INDIAN ACADEMY OF CEREBRAL PALSY

Children's Orthopaedic Centre, Bobby Apartments, Lady Jamshedji Road, Mahim, Mumbai - 400 016.

Official newsletter for members of IACP

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Editorial

Excellence In Cerebral Palsy Care

Cerebral Palsy is a multifaceted problem. As such it requires multifaceted answers by different disciplines. How does one achieve excellence in care of individuals with cerebral palsy? What are the tenets?

Assessment - A thorough assessment of the patient is of utmost importance. This should be in terms of the total disability and not only speciality specific. A systems checklist outlining the various organ systems affected is greatly useful. An idea of the prognosis of the patient should be gathered to avoid unnecessary extensive treatments.

Team work is essential for comprehensive evaluation and treatment. A neurological examination is a must to diagnose conditions of known aetiology and also those of a progressive nature. Other specialities have to be involved for various problems e.g. cognitive and behavioural, auditory and ophthalmic, learning disabilities, speech, physio and occupational therapy. An orthopaedic surgeon should be involved early on as deformities and hip displacement can develop very early in life and this should be monitored and tackled early.

Communication is the key word between different team members for the good of the patient. What are the patient's problems and needs? What are the goals we are working for? A clear definition of goals is very important. Goals have to be realistic and likely achievable. How best can these be achieved? Treatment strategies have to be clearly defined.

Documentation and follow up is of the utmost importance to know the benefits or lack of it for certain treatment strategies. This helps in modification of goals and treatments. Regression of milestones may point to other problems or causes which must be identified for effective management.

Research and innovation is required at all levels to develop the best and most cost effective treatment strategies. What doses of treatment are appropriate and effective? What are the limits of treatment? It is evident that such research is based on good documentation and follow up.

Dr. Ashok Johari - President, IACP

Inside this Newsletter

4th Annual National Conference of Indian Academy of Cerebral Palsy held in Mumbai (2nd - 3rd Jan. 2010)




Inauguration by (L-R): Prof. Sitanshu Mehta - Chief Guest, Dr. Prem Sheth - Guest of Honour, Dr. A.N. Johari - President, IACP Dr. G. Shashikala - General Secretary, IACP



Scientific Presentation by Guest Faculty

Scientific Presentation by Guest Faculty




Honourable Chairpersons




Professionals engrossed in listening to the Presentation

From Secretary's Desk

The Mumbai conference was an eye opener for all of us clinicians! The contribution of assistive tech help in improving quality of life of persons with cerebral palsy was brought out really well. However, I would like to share a few after thoughts on conducting conferences which were and probably are at the back of many of our faculties during our conferences. Who are the target audiences in a multidisciplinary forum like ours? If we have specialty based proceedings, how are we going to facilitate inter disciplinary learning? Why our delegates do not attend family forums which are essentially learning experiences? Shouldn't our conferences be more interactive & pro active in policy discussions & guidelines as well as thought provoking debates? Disability is a complex, human issue and often demands unconventional, trans disciplinary solutions. How do we look at trees [specialties] with reference to the forest [development] all the time? How do we come to meaningful conclusions if we don't argue at all? Keeping these in mind, we have come up with some guidelines for conducting conferences and I hope to have at least trickling responses from members in my mail box.

The Conference in a way highlighted different perceptions of social model believers and the medical model proponents. Professionals are supposed to be non judgmental & parents are emotional but both bring in elements of empathy. The group called parent professionals are supposed to make a healthy blend of both which certainly is a double - edged sword & a tall order anyway. But this group needs to temper its individual opinions and refrain from generalizing it. All of us need to understand that when we talk of Family Centered Services, we do not mean shifting all responsibilities to families but help families with different competencies make informed choices as per their value systems, feasibility, situations & priorities with out any class bias!

Main streaming or for that matter some of the costly technology interventions are not for the mildly involved children from rich families alone and nor are the discussions of health monitoring out of place for group home care recipients. Mainstreaming need not aim at formal education for all but can be a medium through which literacy with refined social skills can also be nurtured. Certainly, we need to consider options for those with out a family or with no sibling support but to consider IACP platform as inappropriate for such discussions and voicing the same suggests ideological intolerance.

A fight for inclusive policies for health, education & livelihood is a fundamental right of all persons with disabilities. LET OUR THOUGHT PROCESSES AND FOCUS OF ACTION AT IACP BECOME INCLUSIVE FOR ALL WITH OUT MODEL, CLASS & DISABILITY DEGREE BIAS!!! LET US BE UNITED IN KEEPING THE BIGGER PICTURE OF WELFARE FOR PERSONS WITH CEREBRAL PALSY at a higher pedestal than loyalty to outdated thought processes.

G. Shashikala
General Secretary, IACP

Appeal

National Cerebral Palsy Day

Professionals, Rehabilitation Institutes and Families of people with Cerebral Palsy are hereby requested to Celebrate "National Cerebral Palsy Day" on 3rd October 2010 to Create Community awareness at National Level and Strenghthen local level units.

Your are requested to send reports with photographs to Dr. G. Shashikala, General Secretary for Publicaiton.

Positioning and Mobility Aids, Role of Assistive Technology in well-being of children with neuro-disability.

Dhruv Mehta, Physical Therapist

The quality of life and the well-being of the persons with cerebral palsy and that of parents and carers can be greatly enhanced by the judicious use of good, simple, user friendly positioning and mobility aids. A good team work between the child/adult who is going to use the device, the parents and carers, the trans -disciplinary team of doctors, therapists, orthotic engineers and bio-medical engineers and assistive technology experts goes a long way in assisting persons with disability to perform everyday tasks of living.

Positioning and Mobility aids for well-being for persons with cerebral palsy, and other conditions can be both hi and low tech. Whatever type of technology that be used for Positioning and Mobility the following criteria have to be kept in mind.

1) The aid/device should be adjustable for the growing child/and if possible should have universal design.
2) Preferably is made of low cost material.
3) Child should be comfortable and happy using it.
4) Function is enhanced by using the aid/device.

The aids should give independence, meet the users needs and help in social integration .Local customs, living conditions, environment are key issues that need to be addressed.

Aids for Positioning and Mobility, both hi and low tech can be made out of

1) Metal (steel, aluminum and its various combinations)
2) Plastic, with various densities.
3) Wood, plywood.
4) Fiber.
5) Cardboard and paper.
6) Sandbag, mud.
7) Rubber, foam, coir, elastic and its various combinations.

Positioning Aids.

Good alignment of body segments and good posture is the foundation on which-

1) Head and trunk control is achieved
2) Eye-hand-foot, co-ordination is achieved.
3) Communication and Oro-motor function is achieved facilitated.
4) Stability and symmetry is achieved.
5) Sensory-motor performance is optimized.
6) Interaction with the environment is facilitated.

Positioning aids that enhance function as per the needs of children with cerebral palsy are-

1) Side-lying boards.(to minimize influence of atnr, extensor attitude, give midline orientation).
2) Triangular pillows. (to prevent scissoring, adduction,give a broad-base for stability).
3) T-rolls. (to give pelvic symmetry, prevent wind-sweeping of hips)
4) Cushions and mattresses that are made out of soft material (to give comfort and prevent pressure sores).
5) Wedges (used in supine/prone and vertical positions)
6) Collars/Spinal braces,foot and arm splints - to facilitates postural aligenment,head,trunk control,for manipulation and mobility.
7) Maple leaf brace (to control pelvis and give symmetry).
8) Swash brace (to control scissoring and adduction).
9) Rolls eg. in prone used for head,trunk extension and arm weight bearing.
10) Twisters : (to prevent torsional mal alignment), theratogs,to give postural alignement,stability,body awareness,functional joint alignment and thus facilitate function).
11) Corner chair with lap tray.(to facilitate sitting, and eye-hand,mouth co-ordination,perceptual and motor developement).
12) H-shaped stool/chair with lap tray.(same as the corner chair,but more so for those who have predominance of adductor spasticity).
13) Chair with lap tray, head, back rest, leg rest, knee blocks, adductor pommel.(same indications as corner chair and h-shaped chair,but for a bigger child,eg a school going child).
14) Tumble form devices.(to aid positioning for children who have predominance of extensor attitude,those with extrapyramidal form of cerebral palsy,dystonia).
15) Chairs with positive and negative seating.(positive seating,forward tilted- useful for those who have hypotonic type of cerebral palsy,and negative seating, backward tilted useful for those with extensor spasticity, and who slide forward in the chair).
16) Chairs which acommodate dystonic spasms.(chairs that have hinges so that seat and back accomodate involuntary movements and spasms, so child does not get undue pressure at bony prominences).
17) Prone and Supine standing frames, with / without castors (for facilitation of standing, weight bearing, sensori-motor, perceptual development).

