INDIAN ACADEMY OF CEREBRAL PALSY

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

Official newsletter for members of IACP

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RESEARCH INTO CEREBRAL PALSY

A Luxury or A Necessity ?

Patient care and rehabilitation have occupied the full time attention of those managing cerebral palsy. It is imperative now that a part of our endeavour is directed to research in the subject, particularly dealing with problems peculiar to our scenario.

As a first priority we need to determine the epidemiology of cerebral palsy in India. One would say that this is a tall order for individual practitioners to deal with! However a start can be made by collecting representative data from the north, south, west and east. This would also generate data pertaining to related aspects e.g. sociological, attitudinal and educational.

Our children face barriers to integration and mainstreaming. These are attitudinal barriers in the minds of the 'healthy' other segment of society to disability in general. Research into these attitudes will help create awareness for change. We need to collect and compile and write on this as this is our problem.

On the clinical side the west has been giving us the solutions so far. Our strength lies in the volumes of work we have. Our problems are different in many ways. Whilst we see the whole spectrum of presentation, late presentations and huge deformities are common. These demand different solutions. How do our approaches differ? What are the results? Are these approaches valid and sustainable? Data has to be painstakingly collected by accuracy and reliability of measurement and proper analysis.

Another case in point are the various scales we use for evaluation of our patients. These need modification and post hoc validity studies in the Indian scenario. The huge untreated population provides us with natural history studies which can be valuable to see what happens over the life span and what problems this population faces as they age.

It is time we get into the research mode and in the spirit of research. This is no more a luxury now but a necessity to evaluate and validate or refute our own approaches, practices and results. Let us define our problems clearly and come up with solutions which are validated through research.

Prof. Ashok N. Johari
President

Inside this Newsletter

5th Annual National Conference of Indian Academy of Cerebral Palsy held in Jabalpur (October 2010)

FIRST ROW - Top to bottom, Left to right 1) Inaugural function. 2) Souvenir Release - Dr.Jitendra Jamdar Patron 5th IACP Conference, Dr.H.K.T.Raza Guest of Honour, Dr.G.Shashikala (Hony Secretary IACP) Dr.Ashok Johari National President IACP, Shri Ishwar Das Rohani Speaker Vidhan Sabha (MP) & Chief Guest. Prof.Dr.K.K.Kaul, Guest of Honuor, Dr.Pradeep Dubey Chairman Organising commitee , Dr. Gaurav Kochar Organising Secretary. 3) Lamp lighting ceremony by the dignitaries. 4) Souvenir Release.

SECOND ROW - 1) Lamp lighting by Chairman & Gen. Secretary Organising Committee. 2) Felicitation of Prof K.K.KAUL by Ms Shilpi Kochar 3) Felicitation of Dr. Pradeep Dubey by Ms Anubhuti
4) Chief Guest Honouring Dr. Ashok Johari.

THIRD ROW -1) Inaugural speech by Chief Guest. 2) Address by Prof. K.K.Kaul, 3) Address by Dr. Pradeep Dubey 4)Standing for national anthem.

From Secretary's Desk

Reflective thoughts on our conference

The 5th IACPCON was a pleasant departure from our usual protocol of annual conferences. The conference was a mini affair in terms of attendance due to overlapping with Dusshera & a hectic Cerebral palsy day celebrations across the country just prior to it. I hope we covered this event exhaustively in our Nov-Dec newsletter to motivate more of our members to actively celebrate this community initiative in their respective areas from this year onwards. I can only assure you from my experience at Nagpur, many of our administrators are very keen to support us if only we can reach them with concrete plans. So, put your executive brain on an overdrive & send us your reports on your CP day celebrations of this year's theme "Prevention of cerebral palsy- an ounce of prevention better than a pound of cure!"[An evergreen quote from my P&SM professor!]

The highpoint of Jabalpur conference was a 3 hr brain storming GBM, a scintillating presidential oration on "Golden rules of orthopedic intervention" & a very absorbing debate on prevention of cerebral palsy whose proceedings we are publishing in this issue to give lot of ideas for our CP day program. It was not just all day's work only but was capped by a fun filled, relaxing entertainment where all of us sang, danced & came back home thoroughly refreshed!

We could not have asked for any thing more. I sincerely thank Dr.Pradeep Dubey & his team & all faculty for a fine conference. Believe me, I have already begun to look forward to a great CP day celebrations & a better& more fruitful IACPcon & elections for the next team! Hope to see all of you at the remarkable city of Kolkatta!

