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DPT

DEVELOPMENTAL PEDIATRICS TODAY



Monthly e-Newsletter of IAP Chapter of Neurodevelopmental Pediatrics

IAP CHAPTER OF NEURO DEVELOPMENTAL PEDIATRICS

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Editorial

The Learning Curve

Increase in frequency of publication should bring joy to any magazine team in this era of short attention span. But the monthly e news letter that we are now promising fills my mind with not a little trepidation. It's a high promise that's tough to deliver and at the same time a huge responsibility. So it's not just the intellectually less endowed, the subject of this editions lead article, who find the going tough in the knowledge driven world of today.

Coming to that, my friend Dr Chhaya has diligently laid out the road map to exploring the clinical spectrum of cognitive impairment. The arrival of the latest weapon in the diagnostic armamentarium, Next generation sequencing shouldn't divert attention from the clinical examination. Many a time all that we can offer after costly tests is no different than what was offered before that. Unless there's a question of recurrence that needs to be addressed many parents might be unwilling for extensive work ups as well. But prognostication also is needed. And till the latest tests become universally available and affordable, we might be left with no option but go for the older generation tests.

The chapter members continue to surprise with their amazing versatility and a big applause is in order. It would be unfair if I do not mention that my friend Dr Leena Srivastava did all the work for this electronic edition. Yours Truly just penned this Editorial. But then that's what friends are for ...

Dr. Santhosh Rajagopal

Chief Editor



Chairperson's Message



Dear friends,

We as a Chapter have been trying to put in our bit towards improving care of differently abled children in our country. I am proud of the commitment of all our members towards this goal. There is a lot we have done and I congratulate Dr Samir Dalwai and Dr Chhaya Prasad for leading this young Chapter energetically; so much so that we have become recognised in IAP as one of the most vibrant, active and focused group of pediatricians. Chairing this bunch of 'activists' is a huge responsibility and I hope Dr Leena Srivastava, myself and our new team will be as efficient as our predecessors.

We intend to activate our members by having this monthly e-newsletter of the IAP Chapter of Neurodevelopmental Pediatrics – We named it DPT – Developmental Pediatrics Today – with the aim of vaccinating the target group by stimulating developmental pediatricians to work with the latest information in the field. We hope that regular communication through DPT will increase interest in the subject and improve our Chapter membership.

We need to work on update of our guidelines create new guidelines on Down's syndrome, Cerebral palsy, Intellectual impairment and visual impairment; roll out TOT of the 4 guidelines the Chapter published; advocacy for LD; and outreach programs to care for the high risk groups.

We are thankful to IAP Telangana for offering to host the next National Conference of IAP Chapter of Neurodevelopmental Pediatrics on Oct 6th/7th 2018.

Wishing you all a wonderful year of selfless activity for the special children.

Regards,

Dr. Jeason C. Unni

Chairperson

IAP Chapter of Neurodevelopmental Pediatrics



Snippets from the Secretary

“And now let us welcome the New Year, full of things that never were.. .”

-Rainer Maria Rilke

A neonate is born-Developmental Pediatrics Today DPT...It will require a lot of caring and nurturing from the parents & family- editorial team and the OB and of course stimulation and positive reinforcement from you all ie. it's environment.

This example itself reminds us of the gospel truth that we all learnt in Pediatrics that nature and nurture both play important roles in a child's development. Yet how many of us actually remember to play a role in guiding the parents in creating a stimulating and secure environment for a child.

This stimulation may be just a safe and secure home environment for a growing child(such a simple requirement... but do we make sure our children get that?..)

This stimulation may be in the form of optimum nutrition and a stimulating environment conducive for learning...(many of our children are deprived of this as well... !!)

As Pediatricians with a special interest in Developmental Pediatrics we can't hold ourselves responsible for this but we can make parents and caretakers aware of these basic needs... We can train parents to care for a child, play with the child with age appropriate toys.. Ironical as it seems it may not always be the financial inadequacy but many times it is the inadequacy of skills of parenting.. (I have faced moms who say they don't know how to talk or play with a two year old as many of you would have heard as well..)

