



INDIAN ACADEMY OF CEREBRAL PALSY

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Official newsletter for members of IACP

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President's Message

MILESTONES OF ACADEMY

Hearty congratulations! To each and every executive and all the members of our academy (IACP – Indian Academy of Cerebral Palsy) for making possible to develop it so rapidly as if it is flying, a much needed way to achieve various milestones in the present era of “Fast Life” wherein researches are getting outdated just in 6 years period. Of course, all this is happening all around the world due to rapid development of various technologies. However, “Fool with a tool (technology) is still a fool” Therefore, balancing the qualities of heart, the wisdom and mind (the tools use) is essential in holistic approach to the child having cerebral palsy.

Indeed, as first step for the welfare of these children, developing a scientific body was conceived long ago, but the factual birth could take place in the year 2004 with registration to the government. There after the academy immediately started having annual scientific meetings (by now seven), constituted its own constitution, formed various scientific study guidelines, started national cerebral palsy week for social awareness. The exemplary progress also got reflected in having more than 500 life members from various specialties of Allopathy and additional medical fields (only academy opened to all the medical fields who can scientifically contribute to the welfare of the families having child with cerebral palsy. This leap would have been impossible without the efforts of great visionary founder members, executives and of course all of you the members of the academy. Soon we will have another leap. What is that?

The perfect research studies are essentially needed for us to have holistic approach towards our children on the globe. Balancing the need to develop existing biological (within) potential powers and properly applying newly developed outside strengths (tools and drugs) can provide the best of the world to them. With this idea, the academy has provided a platform to discuss our studies (advances) scientifically by conducting annual conferences. Not only this now we have one more platform: Indian Journal of Cerebral Palsy (IJCP), Registered with ministry, New Delhi.

I would request you to understand that ‘Reading maketh a full man, conferences a ready man and writing an exact man’ (Sir Francis Bacon – 1561- 1626). So let's march forward & utilize this opportunity to publish your case reports and series; and make IJCP a great tool for our continued efforts of Knowledge Sharing. All the scientific discoveries are essentially needed so that our present and coming generations do not face:

Professionals' bias and the families' confusion as to what is best for their child.

Prof. A.K. Purohit



7th Annual Conference of IACP and International Conference on Cerebral Palsy held in Lucknow from 6th to 10th March 2013

International Key Speakers



Key Speakers are Honoured



From Secretary's Desk

Six months of the year of 2013 and over 6 years of IACP's active work have gone by. As one reflects one feels we have much more to do, to work diligently, cohesively in the core group of IACP, the members have also to get involved and equally participate for the total welfare of childrens and adults with cerebral palsy and their family and care givers. We have to use multiple avenues to sensitize people, raise awareness, network with NGO's and like minded people to strengthen our work. Its very heartening that Parent-Professionals are doing this grass-root and linking up work with policy makers, professionals. Dr G. Shashikala in this regard has been a great source of strength for all.

We had an International conference on Cerebral Palsy and Developmental Medicine at Lucknow. Whilst many eminent faculty from abroad working in the field of Cerebral Palsy made the conference rich, one felt very sad that it was poorly attended. The local organizers, IACP and other associated organizations should have encouraged post-graduate students, interns, kept the conference fee less, and structured the conference so that workshops where participants had to pay were pre or post-conference. We all have to make a serious note of this that our national, annual IACP conferences are so structured and planned that we have good attendance and more so for an International conference, for the faculty from abroad should leave our shores with positivity and not the contrary.

It is good now for IACP that from now World Cerebral Palsy Day will be on October 2nd, so the National CP Day and World CP Day Celebrations now can be celebrated together. We need to congratulate Dr. Husein Jetpurwalla and his mother Dr Fatema for winning a prize in the contest for making a one minute film on the occasion of the first World CP Day. IACP is able to link up with institutes which are passionate and keen in the care of cerebral palsy. Polio Foundation has shown its eagerness to conduct our annual conference in December this year. They had also extended an invitation to hold a seminar for parents and therapists and give guidance for children with cerebral palsy.

So friends lets resolve, mid year, that we will all put in our effort to bring more positive results in the different spheres of care for persons with cerebral palsy, bring in more sunshine and joy and bring in more visible changes which will create its own ripple effect.

Dr. Dhruv Mehata, General Secretary

Editor's Pen Writes

On advocacy and knocking on the doors of policy makers

Advocacy means the pursuit of all those influencing outcomes that make difference to the current lives of people .It needs active effort emerging out of strong commitment & unwavering faith in scientific fundamentals It does not mean complaining & being armchair critics. As Mahathma Gandhi said, we need to be the change that we want to see in the community.

Our conferences & CMES are meant to increase the knowledge base of our members by a process of KNOWLEDGE TRANSLATION. After every conference, I keep wondering if we have really done that considering the poor attendance of IACP members in all our conferences. Most of our conferences end up having local participants-specially therapists & if for some reason local members do not feel that they need to learn more as we saw in Lucknow, our invited faculty end up addressing vacant halls or to one another. Is it worthwhile spending so much on conducting conferences which are poorly attended by our own members? At this rate, how are we going to bring in the change in the field of disability which for ages has been a poor cousin of all health initiatives?

Our National CP Day celebration, we thought would be one such initiative for better advocacy. We would like our members to pursue activities of high, medium & low impact & knocking on the doors of policy makers would be of the highest impact.

Dr. Satender Singh from Delhi has shown all of us as to how to pursue issues to their logical end. Having done a squirrel attempt to wake up the local administration, I can only vouch for the ordeals & impediments on the way but that should only make us more determined. Knowledge translation will not occur amidst our colleagues unless disability medicine is taught better in medical colleges which means we need to bulldoze our way to MCI to make a difference in medical curriculum! A few steps are not enough but we need marathon runners to reach the end! How many of our complaining colleagues & parents will join is any one's guess. Let us see how many of you will try joining hands with us on this year's CP day which endorses celebration of excellence & abilities of the differently abled! Should n't we feel small in front of them as torch bearers?

As a parent professional, I have learnt that eternal optimism is a fantastic weapon against adversity & hope all of you are also birds of the same feather.