Mobility Aids.

Mobility and posture are intricately interwoven. Good posture makes good mobility possible. Cerebral palsy is a sensory-motor disorder; good posture gives good sensory feedback and thus enhances mobility. From the good neuro-musculoskeletal balance and alignment weight shifts and transfers,hence functional mobility is facilitated both indoors and outdoors.

Mobility aids are :-

1) Low trolleys/ patlas with castors. (used in prone to move about,to stretch flexion contractures).
2) Scooter-boards.(used in sitting for mobility, pushing wheels, or using push-blocks).
3) Anterior walker, with abductor spreader, with /without wheels., folding and non-folding type.(those who have predominance of extensor attitude)

4) Posterior walker with abductor spreader, with and without wheels ,and can be folding and non folding type. Both the anterior and posterior walker can have pelvis, trunk support and overhead bar and harness support for trunk if needed (for those who have flexion predominance).

5) Forearm gutter walker (for those who have poor stability, ataxia, rheumatoid arthritis, multiple epiphyseal dyplasia, those who need wider distribution of weight-bearing surface).

6) Canadian crutches, axillary crutches, elbow crutches, quadcanes, tripods, canes,gait poles(bamboo poles).for balance and propulsion.Canadian,and axillary crutches give better posture, elbow ctutches more safety canes beneficial for balance/ equilibrium.

7) Wheel-stools, with castors.(can be used for mobility by pushing with feet,used by parents therapists to prevent their backs).

8) Wheel-chairs, manual, motorized, one arm driven wheelchairs.(for mobility by self, or for facilitation, ease for parents/ carers).

9) Tricycles, leg driven, arm driven, manual and motorized.

Most of these Positioning and Mobility aids can be made by using low cost materials like paper ,cardboard, mud, sand. Appropriate paper based technology has proved tremendously useful in making such aids for persons with cerebral palsy. Recycled paper and card board are used to make these aids. It is cost-effective, no workshop or special tools are required. A wide variety of items can be made that are strong, durable and environment friendly. A family/therapist can exactly make the furniture they want for their child and change them as the child outgrows (in contrast to metal and plastic, which are expensive).The device made with APT technology is light in weight, and is gentle to touch and protective. Besides paper, card-board, throw away strings, socks, tights, cement bags, jute bags, and things that can be recycled are used in various combinations. Wheat, maize ,rice maida and cassava flour are used for making the paste. The pioneering work of Bevill Packer and his wife Joan, at Zimbabwe two and half decades ago has created world-wide interest and many have benefited by aids made out of APT. Jean and Kenneth Westmacott, in England, David Werner and their team at Ajoya, New Mexico,many places in Europe, Africa, Asia, at Childrens Orthopedic Hospital, Mumbai, and Spastics Societies of India,(to the authors knowledge at Vidyasagar, and Spastics Society of Tamil nadu) much work has been done by professionals and parents.

Particularly in the Indian context we have to explore and look for low cost technology, particularly something like appropriate paper-based technology. More often than not grass root simplicity is far better than complicated, expensive, scientific sophistication.

We the health care professionals should create and help people to create aids/assistive devices from low cost technology, recycle waste, particularly for the growing child, enhance parental and community's involvement in making these low cost aids thus easing their financial burden, and improving the well-being of the children. *

IACP WORKING COMMITTEES

1. ***Membership & Credentials Committee***
   (Already formed during Sept meeting)
   Chairperson - Dr. M. S. Mahadeviah.
   Co. Chairperson-Dr. A. K. Purohit
   Member - Dr. Asha Chitnis
2. ***Website Committee***
   Chairperson & Web Master - Dr. Vipul Shah
   Co - Chairperson - Dr. A. N. Johari
   Member - Dr. G. Shashikala.
3. ***Newsletter, Brochure & Publication Committee***
   Chairperson - Dr. G. Shashikala
   Co - Chairperson - Mr. K.D. Mallikaurjuna
   Members - Dr. Dhruv Mehta & Dr. Sanjay Marwah.
4. ***Academic Committee***
   Chairperson - Dr. A. K. Purohit {Surgery}
   Co - Chairperson - Dr. Sandhya Kadse{Pediatrics}
   Members - Dr. Asha Chitnis {Physiotherapy}
   Dr. Vandana Giri{Occu. Therapy}
   Mr. Pankaj Sinha {Orthotics}
   Mrs. Usha Dalvi (Speech Therapy)
   Dr. Shabnam Rangwala (Assistive Technology),
   Dr. Sanjay Marwah (Adult Disability & Life Span Care)
5. ***Research & Fellowship Committee :***
   Chairperson - Dr. Pratibha Singhi,
   Co Chairperson - Dr. Sandhya Kadse
   Members - Dr. Viraj Shingade, Dr. Sunanda Kolli
6. ***Psycho Social & Educational Committee :***
   Chairperson - Mr. K. D. Mallikarjuna,
   Co - Chairperson - Dr. Anita Suresh,
   Members - Dr. Pranali Somkuwar,
7. ***Family Forum, Advocacy & Awareness Committee :***
   Chairperson - Dr. Dhruv Mehta,
   Co - Chairperson - Dr. Snehal Deshpande
   Members - Dr. Shashikala, Dr. Fatima Jetpuriwala
8. ***International & National Liasoning Committee :***
   Chairperson - Dr. Ashok Johari,
   Co - Chairperson - Dr. Shashikala,
   Members - Dr. Vipul Shah, Dr. Viraj Shingade
9. ***Finance & Endowment Committee :***
   Chairperson - Dr. Ashok Johari,
   Co - Chairperson - Dr. Shashikala,
   Members - K. D. Mallikarjuna, Dr.Dhruv Mehta

STEM CELL THERAPY for CEREBRAL PALSY

Dr. Anaita Udwadia Hegde, Consultant Pediatric Neurologist

Stem cells are unique cells with the remarkable potential to develop into many different cell types in the body. These cells can divide without limit to replenish other cells, thus forming a sort of repair system for the body.

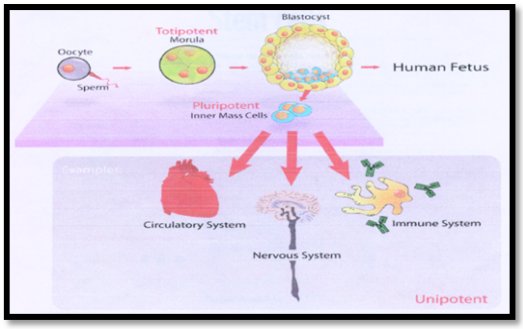
Stem cells can be basically classified into two types based on their origin of derivation Embryonic Stem Cells (ESCs) and Adult/Tissue Specific Stem Cells (TSSCs). The Embryonic stem cells (ESC) are derived from either the zygote or the blastocyst. (image 1) The cells derived from the inner cell mass of the blastocyst on day 5-7 are called the Pluripotent cells, which can develop into all three tissue lines endoderm, mesoderm and ectoderm.[1]

The Tissue specific stem cells (TSSC) are either Multipotent, Unipotent or Induced Pluripotent stem cells. The Multipotent stem cells are derived from the fetal or umbilical cord blood cells and can be developed into one of the three tissue lines either endoderm , mesoderm or ectoderm. These cells can also be derived from the bone marrow and the peripheral blood. The Unipotent and Induced Pluripotent stem cells are both derived from the mature cells of organs/tissues. While the Unipotent cells can only multiply into the cells or tissues of their origin, eg. Neural cell can only divide into neuronal tissue, the Induced Pluripotent cells are in fact the adult stem cells which have been genetically reprogrammed to behave like an embryonic stem cell. i.e. the cell is derived from an adult cell, worked on genetically and now behaves like an ESC with the ability to divide down any cell line.

