



# INDIAN ACADEMY OF CEREBRAL PALSY

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

Official newsletter for members of IACP

## NATION PAYS HEARTFELT TRIBUTES TO DOYEN OF REHABILITATION OF PERSONS WITH CEREBRAL PALSY

Dr. Perin K Mullaferoze



SPECIAL ISSUE ON  
1<sup>st</sup> NATIONAL CEREBRAL PALSY DAY  
3rd October 2010

# National Cerebral Palsy Day

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## Presidents Message

### National Cerebral Palsy Day - 3rd October

After the decline of poliomyelitis, cerebral palsy today is the highest cause of locomotor disability in children. The estimated incidence is 2 to 3 per thousand and there are atleast 3 million children with cerebral palsy in India.

Cerebral palsy is a multifaceted problem with many systems of the human body which are affected. This requires a team approach and infrastructure in its management. Sadly this is lacking. As a result of lack of awareness, patients present late, much beyond the golden period when a definite impact can be made by treatment. Hence the **need to create social awareness and to sensitise our population and government to the problems of cerebral palsy patients is acute.**

On the above premise, the Indian Academy of Cerebral Palsy, decided to celebrate Oct. 3rd as the National Cerebral Palsy Day. This was celebrated with full gusto all over the country. Though the organizational resources were meagre, the response was very enthusiastic as reflected in news from various parts of the country which you will read in this newsletter. The CP day brought with it a team spirit which is rarely seen. A unique bonding was seen between those affected and their care givers.

All IACP members must support 3rd October as the National Cerebral Palsy Day so that a big boost is given to this movement. I am sure that this will produce a change in the life and future of patients with cerebral palsy.

**Dr. Ashok N. Johari**

President, Indian Academy of Cerebral Palsy

## From Secretary's Desk

### On Mentors & the shining lights for community initiatives!

In a world in which, increasingly SELF is the role model, talking about Mentors is probably old fashioned. But as a gracefully aging professional, I strongly feel the need to talk about it because life's vagaries are such that no amount of self belief can throw shining light in blind alleys.

Our idea of National Cerebral palsy day was born out of one such realization when we looked back at the history of cerebral palsy care movement in India. To have known the First Lady Orthopaedic surgeon of this country-Dr.PKM as she was fondly called, will always remain a personal privilege & fortune of my professional career. I cannot add anything more to Dr.Dhruv's memoirs excepting to say that I got into this field not only because of my personal need to find solutions to cerebral palsy puzzle but also because of seeing the commitment of an aging doctor who called herself as a "Wounded soldier in the battle against cerebral palsy." That was the answer I got when I poured out my anger & agony as a parent on the rampant ignorance of medical professionals on cerebral palsy care in India in the mid eighties.

Dr.PKM called herself as a soldier while many working in this field then as well as now, act as if they are army generals or worse, as chiefs. She brought so much of simplicity & loyalty to work. Is it a surprise to any one that she has left behind a few of us at least walking in that path!

Two decades down memory lane, we managed to form IACP at her "Karmabhoomi"- Mumbai & befittingly at our Mumbai conference, decided to honor her memory on her Birth centenary day as National Cerebral Palsy day. I witnessed the power of community initiatives during the celebrations all across the country & felt her towering presence hovering around me in a clairvoyant way & kept thinking if we have moved the battle against cerebral palsy any further. May be a few victories but the winning post is nowhere near & the war & warriors need to go on!

These celebrations leave me with a few more years of inspired work & a humble acknowledgement of the powers of Mentors. They give you the zeal to pursue academic excellence, commitment to give back a little to the community we all belong to & hold a small torch to the path of professionals' social responsibility and I exhort my younger colleagues to join us in this exciting journey. **Long live Dr. PKM's memory in the annals of Cerebral palsy care in India.**

**Dr.G.Shashikala**

General Secretary, Indian Academy of Cerebral Palsy

## Dr. Perin K. Mullaferoze

Dr Mullaferoze was born on 3rd October at 127, cumballa hill to Kavas and Tehmina Mullaferoze. The family was poor, and Dr. Mullaferoze was a sickly child, had constant fevers, was educated till 4th std at home in Gujarati. Then did schooling at Queen Mary's school Byculla, she became head girl of the school. She then studied at Elphinstone college, and was Inter-collegiate Badminton champion. Dr. Mullaferoze did her M.B.B.S from the Grand Medical College and J.J Group of Hospitals. She went to England for her surgical training from 1936-1940, became LRCP, and FRCS. When she came back to India, she was general surgeon at Cama Hospital from 1940-1943. She was offered posts at AIIMS, and Lady Hardinge Hospital New Delhi but she declined.



In 1943 She offered her services for the Indian Army Corps during world war 2, first as a captain, later rose to become Lt. Colonel. She worked in Alipore, Asansol, Ranchi, Dacca and Batavia ( Indonesia) in extremely difficult circumstances. At one time in a span of 2 months she had performed 530 surgeries. The recommendation of her superior officer was " O.I.C Surgical division, has Skill and organizing ability of a higher order, sound diagnostician, skillful operator, unlimited capacity for hard work, excellent clinical teacher. In administration of her division, she showed firmness and ability. I can confidently recommend her for a surgical appointment at a teaching hospital." In 1947 for her medical services during the war, she was awarded a military Order of the British Empire.

In 1947 Dr. Mullaferoze associated with a voluntary body which was helping in rehabilitation of post poliomyelitis afflicted children in Mumbai as no facility existed. The society S.R.C.C was formed and Childrens Orthopaedic Hospital was founded in 1950. Dr. Mullaferoze and Dr. K. T Dholakia were honorary surgeons working under Dr Kini. Dr Mullaferoze took over as medical director in 1953. She took great pains and worked relentlessly to upgrade the hospital and provide the best facilities to the patients. Initially she dedicated all her expertise as an orthopedic surgeon in the treatment and prevention of Poliomyelitis, and treatment of congenital deformities. By 1956 children with cerebral palsy at Childrens Orthopaedic Hospital showed a phenomenal rise and Dr Mullaferoze felt a proper well coordinated setup was the need of the hour. She Visited the U.K and saw the work of the Bobaths, Mrs Collis, went to Japan and then U..S.A. On an exchange of persons programme, she along with a physiotherapist and a school teacher were deputed to visit and learn from centers of excellence working for Cerebral Palsy in U.S.A. They saw Institute of Physical Medicine and Rehabilitation, New York and State rehabilitation Hospital, West Haverstraw. She was impressed by the Team Approach where each professional contribution and evaluation was duly considered, and out of interactions at Meetings and discussions further treatment programme was planned.

In 1963 , the pilot project of the Cerebral Palsy unit, first of its kind in India and South-East Asia started at Childrens Orthopaedic Hospital. , with Dr Mullaferoze, Orthopaedic surgeon and medical director, and head of the cerebral palsy unit, Dr E.P. Bharucha-Honorary Neurologist, Dr P.E Bharucha -Honorary Paediatrician, Mrs Ella Castellino (D'souza) Physiotherapist and Co-ordinator, Ms Z.S.Ghadially, and Ms Gita Dalal both Physiotherapists, Mrs V.P.Gadre Occupational Therapist, Mrs Z.Rangwalla - Speech therapist, Mrs K.Dighe- Educationist, Ms H.J.Avari Medical Social Worker, Sister desh mukh, Ms Sudha Patel Psychologist, Dr P.C.Shastri-Psychiatrist, Ms Asha Dangarwalla Medical Social Worker joined later. Dr Mullaferoze was the first person to introduce the concept of a multi-disciplinary team approach.. She was very strict, but her focus was the growth and development of the child and the well-being of the family. The problems of children with disability touched her to the core of her heart. The rich & the poor a got her equal attention and care. In the counseling sessions & the subsequent reassessment sessions for the child's progress with her whole team of therapists, social workers and psychologists, she instilled a sense of hope, promise and uncompromising care. She gave insights that were so simple, practical and meaningful for the families.