Dr. G. Shashikala, Editor & Vice President

Minutes - 7th I A C P Annual General Body Meeting

DATE: 9th March 2013; VENUE: Convention Center, Lucknow

Participants:

Dr .A. K. Purohit , Dr. G. Shashikala, Mr. K.D. Mallikarjuna, Dr. M.S. Mahadeviah, Dr. Asha Chitnis, Dr. Dhruv Mehta, Dr. Vipul Shah, Dr. Pratibha Singhi, Dr. Trupti Nikharge, Dr. Sanket Khadilkar, Dr. Sujata Noronha, Dr. Gajanan Bhalerao, Dr. Deep Chandra Gupta, Dr. Ved Prakash Singh, Dr. Sanjay Keshkar, Dr. Ratnesh Kumar, Dr. R. Jhalani, Dr. Mansi Agarwal, Dr. Fatema Jetpurwala, Dr. Sakti Prasad Das, Dr. Gopi Kitnaswamy, Dr. Harish Badigel, Dr. Sandhya Khadse, Dr. Hirendranath Das, Dr. Gautam Kodikar Dr. Harish Badiger, Dr. Saroj Kumar Jha and Dr. Madhavi Kelapure

Agenda:

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| <ol style="list-style-type: none"> 1. Welcome by the President 2. Membership Scenario 3. Advertisements in Newsletter 4. Conference Organization 5. Report of last year GBM | <ol style="list-style-type: none"> 6. CP day report 7. Protocol Committee Report 8. Return of excess funds 9. Annual accounts 10. Next IACP Conference |
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Topic

1 Welcome by President

Discussion

- President, Dr. Purohit welcomed all the members and briefly talked about the current scenario of the IACP. He said the present membership has crossed 400 and that the 7th annual conference is being held at Lucknow.
- He broke a new development that the IACP has successfully got the permission from Delhi to publish **Indian Journal of Cerebral Palsy**, and the sole aim of this journal will be to bring the science in all aspects related to Cerebral Palsy.
- Dr. Purohit will be the editor of Indian Journal of Cerebral Palsy. Dr. Pratibha Singhi was requested to extend the help in overall bringing up the journal. At the end it was proposed by Dr. Shashikala that every EC member will be responsible for arranging one article for the journal. It was also decided that a supplementary issue of Indian Journal of Cerebral Palsy be published which will contain the abstracts of all conference scientific sessions.
There was a general discussion about how we can develop the IACP as a very strong national body with representation from all over India.

2. Membership Scenario

- Dr. Dhruv Mehta pointed out that we need to increase the membership drive. Other branches should be encouraged as currently we have more therapist than clinicians in the membership body. It was also affirmed that **state chapters** should be formed once a state has a membership of 25 plus.
- Membership Certificates will be given to members only after completion of two years, with attendance in the two annual conferences. Till such time, they will be given a provisional certificate.

3. Advertising

- It was declared that IACP newsletter can have 4 or 5 advertisements. But it should be clearly mentioned that advertising does not endorse or promote any one company or product.

4. Conference Organization

- It was discussed that a conference committee should come up with strict guidelines on conducting a conference.
- Mr. Mallikarjuna announced that a conference committee was already formed. This committee will always be chaired and co-chaired by the President and General Secretary respectively. Following will be the additional members of the conference committee.

1. Surgery - Dr. Ashok Johari /Dr. Ratnesh Kumar
2. Developmental Pediatrics - Dr. Pratibha Singhi
3. Physiotherapy - Dr. Asha Chitnis
4. Occupational Therapy - Dr. Vandana Giri
5. Assistive Technology - Dr. Sakti DAS
6. Special Education - Mr. Mallikarjuna
7. Speech Therapy - Mr. Mallikarjun has taken the responsibility of finding out the interested member for this position
8. Transitional care - Dr. Shashikala is interested.

- It will be mandatory for the local organizers to have a regular communication with the conference committee. Dr. Purohit stated that a midterm executive meeting should be held at the venue 6 months in advance of the conference every year. This will be for the EC members to discuss the conference preparation with the local organizers. While the expenses for their travel will be decided upon by mutual understanding, the hospitality of the EC will be totally local organizers' responsibility.
 - President announced a rule that every organizing committee should donate 10 percent of the registration fees amount to the IACP.
5. **Report of last year / Miscellaneous** Dr. Mehta announced that the IACP was invited by Ramkrishna Mission, Rajkot for a joint seminar on the 29th and 30th of September 2012. This seminar was on the theme of 'Cerebral Palsy, A Mission'. The faculties were Dr. Purohit, Dr. Nagda, Dr. Mehta and Dr. Chitnis. It was very well received with audience of 300 plus. · Mallikarjun suggested that committee members who are not active should be replaced. This will be discussed and coordinated by emails.
 6. **CP day 2012** Dr. Mehta briefed about successful celebration of National CP Day celebration on third October 2012. He also requested members to send their reports on time. The theme for next year CP day celebration was finalized as 'Celebrating Abilities'.
 7. **Protocol Committee Report** As was decided in the previous GBM, committees were working on the protocols of Early Diagnosis, Early intervention, Orthopedics, Therapy, Mainstreaming. Dr. Shashikala and Dr. Asha are ready with their respective protocols. Dr. Taral Nagda will be the in charge of Surgical Protocol Committee and he is working with his members, Dr. Viraj Shingade, Dr. Jitendra Jain, and Dr. Shakti Das. They will be reporting to Dr. Ashok Johari.
 8. **Return of excess funds** Dr. Keshkar and team issued a cheque of Rs 25000/- to the president towards balance amount of 2011 Kolkata conference proceedings. Their loyalty was applauded by all the members
He also had membership fees of 15 new members which was supposed to be handed over to the treasurer.
 9. **Annual Accounts** Mr. K. D. Mallikarajun gave a statement of accounts. It was proposed by Dr. Chitnis and seconded by Dr. Shashikala and Dr. Khadase. GB approved the presented statement of accounts.
 10. **Next IACP Conference** Venue for the next conference
2013 - Ahmadabad people are willing. Final decision to be taken within 15 days
2014 - Hyderabad
2015 - NIRTAR·Cuttak
Dr. Bhalerao did suggest Pune for 2016 but Dr. Purohit suggested that venues should be decided only two years in advance.

Indian Journal of Cerebral Palsy

IACP happy to inform you that very soon it is going to publish a Research Journal biannually. This is first of its kind Indian Journal published exclusively on cerebral palsy and its associated disorders.

We request all of you to utilise this platform for disseminating your research on current trends and practices to adopt best quality services in the management of persons with cerebral palsy. For further details please contact:- Prof. A. K. Purohit, Editor in Chief, Indian Journal of Cerebral Palsy. Email: akpcpcp@gmail.com

REPORT OF INTERNATIONAL CONFERENCE ON CEREBRAL PALSY AND 7TH IACP CONFERENCE HELD IN LUCKNOW FROM 6-10 MARCH 2013

The International Conference on Cerebral Palsy and Developmental Medicine and 7th IACP conference was held in Lucknow from 6th-10 March 2013

The meeting was supported by American Academy of Cerebral Palsy, World Federation of Neurorehabilitation, European Pediatric Neurology Society, International Child Neurology Association, Pediatric Orthopaedic society of India and All India Occupational Therapists Association. Scientific committee consisted of 20 faculties from all parts of the globe with Dr Freeman Miller as its International Chair and Dr G. Shashikala as its Indian chair.