IN THE SERVICE OF ACADEMY AT ALL TIMES,

Dr.G.Shashikala
General Secretary

IACP Guidelines for CP Day Celebrations on 3rd October 2011

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 govt.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 31st October 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.

Strategies for Prevention of Preterm Births

Dr.Vikram Rajan, Neonatologist,Nagpur

Preterm Birth remains a tremendous challenge as Preterm infants take up a significant amount of health care resources and have increased mortality / morbidity. There has been a steady rise in preterm births since 1990 which has alarmed health care professionals despite efforts to prevent preterm births. This has contributed to the current concept of preterm birth as a syndrome in which multiple factors interact to promote premature parturition.

Preventive strategies :
Primary Strategies: Target women who will enter their reproductive years.

Secondary Strategies: Target women who have increased risk of Preterm birth.

Tertiary Strategies: Target women in whom preterm parturition has begun.

Efforts to prevent Prematurity

Category of Prevention		Intervention
I)	Primary	
	a) Before conception	- Public Health policies - Nutritional Supplements - Cessation of smoking
	b) After conception	- Nutritional Supplements - Cessation of smoking - Antenatal Care & Oral Hygiene
II)	Secondary	
	a) Before conception	- Repair of defects in Uterus - Home visits - Antibiotics if needed to Rx infections
	b) After conception	- Reduction of Blood Pressure - Reducing activity / Intensive Prenatal care - Nutritional supplementation - Antibiotics to treat urinary infections - Hormonal Rx - Stitch placement to close mouth of Uterus
III)	Tertiary	- Early Diagnosis - Cessation of labour pain - Corticosteroids to help baby mature - Prevention of streptococcal infection - Treatment of early rupture of membranes - Drugs to prevent onset of labour pains - Routine Caesarean delivery

Reference:
CT.Lang &Jay d Lambs- Goals & strategies for prevention of preterm births-An obsteitric perspectiv- Pediatric Clinics of North America-Vol56-no 3-june 2009.

Recommendations for Prevention of Cerebral Palsy.

As per- International Classification Of Functioning, Disability & Health Frame Work, WHO 2002

"Money spent on prevention is money saved for cumulative benefit of society"

1] **Primary Prevention -** This is important and most cost effective. Greatest emphasis should be laid on preventing impairment happening in the first instance itself.

Health services - Immunization
- Nutrition-Iodine & Iron
- Before, during and after birth care and Prevention of Pre term births
- Prevention of stress & infections, Reduction of increased blood pressure & increased glucose in the mother and adequate maternal health care during pregnancy & delivery.

Improve living conditions and negate poverty effects
Public education & positive eugenics

2] **Secondary Prevention-** Reduce disability affecting the body structure & function by medical & habilitation strategies of early diagnosis ,early intervention and life span care. Minimize limitation in activities by personal & contextual factors & choices covering the five F's(Dr. Gorter) Family, Function, Fitness, Future, Friendship in the context of fun .

3] **Tertiary Prevention-** Improve participation in societal roles by enablement (education) & empowerment (earning ability) so as to ensure quality of life (overall assessment of well being in all domains) as per the expectations, values, societal norms & cultural beliefs of persons with disability & their families.

Indian Academy of Cerebral Palsy

CME on Research Methodology in Developmental Disabilities.

16th - 17th July 2011, Venue: Spastic Society of Karnataka, Indira Nagar, Bengaluru

TENTATIVE SCHEDULE

	Saturday, 16th July 2011	
9:00 to 9:30 AM	Registration	
9:30 to 10:00 AM	INAUGURATION and Group Photograph Key note: Priorities and problems in research: an IACP perspective	
10:00 to 10:30 AM	TEA	
10:30 to 11:15 AM	Session 1	Research process and the language of Research)- Dr.N.Girish
11:15 to 12:15 AM	Session 2	Introduction to Evidence Based Methods Dr.Srikala Bharath
12:15 to 1:30 PM	Session 3	Designing the study part 1 – Dr.Jagadisha
1:30 to 2:15 PM	LUNCH	
2:15 to 3:45 PM	Session 4	Designing the study part 2 – Dr.Jagadisha
3:30 to 3:45 PM	TEA	
3:45 to 5:30 PM	Session 5	Bio-statistical issues in Medical Research Dr.Ganga Boriah
Sunday, 17th July 2011		
9:00 to 10:30 AM	Session 6	Statistical inference – Dr.Ganga Boriah
10:30 to 11:00 AM	TEA	
11:00 AM to 12:30 PM	Session 7	Research and practice: bridging the chasm – Dr.Sanjeev Lewin
12:30 PM to 01:30 PM	Session 8	Ethical issues in Research – Dr.Srikala Bharath
1:15 to 2:00 PM	LUNCH	
2:00 to 4:15 PM	Session 9	Using computers for research Dr.Girish, Sri.Girish B G, Kum Manjula
3:15 to 3:30 PM	TEA	
4:15 to 5:15 PM	Session 10	Tips for undertaking a study – Dr.N.Girish
5:15 to 5:30 PM	Open house and VALEDICTORY	