She innovated splints, surgical techniques, adopted injection phenol technique to reduce spasticity. Those who saw her operate reflect that she handled tissues with great respect and delicacy. She was very methodical. She would personally taste the food that would be served to the children in the wards, wanted aids and appliances in the neatest of condition, in fact there was a special shoe-shine day at the hospital. She would go out of her way and help those were too poor with nutritional supplements and conveyance money. She spoke fluently in 5 languages, English, Gujarati. Marathi, Hindi and Konkani. She conducted regular courses for therapists, held seminars and wrote several papers on Cerebral Palsy. She would be heartened if some cerebral palsy services started in small towns /other cities and would enthusiastically ask how these centers were running. She motivated parents to come together and have support groups, write their accounts to motivate other parents. Patients who grew up always came to thank her ,meet her over the years.

Dr Mullaferoze's vision, sincerity, dedication, tenacity and zeal to serve and ameliorate the problems of children with cerebral palsy and other disabilities are indeed beyond measure, beyond words. She lived a simple life, kept a low profile, was a avid book reader, enjoyed listening to the radio, abhorred the television, was an animal lover, was a champion of nobility of the medical profession. Blessed are those who have been treated by her and those who got trained under her

The Indian Academy of Cerebral Palsy has indeed given a fitting tribute to Dr Perin Mullaferoze to observe her birthday each October 3rd as National Cerebral Palsy Day.

The torch that she has lit, of care, commitment and compassion should be kept aflame so that it lights the lives of all children and the families with whom we get involved. Taking inspiration from her, may we work together and create few more model centers in each city and small town of India. May we reach the un reached which she always had thought of by having satellite centers in the periphery.

Dr Mullaferoze transformed lives of patients, families and

the medical people who worked with her. May we have the strength of spirit and flesh to carry on the noble task that she initiated & passed on to some of the founder members of the Indian Academy of cerebral palsy.

She shall live in our hearts & our work through IACP for ever!

By Dhruv Mehta

With contributions from Dr Nadir Bharucha and family, Dr G.S.Chawra, Mrs Ella D'Souza, Dr P.C.Shastri, Asha Dangarwalla, Dr Fateema Jetpurwala.

## Gems from Dr. PKM's thoughts.

- ☛ Always at the back of my mind there is a query, how much good can I do ?
- ☛ To do good is my religion.
- ☛ Make therapy for children fun and functional.
- ☛ Be informed, read, travel and see different centers, broaden your horizons, but then leave the book and read the child.
- ☛ Be simple, try and do things with your hands, try and improvise, work with passion, pay attention to the smallest detail so the whole picture will then have order.
- ☛ Do not be mediocre, be intense & meticulous.
- ☛ Listen to the silliest complaints of a patient, a good medical history is half the battle won and also the family's heart.
- ☛ Make your children meet the challenges of daily living, do not handle them like glass, take care but teach them to fall and rise.
- ☛ Simplify things, the most illiterate, rural person should understand what you are saying and want to convey.
- ☛ Get involved in well-being of the child with cerebral palsy and their families and treat in the context of the family and cultural situation.
- ☛ Learn as deeply about your profession as you can, respect other professionals and work in harmony to give the best to a child with Cerebral Palsy and their families.
- ☛ Be sensitive, have compassion to answer the total needs of children with cerebral palsy.

## IACP Consensus Statement on CP day celebrations.

### Theme for the year 2010 - Demystifying Cerebral Palsy by action through Awareness & Advocacy

It was agreed upon to work at four socio ecological levels - 1. Child & Family. 2 Schools & Educational community. 3. All Media. 4. Administration .[with increasing impact factor from low to high respectively.]

In the absence of adequate infrastructure for implementation and follow up with camp methodology, for the time being participants were requested to concentrate on local environmental barriers through awareness and advocacy efforts as follows. The camp methodology will be taken up in future initiatives after creation of necessary infrastructure.

#### Plan of Action :

1. Form local core groups to implement activities with local funding.
2. Child & Family A] Conduct painting, sports & other cultural activities and offer encouragement. Involve a local achiever as a role model & mentor to set an example to younger persons. B] Organize walks involving children & adults with cerebral palsy, parents, professionals and public. C] Informative exhibition & posters for information of parents. D] Panel discussions, Q & A sessions with experts.
3. Schools - Both Main stream & Special Schools to be involved via workshops, training programs & round table discussions. To help in this effort IACP will provide a draft protocol on main streaming if requested.
4. Media - Publication of articles in news papers, talks on radio & local TV. Support for an advertisement on National TV to be worked upon with help of brand ambassadors.
5. Administration - Interact with local disability commissioner and Dept of empowerment & social justice both at local, state & central government levels with the help of institutions like NIOH, NIMH, NIMHANS, AYJNIHH, NCERT, & National Trust & NGO's like Spastic Societies, Lion Clubs, Rotary clubs, Parivar & Parents' self help groups as well as all related specialty academic bodies & IMA.
6. Participating delegates of the meeting were requested to implement as many of the above programs as locally feasible and send reports to General Secretary IACP before for publication in the Nov News Letter & IACP web site
7. It was also agreed upon to learn from the experience of first year to improve the guide lines for future initiatives.

## Free Plane Joy Ride over the Mumbai



Captain Sanjay Mandavia, of Fly Wings Aviation Pvt Ltd and their team ( a parent of child Hitansh who has cerebral palsy ) on the occasion of the 1st National Cerebral Palsy day gave a free plane joy ride over the Mumbai skies for 30 minutes in two small chartered planes for 16 children with cerebral palsy from poor families and institutions, There were children from Missionaries of Charity, Mother Teresa's Home, Adapt - formerly Spastics Society of India, Happy Hours Centre, Child Development Centre - formerly Childrens Orthopedic Hospital., Anandi school, Manav Kalyan Kendra-Navneet Hitech Hospital, Sobati Parents Association ( National Association for the Blind)., and Cheshire Home.

The joy of the children and their families was so touching, it was a great

event in their lives. They were given a warm welcome by the officials at the airport and taken care of with great sensitivity. To cheer and support this plane joy ride event Dr Ashok Johari and Dr Mrs Usha Johari were there at the airport for the whole event, so also Dr Fatema Jetpurwalla and family, with son Husein, Dhruv Mehta, Dr Vikas Nikam, therapists, social workers and many well wishers. On return to the great joy of all ,Shahrukh Khan and Karan Johar wer there at the airport, and they were briefed about the importance of the CP day, and Shahrukh Khan was kind enough to pose for photographs with the children. Many news paper reporters and channel people were there to interview the children before and after the flight.★

## Radio Talk on Cerebral Palsy



For increasing awareness of Cerebral Palsy, with the support of Jasmeet Arora ( an aunt of a young girl with cerebral palsy ) and Mrs Aruna Prakash who conducts radio talks and interviews a radio talk at a radio channel Jago Mumbai, community radio was organized on 30th September 2010. Dr Ashok Johari, the President of the Indian Academy of Cerebral Palsy , and Mr Dhruv Mehta, Joint Treasurer IACP were interviewed by Mrs Aruna Prakash for about half an hour on the different issues pertaining to cerebral palsy from causes to prevention to therapy and facilities available, about the work of the Indian Academy of Cerebral Palsy and parents support groups and of success stories. The talk was in Hindi, and the whole staff of the radio channel were so welcoming and interested in this event and showed their desire to do regular talks on the different aspects of cerebral palsy and to interview and have talks of various other professionals working for the welfare of the persons with cerebral palsy. The talk was aired on 3rd October the National Cerebral Palsy Day.★

## Unequivocal pledge to fight this disability, Report from Chandigarh by Dr. Prathiba Singhi



Hundreds of children living with Cerebral Palsy, their parents, doctors, medical experts and rehabilitation professionals took an unequivocal



pledge to fight this disability, which affects mostly children, on the occasion of the First National Cerebral Palsy Day, which was organized by PGI and Prayas Spastic School at Prayas Building, Sector 38, Chandigarh, had organized a seminar on Cerebral Palsy and counseling session for parents as well as drawing and painting competition for the affected children as part of the nation-wide commemoration of the day.