There were India total 550 registrations with more than 125 participants from more than 40 countries of the world giving it a truly international flavor, the meeting was organized by the R.P.SHAH Memorial Trust for Children with Disabilities and its medical director Dr Vipul Shah was the organizing secretary. The Meeting was recognized by Medical Council of India, All India Occupational Therapists Association and Indian Association of Physiotherapists for CME credits.

On the 6th and 7th March there were in total 12 preconference workshops which were attended by 200 delegates, this included workshop on Communication and Play, Surgery or Botulin Toxin for Upper Limb, Gait Analysis, Early Diagnosis and Scales in Cerebral Palsy, Early Referral and Early Intervention Workshop, Hands on workshop on the importance of Stance phase, Paper based rehabilitation technology, Therapeutic Handling Workshop, Felite Afo's workshop and SPIO workshop. All preconference workshops were well received by the delegates however for the organizing team the high point of the preconference workshops was the hands on Felite Afo's workshop where the delegates and the faculty Nancy Hylton from USA continued late till 8 pm interacting and doing hands on training. Close to 20 parents were part of the early diagnosis workshop and therapeutic handling workshop and learnt from the esteemed faculty about correct treatment and handling techniques.

The conference had 7 parallel halls running which included a separate hall in which Indian federation of Neuro rehabilitation was running its parallel sessions, this was headed by Dr Nirmal Surya from Mumbai its president. On day 1 i.e 8th March there was a plenary session named as Dr P .K.Mulla Feroz Memorial Lecture Series where lectures were delivered by Dr Hans Forsberg, President, European Academy of Childhood

Diseases, Dr Anirudh K Purohit- President Indian Academy of Cerebral Palsy, Dr Lieven Lagae, President European Pediatric Neurology Society, Dr Stephene Clarke- President, World Federation of Neurorehabilitation, Dr Anil Srivastava, President AIOTA, Dr Soniya Nityanand, Head stem cell research unit, SGPGI, Lucknow and Diane Damiao, Past President, American Academy of Cerebral Palsy and Developmental Medicine. The evening was marked by a gala dinner where a troupe performed Kathak, the traditional dance of Lucknow which was very well received followed by Dinner for the participants.



ON 9TH March there were plenary lectures by Dr Leeland Albright, USA, Dr. Satyendra Phaswal, Dr Freeman Miller, USA, Dr Sarojini Budden, USA, Dr Antigone Papavasileiou, Greece, Sunil Agrawal, USA and Nancy Hylton, USA. In addition the most amazing part of the meeting from Indian perspective was the start of the meeting at 7 am sharp with breakfast sessions (there were 20 breakfast sessions during the meeting) and the intense 2 hour duration instructional courses (there were 30 instructional courses). In the evening there was a celebration dinner in which Talaash band from Mumbai enthralled the audience.

On the 10th of March Reaching for The Stars which is the biggest parent lead charity in USA made a presentation in the plenary session with Dr Vipul Shah who will head the Asian initiative of this organization making the presentation on behalf of Cynthia Gray and Micheal Kutcher. The meeting ended with the valedictory session in which Dr Freeman Miller and Dr Shashikala were honored on stage by Mr K K Shah the patron of the R.P.SHAH Memorial Trust and by Mr Ashok Shah its Chairman. Mr K K Shah also announced the Geeta Shah Memorial prize worth Rs 25,000 Rs ie USD 500\$ which was won by Erika Williams from Australia for her services towards the cause of children with cerebral palsy in Cambodia. The meeting dispersed with a closing statement by Dr Vipul Shah and promise to conduct a bigger and better meeting in Goa in 3 years time.

As the organizing secretary of the meeting I wish to bring on record the exemplary efforts of Dr Shashikala and Mr. K. D. Mallikarjun from IACP Side which allowed this meeting to happen, thanks are also due to other members of the IACP including all members of the IACP central committee for chipping in as and when requested.

Dr. VIPUL SHAH, Organising Secretary, IICPDM

Photos are on 2nd Inner Cover and 4th Back Cover

Guidelines for conducting IACP Conferences & CME Programs

1. The Annual conference dates will preferably be set for the year end - 3rd week of November or December taking care to avoid clashing with major medical conference & festival dates to ensure local fraternity participation in the chosen city .
2. Annual conferences will primarily carry Academy's name & the local group as co hosts even if it is another Academy or their subchapters.
3. The local Organizing committee should have at least one permanent life member of IACP at the decision making level to ensure that its aims & policies are being reflected in conference Program.
4. As on date, IACP will not be able to fund any conference except offer a token seed Amount of Rs.25,000/only which will have to be returned at the end of the conference. Local Organizing committee will function transparently & will share the profits equally with the Academy. To ensure this, IACP treasurer will be a part of the finance committee of the organizing group in absentia & will assist them in raising funds from any known source ,if possible. The conference committee of IACP will also help them in all matters including suggestions on the program as also the president & secretary all through.
5. No IACP member will demand travel allowances even if invited as a faculty & this would be entirely the prerogative of the local organizers .However, all EB members should be given local hospitality by the organizers so that annual GBM can be attended by them, which should be compulsorily arranged by the local organizers. In the event of any EB member being a part of the organizing committee, he or she will automatically be a member of the next conference committee of IACP so as to help the subsequent conference conduct with his experience.
6. As IACP is a multidisciplinary body, every conference must cater to the needs of all specialties apart from considering local needs in drawing up the program..
7. The conference duration will be for three days starting with pre conference workshop or workshops on Friday . The number of pcws are left to the local convenience & topics chosen should be based on local need assessment. It is extremely important to highlight the advantages of pcws which will help leisurely and interactive treatment of the topics chosen to mentor as well as train younger members , facilitate inter disciplinary learning & develop guidelines & protocols to implement uniform quality of developmental services by members. Such programs must compulsorily distribute handouts of presented information. Every conference must at least come up with one preliminary guidelines on one of the need based or priority leading topics which should be discussed in subsequent conferences & consensus protocols published in our News letter for improving the knowledge base of our members & evolve clinical best practice guide lines.
7. IACP conferences must award CME credits for participating delegates as per existing norms.
8. During every conference, we must compulsorily conduct family forum meetings in the prime time schedule and allow interactive participation of parents and adult Persons with cerebral palsy to get feedback on their perceptions of existing Service models , felt needs and suggestions for developing inclusive health , social Policies & research initiatives rather than having mere Q&A sessions. It has been observed that many guest faculties and delegates do not attend these meetings. Listening to the opinions of care receivers is an extremely important learning experience for service providers in the evolutionary process of sensitive health & developmental care as long as care is taken to avoid indulging in blame game from either sides. Felicitation should be confined to 1 or 2 persons to recognize their courage in fighting the disadvantage or to support their ongoing efforts. Care should be exercised in minimizing accessibility barriers at the venue which are rampant in our environment. Utmost sensitivity needs to be brought into these programs so that feelings of parents and mainly challenged person are not hurt. What we need to celebrate is their monumental courage and not their disabilities or achievements in an effort to NORMALIZE them.
9. The field of Disability is a poor cousin of general health , education & employment initiatives and is cash starved. Recognising this fact, our conferences need to be less pretentious, high on scientific content, policy molding efforts & inculcating innovative teaching modules like debates on controversies & issues, Hands on work shops, role plays rather than using stereotyped didactic lecture & symposia format. We need to give information rich books & booklets & articles made by persons with disabilities instead of mementoes & conference bags.
10. If the organizers cannot accommodate 3 days, we can call the program as a CME and have 2 days of training for new members and graduate entrants to improve their professional training & quality of service provision. Such programs must compulsorily provide hand outs on all the topics covered.
11. The organizing secretary must submit a short but comprehensive proceedings report with in three months after the program for publication in the next news letter of IACP along with the summary of evaluation forms compulsorily given & collected from delegates to improve our conference content as well as conduct wise.
12. During the annual GBM, the venue, theme & tentative program of the next conference should be announced to provide advance information to members to plan their participation.
13. Free papers presentations are compulsory in conferences. Papers should be made according to EBM guidelines. Poster demonstrations are also to be encouraged. At least one IACP scientific committee member must be one of the selectors.