Parenting entails a lot but the biggest contribution we could make to a child's developmental trajectory is to simply guide parents to stimulate the child by talking, interacting, reading, singing to and even dancing with the child. Making them aware that screen is not a substitute parent or teacher and nothing can replace the two way communication and reciprocity of healthy human interaction...Help them discover the joy of parenting through this...

Did you know...

- “Child cognitive outcomes showed that compared with children who received no responsive stimulation, the children exposed to responsive stimulation had significantly higher mean scores for IQ, executive function, and pre-academic skills.” [http://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(16\)30100-0/fulltext](http://www.thelancet.com/journals/langlo/article/PIIS2214-109X(16)30100-0/fulltext)
- “Children younger than 2 years who watch more television or videos have expressive language delays.” <http://pediatrics.aappublications.org/content/128/5/1040.long>

(Attaching links to some recommended reads in this context.)

Similarly also invite interaction from you all to together discover some thoughts about development in children that we can make a difference in...

Signing off with-

‘The best inheritance a parent can give his children is a few minutes of his time each day’...Orlando Battista..

Happy learning friends!

Dr Leena Srivastava

National Secretary

IAP chapter of Neurodevelopmental Pediatrics

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IAP FELLOWSHIP IN DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS - REPORT

Dr Chhaya Sambharya Prasad

National Coordinator, IAP Fellowship in Developmental and Behavioral Pediatrics

Immediate Past Secretary, IAP Chapter of NDP 2015-17

IAP Chapter of Neuro Developmental Pediatrics

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• Under the IAP Action Plan 2015, with able leadership of Dr SS Kamath, National President IAP 2015 and Dr Samir Dalwai, Convener IAP Committee on Child Development and Neuro Developmental Disabilities [Chairperson IAP Chapter of Neuro Developmental Pediatrics], the humongous task of launching the academic training program for pediatricians - IAP Fellowship in Developmental and Behavioral Pediatrics was undertaken. The Chapter proceeded with blessings of Prof MKC Nair, Vice Chancellor, Kerala University of Sciences, and his constant encouragement and guidance.

• The academic program was created for the pediatricians with an aim to develop an excellent understanding of the early child development, developmental neurology, neuro-developmental disabilities, genetic disorders, sensory impairments, behavior problems, social emotional problems, educational and academic rehabilitation, child guidance, parenting skills, behavior therapy and counseling, amongst children and adolescents, so that the pediatricians can provide their services in areas where such expertise is not available and also exhibit competency in skills required for developmental assessment, planning and implementation for early identification, early intervention and remediation for the neuro developmental and behavioral disorders.

• It was also considered that such a training program will provide skills and proficiency for prevention of severe disabling conditions in children. The program would also help other Rehabilitation

Professionals to develop competencies in organizing the interventional programs while coming together and working as an Inter Disciplinary Team.

• The Fellowship Governing Council was formed and committee members were deputed responsibilities - Dr SS Kamath Sir as the Chairperson for the Advisory Committee; Dr Abraham Paul Sir as the Chairperson and Dr Jeelson Unni the Co Chairperson for the Accreditation and Inspection Committee; and Dr Samir Dalwai as the Chairperson of the Academic Committee.

• Rules and regulations for running the program were framed and Guidelines for Accreditation were laid down. The huge task of writing the Eligibility Criteria for Accreditation, Eligibility Criteria for Candidates to apply, Curriculum, Syllabus, Fees, Stipend, etc was undertaken by the committee members. Criteria for number of seats per Institute were also written.

• The First Advertisement for Accreditation featured in IP Journal December 2015, inviting Child Development Centers / Institutes across the country to apply for running the academic course. Many Institutes across the country applied, some rejected





as they were not able to meet the eligibility criteria as listed by the Governing Council Committee. The others were selected for Visit and Inspection was conducted by Experts. Eligibility Criteria for selection was stringent and each and every criterion was documented by the inspectors and report submitted to Inspection Committee.

