and A2As.

Results: Over the 2-year period, 984 children with a diagnosis of ADHD were seen at 1779 visits. Of the 984 children, 342 (34.8%) were prescribed a stimulant, and 243 (24.7%) were prescribed an A2A. Both medications were prescribed at the same visit at least once during the 2-year period for 97 children (9.9%). Alpha-2 agonists were prescribed more often at site 2 than site 1 (OR [odds ratio] = 1.62, $p = 0.015$). Stimulants were more likely to be prescribed for older preschool-aged children (OR = 1.66, $p < 0.001$), and A2As were more likely to be prescribed for younger children (OR = 0.82, $p = 0.02$). Both stimulants and A2As were more likely to be prescribed to children with ADHD and comorbid conditions.

Conclusion: Alpha-2 agonists are commonly used by some DBPs for preschool ADHD. Variation in the use of A2As across sites may indicate a lack of consensus on when to use these medications and suggests a need for comparative effectiveness research to better define the relative benefits and side effects of A2As and stimulants for the treatment of preschool ADHD.

Journal Scan

EFFECTS OF YOGA ON ATTENTION, IMPULSIVITY, AND HYPERACTIVITY IN PRESCHOOL-AGED CHILDREN WITH ATTENTION-DEFICIT HYPERACTIVITY DISORDER SYMPTOMS

Cohen, Samantha C., et al. Journal of Developmental & Behavioral Pediatrics: April 2018 - Volume 39 - Issue 3 - p200–209

Original Article

Objective: Behavioral therapies are first-line for preschoolers with attention-deficit hyperactivity disorder (ADHD). Studies support yoga for school-aged children with ADHD; this study evaluated yoga in preschoolers on parent- and teacher-rated attention/challenging behaviors, attentional control (Kinder Test of Attentional Performance [KiTAP]), and heart rate variability (HRV).

Methods: This randomized waitlist-controlled trial tested a 6-week yoga intervention in preschoolers with ≥4ADHD symptoms on the ADHD Rating Scale-IV Preschool Version. Group 1 (n = 12) practiced yoga first; Group 2 (n = 11) practiced yoga second. We collected data at 4 time points: baseline, T1 (6 weeks), T2 (12 weeks), and follow-up (3 months after T2).

Results: At baseline, there were no significant differences between groups. At T1, Group 1 had faster reaction times on the KiTAP go/no-go task ($p = 0.01$, 95% confidence interval [CI], −371.1 to −59.1, $d = -1.7$), fewer distractibility errors of omission ($p = 0.009$, 95% CI, −14.2 to −2.3, $d = -1.5$), and more commission errors ($p = 0.02$, 95% CI, 1.4–14.8, $d = 1.3$) than Group 2. Children in Group 1 with more severe symptoms at baseline

showed improvement at T1 versus control on parent-rated Strengths and Difficulties Questionnaire hyperactivity-inattention ($\beta = -2.1$, $p = 0.04$, 95% CI, −4.0 to −0.1) and inattention on the ADHD Rating Scale ($\beta = -4.4$, $p = 0.02$, 95% CI, −7.9 to −0.9). HRV measures did not differ between groups.

Conclusion: Yoga was associated with modest improvements on an objective measure of attention (KiTAP) and selective improvements on parent ratings.

Reviewer's comments

Behavior therapy and non pharmacological interventions are the mainstay of treatment of ADHD symptoms in pre-school children and role of medication usage is limited (refer national consensus guidelines on management of ADHD published in Indian pediatrics in 2017). Yoga may be added to the list of non-pharmacological interventions in the guidelines at the time of next revision and case for addition of A2 agonist in management of preschool children may be considered based on available evidence.

The Govt of India Revised Guidelines for conducting Examinations for Persons with Disability

Dr Jeeson C Unni
Editor-in-chief, IAP Drug Formulary
Sr Assc Consultant, Dept of Child Health and Adolescent Medicine, Aster Medcity, Kochi

The 'revised guidelines' recently released by the Union Ministry of Social Justice and Empowerment for Conducting Examinations for Persons with Disability seems unfair, to say the least, as it is a retrograde step that partly downsizes the 2013 recommendations that sought to empower the differently abled children of our country.

The reason for the 'revision'

1. Representations from the Union Public Service Commission (UPSC) and others that 2013 Guidelines was misused by some students who coached their scribes before examinations. They were labeled as 'cheats'. If a normal child is found cheating, only that child is punished by disqualification. The UPSC demanded changing the Guidelines for all differently abled candidates.