Doctor's efforts bring disabled-friendly ATMs at GTB Hospital

Statesman, The English Daily News Paper

Chandan Prakash Singh, New Delhi, 24 April 2013

Satendra Singh, a doctor at a University College of Medical Sciences (UCMS), is happy after winning a long fought battle. His efforts have resulted in installation of two automated teller machines (ATMs) inside Guru Teg Bahadur (GTB) Hospital.



The machine, accessible for person with disabilities, is an outcome of a firm persuasion by Dr Singh, who himself is a person with locomotor disability.

Recalling the efforts he made to achieve this goal, Dr Singh said that despite directions from the Reserve Bank of India (RBI) in 2009 and interference of Chief Commissioner for Persons with Disabilities (CCPD), who wrote to the Department of Banking Operations and Development in the year 2011, to make ATMs disable-friendly, not much action was taken and nothing came in concrete form.

He further said that the RBI master circular advises all the banks to provide ramps to their ATMs so that wheelchair users and persons with disability can easily enter the booths. The arrangements should be made in a particular height so that there would be no possibility of impediment for wheelchair users.

New ramp constructed at Bank of Baroda ATM at GTB Hospital

However, when Dr Singh filed an Right to Information (RTI) application to the RBI on behalf of the Enabling Unit (for persons with disability) at UCMS, it came to light that the RBI has no information on such ATM's.

"It is the responsibility of the RBI to implement its circular. But it does not have any information on ATMs and their accessibility status," said Dr Singh.

He said that since both the Bank of Baroda and Canara Bank ATMs, located inside GTB Hospital premises, were inaccessible without ramp he wrote several letters to the respective bank managers and even organized Canara Bank AGM's meeting with Medical Superintendent of GTB but all in vain.

"Later, this year, I complained to CCPD and they sent notices to the General Managers of both banks after which Bank of Baroda immediately complied by constructing ramp with stainless steel railings but Canara Bank did not comply. At this, CCPD sent another notice to Canara Bank which led to the beginning of a construction of ramp at Canara Bank ATM too," said Dr Singh.

He further said that rather than complaining about each and every ATMs in the Capital, Banks should show their accountability and should immediately construct a ramp so that ATMs should be accessible for persons with disabilities.

***IACP Mainstream Protocol is available. For copies please contact - The Editor, IACP Newsletter
Email : shashi_kola@rediffmail.com***

A Peep into Adolescents Mind-for Parents

My Declaration of Self Esteem by Virginia Satir

I am ME. I am Unique.

There isn't another human being in the whole world like me.

I have my very own fingerprints & my very own thoughts.

I was not stamped out of a mould like coca cola top to be the duplicate or another brand.

I own all of me-my body, my mind & all its thoughts & ideas, my feelings whether joyful or painful.

I can do with it what I choose. I own my ideals, my dreams, my hope, my fantasies & my fears.

I reserve the right to think & feel differently from others.

I grant to others their right to thoughts & feelings not identical with my own.

I own all my triumphs & successes.

I own also all my failures & mistakes.

I am the cause of what I do.

I am responsible for my own behavior.

I will permit myself to be imperfect.

When I make a mistake or fail,

I know I am not the failure, I am still o.k.

I will discard some parts of me that were unfitting

And will venture into new ways & deeds.

I will laugh freely & loudly at myself- a healthy self -affirmation! I will have fun living inside my skin.

I honor myself, I have value & worth.

I will remember that the door to everybody's life needs this sigh

Believe Me, I AM ME & I AM O.K.

ADOLESCENCE IN CEREBRAL PALSY---ISSUES OF CONCERN FOR CARE, SUPPORT AND ENABLING- TRANSITIONAL CARE REINFORCEMENT

ADOLESCENCE IN CEREBRAL PALSY---ISSUES OF CONCERN FOR CARE, SUPPORT AND ENABLING- TRANSITIONAL CARE REINFORCEMENT FROM WORKSHOPS & ADVANCED COURSES DONE ON TRANSITIONAL CARE DURING IACP CONFERENCES 2nd ANNUAL CONFERENCE OF IACP. 30th November 2007 VENUE - Spastic society of Karnataka -Indiranagar- Bangalore Health Monitoring Lecture to Parents during Mumbai conference, Jan 2010 Advanced course on transitional care during Lucknow conference-March 2013.