Induced Pluripotent Stem Cells: In late 2007, scientists identified conditions that would allow some specialized adult human cells to be genetically reprogrammed to assume a stem cell like state. This new type of stem cells is called 'Induced Pluripotent Stem Cells' (iPSCs). Although these cells meet the defining criteria for pluripotent stem cells, it is not known if iPSCs and ESC differ in clinically significant ways.

Pluripotent stem cells have a great therapeutic potential but they also have some technical challenges. A lot is yet to be learnt as to how to control their development into all the different types of cells in the body. Secondly, there are chances of rejection of the stem cells by the immune system of the host. Another serious consideration is that the idea of using stem cells from human embryos or human fetal tissues has lot of ethical concerns.

Induced pluripotent stem cells have the advantage of very low chances of rejection by the host immune system as the tissues derived from iPSCs will be a nearly identical match to the cell donor. We need to realize that this is all still in vitro (laboratory cell cultures) studies and in vivo animal model studies. No trials have been approved in humans yet.

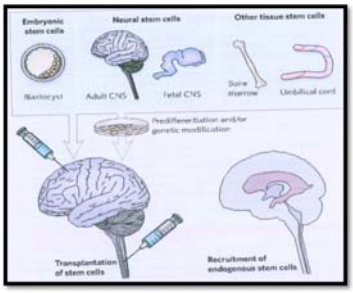


Adult stem cells face several limitations to their full therapeutic use. Adult stem cells are often present in only minute quantities and can therefore be difficult to isolate and purify. There is also evidence that they may not have the same capacity to multiply as embryonic stem cells do. Finally, adult stem cells may contain more DNA abnormalities caused by sunlight, toxins and errors in making more DNA copies during the course of a lifetime. These potential weaknesses might limit the usefulness of adult stem cells.

Uses of stem cells :

The use of stem cells in still largely limited to 'research'. Though there are many individual case reports and some studies, illustrated with variable outcomes, there are but few structured studies based on firm scientific and ethical grounds, with long-term follow-up of patients, to validate the use of stem cell therapy concretely in any disorder.

There may be several 'potential' uses of stem cells in human disorders. The various neurological conditions where stem cells are being used on research basis are Parkinson's Disease, Spinal Cord Injury, Multiple Sclerosis, Cerebral Palsy, Duchene's Muscular Dystrophy, Stroke, Amyotrophic Lateral sclerosis, Huntington's disease, Alzheimer's , Leukodystrophies and Autism. For these conditions, the stem cells are isolated and transplanted to the diseased brain either directly or after genetic modification or differentiation. The cells are either differentiated into neural/ glial cells or cells producing neuroprotective molecules. Even the patient's own endogenous stem cells can be collected, stimulated and then recruited to the diseased areas to produce new neural/glial cells. Thus the stem cells in neurology can be used to serve for Replacement, Remyelination and/or Neuroprotection. The various routes of transplanting ste cells are intravenous, intrathecal, intraventricular and or intracerebral.



Role of stem cells in cerebral palsy:

In children, the most potential use of stem cells is speculated to be in providing normal cells in disorders with genetically driven deficiencies or abnormalities namely neurodegenerative disorders. Cerebral palsy a condition due to injury and damage to the early immature brain due to various perinatal insults leads to extensive neural tissue damage, scarring and loss. Stem cells may serve to replace the lost neurons and thus restore the normal cellular architecture. Having said that, there are yet no standard protocols set for this purpose. Many centres have tried different indigenous regimes and come out with variable results. Unfortunately, majority of the reported cases easily assessable on the net are only individual case reports.

There are just a few studies done to scientifically to assess the benefit of stem cells in children with cerebral palsy.

In the study conducted at the X-cell centre in Germany, 45 patients with cerebral palsy were given intrathecal stem cell transplants. On follow-up, 67% showed improvement in their spasticity, motor and cognitive function and speech.2

In another study, conducted at the Institute of Clinical Immunology, Russia, 30 children with cerebral palsy were given stem cell transplantation and compared with 30 children with CP managed only on therapy and medications. A cell suspension from immature nervous and hemopoietic tissues was injected into the subarachnoid space of a recipient through a spinal puncture. Motor and mental faculties of each of patients were evaluated at 1 year after the stem cell transplantation therapy. Apparent clinical improvements were noted in 28 of cell-grafted 30 patients. Collectively, the results suggested that stem cell-based therapy may be highly effective in treatment of cerebral palsy patients who are refractory to standard medical interventions.3

In the study by Ramirez et al in 2004, 8 children with CP underwent umbilical cord stem cell transplants. All of them showed some improvement in mobility and/or cognition. 75% of them improvements in motor function.4

As can be seen the numbers are still very small. All these patients were injected under the control of detailed research protocols. Each study did a different cell type, method of cell culture, injection mode, site and cell number. Each followed different parameters of motor, cognitive development and only one study had controls. The longest duration of any study was one to two years. There is no data on any long term potential multiplication or over multiplication problems. None of the studies have so far explicitly mentioned the detailed methodology or given adequate data on the logistics. There is no proven consensus on the type of cell lines to be used, the route of transplantation, the quantity of cells, the number of injections, the monitoring parameters, the optimum time of transfusion, the mode of tracking, etc. There is a real need to formulate a consensus on the above issues so as to facilitate a scientific and ethically appropriate guideline for stem cell transplant in cerebral palsy.

Timing of the SCT is another issue. There are studies to show that the maximum benefit in cell division, differentiation, connectivity and provision of neuroprotective factors would be at the time of brain insult in early neonatal life or infancy. Whether we could use the patients own cord blood cells at such a time seems most promising, yet only done in animals till date.

While Stem cell transplant seems very "promising", at the moment it largely remains an 'experimental' modality of treatment. Scientist feel that while it seems to work well in the laboratory it does not seem to translate as well when used on animals and less so in humans. It would be too premature to advocate SCT as a routine therapeutic intervention for children with cerebral palsy. While studies abroad are under strict FDA approval and guidelines, most studies in the developing countries are like commercial ventures. Caution should be exercised when advocating or trying newer experimental modalities of therapy such as stem cell transplantation.

REFERENCES :

1. *Information from the website www.stemcells.nih.gov*
2. *Information from the website www.xcell-centre.com.*
3. *Cell Therapy of Cerebral Palsy, V. I. Seledtsov et al; Bulletin of Experimental Biology and Medicine, Vol 139; Number 4/April, 2005.*
4. *Umbilical Cord Stem Cell Therapy for Cerebral Palsy; F Ramirez et al, Medical Hypotheses and Research, Vol 3, Number 2, April 2006.*

IACP INCOME AND EXPENDITURE FROM 20.11.2008 TO30.12.2009

EXPENDITURE	Rs	INCOMES	Rs
To Bank Charges	428	Opening Balance	353661
To Printing & Stationary	31900	Cash at Hand	2000
Internet Charges	2000	By Life Membership	54175
To Mailing Charges	12600	By Donation	20000
To Website Hosting, Maintanance	2000	By Bank Interest	10580
Design			
To Domain renewal Charges	1849		
Web site space Charges			
To salaries	2000		
Post Box annual rent	350		
To transport	1500		
IFCPLOAN TRANSFERRED	80000		
Cast at Hand	2000		
Cash at Bank	323834		
	46061		
	46061		44016
Excess Expenditure over Inc	20045		
LIABILITIES	**Rs**	**ASSETS**	**Rs**
		Cash in Hand	2000
		Cash at bank	323834

MINUTES OF 4th IACP ANNUAL GBM HELD AT BOMBAY HOSPITAL AUDITORIUM ON 02.01.2010

The meeting was attended by the following 19 members
Dr. A. K. Johari, Dr. M. S.Mahadevaiah, Dr. A. K. Purohit, Dr. G. Shashikala, Dr. Viraj Shingade, Dr. Vipul Shah, Dr. Sanjay Marwah, Mr. K. D. Mallikarjuna, Dr. Asha Chitnis, Dr. Pranali S, Dr. Dhruv Mehta, Dr. Gaurav Kochar, Dr. Vandana Giri, Dr. Fatima I Jetpuriwala, Mrs. Asha Sonawane, Dr. Snehal Deshpande, Dr.Shabnam Rangwala, Dr.PDSinildas, Dr.Aboobacker.