To make guidelines in compliance with Right of people with disabilities act passed in 2016 which provides for reservation in Government jobs for persons with benchmark disabilities.

Major changes made in the guidelines and their problems

1. It has fixed education criteria for scribe that he should be one step qualification below which was not there in 2013 guidelines. Whether it means one year below in the same degree or one degree below is not clearly stated. The statement does not address the situation wherein the candidate and the scribe are from different streams. Setting the criteria would restrict the choice available for the candidate to opt for the scribe.

2. It says that for certain classes of candidates with benchmark disabilities, a certificate be furnished from a designated official, indicating that the candidate has a physical limitation and needs a scribe. A separate certificate will add an additional compliance burden on these candidates and also question the relevance of disability certificate that the candidates possess.

3. The candidate is to be given an opportunity to choose his preferred mode of giving the examination only to the extent possible by the relevant Board of examinations. The guidelines by providing the discretionary power to the examination conducting body over the mode of the examination converts what the candidate is legally entitled to the decision of persons on the concerned committees of the authorized examination-conducting body.

Changes that may be suggested for consideration

1. The educational criteria should be removed

2. Exam conducting bodies should be mandated to provide a preferred mode of exam for these candidates rather than making it discretionary

3. The bodies should themselves provide the scribe whose details should not be disclosed before the exam and should be changed with each exam

4. The policymakers should recognise that differently abled children are at a disadvantage not because of their disability but because of the hostile environment. Thus, it is the duty of all concerned to make systems more disabled friendly.

Medical Interventions in the differently abled

Dr Santhosh Rajagopal

(The name of this monthly column on policy issues in the sector is deliberately kept as rights since that is the paradigm governing the differently abled now.)

Just this week the Madras High court refused to grant a request to do euthanasia on a spastic diplegic who required extensive support. That the parent was driven to this is of course a personal tragedy which many of us cannot fathom. Let me quote form the writ petition:

"Continuous bawling of the child causes severe disturbance and trauma to people inside the house as well as the neighbours and my other two children face social embarrassment as well as isolation. No asylum or home of any kind is willing to give any kind of shelter or palliative care to my son."

The father wanted the child to be put to sleep by withholding all forms of nutrition and support. The court sent the child to a team of doctors who opined that while the condition was irreversible the child was not in persistent vegetative state. Court refused the request and in the meantime a home came forward to take care of the child. The father refused and offered to take care himself.

While this is a case where request for euthanasia was made, there are more complicated ethical minefields here. For instance, if the child mentioned above (who can just about smile and cry and requires extensive support) goes into respiratory failure due to infection or other disease. Would the parent or doctor dither putting the child on ventilator? If they do, are they being unethical? It is quite possible that the parent might refuse such care. It is also possible the medical team might suggest that the child be not put on ventilator or other supports.

In India it is not uncommon for caregivers to refuse ventilator/ECMO support for elderly patients who are not in a position to take decisions. Most often the choice is hidden in clinical language. A more conscientious clinician might record the refusal. But when it comes to minors and that too minors with severe developmental disabilities the situation is more complex. Let us examine the legal angle here.

The Right(s) Choice

The Juvenile Justice Act 2016 is a landmark piece of legislation in that it provides for care and nurture of both children/juvenile in need as well as those in conflict with the law. There are several clauses that would ensure that disabled children get equality. The general guiding principles in Chapter 2 states

“There shall be no discrimination against a child on any grounds including sex, caste, ethnicity, place of birth, disability and equality of access, opportunity and treatment shall be provided to every child”

The National Commission For protection of child rights is empowered to enquire into and take action on any denial of facility to children with special needs.

The most pertinent piece of law that would operate in a case where a child who is severely challenged needs ventilation or such care is the Supreme Court judgement in the euthanasia case which followed the Aruna Shanbaug plea.

The judgement clearly lays down that in cases where the patient is incapable of making decisions the decision not to resort to artificial prolongation or to withdraw life support has to be taken by a committee of expert doctors after talking to relatives .The caveat is that a cooling period of one month is suggested for allowing for appeals. It is not clear how this can be implemented in cases where not connecting to a ventilator might result in death in hours. Even in cases of dialysis death can supervene in hours/days due to electrolyte imbalance.

It is obvious that the JJ Act provision of non -discrimination will have to guide the team when it takes up a case when a special child is critically ill. The touchstone should be “Would we put this child on life support where he/she a normal child?” If the answer is yes then the committee has to take the decision to provide support as law stands today.