INTRODUCTION:

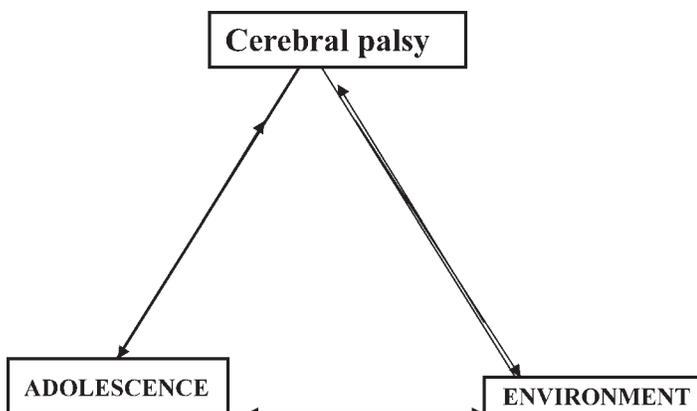
With popularization and implementation of early intervention programs for cerebral palsy gaining momentum across the country, emergence of the first generation of adolescents who probably have received some form of early intervention at least is a reality. The Academy members genuinely experience the manifold challenge of creating services for transitional care in a Lifespan approach model. A humble but informed attempt was made to arrive at a consensus on defining the domains and outline a tentative plan of action. Participant members are fully aware that these concerns need to be presented to the rest of the members of the Academy for wider & comprehensive discussions before we convert these suggestions to an accepted Protocol

NATURE OF THE WORKSHOP

Conceptual as well as operational pre protocol, interactive program

OBJECTIVE

- 1]. To involve the participants to identify areas of concern that need to be addressed in dealing with adolescents with cerebral palsy in day to day work at micro and macro levels
- 2]. To enable the participants to understand the process of triangularisation i.e-cerebral palsy, adolescence and environment as interdependent, reciprocally influencing as well as influenced tri directional phenomena.



- 3] To enlist the key points, cluster them into domains and organize the intervention methods under a guiding principle with suitable examples

METHODOLOGY-Focused Group Discussions.

SPECIALIST COORDINATOR & GROUP LEADER- DR.SHEKHAR SHESHADRI Prof. of Psychiatry. NIMHANS

PARTICIPANTS-

Multidisciplinary group representing parents and professionals

Mrs.Rukmini Krishnaswamy, Dr. A. K.Purohit, Dr. G. Shashikala, Ms. Jayashri, Ms. Sharada, Ms.Preetha, Mr. Narayanan, Ms. Usha, Dr. Manai Lewin, Dr. Suchanda, Ms. Revathi Sunder, Ms. Vijaya Menon, Mr. Chand Pashe, Mr. Saroj Kumar, Mr. M. G. Prakasha Hulla, Mrs. Jayashri Sengupta, Mrs. Kairali Nair, Mrs. Padmavathi.A.V, Mr. K. D. Mallikarjun.

DRAFT prepared by Dr. G. Shashikala.

KEY ISSUES OF CONCERN.

1. Identity crisis.
2. Accessibility to creative, aesthetic and mainstream spaces.
3. Sexuality-Affirmative reaction, Passive enabling, Legitimacy, Preventive & safe Practices, Abuse, dependency vs independence, relationships [with in family circles]
4. Gender bias.
5. Aging of Parents
6. Anticipatory guidance with developmentally pro active approach.
7. Meaningfulness, responsibility & nurturing.
8. Communication-Structural as well as conversational optimization
9. Behavioral frustration - external & internal, motor agitation & learned helplessness.
10. Companionship, affiliation, aesthetic intimacy, relational intimacy, affectionate & romantic intimacy, friendship.
11. Attention seeking & insecurity, self denial.
12. Access to information regarding status, future & safety
13. Identity [acceptance based on comprehension]-Representation, inferiority & fulfillment of roles.
14. Group & social skills-efficacy, esteem, security, self worth, rejection & isolation, peer acceptance, empathy, negotiation, assertiveness, compromise & conflict resolution
15. Potential limits, enabling, re assurance.
16. Outcomes - trade off [giving up for a gain]- temper tantrums
17. Institutional dynamics [attachment behaviors], rebelling against authority.
18. World of feelings, emotions & creativity, personal introspection, reflection.
19. Acceptance of limitations, knowledge regarding causation of disability.
20. Hygiene & health.
21. Adaptation [two way process involving social responsibility & responsivity].

- a] assistive technology. b] educational, vocational, career & placement options c] Intra familial comparisons d] conflict with parents & siblings.
22. Handling stress & anxiety.

Based on these listed concerns, clustering was done into six major domains and participants were randomly allotted into focused groups for further discussion. The collective opinion was presented from each group by a representative.

DOMAINS IDENTIFIED FOR FURTHER ACTION:

- 1] IDENTITY [intra personal].
- 2] INTER PERSONAL INTERACTIVITY.
- 3] SKILLS.
- 4] BEHAVIORAL REFINEMENT.
- 5] HEALTH & SAFETY.
- 6] EMPOWERMENT.

A] INTERPERSONAL INTERACTIVITY

Participants: Dr. Shashikala, Mrs. Jayashri Sengupta, Mrs. Kairali Nair, Smt. Padmavathi Nair

Guiding Principle:

Adolescence is often a trying time of transition for a child as well as parents. According to Steinberg, teenagers need to establish themselves as individuals- in their own mind [identity] and in the eyes of others around them [interpersonal growth]. This also implies becoming a person of one's own, grow out of the shadow of parents and in the case of adolescents with cerebral palsy, even the other developmental care providers. To provide a barrier free, safe & supportive inter phase for optimal as well as stable relation building strategies and nurture them reciprocally without pathological bonding both at micro & macro levels would be the salient feature in creating services under this domain.

Key points:

- a] Affiliation b] Institutional dynamics, attachment behaviours, rebellion against authority c] Adaptation-intra familial comparison-conflict with parents & siblings d] Potential limits vs optimization & enabling, reassurance e] Relational, Affectional romantic & aesthetic intimacies - understanding and differentiation f] Compromise & conflict resolution, Empathy g] Peer acceptance, rejection & fear of social isolation h] Handling emotions & assertiveness.

INTERVENTION METHODS:

- 1] Family is the breeding ground for successful relation building abilities. Parental conflict often primes children for relating ineptitude. Adolescence in disabled children often makes their future picture clearer to parents and each parent may drift back temporarily into transitory denial, non acceptance and grief. Mothers passing through menopausal phase may get depressed & unknowingly precipitate emotional drifting in teenagers. Hence, ANTICIPATORY GUIDANCE & FAMILY COUNSELLING would be the first step.
- 2] Parents and service providers need to look at adolescents beyond their impairment essentially as individuals going through a normal developmental

phase. While some functions may be affected by cerebral palsy directly, the enriching world of emotions and feelings remain untouched very often. Realistic fulfillment of unmet needs should be accepted as a potential help for positive social integration. Letting them accept these needs as natural and reaching out at times of conflict unobtrusively will model relation building skills.