- Senior members of the Disability Group and experts from across the country and abroad such as Dr Sunny Kurian, Dr Sitaraman, Dr M Mahadeviah and many others helped with the Inspections for the accreditation process. The Inspection Reports were further verified by the Accreditation and Inspection Committee Chairperson Dr Abraham Paul and Co Chairpersons Dr Jeeson Unni sir. Accreditation Approval was provided to 7 Child Development Centers in 2016 and 2 more centres in 2017. Interviews were held at the Accredited Institutes for selection of suitable candidates.

- The first examination of the IAP Fellowship in Developmental and Behavioral Pediatrics was a Milestone in the history of the IAP Disability group. Dr Nandini Mundkur provided all local logistics for holding the exams at her Centre for Child Development and Disabilities, Bangalore. The examiners were - Dr M Mahadeviah, a very senior founder member of the Disability Group and Medical Director of the Spastics Society Karnataka; Dr S Sitaraman, again a senior member of the Chapter and Prof and Head

at Dept of Pediatrics, SMS Medical College Jaipur- In Charge of the Child Development Centre there; Prof Dipty Jain, Prof and Head of Dept, Pediatrics at IGMC Medical College and a very senior Research Member with INCLIN for many years. The examiners conducted the exam in most meticulous method and maintained the highest standards. Their contribution is commendable.

- At present the Academic training program is running successfully at 9 centres across the country. There are total 11 seats each year. The topper of the first Batch Dr Shruti Kumar was felicitated by a Medal and Award Certificate at the 55th Pedicon Nagpur.

- The IAP Fellowship Program trains the pediatricians to enhance Parents Participation to integrate the right interventions in the home environment, to help the society develop a 'Right Attitude towards a Child or Adolescent with Special Needs'

- The IAP Fellowship Program trains the pediatrician to be a Specialist in the Science of early childhood development and childhood disability and to deliver high quality clinical outcome in every single case and to actively participate for awareness, advocacy and promotion of various policies provided for the children and their families.

The chapter thanking the members involved in the accreditation process at the GBM at the Pedicon 2018 Nagpur.





Idiopathic Intellectual Impairment

Dr Chhaya Sambharya Prasad

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Idiopathic Intellectual Impairment refers to individuals with low intelligence who show no evidence of gross chromosomal defects or single-gene anomalies. It may also represent the lower end of IQ distribution. This impairment (backwardness) is defined as one which makes less progress than normal. Intellectual impairment means a person with the intellectual capacity that developed at a below average rate during the early developmental years. Several syndromes (such as Downs, Fragile, Rett syndrome, and other well known conditions) can be easily suspected because of their association to specific dysmorphisms, behavioural peculiarities, and multiple congenital abnormalities. However, a consistent percentage of children with intellectual disability do not present a recognizable phenotype which is striking of a well-recognizable syndrome. Determining a specific etiologic diagnosis is central to understand the nature of the problem, providing answers to questions regarding prognosis, recurrence risks, directing specific therapies, and achieving meaningful inclusion of individuals with disability into society.

Intellectual impairment is one of the most frequently diagnosed disabling conditions in our society, and a lifelong disability characterized by impairment of cognitive and adaptive skills. The aetiology is very heterogeneous and, unfortunately, in more than one-half of cases the cause is still unexplained. Anything that damages and interferes with the growth and maturation of the brain can lead to intellectual impairment. This might happen before, during or after the birth of the child (including complications of pregnancy/birth, toxics, malnutrition, trauma, infections, under stimulation etc). Moreover, genetically determined aetiology (comprising chromosomal aberrations, single-gene disorders, and other genetic conditions) account by itself for 17 to 41% of cases, depending of the different techniques of analysis.

Mental Ability is always more likely to be under estimated than over estimated, especially in case of persons from lower socio economic groups.

India is a vast country with variable social, cultural, geographical and economic background.