We also need to understand that parents of such children will have complex psychological needs .The decisions that they take in the face of obvious suffering of children should not haunt them for the rest of their lives. It is therefore self -evident that a counselling process should precede the decision making process. The solution of taking out pre-existing disability from the equation might look simple but is fraught with complexities. In the case of a normal child the prospect of being in a vegetative state might prompt a decision not to initiate life sustaining treatment .But in cases like above where the quality of life even before the acute illness was low ,how does one become disability agnostic?

There is an urgent need for a national consultation on this and related matters of medical care for the differently abled. Our Chapter can take the lead in this.

Primitive reflexes
The Moro reflex

The Moro reflex is an infantile reflex normally present in all infants/newborns up to 3 or 4 months of age as a response to a sudden loss of support (as the baby is gets stronger. Moro Reflex begins to improve and vanishes completely by 5-6 months), when the infant feels as if it is falling. It involves three distinct components:

spreading out the arms (abduction)

unspreading the arms (adduction)

crying (usually

Phase 1 - The baby will experience what can be best described as a sensation of free-falling, where the baby reacts by lifting and stretching their arms. Baby may even let out a sharp gasp.

Phase 2 - The baby will curl the arms and legs closer to their body into a slight fetal position.

The primary significance of the Moro reflex is in evaluating integration of the central nervous system - presence in the newborn is an important indication of a normally developing nervous system in newborn. It is distinct from the startle reflex, and is believed to be the only unlearned fear in human newborns.

5 usual Triggers of Moro Reflex

Moro reflex is triggered by any sudden changes in sensual stimulation. There are many such triggers, but the common ones are:

1) A loud noise

2) A sudden touch

3) An abrupt change in the intensity of light

4) Any event that puts the baby off balance - such as a drop in altitude (when being placed into a crib, taken out of a bath tub for example).

5) A change in the direction of the baby’s body.

How to Calm a Baby Experiencing Moro Reflex?

The Moro Reflex could be very disturbing for a baby. The baby, while getting used to the outside world which is very different compared to the tight space inside the womb could develop the reflex in response to any of these triggers. . So when experiencing Moro reflex, drawing the baby's stretched arms and legs closer to their bodies to hold them in place will calm them down.

A swaddle restricts the baby's movements and helps draw their extended limbs back. This is why swaddling (fabric that wraps around baby's body like a cozy cocoon) is practiced around the world as a common way to calm infants.

Interpretation of Moro Reflex

The Moro reflex may be observed in incomplete form in premature birth after the 28th week of gestation, and is usually present in complete form by week 34 (third trimester). Absence or asymmetry of either abduction or adduction is abnormal, as is persistence of the reflex in older infants, children and adults. Absence indicates a profound disorder of the motor system or a generalised disturbance of the central nervous system. An absent or inadequate Moro response on one side is found in infants with hemiplegia, brachial plexus palsy, or a fractured clavicle. Persistence of the Moro response beyond 4 or 5 months of age is noted only in infants with severe neurological defects. In individuals with cerebral palsy, persistence and exacerbation of this reflex is common.

The Moro reflex is impaired in the early stage of kernicterus and it is absent in the late stage of kernicterus.

Function

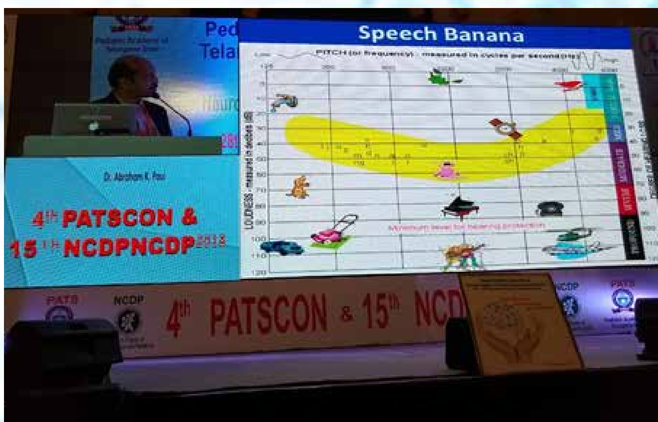
The Moro reflex may be a survival instinct to help the infant cling to its mother. If the infant lost its balance, the reflex caused the infant to embrace its mother and regain its hold on the mother's body

National Conference

The annual conference NCDP 2018 which was held this year in association with PATSCON at yderabad on 29-30th September 2018 with a pre conference workshop on the National guidelines on Neurodevelopmental disorders on 28th September. The local organising committee with Dr Himabindu Singh, Dr Sudarshan Reddy, Dr Srikrishna and their whole team managed to carry out the whole event meticulously and well. CIAP President Dr Santosh Soans, IAP Hon'Secretary General Dr Remesh Kumar and Dr Bakul Parekh graced the occasion. Seniors of the NDP chapter Dr SS Kamath, Dr Abraham Paul , Chairperson Dr Jeeson Unni, Past Chairperson Dr Samir Dalwai, Secretary Dr Leena Srivastava and past secretary Dr Chhaya Prasad along with the senior members of the chapter deliberated in the scientific sessions which were well appreciated. Around 473 delegates from across the country attended the conference and greatly appreciated the scientific sessions.