## Children Orthopedic Hospital Celebrated National C P Day



Childrens Orthopedic Hospital (they now call it Centre for Child Development has forwarded these photographs of the National CP day function they had on Friday 1st of October. Dr Chawra ,Former Medical Director spoke on madam and her work. Trustee Charu Jhaveri, Sadhana Joshi, Head of Therapy Services, and Dhruv Mehta, Mrs Sudha Bhawe, a trustee and Mrs. Priya , Principal of the school run by the society were present. There was dancing & fancy dress for children &

over 30 children participated with great enthusiasm and later there was singing by adults with cerebral palsy.

## Walkathon-Panel Discussion-Parents Awareness and Cultural Programmes at Bangalore-report by Dr.Mahadeviah.



I am very happy to inform you that our first cerebral palsy awareness day was celebrated in Bangalore with His Excellency the Governor of Karnataka Sri H.R. Bharadwaj flagging off a WALKATHON with participation of

nearly 800 people including children, parents, and professionals of 5 NGOs taking part.

The walkathon was followed by a panel discussion attended by 300 parents. There was good coverage in the media. Grateful thanks to the staff at Spastics Society of Karnataka and other participants Shristi Academy, Asha, Fame India, NIMHANS, APD.

C.P. Day was celebrated in Mysore under the auspices of Mysore Spastic Society under the leadership of our member Mrs. Shashikala Ramnath. I was invited to address the staff of J.S.S.

Medical College Hospital, physiotherapists, occupational therapists, and parents numbered about



300.

All in all it augurs well for the academy and motivates to help our children and parents.★

## Snehakiran Spastic Society celebrated National Cerebral Palsy Day at Mysore-Report by Mrs.Shashikala Ramnath

National CP Day was celebrated jointly by Spastic Society of Mysore, the Academic Society of the JSS Medical College & Hospital & the Occupational Therapy & Rehabilitation Centre, JSS Hospital, Mysore, on Oct 4th, at the hospital Auditorium.

A press Meet held on Oct 1st had ensured public awareness & focus on the observing of the day, the incidence of CP, the need for therapeutic services & available centers working for the cause.

Dr. M.S. Mahadeviah, doyen in the field of Developmental Disabilities, for over 4 decades, was the Chief Guest at the function. After the traditional invocation & of the lamp, Dr. Narayanappa, Head Pediatrics & Chairperson, Academic Society welcomed the gathering & gave an introduction of Dr. Mahadeviah & his dedication to the field.

Dr. M.S. Mahadeviah then gave an extensive power point presentation on diagnosis, causes & management of CP. He also gave useful remarks about how doctors could change their approach to CP Management & ensure early intervention happens.

The Principal, JSS Medical College, Dr. Basavanagowdappa, briefly spoke

& appreciated the work done by the JSS Occupational Therapy Dept, and Snehakiran Spastic Society & assured all support from the medical fraternity towards this cause.



Sashikala Ramnath, Occupational Therapist, JSS Hospital & Core Committee Member, Snehakiran, gave a brief outline of numbers of families needing help in Mysore, surrounding districts, and those coming in from Kerala too. She gave an account of the work being done, right from the NICU level up to young adults. It was imperative that the medical & para professionals gear up to meet the

challenge of providing services.

An 8 minute film on Snehakiran enlightened the audience on the work done at this NGO. The audience comprised of students of the JSS Medical College, Physiotherapy, Speech therapy, Nursing & Medicosocial Work, and the students of Snehakiran & their parents.

Dr. M.S. Mahadeviah released Early Intervention Posters in English & Kannada, that would be displayed in local hospitals, clinics, nursing homes. The simple illustrations would help the general public identify warning signs in kids needing help & take them to Snehakiran for help. Vinay, a student in UKG, in a regular school in Nanjangud, who is affected by CP, was gifted a wheelchair.

Sri Raghunath, President, Snehakiran, appreciated the support of the JSS team & gifted both Dr. M.S. Mahadeviah & Dr. Basavanagowdappa, JSS Medical College, with paintings done by the students of Snehakiran.

The program ended with a brief vote of thanks & the hope that the celebration would be remembered & many more families reached out to, in the future.★

## General Body Meeting Minutes

DATE: 16th October 2010; VENUE: Krishna Hotel, Jabalpur

Participants: Dr. Ashok Johari, Dr. G. Shashikala, Mr. K.D. Mallikarjuna, Dr. Anaita Hegde, Dr. Dubey, Dr. Vipul Shah, Dr. Asha Chitnis, Dr. Dhruv Mehta, Dr. Gaurav Kochhar, Dr. Gajanan Bhalerao, Dr. Harish Badiger, Dr. Sanket Khadilkar, Dr. Reena Mody and Dr. Madhavi Kelapure

Duration of meeting: Three hours

### Agenda:

Report of last year, Directory of professionals, services / Institutions for Cerebral Palsy, Fund raising, Publications, Official Website status, CMEs, Review of committees/ new committees, Annual accounts, Next IACP Conference.

### Report of last year [2009]

General Secretary Dr. Shashikala briefed members about the current **membership status**. As compared to last year's 450, the current members' strength is **392**. She said the decline in the strength was due to the student members who have not renewed their memberships. This is a disadvantage of having student members and therefore we should try and target more professionals for members. It was decided that all the members will be given Membership Certificates.

Dr. Ashok Johari gave a run through of events, most prominent being the '**National Cerebral Palsy Day Celebration**' as announced by IACP on the 3rd October. The day was celebrated in cities all over the country as per the guidelines declared by IACP. There were programs at different cities of Maharashtra, Gujarat, Uttar Pradesh, Rajasthan, South India and so on and so forth. As per IACP consensus, there were programs impacting at all levels: Government, media as well as families and society. Representatives who were present in the GBM (Dr. Shashikala, Dr. Mehta) gave detailed account of celebrations at their respective cities. Dr. Ashok Johari spoke about other celebrations of which he had received the reports. **It was decided to have a separate newsletter detailing the CP Day.**

Organizers will be given certificates for their efforts.

Members decided to open a separate **CP Day Account** for the CP day funds. **(This account is to be opened in Mumbai)**

### Directory Project

It was decided that IACP should prepare a directory of services, facilities available all over India about all possible aspects of Cerebral Palsy. This will include professionals working in the field, Institutions, Special Schools, Vocational Training Centers, Residential Centers, Remedial Centers etc.