EB members Dr.Pratibha Singhi & Dr.Sandhya Kadse had sent prior information on their inability to attend the GBM which was accepted by the GB.

Dr.Ashok Johari, President IACP, opened the meeting outlining the agenda and briefed the members that there were no elections during the Nagpur GBM held on the 23rd Nov 2008 and a new body was nominated unanimously as already published in the April 2009 newsletter. However due to certain confusion regarding the post of General Secretary the present team could start functioning only from July 2009 virtually loosing out over half an year. The first IACP brochure was released jointly by the President & the General Secretary. However Dr.Johari announced that the present brochure will not be printed in large numbers to incorporate any new ideas and suggestions. The existing brochure will be sent to members on request by E mail. The president also out lined that it has been a quite year but lot of basic organizational work like drafting of the constitution, formation of committees and delegation of responsibilities to the EB members were done.

General Secretary, Dr.Shashikala reported on the minutes of the of EB meeting held at Mumbai on the 6th Sept 2009, the details of which were published in the Nov 2009 newsletter and circulated to all the members. Some of the suggestions of the Sept EB meeting were deliberated during this meeting also and necessary action will be taken for implementation. Dr.Shashikala informed the GB that 50 new members were added since Nagpur conference.

Mr.Mallikarjuna, Treasurer IACP, presented accounts for the period 20.11.2008 to 30.12.2009 and was passed unanimously. The details will be published in the next news letter.

Dr.Asha Chitnis expected the membership to go up by another 50 by the end of Mumbai conference and sought clarification if the student members were also included in the IACP Early Bird membership of 500. It was clarified that student members were not part of the Early Birds. It was also clarified that as per the EB decision taken during the Sept meeting, new life memberships from now on will be provisional for the first three years and will be confirmed as permanent members after three years. It was also decided that IACP would not accept out station cheques from now on and only Demand Drafts will be accepted.

Mr.Mallikarjuna was requested to expedite obtaining PAN card for IACP. Dr.Purohit was requested to help in getting exemption under IT act 80G an issue that was raised by Dr.Mahadevaiah. It was also decided to announce the names of donors in the news letter.

Mr.Mallikarjuna has already compiled the directory of IACP members, specialty wise and will be put up on the web site. Members expressed concern about the incorrect addresses in the IACP member registry. Hence it was suggested that once the details are available on the web site all the members are requested to update their addresses by contacting Dr. Vipul Shah ,the present web master of IACP web site. Mr. Mallikarjuna indicated that the cost of publishing directory will be approximately Rs.10,000 apart from mailing charges and this was approved by the GB

Dr.Viraj Shingde suggested using group SMS also to reach out to members along with reaching by post & email. Dr. Shashikala requested all the members to take local responsibility in verifying the receipt of IACP communication including newsletter and act as regional coordinators.

The most important agenda of the GBM was to pass the constitution. Dr.Johari opined that the requisite quota of 10% of members was not present to pass the constitution. But Dr.Vipul Shah and Dr.Viraj Shingade expressed the opinion that this has been the case in most of our General Body meetings due to the membership being spread across the country. Dr. Johari said that this was a general problem with most of the other academies also. Hence the GBM was adjourned and reconvened with an interval to treat the existing number of members as quorum as per convention. After reconvening the general Body unanimously passed the constitution which will be republished in the next newsletter and same will be put up on the web site.

National Cerebral Palsy Day : Dr.Shashikala raised the issue of celebrating one day in every calendar year as National Cerebral Palsy Day across the country to create community awareness and forge local professional unity. Dr. Ashok Johari proposed celebrating 3rd October of every year for this purpose as it is the birth day of our first & founder President Late Dr.Perin K. Mulla Feroze who pioneered cerebral palsy care in the country. This proposal was unanimously accepted by the GBM and was decided to put this into action from 2010. IACP members are free to raise local sponsorship for this event but will be required to send full report to the central body for publication in the May news letter.

Newsletter publication : The dates for publication of Bi annual news letter were fixed as May and November of each year. Members were requested to contact the publication committee if news letters do not reach them by 10th of these months either by post or E mail. The responsibility of providing correct contact details rests entirely with the members. ∗

APPEAL

Dear Members

You are requested to update contact details correctly to receive prompt information from the academy. Members can also inform the academy about any of their achievements for publication in news letter. They can also contact any EB member for any information need and advise on technical matters.

Proceedings of the 4th IACP CON

The 4th IACPCON was held on 2nd and 3rd January in Mumbai at S P Jain Memorial Hall, Bombay Hospital.

The theme for the conference was "Partnering with technology in treatment of Cerebral Palsy"

151 people registered for the conference comprising of 20 doctors, 98 physiotherapists, 18 occupational therapists, 8 speech therapists and 7 special educators. The conference threw light on the use of new technologies available in the treatment of cerebral palsy in different avenues through 7 Symposia and Scientific Sessions.

Symposium 1: Partnering with Technology:

Our first speaker Dr Anaita Hegde spoke on advances in stem cell surgery. Stem cells are unspecialized cells that can divide to form a specialized cell in any cell line. It could be a totipotent cell, a pluripotent cell, multipotent cell or unipotent cell. However the use of stem cells had ethical issues and risk of graft vs host rejection. Recently a concept of induced pluripotent cell has come up where any cell of an adult human being can be converted to a pluripotent cell. This advance has bypassed ethical issues and considerably reduced risks of rejection. However these cells are difficult to culture. The stem cell research shows great promise however presently enough evidence is not available to advise our patients.

The next speaker Dr A. K. Purohit briefed upon the use of intrathecal baclofen pump in treatment of spasticity and dystonia. Intrathecal baclofen pump is a less invasive process where baclofen pumps are put in the back or iliac fossa to get continuous release of baclofen. His case studies reflected that the use of baclofen pumps helped reducing the impairment and gave ease to the caregiver. He concluded that ITB significantly reduces non-progressive, resistive spasticity and dystonia. It improves motor performance in patients with good balance and control in body preoperatively. Large doses of baclofen are required in dystonia. Soft tissue release is required to correct residual spasticity.

In his talk on Central Neuromodulation in Cerebral Palsy, Dr. Paresh Doshi updated on role of neuro surgeries in management of movement disorders in cerebral palsy. Dystonia is a result of disinhibition of striatal neurons projecting to globus pallidus resulting in sustained co-contraction of agonist and antagonist muscles. He discussed the role of thalamotomy, pallidotomy and deep brain stimulation. He elucidated on use of stereotactic systems to perform the surgeries. He provided studies showing subjective and objective improvement in patients post lesional as well as after deep brain stimulation. The advantage of DBS is that the programming can be altered externally depending on the need.

The conference was inaugurated by lighting of the auspicious lamp by president Dr A.N Johari, General secretary Dr.G Shashikala,,Chief Guest Prof. Sitanshu Mehta, Dr Prem Sheth and Dr Dhruv Mehta. It was marked by invocation by Mr Ranjan Raman.