Communicable diseases and congenital diseases are still a major problem adding to the number of persons with disabilities. Evaluation of intellectual impairment is a big challenge with different social background, economic factors, extended family systems, low literacy rates, and virtually different habits/A.D.L. Intellectual impairment is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior and may present as deficits in conceptual, social, and practical adaptive skills. It is a variable, heterogeneous manifestation of central nervous system dysfunctions, occurring in 1-3% of general population. An estimated 10% of the world's population experiences some form of disability or impairment (WHO Action Plan 2006-2011) Global Prevalence: 4%-10% (Yeo 2001) 4% in developing countries and 7% in industrialized countries (Metts 2000) India and South Asia Prevalence: 1.5-21.3% in WHO South East Asia member countries (<http://www.searo.who.int/>) 8% -2.2% for India (Census 2001, NSSO 2002). Different prevalence rates for disability are available in India. According to the Census 2001, there are 2.19 thousand people with disabilities in India who constitute 2.13 % of the total population (Census 2001). Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, locomotor and mental disabilities (Census 2001).

Children with intellectual developmental delay (IDD) may have delayed gross motor milestones, learning to sit up, crawl, or walk later than other children, or they may learn to talk later. They take longer to learn language, social skills, and taking care of their personal needs, such as dressing or eating. Learning takes longer time, requires more repetition, and skills may need to be adapted to their learning levels. Both adults and children with intellectual disability may also exhibit some or all of the following characteristics:

- Delays in speech and language development
- Deficits in memory skills
- Difficulty learning the social rules
- Difficulty with problem solving skills
- Delays in the development of adaptive behaviors such as self-help skills



In early childhood, a mild intellectual impairment may not be obvious, and may not be identified until the child begins school. Even when poor academic performance is recognized, it may take expert assessment to distinguish mild intellectual impairment from a specific learning disability or an emotional/behavioral disorder. People with mild intellectual impairment are capable of learning reading and mathematics skills to approximately the level of a typical child aged nine to twelve (as published by DK, Ardinger HH, Holmes 2000). They can learn self care and practical skills, such as cooking or using the local mass transit system. As individuals with intellectual disability reach adulthood, many learn to live independently and maintain gainful employment.

According to the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), intellectual disability is considered to be approximately two standard deviations or more below the population, which equals an IQ score of about 70 or below. The assessment of intelligence across three domains (conceptual, social, and practical) ensures that clinicians base their diagnosis on the impact of the deficit in general mental abilities on functioning needed for everyday life. This is especially important in the development of a treatment plan. Intellectual disability involves impairments of general mental abilities that impact adaptive functioning (refers to the skills needed to live independently) in below mentioned domains, or areas, which determine how well an individual copes with everyday tasks:

- a) The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- b) The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- c) The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

While intellectual impairment does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.

It is formally diagnosed by professional assessment of intelligence and adaptive behavior. The diagnosis is not based only on IQ scores, but also the adaptive functioning as mentioned above. To assess adaptive behavior, professionals compare the functional abilities of a child to those of other children of similar age. There are many adaptive behavior scales, and accurate assessment of the quality of someone's adaptive behavior requires clinical judgment and experience as well. The following ranges, based on Standard Scores of intelligence tests, reflect the categories of the American Association of Intellectual Developmental Disorders (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders-V, and the International Classification of Diseases-10.

Class IQ

Profound Intellectual Disability	Below 20
Severe Intellectual Disability	20-34
Moderate Intellectual Disability	35-49
Mild Intellectual Disability	50-69
Borderline Intellectual Functioning	70-84

A three-generation pedigree helps to find out intellectual impairment in the family, and a detailed pre-, peri- and postnatal history should help to establish a definitive cause. A dysmorphic child may be at risk from the stress of birth, and later delay may be erroneously attributed to birth injury. A careful developmental history, with emphasis on milestones, formal assessments and behaviour, is also a must. Medical records should be sought or requested to validate any diagnosis of malformations. An accurate EEG study and/or brain MRI are sometimes sufficient to suspect several well-known and relatively common disorders (such as Rett's syndrome, Angelman syndrome, neurocutaneous syndromes such as Tuberous Sclerosis, etc.). The degree of Intellectual Impairment is an important indicator: the so called "chromosomal" phenotype, which is well known to accompany larger aberrations, is frequently characterized by moderate-severe Intellectual Impairment associated with one or more of major signs, including congenital malformations. The behavioural phenotype is also distinctive for several well-known syndromic conditions, such as Williams syndrome, Angelman syndrome, Prader-Willi syndrome. Abnormalities in head size, growth parameters, and neurologic signs should also be carefully investigated.