- 3] Freedom for communication and exchange of ideas and strategies in individual or group therapy setting is a very helpful tool. Keep channels of communication always open. Adolescents have a great need for group confirming behaviors & this can be used to resolve many conflicts.
 - 4] Simple, safe instruction to identify limits, to realise the availability, accessibility and responsiveness of the interactor and display rules of emotions & safe methods of gratification with in acceptable social norms & limits
 - 6] Teach techniques of self control & gratification needs and channelisation of emotional energies elsewhere particularly in rebelling against authority and aggressiveness Ability to compromise and resolve conflicts amicably are excellent inter personal skills
 - 7] Adolescents should be counseled to learn the essential trait of empathy which involves emotionally appropriate understanding of others and perceive .others needs particularly the limitations of aging parents. Being able to manage emotions towards others is at the core of handling relationships successfully.
 - 8] Inculcate an attitude of reflection and help them judge the pros and cons of their actions and learn from outcomes. Correction of self is an often neglected aspect of interpersonal growth.
 - 9] Professionals need to know the principle of goodness of fit according to the temperament and attachment behaviors of adolescents and offer anticipatory guidance. Encouraging teenagers to develop a habit of reading or access information through web sites may appeal to many youngsters as an unobtrusive method of gaining information.
- All these need development OF CRITICAL & CREATIVE THINKING, PROBLEM SOLVING & DECISION MAKING LIFE SKILLS
- 10]. Adolescents should always be made to feel that help is always available. Both parents and professionals can become mentors, friends, philosophers and guides at this troubled times of transition

B] IDENTITY

Participants: Dr. Maria Lewin & team

Definition: acceptance of self based on comprehension.

Guiding Principle

To establish acceptance by parents, family & society at large, recognition of inherent potential skills & talents, encouragement & promotion of these core abilities & ensure a platform for self existence.

Key points

- 1] Recognition of Potentials & scientific, non categorical assessment of abilities & limitations in specific domains & environments - home [Social skills] & other structured environments like visiting friends or family functions or other gatherings [Communication & acceptable behaviors in more cognitively restricted children]
- 2] Allocation of responsibilities
 - a] Home-as in family get- together, simple household tasks.
 - b] Beyond home as in public spaces like markets-buying small items/ money matters.
- 3] Access; Individual-Barrier free access to basic facilities like toilets in public spaces, use of telephone booth, bus stands, railway stations, malls, theatres, parks & play grounds with negotiable entrances for wheelchair & other mobility aid users.
- 4] Awareness of changing needs of growing up from childhood to adolescence, information on available service amenities for attaining maximum potentials.

INTERVENTION METHODS:

- A] Provide training in areas of interest & develop specific skills for continuing education & sheltered vocation as per individual need.
- B] Psychometric evaluation like DAT [Differential Aptitude testing], CAT [Child apperception tests] to understand their self & non self perception & thinking, high school functional questionnaire to identify strengths & weaknesses & prospects of choosing careers & educational streams.
- C] Promote measures to build a sense of self worth & confidence.
- D] Provide a plat form like national cp day cultural celebrations & sports competitions for exhibition of talents & abilities, community walks & poster demonstrations, painting & handicraft exhibitions annually.

C] SKILLS

Definition: Skills are abilities or expertise for adaptive functioning.

Dr. Suchanda & team- input from Dr.Shashikala following discussins & presentation in Mumbai & Lucknow conferences

Guiding principle:

To optimize individual functional potential in all areas of development towards effective coping to the demands made by different environments.

Adolescence is a transition from childhood towards achievement of adulthood which generally implies independent living. This may not be fully possible for all persons with cerebral palsy physically but independence in psychosocial competence is an achievable goal for most excepting for a minority.

During childhood , early intervention aims at developing skills in motor & communication & early schooling areas in a more protective environment but adolescence needs accent on psychosocial competence in more demanding & less protective environments in areas of abstract emotional, thinking, feeling & behavioral domains encapsulated in the word "Emotional Intelligence". The specific skills required during this phase are called LIFE OR LIVING SKILLS & are abilities for adaptive & positive behavior that enable individuals to deal effectively with demands & challenges of everyday life [WHO, 1997] Life skills enable us to translate knowledge, attitude and values into actual abilities - "what to do and how to do it" - a set of core abilities sometimes described as emotional intelligence.

There are 10 generic life skills which are as follows:[NIMHANS Public information brochure-UNICEF GUIDE]

- 1] **CRITICAL THINKING:** It is the ability to analyze information & experiences in an objective manner.
- 2] **CREATIVE THINKING:** It is an ability that helps us look beyond our direct experiences & address issues in a perspective which is different from the obvious or the norm.
- 3] **DECISION MAKING:** The Process of assessing an issue by considering all possible/ available options & the effects these different decisions might have on them.
- 4] **PROBLEM SOLVING:** Having made the decisions about each of the options, choosing the one, which suits best, following it through even in the face of impediments & going through the process again till a positive out come of the problem is achieved.
- 5] **INTERPERSONAL RELATIONSHIP:** It is a skill that helps us to understand our relations with relevant others & relate in a positive / reciprocal manner with them [Already covered under interpersonal interactivity-Domain A].
- 6] **EFFECTIVE COMMUNICATION :** Communication is an ability of sending messages from a sender to a receivers familiar & unfamiliar in familiar , different & unfamiliar environments to express ourselves freely & understand others verbally or nonverbally in an appropriate manner . Communication is a bidirectional event & when effectively done results in positive experiences to both the sender & receiver & lays a good foundation for responsible behavior & interaction
- 7] **COPING WITH EMOTIONS:** It is an ability which involves recognizing emotions in others & ourselves, being aware of how emotions influence behavior & being able to respond to emotions appropriately.
- 8] **COPING WITH STRESS:** It is an ability to recognize the source of stress [stressors] in our lives, its effect on us & acting in ways that help to control our levels of

- stress.
- 9] SELF AWARENESS: This includes our recognition of ourselves, our character, strengths & weaknesses, Desires & dislikes. This is the core skill required to develop one's Identity which has already been covered under domain Identity[b].
- 10] EMPATHY: Is an ability to imagine what life is like for another person even in a situation that we may not be familiar with. It helps us to understand & accept others & their behavior that may be very different from ours. It is again covered under interpersonal interactivity

Coping with stress & emotions will be covered under behavioral refinement.

All these skills are interlinked & occur in a dynamic & experiential manner.

For ex : Self awareness needs managing emotions+ Coping with stress+ Critical thinking+ Creative thinking.

Interpersonal skill needs Self awareness+ Effective communication+ Empathy.

Empathy needs Effective communication + Interpersonal relations + Self awareness.

Effective Communication needs Critical thinking +Empathy + Creative thinking.

Problem solving needs Critical thinking + Creative thinking.