In his presidential address Dr Johari welcomed the delegates for the 4th IACPCON. He insisted on need for collaboration and interaction between diverse specialities and the wise use of available technology to improve mobility, ADL's, and communication skills in children with cerebral palsy. He sincerely thanked Dr Dhruv Mehta and Dr Asha Chitnis for organizing the conference. Our key note addressee, Prof. Sitanshu Mehta shared his bitter and sweet experiences in bringing up a child with cerebral palsy. He believes that in Indian society the space around a child with cerebral palsy is cluttered with three things - indifference, arrogance and mystic beliefs. He staunchly advocated removal of these three things to allow space for technology to function around the child.

Symposia-2 Partnering with technology: Aids and adaptations to enhance quality of life.

The first speaker Dr Shabnam Rangwala showed what hi tech and low tech adaptive equipment is available to improvise quality of ADL's. She showed various assistive devices to aid feeding, drinking, dressing, reading and writing. She suggested modifications for toileting activities. She insisted on use of universal designs and broad spectrum solutions that give products and environment that are usable and effective for all.

Challenges to access information leads to insecurity and hence Ms Devyani introduced the technological advances to enhance communication in children with visual impairment. She updated use of assistives like large prints, handheld magnifiers, screen magnifiers, large print keyboards, Braille embossers or those with intact U.E, Screen Reading softwares, OCR, KNFB readers.

Mr Pankaj Sinha spoke about the significance of use of orthosis. Correct orthosis improves stability and controls ground reaction forces or betters proximal joint stability and mobility. AFO's provide direct support to ankle and indirect support to hip and knee joints and prevents hyperextension or crouch. Latest designs in orthosis include V3 variable varus, valgus cell, versatile CAD CAM technology, free walk KAFO's which are light weight and have automatic locking mechanisms initiated by extension.

To add to this Dr Medini Padhye spoke on challenges in prescription of orthoses. She emphasized the importance of correct alignment for recruitment of appropriate muscles. Alignment deficiencies lead to inappropriate weight bearing. An effective orthosis should help to correct any deviation in alignment providing equilibrium of body segments with each other. She described use of static and dynamic AFO's ,supramalleolar AFO's, FRO's, and of U.E use of mucky splints and abduction splints.

Symposia 3 Partnering with technology in communication in cerebral palsy.

Hearing defects are 3.5 times common in asphyxia. It is commonly seen after hyperbilirubinaemia. There can be conduction defects which are curable or sensory neural which require use of hearing aids. Ms Anjali Kant showed various types of aids where receiver can be placed either behind the ear, in the ear or in the canal depending on the lesion. She suggested use of assistive devices like personal FM systems, Infra red systems, Induction loop systems, Telephone amplifier systems, sonic alerts that flashes light on door/phone bells. Cochlear implants are hearing prosthesis useful when defect is severe and hearing aids are not helpful.

Hi Tech and mid tech assistive devices for facilitating communication were introduced by Dr Anita Suresh. It included various types of computer access devices, specially modified pens and pencils, battery operated communicators. She elaborated ways to establish conversations using basic mid tech devices like big/ little mac communicators, talking photo albums. Her list of high tech assistives for communication included various word predictors, softwares converting text to speech and vice versa. She enlisted websites from where the softwares could be downloaded.

Literacy is a human right, gives empowerment and liberation. It is a channel for innovation and creative thinking. This was put forward by Dr Reena Sen in her presentation on use of low tech assistive devices for facilitating communication and literacy. Patients with severe speech impairments need to develop competencies for conventional forms of literacy. This can be brought about by the use of simple low tech devices or communication such as picture books, communication books and boards, thus providing them with alternate learning access. Hence seeing literacy as everyone's right.

Symposia 4 Partnering with technology in therapy

Dr Anita Prabhu emphasized on sensory processing problems in children with cerebral palsy. Sensory integration therapy was introduced by Jean Ayres. She used equipment to provide intense vestibular, proprioceptive and tactile inputs to these patients. These sensory issues can be assessed using sensory profile, short sensory profile, sensory integration and praxis test. Modern equipment is now available like hug machine, swings with hug machine, vibrating toothbrush and jigglers.music therapy could be used for its calming effects. She stressed on fidelity of society towards SIT which is very poor and needs to be improved.

Use of low tech equipment for positioning and mobility was highlighted by Dr Dhruv Mehta. The aids used should of universal design, should be adjustable to the needs of the growing child and should be comfortable. These aids should give some amount of independence, and meet the users need. Positioning aids such as triangular pillows, wedge, maple leaf braces, swash brace and mobility aids like low scooter boards, anterior and posterior walkers, forearm gutter crutches are all useful.

Dr Snehal Deshpande outlined various adjuncts that can aid therapy like use of compression garments like theratogs, lycra suits, strength training using pilates, therabands nad tubes and dumbbells. Automatic training that includes partial body weight support, robot assisted training, isokinetic training, pedals. She touched upon the use of additional therapies like taping, gym, yoga, aromatherapy, aquatic therapy, music therapy, craniosacral therapy and hippotherapy in the management of cerebral palsy.

In her session on strength, endurance and fitness training Dr. Asha Chitnis stressed the importance of strength training in cerebral palsy. Impaired neural drive leads to inappropriate muscle coactivation. This decreased physical activity causes disuse. Strengthen isolated movement and strength in synergy both are poor. Therapists need to consider both aerobic and anaerobic capacity of the muscle and agility of muscles. The recent trends in western world for strength training include aquatic training, stationary cycle, universal exercise units isokinetic machines, motorized movement therapy, vita glide for upper limb. With this in mind the therapists should set the strengthening program based on the goal and its requirements (muscle work). She concluded by saying that the strengthening program improves impairment to achieve functional gains that enhance participation.

Free Papers 1:

Dr. Roselin: Use of Botulinum toxin A to augment therapy in children with Cerebral Palsy a year follow-up Retrospective Study.

Dr Reena: Efficacy of early age vs late age botulinum toxin A, a comparative pilot study.

Dr Maya: Repeated multilevel injections of botulinum toxin A is safe and effective for functional outcomes in children with cerebral palsy when combined with serial casting and therapy.

Dr Madhavi: Correction of severe crouch gait in Spastic Diplegic by Mutil Level surgery.

Dr Aizaz: A preliminary introduction of Primus Machine on Cerebral Palsy Patients.

Symposia 5 Partnering with technology in orthopedics

In this enlightening session by Dr Ashok Johari on spinal deformities in cerebral palsy, he highlighted on scoliotic deformities and related complications. Scoliosis is a multidimensional displacement of spine commonly seen in quadriplegics that compromise sitting posture. Progression of this curve continues even after skeletal maturity. Goal of surgical intervention is to achieve good sitting posture on level pelvis and is preferably done after skeletal maturity is achieved at 13-16 years. Surgery includes multisegmental fixation, pedicle fixation providing purchase in all 3 dimensions, Growth rods are used so that growth is not hampered in younger children.

Dr. Abhishek Srivastav spoke on the assessment of Gait in C.P. The recent technological advances in assessment of cerebral palsy revolve around extensive use of gait labs. Gait lab assesses the temporal and spatial components of gait. It detailed kinetics and kinematics of gait in all three planes in all phases of gait cycles. It is an excellent tool to assess gait and effect of intervention on gait.

Symposia 6 : Partnering with technology in Psychosocial and Education.

Dr. Smita Desai practicing at Drishti acquainted the audience with Systems for management of individual program. The need for technology in imparting educational programs to children with special needs was felt as there was an obvious lack of standardization in therapy plans, creating these plans was a time consuming process, and there were limitations to the number of people who could benefit from these plans.

The SMIP is a web based system which has been indigenously developed at DRISHTI, more than a decade ago. It has a common pool of resources, across various disciplines, which is used to generate programs to reach out to children with special needs across the country and the world. The future ahead lies in using this web based program to reach out to the maximum number of people in need of help.

Dr Pranali Somkuwar spoke on art and science of interdisciplinary communication between schools and health professionals. Her lecture covered the nature and need for interdisciplinary communication. She discussed the Greenspans development pyramid.

She discussed barriers for mainstreaming and solutions for the same. And in her conclusion she said that developmental educators and psychologist are bridging professionals between health and educational domain.