National Conference

The Inaugural function included distribution of gold medals and fellowship scrolls of the IAP fellowship of Developmental Behavioral Pediatrics at the hand of the CIAP dignitaries. This was the second passing out batch of the fellowship which is run by the chapter . A highlight of the conference was the Dr Y.R. Reddy oration delivered by Dr SS Kamath -'Scholastic backwardness-the way forward'. This was followed by felicitation of the stalwarts. Dr Arun Singh , National advisor on child health, RBSK , Ministry of Health and Family welfare, GOI ,Dr Vineet Saxena, VP-IAP Central zone were other speakers who were present at the conference.



Preconference Workshop

The pre conference workshop on 28th September held at Niloufer hospital had around 72 delegates. A lot of active participation was seen at the morning session and the hands on session in the afternoon.

North Zone ToT of IAP Guidelines for Neurodevelopment and Behavioural Disorders held at Chandigarh on 16.9.18

NDD Autism Guidelines session

NDD Autism Guidelines session at Faridabad by Dr Himani Khanna

IAP Action Plan - NDD Workshop at Karpedicon at Darwar, Karnataka

Events across the country

Cerebral Palsy Day

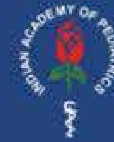
It was a pleasant moment to host the nation wide campaign against CP "National Cerebral Palsy Day" Celebration at Kanchanjangha Stadium in Siliguri on 03/10/18. We, the Cradle Child Development Centre in siliguri organized the event in association with the Indian Academy of Cerebral Palsy (IACP). Ex Prof. Dr. Mridula Chatterjee who is among the veteran child specialist in North East India, Pediatric Neurologist of Cradle CDC Dr. Dipankar Gupta, Mr. Madan Bhattacharya who is a well known social activist here in Siliguri, were present as the chief guests for the event.

Events across the country

Sensitization of faculty and residents of neonatology dept SGPGI towards Developmental Pediatrics by Dr Shruti Kumar

Poster presentattion and course on medical genetics in SGPGI Lucknow

Dr Shruti Kumar From SGRRIM&HS Dehradun –
A Talk on Early Intervention in a CME in IAP Lucknow



Aster KIND Annual CME

Early Child Development
'Nurturing Our Tomorrow"

11 November 2018 | 8:30 AM - 4:30 PM
Knowledge Hub, Aster Medcity

Applied For CME Credits

A joint initiative by
Aster KIND, Aster Centre of Excellence in Child & Adolescent Health,
IAP Chapter Of Neuro Developmental Paediatrics & IAP Kochi Branch

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Membership Application Form

(Please fill in capital letters; All Information Mandatory; Pl do not leave any blank spaces)

1. Surname: ____________________First Name: _____________Middle Name:____________

2. Date of Birth ____

3. Central IAP Membership Number (For Pediatricians Only) :______________________

4. Permanent address: ..……………………………………………………………………..

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5. Office Address………………………………………………………………………………

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6. Email:………………………………………….. Landline Telephone:………………………..

7. Mobile Phone Number (1)…………………………….(2)……………………………………

8. Present Work Status: Private __ Govt.__ Medical College__ Voluntary Agency __

9.

Qualifications	Name of University	Year of Passing
MBBS		
MD Pediatrics		
DCH		
DNB Pediatrics		
Others		

10. Areas of Interest of Work ____

P.T.O

11. Membership Subscription:

a) Life Membership for Central IAP Members – Rs 1000

b) Life Associate Membership for Doctors other than Pediatricians – Rs 1000

c) Life Affiliate Membership for All Other Professionals – Rs 1000

12. Demand Draft / Cheque to be drawn in favor of "**IAP Chapter of Neuro Developmental Pediatrics"** payable at Ernakulam.

On online transfer please e-mail the scanned form with transfer details to cdgiap@gmail.com **with cc to** leena.sri2012@gmail.com

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