**Dr. Asha Chitnis** will be the **Project in-charge** and will be assisted by Dr. Gajanan Bhalerao.

Provision for budget for directory needs to be discussed. **Funds would be allocated for this project by IACP as per the requirements.**

**Deadline** for the project completion: **April 2011**. Final rights for publication of this directory will be reserved with IACP. This directory will be a printed copy to be published once in 5 years.

One of the first steps towards this could be making **Membership Database of IACP** on official website to be available for all members. This is already available with Mr. Mallikarjuna and he

will be giving the same to Dr. Vipul Shah to be uploaded on the website. Mr. Mallikarjuna proposed an amount of Rs 15000/- for membership database which was approved by all the members.

### Fund Raising

**Dr. Anaita Hegde** will be the **in-charge** of fund raising committee. It was suggested that every state should arrange a fund raising event once in 2 months. Events could involve Cerebral Palsy kids, Celebrities. **(Dr. Anaita Hegde will be the co-chair of this committee but would be actively involved)**

IACP will have to procure **80G certificate** from the charity commissioner in order to receive donations. Mr. Mallikarjuna took responsibility of the same.

### Publications

It was suggested that IACP have two publications per year. For the coming year these will be: IACP guidelines for Prevention of Cerebral Palsy, Resource Directory for Cerebral Palsy

### Official Website Status

Following modifications need to be uploaded on the present website: Archives of all previous Newsletters, A statement on Stem Cell Therapy in CP.

Donation form, Introduce tweeter s/ blogs, Open an IACP account on Facebook, Membership database. Members should also be sent personal emails whenever a new feature is being introduced on the website.

### CMEs / Training programs

Regular CMEs / Courses should be conducted under the banner of IACP.

A course on **Research methodology** will be conducted by **Dr. Gajanan Bhalerao** in **February / March 2011**.

Sufficient notice should be given to professionals through the website. Profit of the courses should go to IACP

### Review / New Committees

**Credential Committee** members should screen and select the application forms for new memberships. Dr. Asha Chitnis and Dr. Dhruv Mehta are supposed to report to the general secretary regarding this.

News-letter should have a new modified write up on **IACP Guidelines for conducting conference**. It was also decided that IACP should have a **CP day Committee**.

The committees, from which there was no response or activity, were modified. The new members' modification is with Dr. Shashikala.<sup>1</sup>

### Annual Accounts

Mr. Mallikarjuna gave final accounts of last year which was approved by members. Similarly, Dr. Johari read accounts of Mumbai Conference.

### Next IACP Conference

Probable Venue: 1. Kolkatta 2. Pune; Probable dates: December 2011. Theme for next year national day celebrations- Prevention of Cerebral Palsy.★

## Pleasant Evening -Talks, Drama, Music, Poetry, Singing and Showcase of Talent of Persons with Cerebral Palsy at Bandra-Report by Dr.Dhruv Mehta

The main programme planned for observing the 1st National Cerebral Palsy Day on 3rd October, Sunday was in the evening from 5 to 7.30 at St Joseph's Convent High School, Bandra (West). About 400 odd people gathered



for an evening which was very memorable, with its talks, drama, music, poetry, singing and showcase of talent of persons with cerebral palsy.

Shobha (person with cerebral palsy), Dr Ashok Johari, Mrs Ella D'souza, Dhruv Mehta, Asha Chitnis lighted the lamp in memory of Dr Perin.K.Mullaferoze, founder president of IACP, on this unique occasion of first



national cerebral palsy day, and 100th Birthday event of Dr Mullaferoze.

Dr Ashok Johari paid tribute to the work of Dr P.K.Mullaferoze, spoke about the work of IACP, and the task ahead for the academy, and how this event of the 3rd is being celebrated throughout the country, and how the academy is going to sensitize the government on the strength of the work done for the 1st National Cerebral Palsy Day.

Mrs. Ella D'souza, Director Happy Hours Centre, Khar-Mumbai, gave a historical background of how cerebral palsy work got initiated in India, at Childrens Orthopedic Hospital, and how along with Dr P.K Mullaferoze the entire multidisciplinary team working for the cause of Cerebral Palsy had laid foundations for a really good model centre. She also spoke about the need of residential homes for adults and senior persons with cerebral palsy.

Dhruv mehta spoke of carrying the torch lit by the seniors and teachers forward, nurture it, stand up and stay committed in the cause for the welfare of those who have cerebral palsy and their families, and work for sensitization of the community.

Mr Vaibhav Sakhare, Government Officer from the Sarva Shikshan Abhiyaan spoke of the schemes of the government for the welfare of persons with cerebral palsy, and government's willingness to organize seminars to educate families and NGO'S about the support given through the government with its various schemes.

Mrs Sayali Masurkar from Cheshire Home spoke of the need for acceptance and inclusion of children with cerebral palsy in the schools and society, and the need to have sensitivity for their problems and work in partnership with schools and parents to find out solutions, a parent also spoke about how committed NGO's with teamwork can help children with cerebral palsy.

These talks were followed by lovely cultural programmes. There were songs from children and all from the Happy Hours Centre, there was drama (Mock Parliament) by Shartul Foundation, highlighting the issues, problems faced by persons with disability for awareness and advocacy. There were songs from children and staff from the Vedanta Centre, Songs by Ranjan Raman and Avni Trivedi, both persons with cerebral palsy. There was poetry recitation by Jemima Miranda, (English) Srimohan Vyas (Hindi) (poems were composed by Dhruv Mehta).

There was show case of talent, Dhiraj Shigwan, who is 1st degree black belt and a teacher now, with his academy gave a karate demonstration. The audio-visual of the programme was

done by Sajjad Khan who helped the IACP second time with his technical support. He is a person with cerebral palsy. A Film of 7 achievers which was done with the help of Mr Pulkit Pandya (a parent of a child with cerebral palsy which was to be shown at the evening function could not be unfortunately run because of some technical problem.). Dhruv Mehta gave a vote of thanks and all gathered sang joining hands together " ham honge kamyab



har ek din" (each day we shall grow, achieve progress to work for the welfare of persons with cerebral palsy).

The programme was beautifully compeered by Mr Dyu and Ms Neha of IdeaBox.

Sister Bindi, Principal of St Joseph's Convent High School, and staff and student volunteers helped immensely in the smooth running of the function by their support.

Ramadhar Vishwakarma, carpenter made 5 ramps to make the venue disabled friendly.★

### Be a Member of IACP

- Stand united with IACP members
- Stay up to date,
- Grow your professional network
- Obtain ongoing support and guidance, Gain leadership skills by participating in IACP committees and delegations. As an Academy leader, you will have a voice and vote on key issues affecting the speciality.
- Access to quality CME programame, Promote the speciality to future professionals.

Learn more about becoming a member or request an application by contacting IACP today.

You can also Download application form from IACP website [www.iacp.co.in](http://www.iacp.co.in)

## Rich Tributes paid to Dr PKM-Colourful Cultural evening, Talks, Walkathon, Exhibition, Singing and Showcase of Talent of Persons with Cerebral Palsy at Nagpur- Report by Dr.Shashikala



It is with immense joy that I write to you all about the unbelievable success of our National Cerebral Palsy Day celebrations at Nagpur. In reality this function was one of the most memorable experiences in the 32 years of my professional career.