Dr. Shashikala discussed the Main Streaming Protocol. She feels like there is the absence of well defined systems, parents will have to bring a lot more efforts to make mainstreaming a successful program in the country rather than keep complaining about lack of systems. She put forth a protocol for discussion and recommendations of IACP members. According to the protocol schools should service staff to use IEP as a prescription sensitive to inclusion challenges. Differently able children should have an accommodating curriculum within a regular classroom. All early intervention clinics must prepare children for mainstreaming. Parents should have equal but a non-locational participation. However mainstreaming is not an option for all the children and hence clear guidelines regarding it are necessary.

Professor G.G Ray working in bioengineering department of IIT acquainted the audience with computer based communication. He demonstrated how mouse and keyboards could be modified depending on impairments to simplify its use. This enhances communication; ability to communicate basic needs helps reduce frustration in child with cerebral palsy. He showed a few models that he used for his clients.

A specialty lecture on early age botulinum was given by Dr. Ashok Johari. Spasticity leads to incorrect movement patterns, once these patterns are learnt reeducation is difficult. There is loss of balance between agonist and antagonist leading to progressive weakening of agonists. Spasticity in U E leads to inefficient use of UE, cortical neglect, disuse and hence loss of dexterity. Reduction in spasticity encourages efficient movement patterns, encouraging synaptogenesis, expansion of cortical representation and neural plasticity. Botulinum reduces chances of surgery for contracture and torsional deformities. Indications for early LE botox include Hips at risk, impending deformity, or functional gains such as sitting, transitions. UL indications include protection, transition, manipulation and ADL's. However he also said that repeated botox lead to muscle weakness and tendency to fatigue and hence therapy pre and post botox is necessary.

Free Papers 2:

Dr A K Purohit: A case study on neural fasciculotomy

Dr Anant Bagul: Stem cell therapy

Dr Kavita Agrawal: Review of literature on CIMT.

Learning from each other :

Learning from each other was a session of group discussion whereby clinical practitioners put forwards their case studies for planning a holistic treatment.

Dr Vipul Shah an orthopaedic surgeon elucidated through his videos patients with dystonia benefiting from botox. A discussion to improve their functional gains by PT/OT followed subsequently. He showed improvement in strength by use of muscle stimulator.

Dr Viraj Shingade showed effects of corrective surgeries. However it was pointed out in the discussion that early age surgeries are not considered appropriate as skeletal maturity is not complete and chances of relapse are high. Hence, such cases to be considered for botox first following which strength can be improved which will improve prognosis thus stressing the need of pre surgery therapy.

Dr Bharati Parekh spoke about the use of a new technique - Matrix in treatment of cerebral palsy.

Dr Leena Deshpande discussed her case of ataxic CP kid and role of medications in treatment. In this case the issue of patient compliance for medical as well as physical therapy was discussed. The abrupt termination or starting of medications and therapy affects the prognosis significantly.

Mrs Jyoti Mohite a speech therapist displayed her case of ataxic CP. Role of Oromotor massage, rib cage mobilization as well as proper alignment of patient prior to speech therapy was pointed out.

Mrs Shobha Sachdev a special educator discussed an adolescent cerebral palsy who was already on a holistic management including education, PT, OT, and Speech, however, had issues coping up with her transition from childhood to adulthood.

The family forum meeting conducted by Dr. Dhruv Mehata and Dr. Asha Chitnis with adult achievers with cerebral palsy, was very positive & highly inspirational to parents with their right accent on education, continuing medical help & accepting parental attitude & importance of friendship as well as societal opportunities. The meeting was presided over by Dr. G. Shashikala, General Secretary, parents participated in the family forum said that the proceedings of the conference amply brought out a clear message to parents that developmental issues need to be pursued zealously along with therapeutic endeavors. All the faculty who did justice to these marathon sessions deserve our gratitude. Persons with cerebral palsy were felicitated for their commendable achievements.

10 persons with cerebral palsy were felicitated, for their excellent and empowering achievement Bharat Shah,Utpal Shah,Malini Chib,Divya Taparia,Nilesh Singit,Nuzhat Hamdare,Ranjan Raman,Dhiraj Shigwan,Manisha Burke.

There were lectures/presentations by 1) Health monitoring of adults - Dr. Shashikala 2)After us who? - Meenakshi Balasubramaniam. 3)National trust,advocacy,disability act,awareness,accessibitlity - Nilesh, 4)Index assistive technologies - Ram Agarwal. 5) Mobility solutions - Prasad Phanasgaonkar. 6)Technological advances in mobility and transportation - Dr. A. G. Patil 7)Access for all - Arvind Prabhoo.

OPINION :

Overall feedback: all the sessions were graded from good to excellent.

Lot of people felt that the number o speakers could be less however the duration of symposia should be more. They would have preferred to have CDs or Manuals of the proceedings. Lot of delegates were interested in low cost technologies for Indian scenario. There were recommendations for hands on. Needed inputs of how this knowledge can be used in day-to-day life.

FAMILY FORUM COLUMN

Disciplining the Child - Dr. Sudhir Bhave, Psychiatrist

Every child needs proper disciplining he needs it to develop a socially acceptable behaviour, to distinguish between the harmless and the harmful, and to prevent oneself from entering into undesirable situations later in life. Most parents feel that disciplining can come naturally to them. This is not so. Good disciplining needs a good understanding of the child's psyche.

Parental Authority: It should be:

1. Consistent : Rewarding behaviour (may be covertly) at one time and punishing it at the other leaves the child confused and insecure. Consistency should be both intrapersonal (in the same person's behaviour at different times) and interpersonal (between the two parents or between parents on one hand and grandparents on the other).
2. Reasonable : Don't apply adult standards to the child. Don't be too harsh. Try to look at things through the child's point of view. A child is more likely to misbehave if he is tired, bored, hungry, or bullied. Be more flexible at such times.
3. Democratic : Don't trample the child's rights. Within reasonable boundaries let him choose his games, dresses etc.
4. Firm : Be clear and assertive in your message. The child should learn early that if he does not obey the parents, the consequences are going to be unpleasant. See to it that an important instruction is not ignored.

Some "Do's" of Disciplining :

Keep the rules in the house few, but enforce them strictly. If the child is old enough, he should know the reason for a rule.

In case of a perceived misdeed, give an opportunity to the child to explain. It may turn out that it was not his fault after all. Avoid saying, "Don't answer back"!

Some good punishments :

1. Firm disapproval : Criticize the deed and not the child. Say "Your act was bad" and not "You are bad".
2. Time out : For a child who is screaming or trying to gain attention keep him in an isolated room for a few minutes (may be upto ten) till the crying reduces or stops. The "timeout room" should be devoid of recreational or easily destructible objects.
3. Fining : Take away the child's loved objects (e.g. a toy or a book or watching television) for some time if he misbehaves in the course of its use.
4. Brief restraint : Physically hold a child in a restraining manner if he is physically aggressive. Don't scold or make a fuss or even talk to the child during this, be firm and calm. If on releasing him after a few seconds, he does it again, repeat the restraint. The repetition may have to be done 4 to 5 times in a row.

Restitution: Ask the child to put right what he has put wrong eg. cleaning scribbled walls, cleaning a dirtied floor etc. If this is inadequate, apply "overcorrection" he not only clears that room but is asked to also clean another dirty room.

If the child spontaneously confesses a misdeed, the punishment should not be severe, or else you discourage future confessions.

Behave normally soon after the punishment don't make prolonged fuss. Don't discuss the bad behaviour infront of him once the punishment is over.

If you regret a harsh punishment, apologize to the child.

Some "Don'ts" of Disciplining :

Don't bribe a child for a desirable behaviour e.g. studies, or else he learns to enact a behaviour only if concrete favours are anticipated. Unexpected rewards or praise are O.K.

Avoid shouting or displays of other forms of intense negative emotions. Remember a child wants attention, even if it is negative. And don't let the child get the pleasure of being powerful enough to emotionally upset you. Disapprovals should be shown firmly, with a use of minimum of words (no prolonged nagging or preaching) and very importantly, calmly.