[To be continued in the next issue..]



The Science of Applied Behavior Analysis

Dr. Smita Awasthi, BCBA (Board Certified Behavior Analyst, USA)

The pediatric pedagogy in India emphasizes ABA as the primary choice of treatment once a diagnosis has been made for Autism Spectrum Disorder.

This series of article attempts to essay an introduction into ABA and its practice.

ABA or Applied Behavior Analysis is often considered a type of Therapy specially meant for children with autism. This knowledge is far from being true. ABA is actually all about behavior modification and its principles are used across disciplines such as improving safety in industrial plants (Chhokar & Wallin, 1984), geriatric care, nursing efficiency, road safety and also autism treatment.

Despite the ubiquitous use of this word for therapy the truth is that ABA is a science from which tactics are derived based on individual needs. To take an example a child who is really young and impulsive might learn better if “errorless teaching” or “0 second” prompting is used as compared to another child who is prompt dependent where a better way of teaching could be using “time-delays” for prompting. Treatment plans are thus based on an analysis of specific needs.

How is ABA a science? Firstly behavior which needs modification is defined in measurable terms. Making changes in a persons aggression may not be measurable, however instances of raised voice, hitting others can be measured. Secondly, collecting accurate, reliable and valid data during baseline in pre-treatment condition and during the implementation of the independent variable, demonstrates changes that are specific and observable. At times withdrawing treatments for brief periods and re-introducing them also confirms the effect of the variables affecting behavior change.

Behavior itself is defined operationally prior to a behavior change plan. Children with autism often have poor eye contact. One behavioral definition of eye contact could be “sustaining eye contact for 2 seconds by looking in the pupil of another person when requesting or when receiving an instruction or during joint play”. Looking at/around the face but not in the pupil will not be an instance of eye-contact.

Individuals under autism spectrum disorder have behavioral excesses and deficits. Behavior analysts design programs to increase behaviors like eye contact, sitting span, communication, speech and language, play skills, socialization, academics, self help skills etc and also decrease excessive behaviors like crying, tantrums, self-stim, vocal stereotypy, hitting, obsessions etc.

What is most important here is to practice the science of ABA, one needs to be educated in the subject and be mentored in the application of principles directly under the supervision of a masters level or doctoral level ABA professionals or behavior analysts. Those who begin its practice after attending workshops may do more harm than good.

There are currently 32 certified behavior analysts in India. While recommending ABA to parents with children with autism the Pediatric community needs to guide the parent to ask questions on professional certification and education to avoid the spread of ABA quacks.

About the Author: First U.S. Board Certified Behavior Analyst in India; Founder Director Behavior Momentum India; Trustee BMI-Foundation; Trustee ABA-India

Awards : U.P. Governor’s award, ABA International (SABA) award, Swayam Siddha award from Rotary Metro City Kolkata.



Journal Scan

Updates in DPT from Indian and the global scene-

Principles of plasticity in the developing brain.(Developmental Medicine & Child Neurology 2017, 59: 1218-1223) <http://onlinelibrary.wiley.com/doi/10.1111/dmcn.13546/pdf>

A comprehensive discussion of the multiple range of factors influencing brain development citing some powerful studies. Evolution of a phenomenon called 'Metaplasticity' - life experiences interact to alter behavioural and brain development.

Digital screen media and cognitive development (Pediatrics 2017;140;S57)

http://pediatrics.aappublications.org/content/140/Supplement_2/S57.full

There has been a spurt of research on the influence of screen media on development . The simple recommendations in the end make it worthy reading for application in daily practice for Pediatricians.

Exercise and physical activity recommendations for people with cerebral palsy (Developmental Medicine & Child Neurology 2016, 58: 798-808)

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4942358/>

One of the first cerebral palsy specific physical activity and exercise recommendations. Reduced cardiorespiratory endurance and muscular weakness can be important risk factors for morbidity and mortality in CP. Thus this may be useful to guide practice with individual clinical judgement for developmentally appropriate recommendations to patients of CP especially the GMFCS I-III.