Decision making needs Self Awareness + Critical Thinking.

Managing Emotions needs Managing Stress + Effective communication.

Critical thinking + Creative thinking lead to decision making + Problem solving.

It is important to remember the interdependency of these skills while designing interventions.

INTERVENTION:

- a] Communication related to managing ADL both receptive & expressive through experimental learning methods such as participatory, interactive sessions like group discussions, brainstorming, role play, case studies, games , debate, quiz, Question box, dramas rather than prescriptive methods like morals, guidance & lectures. This is true for all other domains also. It is important for all skill trainers to be FACILITATORS THAN TEACHERS AS ADOLESCENTS GENERALLY RESENT AUTHORITY & EXTERNAL CONTROL .The trainers need to be good listeners & take positions of neutrality & use non judgemental or non categorical style of communication which is empowering than expertise exhibition. There are always methods of being assertive without appearing to be dominating.

- B] Promoting peer group interactions in Inclusive set up, special setup & mainstream set up is an extremely important method. Children in younger age groups do not discriminate peers with disability unless they themselves have unresolved conflicts but normal adolescents often feel superior & a sense of one up man ship in bullying & ostracizing them. Far too often teachers in normal setups consider physical disability as an invariable accompaniment of mental inadequacies & try to blame the disabled child who may not overtly rebel.

It is important to recognize the ABC theory implications in any behavioral difference.

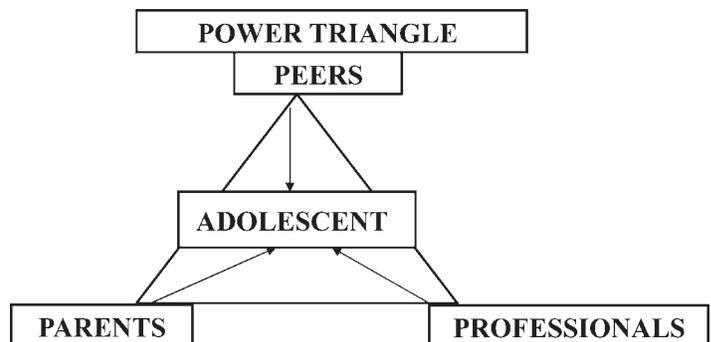
- C] Preparation for communication needs for job placement particularly for Youngsters who use assistive mobility technology & augmented communication devices.
- D] Communication along accepted social norms to avoid social isolation is a vital skill for mainstream interaction.

D] BEHAVIORAL REFINEMENT

Guiding principle:

Comprehensive understanding & judicious management of the root causes of behavioral manifestations, both internal & external in the context of family & society is the prime requirement in this domain. Primary to behavioral management is learning to evaluate any aberrant behavior from an applied behavioral analysis perspective. It is also important to remember that adolescents are at the centre of a power triangle, the three corners of which are parents, professionals [including therapists & educators] & peers. Goodness of fit in the interactions ensure reinforcing behaviors & any constraint or barrier will precipitate behavioral problems.

INTERVENTION



- 1] Training of skills required to understand one's own behavior as a reaction to external cues. Discuss ABC theory- Antecedent, behavior & consequence & try to see which works better. It is generally not possible to control antecedents if the trigger is in the environment

Continued in next issue.....

Accessibility- An Urgent Need For

When we all move around our cities and towns and villages and different districts of India, barring a few heartwarming examples, we cut a very sorry figure for accessibility.

There are so many architectural barriers in schools, colleges, government offices, post offices, theaters, drama halls, restaurants, museums, public places, places of worship, restaurants, railway stations, even hospitals, markets and roads.

Why are we so insensitive to the needs of the physically challenged, the senior citizens, women in their pregnancy, persons with joint problems, those using aids and assistive devices for their mobility.

Why there are such high steps to climb, no railings in sight at many places, no safe footpath to walk or use your pram/buggy/ wheel-chair, potholes, unevenness of tiles to risk walking, where one can lose balance, may fall and suffer injury. Wheel-chair riders and senior citizens have to risk their selves and use the road as pavements are not there at many places, if they are there they are narrow, uneven, risky, have encroachments and are high-steep to climb and get off, do not have gentle curb, ramp to climb or get off. Wheel-chair users have to be lifted many steps day in and day out so that they can participate, get included, which is so undignified, is risky for the person lifted and causes pain to the care-giver/ the lifter. Public and government places do not have disabled friendly, senior citizen friendly washrooms, no proper signage's. The persons with disability act 1996, India empowers all, that every citizen has a right to accessibility, inclusion, non-discrimination and special provisions have to be made that every citizen in India thus has equal opportunity for participation and inclusion.

We the so called able, have been insensitive too long and have not been able to create an environment that is friendly, that has ramps, railing, small steps to climb, uniformity, non skid surfaces, disabled friendly wash-rooms, audio and visual signals and providing where possible lifts, escalators, automatic doors, availability of wheelchairs which are appropriate and in sound condition at important venues and its easy availability, designing buildings with wide doors for access of wheelchairs, sliding doors, doors which open outwards, designing appropriate seating, all this will herald a new change, infuse life, change mind sets that all under the sun matter equally, and has a right to live with dignity, that we all are human beings, persons first, all interdependent, need to coexist together to life a rich and full life, and we are not the labels of able/ disabled, normal and abnormal.

Let us all work hard, diligently, keep persevering so as to create a better locality, town, village, city and India where all enjoy the freedom of Mobility, of Accessibility, Inclusion and participation.

(If your Home. Workplace, Institute has incorporated changes to make accessibility possible we congratulate you. If the changes are wanting it is our appeal do please incorporate the changes at the earliest. If any help, literature to design, or restructure the place we would be glad to give the necessary technical guidance)

Dr. Dhruv Mehata, General Secretary, IACP

Honourable Mentions - World CP Day 2012

We are delighted to announce the 2012 winners, who are sharing in a prize pool of \$25,000.

Honourable Mentions: There were also five Honourable Mention Awards in the Documentary category: Nico Phillips and Peter Fraser (USA and UK), Brian Freel (USA), **Mr Jahir Abbas (India)**, Rhasaan Nichols (USA) and **Dr Fatema Jetpurwala (India)**. Each showcased stories and themes that will touch the hearts of the cerebral palsy community around the world. View them in the 2012 Winners Playlist on the World CP Day YouTube channel.

Humble Request Update your Records

We request all of you to update mailing address, phone number, email address to enable us to keep you posted on latest updates of academy, to send important notices, information on upcoming events from time to time. It also helps us to improve communications and our services.