Avoid hitting the child. It teaches the child to be aggressive himself ("When in anger, hit out"). The child perceives this as the "last punishment beyond which you can not do anything more", and it's cruel. Never delude yourself that you are hitting the child" to improve him". In reality, you are venting out your anger.

Don't punish the child only because others think he is "spoiled". Investigate individual misdemeanors yourself.

Don't scold too frequently. It makes the scolding ineffective.

Don't threaten impossible punishments e.g. "I will never talk to you", " I will drive you out of the house", I will leave you in a jungle" etc. The child soon learns not to take your threats seriously.

Never punish acts which are beyond the child's voluntary control e.g. bedwetting, bad handwriting, tics, hyperactivity etc.

Never issue scary threats e.g. of ghosts, injections, policeman etc.

Don't punish for accidental damage e.g. breakage of a plate which falls accidentally. He in fact needs to be comforted here. If scolded or punished, his regret at the damage vanishes and is substituted by defiance.

Never verbalize anticipation of an undesirable deed e.g., "I know this toy won't see tomorrow. You are certain to break it today itself" or "Handle it carefully you always break these things."

Never use negative lables for a child e.g. "dull", "mischievous", "disobedient", "stupid". Each child keeps behaving in accordance with his self-image, and his self-image is formed by your expressed opinions of him.

Always remember a child behaves well out of love and respect for his parent who himself is a good role model, and not due to the fear of punishment. The basis of good behaviour is love and praise, and not blame or punishment.

A PARENT'S PERSPECTIVE - Mrs.Karishma Anand

I am a parent of a child with cerebral palsy. I had no idea what it means and how many people in the world suffer from it until life made me come face to face with it in the form of my only child , my son, Banraj. In the beginning when the mile stone were delayed, we were consulting doctors for answers; none of them diagnosed the problem as CP. In all case sheets I was told that he was having delayed milestones and thus would eventually come out of it. After consulting a dozen doctors and getting the same response, I was sure that it is delayed mile stones and so when a doctor said that it was not delayed mile stones but CP, I thought he was a quack and didn't know any thing about medicine. But he was the doctor who turned me towards a developmental neurologist and once I was there I came to know what actually was wrong with my baby.

Meanwhile, on the other side of medicine, which is the people who think that they knew more than most of the doctors and unfortunately were also my relatives who started giving me tips on what should be done to make Banraj walk with in a month. I was even directed towards holy men claiming to have the magical powers and could restore what ever had gone wrong.

At the developmental clinic, I was taught the right way to handle my child and to understand his needs and insecurities, his behaviour patterns, his exercises and every other detail that I had never come across during my consultation with various doctors, physiotherapist and other supernatural beings. I started developing something that was lacking in me for a very long time- FAITH.

Today my son is seven years old He walks with the support of a walker &modified floor reaction orthotic (swash and AFO)

He rides a bicycle with full rotation of peddle and at a normal speed. Climbs on bicycle and climbs down on his own,

He is very intelligent, goes to a normal school, has done well in the KG2 final examination and has been promoted to 1st standard.

He swims with full hand strokes with the help of a tube but no other support,

He is very good with orals and is extremely talkative. Climbs bed and other furniture of same height. All this we have been able to achieve because we were all moving in the right direction under the right guidance with the right knowledge of what we are doing and what all is possible.

He goes to clinic 4 times a week and exercises for a period of 1 hour with the help of rings, wooden balls , blocks, rods pyramids, wooden pyramids, big bolsters and big exercising balls. The whole exercise program is designed to exercise every muscle of the body in different postures. Followed by strengthening exercises done with weights in prone, leg lifts etc.

At the clinic we also concentrate on group behaviour & activities related to schooling so that children know how to behave in school and other public places & perform at school like other children.

WHAT NEEDS TO BE DONE :

I wish that more doctors were aware of what CP is and what needs to be done to help parents who go to them with such children. The misguided parents keep spending money on wrong treatments and before age surgeries and wrong kind of exercises and end up doing more harm to the child then good.

I wish that the new researches and developments in the field of CP should reach the patients at a faster speed than it is being done right now.

I wish that the stem cell therapy could be developed faster and applied in CP so that the children can take maximum help from the treatment and lead a life which is better in quality.

I wish that steps were taken to help children in mainstreaming as the teachers do not know what should be done and maximum of the kids with CP who have normal intelligence remain ill-treated and ignored.

I know that awareness is the key to all the problems and so I wish that doctors and general public were more aware as to what needs to be done to special children with CP. As a parent member of IACP, I will support any initiative that is taken by IACP family forum group & join hands with doctors , therapists & educators towards this end. Parents will be the biggest beneficiaries of such efforts. ✻

Mainstreaming - IACP Nagpur Protocol

1. *Creating awareness among the various personnel concerned in as many forums as possible- 1st step.*
2. *Mainstreaming is a movement, not a strategy or philosophy on paper. It is an opportunity to create a society of equal participatory facillity available to all irrespectve of any constraints*

ART AND ORGANIZATION

3. *Talk to school management committee before embarking on admissions. Need to understand communication as a potential medical intervention for its benefits [British Pediatric Neuro.Asso]*
4. *Create staff by in service teachers' training who learn to use IEP as a prescription sensitive to inclusion challenges (barriers and curriculum)*

Intervention Pyramid

[Greenspan]

- *School help at the top*
- *Specific*
- *Interventions*
- *(e.g., speech-language therapy)*
- *occupational therapy,*
- *educational programs,*
- *biomedical approaches, ongoing developmental and family consultation, specific clinical strategies)*
- *Developmentally appropriate practices and interactions in family, peer, and educational environments matched to*

1. *Child's functional developmental level and*
2. *Individualized differences in sensory reactivity, processing, and motor planning and sequencing*
   - *Ongoing, nurturing, trusting relationships*
   - *Protective, stable, secure relationships including basic services*

and family support for safety and security (e.g., physical and emotional contact, adequate food, housing, medical care)

- *School help at the top*
- *Power (?Psychosocial pressure) triangle 3P's*
- *Misfit-Basis of behavioral problems-Need BRIDGING Professionals*

ORGANIZATION :

5. *Formation of central pool of professionals in every system who can offer their expertise irrespective of who is the service requesting organization.*
6. *Intensive training modules to be created by leading experts towards this end where teachers are made to learn & understand each child as unique in his learning potentials. The role of a teacher is to facilitate achievement of participatory functions and not to promote rote learning of facts far removed from real world needs in classrooms*

RESOURCE ROOM :

7. *Main streaming is not just operating a separate resource room. It needs to offer a level playing field to children with physical impairment but with an alert & absorbing mind.*
8. *True inclusive education is where the differently abled are allowed to learn from an accommodating curriculum within a regular class room.*
9. *Running a special cell in a normal school campus is not main streaming but is partial integration.*

GUIDELINES FOR MAINSTREAMING :

10. *MAINSTREAMING IS NOT THE BEST OPTION FOR ALL CHILDREN*
11. *Schools must have clear cut guidelines. Teachers should be alert to the omnipresent possibility of bullying , stigmatization & abuse of these children*
12. *Parents must be told of a possible change to a special school in case inclusion is not helping a child after consultation with experts.*

ROLE OF GOVERNMENT AND OPEN SCHOOLS :

13. *Government schools offering inclusion need support & help from all quarters to see that a well intended service does not fail.*
14. *Preparing children for the open school system is a viable option whose potential as a helpful support should be explored at all cost. It is a bridging facility for creating more employment opportunities*
15. *OMNIPRESENT ATTITUDINAL BARRIERS ARE THE BIGGEST HURDLES & NEED TO BE OVERCOME AT ANY COST.*

INCLUSION AND EARLY INTERVENTION :

16. *Inclusion needs to be tried as a policy even at Early intervention level (may be with siblings.*
17. *All Early intervention clinics should prepare kids for mainstreaming by making school placement as the end point of early intervention.*
18. *Education is a continuum of socio-communicative domain including literacy & functional academics.*
19. *Anticipatory guidance is a duty we need to zealously perform at all intervention centers.*