We began on 2nd Oct with sports meet, coloring, clay modeling programs with 70 children participating from four NGOs and Govt Medical college OT School which in fact was an icing on the cake. The sports meet was inaugurated by Mr.Ramesh Dugarkar, Director of Ishwar Deshmukh College of physical education which was the venue for the whole program. It was a treat for eyes to see children with cerebral palsy and other developmental disabilities competing on real sports tracks with 30 volunteers from NSS wing of the college conducting the event like any other sports meet amidst colorful flags fluttering around cheered by parents and professionals. Coloring & clay modeling almost made the event sparkling with a spirit of play and fun. This was made possible by Dr.Anil Karwande, Principal of the college and Novartis India Limited We also had a radio talk by Dr.Minaxi Wankhede & Dr.Sonali Gondhule on various aspects



of cp in marathi aired by Nagpur AIR conducted by one of our parents Mrs.Priya Raut & articles in Hitavada by Dr. Shashikala & Miss.Nupur pidadi on learning to live with cerebral palsy.

On the 3rd our walkathon was flagged off by Nagpur cerebral Palsy Ambassador Mr.Ashok Kale Managing Director Sanstar Pvt Ltd with a bunch of placards with meaningful slogans done by our parent organizer Mrs.Karishma Anand, leading parents, professionals and persons with disability. Public information pamphlets were distributed in English, Marathi & Hindi.

The evening program started with a friendship bands exchange among the participating children with their normal buddies and a symbolic walk protected by a human chain of volunteers of IDCP college holding placards. We had every form of mobility aids used by the children helped by normal peers and parents to complete the walk to the venue of cultural program amidst thunderous applause of onlookers all along a very busy road of



Nagpur.

We had a poster exhibition inaugurated by Dr.Vivek Poflee & Dr.Anil Karwande which was attended by 400 people questioning and listening to the various information facts skillfully done by OT school post graduates and therapists from various centers.

Dr.G. Shashikala made a power point presentation of achievers with cerebral palsy beginning with Dr.Earl Carlson and ending with significant number of local achievers pursuing various careers. She also paid a touching homage and personal memoirs of our Late founder president Dr.Perin Kavas Mullaferoze on her birth centenary day along with a message from Padmashree Dr.Vikram Marwah who knew her.

The cultural evening was inaugurated by Mr.Praveen C Daradey Dist Magistrate &

collector of Nagpur after invocation by challenged children- "Itni shakthi hame dena dena data". He addressed the gathering with a meaningful message & lit the candles held by children during their soulful rendering of the Immortal Michael Jackson song "Heal the World , make it a better place for you and for me". Imagine the touching moment when 400 voices in the hall joined the chorus clapping all



around!

Colorful fancy dress, group songs(Mile sur mera tumhara), speeches and a scintillating butterfly dance were presented by children on a disabled friendly stage with ramps ending with a meaningful dance drama of lord Shree Krishnas friendship with Pendya, his disabled buddy carrying the message of inclusion ever since mythological times. **The program ended with burst of blue lights drenching the stage with compeering on why IACP has adapted blue as its color!** Parents & a special child Saakshi sang "pasayadaan" wishing welfare for all & we concluded the celebrations with vote of thanks by Dr.Sanjay Marwah

All this was made possible by our dynamic organizing team led by Dr.Sanjay Marwah, Dr.Meenakshi Wankhade Mrs.Neelu somani, Drs. Sadanand Thote & Mrs.Thote and parents like, Mr& Mrs.Bharatiya, Mr & Mrs.Ratnaparkhi, Mr& Mrs.Anand, Mr & Mrs.Kumarswamy. I cannot thank them enough. All the events were nicely covered both in the print media & local television including Fm radio & ETV marathi. Follow up action in the form of a memorandum will be submitted to the collector for Schools' awareness program , transport barriers & accessibility at parks & solutions will be followed all through the year by the core group.★

**For Latest updates in Cerebral Palsy  
Logon to IACP website  
[www.iacp.co.in](http://www.iacp.co.in)  
helps you to connect and share with  
the professionals and persons with  
cerebral palsy.**

## Parents Awareness Campaign, Painting Competition and Talent show at vile parle

3rd October 2010 was celebrated as 1st National CP Day. As a part of National CP Day celebration, an event was organized at Vile-Parle (east), Mumbai, on the prior evening, that is October 2010 at Utkarsha Mandal Hall.

The purpose of get together was to bring about awareness of Cerebral Palsy, to interact with similarly affected families and to try and form a parents support group. Another main objective was to provide with an opportunity to indulge in fun and games and have a care free time.

The principals of special schools like Anandi, and Ashiana, Kalyandeep and therapy centres like Astha were informed about the problems. They appreciated the initiative and expressed interest in the same. 17 children along with parents from these schools and a special educator from Anandi school participated in the programme.

The programme began with a drawing competition, The group was divided into an elder group of 5 participants and a younger group of 11 participants. No specific topic were given. The children enjoyed drawing whatever they wanted. They expressed themselves through their art.

This was followed by a pet show, two pet Labradors had come to play, interact with children. The children came forward to pat the dogs, shake



hands with them, and play games with a ball, they overcame their fears. This turned out to be a lot of fun for everybody.

Last but not the least was a magic show. Children were enchanted by the magicians tricks. They clapped and cheered for him. The guest of honour for the programme and the judge for the drawing competition was Mr Ramakrishna, himself a person with cerebral palsy and a painter (also with mouth and foot painting association). Mr Ramakrishna is a wheel-chair rider, brought along some of his illustrious paintings and also demonstrated his unique extra-ordinary painting skills. Watching him paint was highly motivating and inspiring for everybody. He highlighted the endless ability in a differently abled person. He selected 2 paintings from the older age group and 3 from the young age group as the prize winning painting.

Prizes for the drawing competition were distributed by Dr Mrs Rujhuta Mehta, paediatric orthopedic surgeon, Mrs Anjali Deshpande, Mr Dhruv mehta- both physiotherapists.

Mr Dhruv Mehta gave information of IACP, about getting together and working for the welfare of persons with cerebral palsy. He emphasized the

need for a larger forum to bring about empathy, awareness and change in the society.

All the participants were awarded certificates specially designed and made by Akriti Drolia- herself a person with cerebral palsy, she took active part in organizing the event.

Allergan Pharmaceuticals sponsored the event and also gifts for the participants, and there was excellent support from the utkarsh mandal hall management where the event was held.

Overall the programme was a great success and almost all parents expressed the desire to become members of Indian Academy of Cerebral Palsy.★



### News and Events

- 1) On 28th November 2010, at Jamnabai Narsee School, Mumbai, there was a function organized, by Vikalp Prakashan 'A morning with Vipasha', where eminent poets and writers of Gujarati literature recited poems from her second book of poems 'Whirling around the Islands (Tapuo per Fudadee)', also poems from her first book of poems, 'Walls annoyed by the chipped colours' were also recited. Gulzarji, poet and lyricist was the chief guest at the occasion, he was also there as chief guest 6 years ago when poems from the first book of poems were recited. Vipasha has Cerebral Palsy, and has done her Phd in Philosophy from M.S. University, Baroda.
- 2) Ajitsingh Shekhawat, this year became a Chartered Accountant, from Gandhinagar, Gujarat. He has Cerebral Palsy, has locomotor disability, needs help of writer, and is speech challenged. (His father will send a detailed report today. Father Mahavir Singh Shekhawat is founder trustee of Cerebral Palsied Children's Development Trust, Gandhinagar, and is Editor of Magazine 'Pangumitra').
- 3) Dr Pratik Vyas, finished his M.S (General Surgery), from Civil Hospital, Ahmedabad, and is now attached to two leading hospitals of Ahmedabad, performing different types of surgeries. Dr Pratik has mild Cerebral Palsy.★

## Parents Perspective of raising a child with Cerebral Palsy

By **Mr.K. Kumarswamy, Nagpur**

Human being is one of the finest creations of God. Most importantly he has bestowed him/her the brain to think and to find solutions to any kind of adversities. Over the times, human beings have worked very hard to find solutions as best as possible to most of the problems encountered. Problems encountered may vary like those concerning the society regarding basic living, life style, economics and health in general or specific to certain conditions.