Dr Leena Srivastava

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1. Pre conference workshop at the Pedicon 2018 Nagpur

Master training workshop of " IAP National guidelines on Neurodevelopmental disorders- Autism, ADHD, Learning disability, Newborn hearing screening" conducted by faculty – Dr Jeerson Unni, Dr Samir Dalwai, Dr Leena Srivastava, Dr Zafar Meenai, Dr Kawaljeet Singh Multani, Dr Lata Bhat,

The workshop flawlessly conducted on 3rd Jan by Dr Samir Dalwai, Dr Chhaya Prasad and local coordinators Dr Dipti Jain , Dr Dinesh Saroj received an overwhelming response with around 70 delegates and very interactive sessions.





2. Neuro developmental Pediatrics Chapter Symposium

Neuro developmental Pediatrics Chapter symposium was held on 5th Jan at the Pedicon 2018 with the national guidelines recommendations on early detection and management of hearing loss by Dr Abraham Paul and Autism Spectrum disorder by Dr Jyoti Bhatia.

A panel discussion on the role of IAP National guidelines in office practice by panelists Dr Leena Deshpande, Dr Somashekhar, Dr Shambhavi Seth and Dr Mahesh Mohonto very aptly moderated by Dr Santhosh Rajagopal.

The session was chaired by Dr M Narayanan.

The symposium was well received with lot of interaction from the audience in a hall filled to it's capacity.



The chapter newsletter was released at the symposium followed by the GBM



From Pedicon 2018 Nagpur

Few glimpses of the chapter members where most of them also participated in various other sessions in the main conference of the Pedicon in topics related to and relevant to child development, child rights and abuse, POCSO act, influence of media on children, childhood depression etc along with topics of neurodevelopmental disorders.



Conference on Developmental Neurosciences, Mumbai

The 2nd Annual New Horizons Conference on Developmental Neurosciences was held at Sion Hospital, Mumbai on 20th January, 2018. The conference covered a range of topics in developmental pediatrics, genetics, vaccination, behavior problems and academic difficulties in children and inclusion of children with special needs. The audience of more than 400 delegates from across India included pediatricians, neurologists, psychiatrists and therapists with over 35 eminent experts as speakers.

The theme of the conference is a testimony to the team at New Horizons Child Development Centre (NHDC) who have provided inter-disciplinary treatment to over 10000 children with developmental disorders. Our team of 100+clinicians, researchers and non clinical staff are excited to celebrate 15 years of our journey since 2003 on 10th February 2018 at St Andrews Auditorium, Bandra West from 9am to 1 pm and extend a warm invitation to all for the 15th Foundation Day where children, parents, teachers and clinicians celebrate the vision that 'Every child can do better'.





Achievements



The Chapter of Neurodevelopmental Pediatrics for winning the Third prize in the Best chapter award category at the Pedicon 2018 at Nagpur.



Dr Shruti Kumar from Dehradun for bagging the Gold Medal at the exams held in the first year of the IAP Fellowship of Developmental –Behavioral Pediatrics conducted by the chapter.

Shruti did her one year fellowship in the Pune centre at CDGC, Dept of Pediatrics , Bharati Vidyapeeth Medical College & Hospital under Dr Leena Srivastava as her guide.

She was felicitated with the gold medal at the Pedicon 2018 at Nagpur.

Dr Nandini Mundkur and her team have been invited to the 4th Neurological Disorders Summit (NDS-2018) scheduled during July 23-25, 2018 in Los Angeles, USA, by the conference scientific committee after they came across their recently published review “Pharmacobiological Treatments in Autism Spectrum Disorders “(link attached) published in the International Journal of Current Research and Review.

Jayaraman A, Mundkur N â Pharmacobiological treatments in autism spectrum disorder. Int J Curr Res Rev. 2017. 9(18): 36-39



IAP Neurodevelopmental Chapter



2nd Annual New Horizons Conference on Developmental Neurosciences

IAP Neurodevelopmental Chapter Kozhikode



State level inauguration of VIBGYOR - Autism Support Training Program - at Kozhikode



Dr T P Ashraf former Executive Director Participating in Autism Awareness Program



Autism awareness class by Dr Beena johnson