ACTION IN REALITY :

20. *Systems around individuals with commitment & expertise.*
21. *Teachers opting for inclusive services need financial incentives & possibly some sort of extra recognition & honor.*
22. *Mutual trust among participants & innovative strategies like peer tutoring or mentoring with add on grades are realistic ways to find workable solutions to difficult & complex human challenges.*

PARENTS' & PEERS' ROLE :

Equal but non locational participation of parents needs assertive action

23. *INCLUSION, SENSITISATION & innovative leadership role assortment to peers is mandatory.*
24. *Parent-professional partnership must be a reality & not a rosy slogan to be bandied around*
25. *Need for a SINGLE LANGUAGE initially both for communication as well as education. Research in neurological foundations of learning have demonstrated superiority of mother tongue or single language in early reading speed acquisition which is the basis of all later learning. Parental Obsession about English schools needs to be changed*

PARENT PROFESSIONAL PARTNERSHIP :

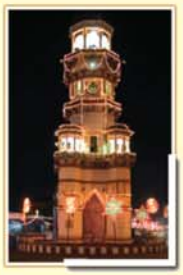
26. *Parents: bring children's wholesomeness, individual values and leisure activities to classrooms.*
27. *Educators: bring empathy & understanding that each child has unique potential waiting to be tapped. Bidirectional Communication is a way for moving forward*
28. *All of us need to get tuned to the recent sociological concept CHILDREN ARE HUMAN BEINGS & NOT HUMAN BECOMINGS [Allan Colver]*
29. *Special schooling is preferable than badly done mainstreaming*
30. *EDUCATION IS A FUNDAMENTAL RIGHT IRRESPECTIVE OF CONSTRAINTS*

THE PYGMALION EFFECT :

31. *Our beliefs will mould children's learning. If we believe they can, they will! It is important to have expectations for succeeding for these children*
32. *Learn to have expectations proportional to the competency of the child. Optimal development & not Normalization should be the goal.*
33. *Highlighting benefits of inclusiveness to normal peers needs to be done on a regular basis to the management, teachers & the other parents of normal children.*

TEACHER REDIFINED :

- *T-THOUGHTFUL*
- *E-EMPATHETIC*
- *A-AFFECTIONATELY AUTHORITATIVE*
- *C-CONCERNED & CARING*
- *H-HUMOROUS & HUMANE*
- *E-ENABLING & EMPOWERING*
- *R-RATIONAL & REFLECTIVE*



5th Annual Conference of IACP in Jabalpur

We are happy to inform that 5th ANNUAL CONFERENCE OF INDIAN ACADEMY OF CEREBRAL PALSY (5th IACPCON) will be held from 15th -17th Oct 2010 in association with Jabalpur Association for Cerebral Palsy.

Theme of the Conference

Intervention in Cerebral Palsy When? What? How?

Scientific Programme

15th October2010

Preconference workshops on
8AM- 9AM--REGISTRATION
9am- 4pm.

Hall A :
Surgical interventions in cerebral palsy.
Coordinator:
Dr.Viraj Shingade

Hall B :
Early intervention
Coordinator:
Dr.Pradeep Dubey

Hall C :
Orthotics & mobility aids Coordinator
Dr.Gaurav Kochhar

INAGURATION ,BANQUET & ENTERTAINMENT :
FRIDAY 15th OCT- 7PM- 10 PM

Organizing Commitee
Patron - Dr. Jitendra Jamdar
Org. President - Dr. Pradeep Dubey
Org. Secretary - Dr. Gaurav Kochhar

Scientific committee
Dr. Ashish Tandon
Dr. Pradeep Dubey

Audio Visual / light & sound
Dr.Mrs. Shikha Singh
Dr. Vivek Shrivastav

Event Management & Reception
Synergies , Mrs. Shilpi Kochhar
Mrs. Tulika

Souvenir committee
Dr. Harsh Saxena
Dr. Ankur Choudhary

Transportation & Accommodation
Dr. Ankur Choudhary

16th October2010

9.00 -10.00 am - **KEY NOTE & PRESIDENTIAL ADDRESS**
Interventions in Cerebral Palsy- When, what & How?- Need to define Indian Guidelines.
Dr. Ashok Johari, President IACP

10.00 - 10. 40 am	: Dr. Jamdar, Rehabilitation Scenario in Central India'
10.40 - 11 .00 am	: Discussion.
11 .00 -11.15 am	: Tea break.
11.15 -12.00 noon	: Gait analysis for Indian scenario. Clinical or instrumented? View points .
Facilitator	: Dr. Ashok Johari.
12.00 -1.00 pm	: IACP NAGPUR Protocol
on mainstreaming	: Open house discussion & Recommendations for action.
Moderators	: Dr. G. Shashikala & Mr. K.D. Mallikarjuna
1.00 - 2.00 pm	: Lunch break & meet the Masters program.
2.00 - 4.00 pm	: 1] Protocol meeting of three pre conference work shop groups & directives for action to the respective IACP committees. [Dr.Aniruddh Purohit/Dr. Asha Chitnis/Dr. Dhruv Mehta] 2] Free Paper Session
4pm-6pm	: IACP GBM

CALL FOR ABSTRACTS

Abstracts on all aspects of Cerebral Palsy are welcome for plenary session, free papers and poster presentation. Abstract are to be typed in English not exceeding 300 words. The same should be sent by email to Dr. PradeepDubey dr.pradeepdubey@gmail.com and Dr. A. K. Purohit akpcpcp@gmail.com as a attached file typed in MSWord. All abstracts must reach the Conferance Secretariat by 15th September 2010. Name of the presenting author must be underlined. The Presenting author will be informed about acceptance of the paper along with the date and time of his/her presentation.

17th October2010

9am-9.40 am	: Non ablative management of Spasticity. Dr. Aniruddh Purohit
9.40-10.20	: Role of General Practitioners in Developmental disorders. Dr.M.S.Mahadeviah
10.20 - 11 am	: Botulinum toxin in management of spasticity. Dr.Vivek Shrivastava
11-11.30 am	: Tea - break
11.30-12.00	: Genetic cerebral palsy implications for prevention & management. -Dr. I.C. Verma
2-1 pm	: Prevention of cerebral palsy- Dream or Reality ?
A debate For	: Dr. Anaitha Hegde/Dr. Vrajesh Udani.
Against	: Dr.Prathiba Singhi / Dr.Ashuthosh Rohtagi.
Moderators	: Dr.Vipul Shah - Dr.M.S.Mahadeviah
1pm - 1.30pm	: Lunch
1.30- 3.30pm	: Family forum program.
3.30- 4-30 pm	: Valedictory Function & felicitation of achievers.

Please contact for further details & registration
Dr.Gaurav Kochhar at tpcrc@yahoo.com or Dr. PradeepDubey at dr.pradeepdubey@gmail.com
log on to www.iacp.co.in.

4th Annual National Conference of Indian Academy of Cerebral Palsy held in Mumbai (2nd - 3rd Jan. 2010)

Family Forum




Professionals and familiies during the discussion of the 4th Annual Family Forum of IACP




Hearty Congratulations for Great Achievements of our dear IACP Members

Royal College of Surgeons of England has conferred FRCS (Lon) Ad eundem on

Dr.Ashok N. Johari

in recognition of surgical work

It is a great moment of pride for the IACP fraternity and we all congratulate Prof.Ashok N.Johari.

AACPDM International Scholarship is awarded to

Dr.Pranali Somkumwar

AACPDM 64th Annual Meeting
September 22-25, 2010, Washington, DC, USA

International Scholarship is awarded to

Dr.Madhuri Khelapure

AACPDM 64th Annual Meeting
September 22-25, 2010, Washington, DC, USA

International Scholarship is awarded to

Dr.A.D.Joshi

AACPDM 64th Annual Meeting
September 22-25, 2010, Washington, DC, USA

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helps you to connect and share with the professionals and persons with cerebral palsy.

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