If we consider all the living human beings born as creation of God, then we must also admit that certain percentage of children born with disabilities, as God's very special children. However, human being with his thinking power, has been successful in finding solutions to some of these problems to a certain degree but solutions are still far from being perfect or near normal. The reasons are manifold. Disabilities although appearing simple, are in reality complicated biosocial issues unsolvable even with amazing advances of medical science world over, unless accompanied by social measures.

Looking back at raising our first born son with cerebral palsy, to say the least, it has been a humbling experience. We have gone through the trials and tribulations, starting from his childhood to adulthood to the present, wherein in he has settled down in life as a successful professional. One of the important lessons we learnt rather early was that there were no easy solutions and the developmental scale for such children was rather different compared to the normal. Just to put this in proper perspective, I would like to say that if the physical developmental growth of a normal child is measured in units of Meters during a time span, the developmental growth of a child with cerebral palsy during a similar time span can be measured only in mille meters and if we are lucky it could be centi meters. At this stage I would not like to speak about mental growth as our son has normal intelligence. Hence one of the most essential needs as a parent of a child with cerebral palsy is that, we need to be very patient regarding the developmental progress of such children. It is said that cerebral palsy is the manifestation of impairment in the development of brain or the nervous system . This leads to implications in the form of dysfunction or mal functioning of several parts of our body including hand and leg movements which brings in the medical specialty of Orthopedics. While our son was a child (27 years ago) we did visit some of the premier National Institutes of Neurology and Orthopedics and looked forward to finding solutions to our child's problem.

However, to our utter shock and dismay, we realized that some of the leading lights of these institutes considered dealing with cerebral palsy as a waste of time as they felt that nothing was possible and even advised us not to waste any more time in seeking solutions and get on with life. Despite such advice coming from an eminent doctor of international repute, we were not convinced. With my wife being in medical profession, she strongly felt that medical solutions were there but the infra structure & systems were not available. That was the time we were guided to Children's Orthopedic Hospital (COH)- Mumbai, and fortunately met Dr.P. K. Mullaferoze , the then director of the institute which offered services to children with cerebral palsy. For the first time in nearly 5 years, we realized that such services were available in our country,

Though far and few and there was a doctor who believed in providing scientific interventions & it was like finding light at the end of a dark tunnel. Even though we were living in Hyderabad at that time, my wife stayed back in Mumbai for three months to learn working with our son. Needless to say this was the first

positive development our family came across in our long journey in coping with cerebral palsy.

My wife being a doctor tried to assimilate as much knowledge as possible on the management aspects of cerebral palsy under the guidance of Dr. Mullaferoze & her team. At the end of my son's 3 months intervention program at COH, we were informed about a German couple Dr.Dobler & his therapist wife Mrs.Schibura Dobler who were at Thakur Hariprasad Institute , to set up a cerebral palsy intervention centre at Hyderabad. Soon after our return from Mumbai, we got in touch with this doctor couple and my son continued to receive intervention. This doctor couple were unique as Dr. Dobler was a neuro pediatrician and his wife an expert in some of the best known therapy intervention methods.

Along with my son's regular intervention program my wife also trained with the doctor couple both on the medical aspects of cerebral palsy as well as the intervention methods so that we were self sufficient in dealing with our son's needs on a long term basis. Thus as a family we felt empowered in coping with cerebral palsy as best as possible under the circumstances. I must confess that it has not been an easy climb uphill both for us and our son with problems at every stage. The worst part was to deal with many unknown factors about future possibilities .By then, it was also very clear to us that there can never be a cure or normalization of development for a child with cerebral palsy. However with regular scientific intervention programs, we can enhance and optimize functional abilities of our son or for that matter any child with cerebral palsy.

As we look back, we feel humbled that all the efforts over the years have been worth while to find our son as a young man now totally independent in most respects, well qualified with an engineering degree & post graduation in management from an IIM and currently working in corporate world. Our earlier years were certainly the toughest not only for us but most parents with children having cerebral palsy due to total lack of information on the few service centers available in the country. Of course, they were pre internet times. Hence, our being directed to COH, Mumbai and meeting Dr.Mullaferoze, 75 years old at that time, was the best thing that could happen in our long journey in coping with cerebral palsy. For all practical purposes, it was virtually the first center in the country which believed in providing scientific medical intervention services. Even at that ripe age, her total dedication to providing services to persons with cerebral palsy became the biggest motivating factor in our life.

It is really heartening to note that during the completion of centenary birthday of Dr.Perin K Mullaferoze, the Indian Academy Of Cerebral Palsy has initiated celebration of National Cerebral Palsy Day on 3rd Oct. This is the most fitting tribute younger generation can pay to a an amazing senior doctor who spent several decades of her life towards providing scientifically authentic, appropriate and comprehensive intervention services to persons with cerebral palsy. May her soul rest in peace and I am sure many families like ours will remember her with gratitude and whole heartedly support this community initiative. As a parent , I do wish IACP success in achieving its goals for improving the services for persons with cerebral palsy further all across the country, a dream Dr.PKM used to share with my wife. I hope many more doctors will follow her footsteps and bring solace to needy families.★

## Report of NIOH Program by Dr.Sanjay Keshker.

The 1st National CP day was celebrated on the 3rd Oct. 2010 at National Institute of Orthopedically Handicapped, Kolkata in memory of the birthday of Dr. Mullaferoze, who was a pioneer in cerebral palsy work in India and was the founder President of IACP.

The theme chosen for this year by Indian Academy of Cerebral Palsy was "Demystifying Cerebral Palsy by Action through Awareness & Advocacy". Accordingly it was planned to organize a Program through Occupational Therapy Department of the Institute for cerebral palsy children & their parents. The program included Awareness program among parents of children with cerebral palsy and competition (art, poem, race, painting, sports etc) & other cultural activities by children with cerebral palsy.

Total participants were 121 (CP child and parents).

The total program was divided into two sessions. During the first half we had Inaugural session followed by competition among CP Children (art, poem, race, painting, sports etc).

### Inaugural session

The program started with welcome speech by Dr. Ratnesh Kumar, Director, NIOH.

Our Chief Guest was Mrs. Mita Bannerjee, Commissioner of Disabilities, West Bengal. She had lightened the lamp and started the programme. She discussed regarding attitude towards PWD, duties of parents, development of all aspect of child, awareness of normal people, Comprehensive law, the Scholarship scheme., allowance for cp child and National Trust Act.

Guest of honour was Mr. Umapada Chatterjee, Additional

Project Director of SSA Project, West Bengal. In his speech, he told regarding inclusive education, identification of cp children in every district of this state, Special Education, aids and appliances of cp children, Education and training of the key person of the family, resource room in grampanchayat and toilet facility in school.

Dr. Sanjay Keshker highlighted about the program. Theme, importance, activities etc. & offered vote of thanks.

Competitions (art, poem, race, painting, sports etc) & other cultural activities were done by CP Children.

From 12pm competition on art and poem among cp children had started. They had done marvelous work in art and poem. This was followed by Prize distribution to all participants. From 1pm to 2pm was lunch period.