To update your records send mail to
K. D. Mallikarjuna, Vice President,
Email: kdmallikarjuna@gmail.com

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REPORT OF SEMINAR FOR PROFESSIONALS AND PARENTS

Polio Foundation, Ahmedabad runs a CENTER FOR CEREBRAL PALSY CHILDREN. They provide multi disciplinary therapy services to the children with cerebral palsy between the age group of less than one year to above 10 yrs. They periodically organise the PARENTS EDUCATION PROGRAMME to provide scientific knowledge and continuous medical education programme for professionals.

This year Polio Foundation invited Dr. DHRUV MAHETA, General Secretary and Dr. AASHA CHITANIS, Associate General Secretary of IACP to be their key Resource Persons to conduct parents education programme and continuous medical education for professionals.

The broad objective of the seminar was to provide scientific information to the parents and the therapists so that the misconcepts about the physiotherapy are clarified. Large number of parents and professionals attended the programme and carried home very useful message.

The seminar had mainly 3 programs

- 1) Interaction amongst Therapists
- 2) Interaction between Therapists and Parents
- 3) Hands on workshop on assessment, therapy strategies and management of children with cerebral palsy.

During the interaction lot of questions were asked by the parents, resource persons clarified their wrong believes.

This was very successful event. IACP and NGO's jointly should conduct such programs frequently, so that it helps the children and their parents.

Photos of the Seminar are on 3rd Cover Page...

MCI asks all medical institutions to be 'accessible'

With not a single medical institution in India being completely accessible for persons with disabilities due to physical barriers in libraries, lecture halls and hospital campus, the Medical Council of India has now issued directions to the Deans/Principals of all the medical colleges/institutions in India to submit compliance report on access facilities for persons with disabilities directly to the office of the Chief Commissioner for Persons with Disabilities (CCPD).

The MCI issued the notice on a petition by Dr. Satendra Singh, Coordinator with the Enabling Unit of the Equal Opportunity Cell of the University College of Medical Sciences, here.

Dr. Singh had made a representation to CCPD to include 'access audits' in all inspections by the MCI and to derecognise all such hospitals that fail this test.

He had also submitted that while the MCI ensured reservation for persons with lower limbs extremities of 50 per cent to 70 per cent, for admission in all the medical courses, a number of medical institutions were completely inaccessible.

Dr. Singh, who himself suffers from "locomotor impairment" had remarked that "people with impairments are made disabled by the insensitive medical institutes and hospitals". He had stated that while the MCI follows strict compliance in assessing building dimensions during inspections, but nowhere efforts are made to see whether the college is accessible to students with disabilities. He had noted that there was thus a need to make these buildings fully accessible to persons with disabilities.

The Chief Commissioner's officer had subsequently issued a notice to the MCI in January this year to submit the action taken report. When nothing happened in the stipulated one month, another strong reminder was sent and the MCI was asked to respond before April 10.

The MCI then issued a directive to the Deans/Principals of all the medical colleges and institutions on March 29 to submit compliance report on access facilities for persons with disabilities directly to CCPD.

But Dr. Singh insists in doing so. "The MCI response is also shying away from responsibility." He charged that "no mandatory directives were passed on including 'access audits' in inspections and no directive was passed in including medical persons with disabilities in such inspections which I specifically asked for."

Apprehensive that the MCI was actually trying to skirt the whole issue, Dr. Singh said, "rather than replying to CCPD itself, the MCI has asked the institutions to respond directly to CCPD, Ministry of Social Justice and Empowerment."

"Persons with disabilities are the world's largest minority. New World report says one in seven people suffer from some form of disability. Article 9 of the United Nations' Convention on the Rights of the Persons with Disabilities (UNCRPD) and Section 46 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, makes it obligatory for India to implement 'reasonable accommodation'," he insisted.

Dr. Singh said while he was only "asking institutions to use the Universal Design (the design of all products and environments to be usable by people of all ages and abilities, to the greatest extent possible)," still the matter was not being handled in the right manner by the authorities.

"A ramp will not only be used by a disabled but also by an 80 year old elderly, pregnant women, small children and trolley workers," he pointed out, adding that "it is my dream to make all the health services in India barrier-free and this is a small effort in that direction."

8th Annual Conference Indian Academy of Cerebral Palsy

20th, 21st & 22nd December' 2013 in Ahmedabad.

Polio Foundation is an NGO providing services to handicapped people for the last 25 years. They have an exclusive unit for children with cerebral palsy.

It is a great pleasure for Polio Foundation to host the IAC P Annual Conference on 20th, 21st & 22nd December' 2013 in Ahmedabad. The theme of the conference will be " MULTI DISCIPLINARY APPROACH TO CEREBRAL PALSY".

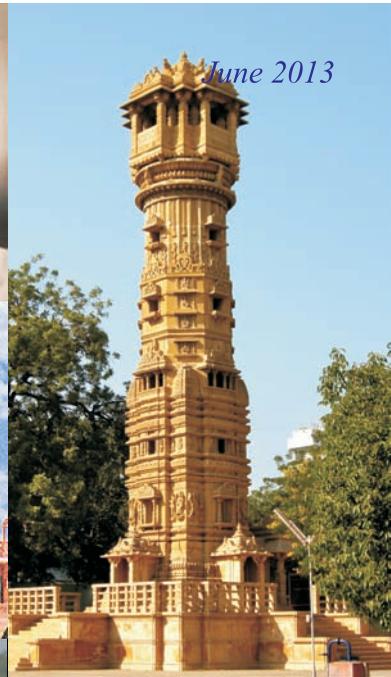
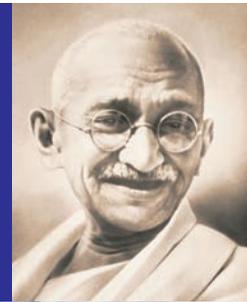
The experts from various related fields are expected to attend the conference. The delegates from branches, such as Pediatric Neurology, Pediatric Orthopedic, Physiotherapy NDT, Occupational Therapy, Special Education, Speech & Language, Social Work and parent education etc are also to attend the Conference. Along with all these, Expert Faculties, Therapists, Service Providers, Parents of children will also join the conference.

Ahmedabad is the City from where the freedom movement started - All are invited to join the conference to make it a grand success which will definitely help the needy cerebral palsy children.

The detail program of the conference would be announced and informed very shortly.

Dr. Mehul Shah

Managing Trustee Polio Foundation
Email : poliofoundation@gmail.com



Get ready for 9th IACP International Conference at Hyderabad, October 2014

Seminar for Professionals and Parents on Management of Cerebral Palsy organised by Polio Foundation, Ahmedabad

Key Resource Persons
Dr. Dhruv Maheta and
Dr. Aasha Chitanis (IACP)

Report is on Page No.