### Second Session

Second Session was technical session and started at 2pm with the speech of Dr. A. Iquebal, (PM&R Sp.) followed by Mr. P. Bajpai (HOD, Occupational Therapy) then Mrs. Rupali Sen (Lecturer, OT).

Then we had called **Four Role Models (CP)** from different places who are already established in their field. Their parents described their struggled life and also inspired other parents. This session was very attractive and useful. Mr. A. Palit (Rehab. Officer) was the key person for this session. Program ended with valedictory function.

### Media Coverage:

This was published in Dainik Jagoran, Janosanta, Rajasthan Patrica & in Pravat Khabar. This was also shown in Doordarsan TV & Local Bangla Channels.

## Demystifying Cerebral Palsy by Action through Awareness & Advocacy-Dehradun



On the occasion of National Cerebral Palsy Day on 3rd October 2010, an Awareness Program with Vocational training Program was organized at NIOH, RC, Dehradun premises. Around 46 participants including

Cerebral palsy Children and their parents were participated in the said program. Ms Poonam Suryavansi a self trained Vocational Instructor was the guest faculty to teach different art and crafts to the CP children and the program was inaugurated by her. Ms. Anjali IED co-ordinator of SSA Dehradun District also present in the said program and most of the children were covered under SSA. Mr. Deepto Mitra, OI/c, RC welcomed all and given inaugural speech.

Ms. Sudha Atreya, Program Officer briefly spoke about our activities. Mr. Aratran Patra spoke regarding Mobility aids used for CP Children. Mr. Himanshu Dash spoke regarding

different orthotics required for CP children. Mr. Kailsh Chauhan spoke about Physiotherapy for CP Children.

Ms. Poonam Suryavansi conducted art and craft session to the CP children. She explained the use of locally available waste papers that can be used for art and craft for the children with Cerebral Palsy. With the use of available old woolen garments and the blue used for banyans in every house, she made different shapes out of those two materials. A drawing competition was conducted and prizes were distributed to all the participants.

The Program was covered by print media with photo graphs. Print media National News Papers Hindustan and Himachal Times expressed their views in details. They have covered our activities and appreciated the efforts of NIOH.

All the staff helped and participated in the Program. Mr. Himanshu Dash gave vote of thanks to all participants and faculties and those who present in the said program. Aratran Patra coordinated the entire programme and expressed thanks to all participants who made the National Cerebral Palsy Day a successful one.★

## Demystifying CP by action through Welcome song-Aizawl-[Mizoram]

North East Regional Centre - NIOH, Chaltlang, Aizawl celebrated "Indian Cerebral Palsy Day - 3rd October-2010" on 4th October 2010 (since 3rd October was Sunday which is Church Day in Mizoram) at SCERT Campus, Chaltlang. The theme of the celebration was as per the Indian Academy of Cerebral Palsy "Demystifying Cerebral Palsy by Action through Awareness & Advocacy". In accordance to the theme NERC-NIOH have planned & organized the



Program for children with cerebral palsy & their parents which included awareness program among parents of children with cerebral palsy and competition (Singing, Wheel Chair Race, Painting, etc) between children with Cerebral Palsy. It was jointly organized by following departments

- SSA, Government of Mizoram
- IEDC Cell of SCERT, Government of Mizoram
- NERC-NIOH, Government of India
- Spastic Society of Mizoram, NGO

The programme was chaired by Pi Sangzuali Vanchhong, a well known government officer working for children with disabilities.

**Inaugural Speech :** (By Mr. Alendra Tripathi, O.i/c, RC-NIOH)

Mr. Alendra Tripathi, Officer-in-charge, NERC-NIOH welcomed the participants, Parents, Officer from Government of Mizoram and informed the parents about the aims & objectives of this programme. He spoke about the contribution of Dr. Mullaferoze, Founder President of IACP. He said "Parenthood is perceived as an expected, positive and rewarding aspect of life. Every parent wishes to have a healthy baby but some persons though not by choice are forced into a situation of having a child with CP. The birth of a baby is usually anticipated with great excitement and expectations of a future filled with happiness and success. This exuberance may become muted with the birth of a CP infant. Parents having a child with CP experience variety of stresses and strains. It is traumatic specially when parents learn or suspect CP in the child, when child enters or is supposedly ready for school, when

parents grow old and worry about the welfare of the child. Some parents get upset when they come to know the disability of the child. Unfortunately not much attention has been or is being directed towards the family members having CP persons despite the fact that they are the directly affected population and also are the prime care-takers to provide life long support and security to the CP persons. The benefits of parental and family involvement in the rehabilitation programme have never been understood better than now. Hence from today all the departments will work together towards the need based intervention programme for families having children with CP."

**Welcome song :** (By DRT Dtudents, RC-NIOH)

NERC-NIOH is running a 2 1/2 years full time Diploma in Rehabilitation Therapy. The 2010 batch students ( C. V. L. Malsawmtluangi, Zothanmawii Chhangte, F. Remsiampuii, Katy Zomawii Vaiphei, P.C. Lalruatzeli, Malsawmdawngliani, Lalmuanawama, Tlanfamkima Hauhnaar )have performed a group welcome song for children with cerebral palsy.

**Experience Sharing :** (By Pi Chhingpuii, Secretary, Spastic Society of Mizoram)

Spastic society of Mizoram is also known as State referral centre for Mental Retardation. This NGO is running a special school for children with MR & CP in Aizawl. The Secretary of Spastic society of Mizoram addressed the parents and children with CP and shared the positive achievements & success stories of children with CP within the Mizo Community.

**Special Songs by CP Children:** (By Michkel, 5 years, Child with CP)

Michkel a 5 years old child having Cerebral Palsy expressed himself by singing a song. (By J. Lalremruata, 6 years,





**Child with CP) J. Lalremruata** a 6 years old child having Cerebral Palsy expressed himself by singing a song.

Special Song for CP children: (By Pi Lalthlamuani)

Ms. Lalthlamuani is a famous professional singer of Mizoram has devoted her song to children with cerebral palsy on the occasion of " Indian Cerebral Palsy Day-2010

**Speech from Government of Mizoram: (By Pi Malsawmthangi, Chief Guest)**

Pi Malsawmthangi, Director, State Council of Educational Research and Training, Government of Mizoram delivered speech and promised to implement the programme and policies made for children with cerebral palsy in the State. She also promised to participants that each and every child will get free and appropriate education as per Right to Education Act.

**Wheel Chair Race: (Participants - Children with CP)**

We have organized the wheel chair race under two categories. The winner of both categories are following:-  
Children below 6 years • Lalremruata - First place. • Michkel - Second Place

Children above 6 years • Lalchhankimi - First place. • Joseph - Second Place • Vanneihluanga - Third place

**Painting Competition: (Participants - Children with CP)**

We have organized the painting under two categories. The winner of both categories are following:-

**Children using crayons (Small children)**

• Lalremruata - First place • Vana - Second Place • Rinfamkima - Third Place • Michkel - Fourth Place

**Painting Competition: (Participants - Children with CP)**

**Children using Water Colors (Big children)**

• Lalthasanga - First place • Lalrokhuma - Second Place • Lalchhauhimi - Third Place • Joseph - Fourth Place

**Prize Distribution:**

The gift packet has been distributed to all the winners and Participants Refreshment & Lunch. Nearly 110 person including participants, parents, officers, NGO members, Students etc has been served refreshment and lunch during the occasion of Indian cerebral palsy day.

**Vote of Thanks: (By Pu Zohmingthanga, DPC)**

Pu Zohmingthanga, DPC, SSA Mission, Aizawl District has proposed the vote of thanks to all participants, Government officers, Representative of NGO's etc.



## Professionals, Parents & Persons with Cerebral Palsy Celebrated National Cerebral Palsy Day at Jabalpur.

IMA, MP in association with Indian Academy of Pediatrics Jabalpur, Dev chhaya early intervention Center, Vandan & Vihaan punarvas kendra Jabalpur celebrated Cerebral Palsy Day at IMA Hall Jabalpur on 3rd Oct. 2010. Shri Gulshan Bamra IAS - DM Jabalpur was the Guest of honour, Dr. Mrs Arunika Bhatnagar President IMA - MP state presided over the function, Prof. Maya Chansoria Head Deptt of Pediatrics, Dr.H.K.T.Raza Past President Indian Orthopedic Association & HOD Orthopedics Medical College Jabalpur & Dr.Ajay Saraf President IMA Jabalpur were Guests of honor. Dr.Pradeep Dubey President IAP was the Convenor of the program. The program was attended by eminent Pediatricians, General practitioners, Rehab. professionals, parents & persons with Cerebral Palsy. Achiever children & their parents were felicitated. The parents of achiever children shared their experience with the audience. The chief guest Shri Gulshan Bamra informed the parents about the newer development in the field of govt. scheme for people with disability. He spent time with the parents & persons with Cerebral Palsy to know about their problems. Medical luminaries present on dias discussed medical issues related with their respective fields. Vote of thanks was proposed by Dr. Pradeep Dubey.★

## National Cerebral Palsy Day Celebrated at Sneh Centre for Pediatric Rehabilitation, Mumbai.



World Cerebral palsy day on 3rd October was celebrated at SNEH...RERC with great enthusiasm. Though the director Dr.Snehal Deshpande was in US attending the advanced NDT baby course, she was available through the email giving the department inputs for the event. We had arranged a fancy dress competition for our children at our clinics at chembur and vashi in which the therapists of each of the clinic were involved in carrying out the competition. The idea behind this concept was to bring out the creativity in our special children. About 25 children participated in each clinic and were dressed up in unique outfits and characters. Three best dressed children were given certificate of appreciation with a prize and all the other children were given participation certificates. This was followed by a small get together with snacks for the children. All the children had a good time and their parents were very happy to see their children do so well. The entire program was a great success in each of the clinic.★



## Report Of Celebrations From Ma Sharada Center—Rajkot



Ramakrishna Ashram, Rajkot celebrated National Cerebral Palsy Day on 2nd & 3rd October 2010 with great enthusiasm.

Various events for physically and mentally handicapped children were conducted On 2nd October, 2010. Competitions were held for coloring, Painting, Fancy dress, singing, dancing, talent show, sports & Elocution contests. There was an exhibition focusing on awareness and basic facts of cerebral Palsy & other developmental disabilities to help Parents and care takers understand the



problems of special Children and start working with right direction from as early age as possible. Exhibition was accompanied with Fun fair for entertaining the children. On 3rd various events like coloring, painting card decoration, Sports, soft Ball throwing, static 25 meter sprint. Cycling, Fancy dress, singing was conducted to highlight children's abilities & make them feel confident. Over all at Rajkot, 140 Participants took part in these events. According to their performance, 1st, 2nd and 3rd prizes were given in the presence of special guests, doctors and parents. children in the presence of special guest, doctors and parents.

### Parents awareness and cultural programme at Pune - Report by Richa Thorat



Here is a report on CP day organised at Dennaath Mangeshkar Hosp, Pune In association with Niwara Physiotherapy centre Pune.

We had invited speakers from faculty of law and education, who themselves were parents of special children. This helped in achieving good interactive session among parents and professionals active among children with cerebral palsy.

Speaker from a vocational rehabilitation set up Mrs. Karnik who raised her concern about growing need for such vocational rehabilitation set up in future for adult. Mr. Raje, an advocate discussed with parents about current government concessions, benefits and PWD act. Issues such as ownership of the property by persons with cerebral palsy and guardianship were on the main front. Mr. Pandey, HOD, Dept of

Rehabilitation of Sasoon Hospital, Pune highlighted the importance of having disability certificate and its procedure for obtaining it. Educationist Sunita Lele discussed about integration of schooling for children with cerebral palsy. There were 200 participants including 80 children with cerebral palsy. This, to our surprise, was overwhelming response as far as Pune social structure is concerned. Most of the parents were enthusiastic towards such educative and interactive sessions. Few enthusiastic parents gave encouraging response to appeal for support group and website to exchange their ideas. Many parents desired to get trained as special educators to support their children. Educationist and Principals of special schools were present they were happy to extend willingness to start parent training programs. Besides all children were enjoying drawing competition, music and dance arranged for them. We concluded the programme with hope that we, as a group of professionals, will be able to help parents to accommodate their pressing needs and will continue to have co-operation in needs which are beyond therapy.

### GUIDELINES FOR CONDUCTING IACP CONFERENCES & CME PROGRAMS

The following are the preliminary guidelines for conducting IACP Conferences. We invite your comments, suggestions & advise to obtain final approval in EB.

#### FOR ANNUAL CONFERENCES :

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.
8. IACP conferences must award CME credits for participating delegates as per existing norms.
9. 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.
10. 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.
11. 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.
12. 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.
13. 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.
14. 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.

### IACP EXECUTIVE BOARD

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### National Cerebral Palsy Day

## Mumbai

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Bandra - Report on Page No. 9



Vile Parle - Report on Page No. 11



Parale - Report on Page No. 11



Centre for Child Development (formerly children's orthopedic hospital, and Sneh Centre for Pediatric Rehabilitation). - Report on Page No. 15



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## National Cerebral Palsy Day

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### Dehradun, Uttaranchal - Report on Page No. 13



### WHY IS IACP'S COLOR BLUE? [Through a Mother's Looking glass]

Mrs. Karishma Anand

I feel IACP has chosen blue as its color because it is a UNIVERSAL COLOR with a deeper meaning. Blue is the color of 'Lord Krishna' it represents a happy childhood. Lord Krishna himself is a beautiful paradigm of a happy childhood. Every child is entitled to this happiness; children with CP are no different.

Blue symbolises freedom, strength and new beginnings. It tells you that life is beautiful even if it's a challenge. Blue skies are emblematic of optimism and better opportunities. The limit less ness of the blue sky tells us that endless possibilities await every life that tries to live. Every child is entitled to a place under the sun and the vastness of the skies tells you exactly that. Blue is the color of loyalty and faith. Blue is power. Blue is also the color of protection.

**Blue represents water, the source of life. It is the color of the sea, the all absorbing sea that teaches us tolerance and acceptance.** Blue symbolism emphasizes the cooling and relaxing qualities of blue, reminding us of the peace and calmness of night.

It is the color of the peacock, our national bird. The peacock may not walk straight and has ugly feet but it dances beautifully. It teaches us to look at the brighter side of life; it encourages us to live with strengths and to ignore the weaknesses. It tells us that even if you don't have every thing you can still be beautiful, be accepted, be acknowledged, be loved and appreciated.

Ed's Note: Professionals & parents as well as persons with cerebral palsy also have blues looking at the state of our services. Can this mother's voice awaken us to do better so that all of us can beat the blues but assert the implementation of the true SYMBOLISM OF IACP'S BLUE COLOR?