Registration Fee for Two day CME : Rs.2000 for IACP Members & Rs.2500 for non IACP Members, DD/Cheque favoring IACP, A/C No. 107910011026466, Andhra Bank payable at Hyderabad to be sent to

Dr.Hema, Principal-HRDT

SPASTICS SOCIETY OF KARNATAKA, NO.31, V CROSS, OFF V MAIN, INDIRA NAGAR, I STAGE

BANGALORE-38, KARNATAKA

Phone: +91(80)40745900; Fax: +91(80) 40745903, Direct: +91 (80) 40745911

For Registration & details contact: Organizing Secretary : **Dr.Gautam Kodikal** at Email: ssk_hrdt@yahoo.co.in or **K D Mallikarjuna,** Email: kdmallikarjuna@gmail.com

For assistance in accommodation, Bangalore contact Dr.Hema, at contact details given above.

Prevention of Cerebral Palsy in India-a Debate

5thIACP Conference at Jabalpur -16th October-12.45 – 1.30 pm.
For the Motion - Dr. Anaita Hegde, Pediatric neurologist.
Against the Motion - Dr.G.Shashikala, Developmental neurologist.
Moderator: Dr.Vipul Shaw, Pediatric orthopedic surgeon.

REPORT ON THE PROCEEDINGS:
Dr. Vipul Shaw opened the debate by introducing the speakers in a jovial way & then

Dr.Shashikala began the topic by stressing on the fact that money spent on prevention of cerebral palsy is money saved for the cumulative benefits of a developing society if life time costs of cerebral palsy care is considered. While there are no reports from our country, we need to consider the report from Center for Disease Control, USA- which is about a million dollars per person- as a huge health expenditure. It is worth while for the Academy to consider this topic as important & come up with some recommendations for action. Needless to say a penny of primary prevention is more valuable than a pound of secondary prevention!
She also clarified that in considering this topic, they were debating on Primary prevention of cerebral palsy at the impairment level itself as per the ICF nomenclature & said as on today, prevention of cerebral palsy is not possible for many reasons. She also pointed that her role was that of a devil's advocate in the arguments & was only to point out the difficulties lying ahead in the path ahead for our action

1] GS- For any prevention efforts to succeed, knowing the epidemiological trends is important. We do not have any nation wide population based statistics on this & the few reports available are all leading teaching institution based small sample studies which are generally skewed as they do not cover any specific defined territory. As the health services across states are not uniform, no conclusions can be drawn on these. So, what are we trying to prevent?
AH- Most cerebral palsies are not caused by any one single cause if we understand the concept of Neuronal injuries due to EXCITO TOXIC CASCADE. While it is true that we do not have good population based epidemiological studies; we should not ignore lessons learnt from small but meaningful research from institutions. They certainly show the trends if not the definitive causes & start corrective action at various levels. We need to learn from other western reports & define the preventable causes in our set up.
2]. GS- In spite of so much money spent on improving maternal & child health care in other countries, the incidence of cerebral palsy has not come down as much as expected in other countries & is almost the same in the past decade or so. This only substantiates my argument that cerebral palsy is not preventable.
AH- This is not true. We are forgetting some of the hidden improvements like the decreasing incidence of athetoid cerebral palsy due to Rh incompatibility & Rubella syndrome.

3] GS: So what? We are having increasing number of dystonic cerebral palsy due to peri natal hypoxic damage & probably the total no. of cases remain same. It looks as though NICU care is increasing the no of cerebral palsy cases.
AH: This is again a skewed interpretation of gains of neonatal care. NICU care might appear to be apparently increasing cerebral palsy incidence or morbidity but we are not looking at the full picture of decreasing mortality & severe cerebral palsy occurrence. In any case, there are more antenatal causes of cerebral palsy than natal & postnatal causes. Birth asphyxia accounts for less than 40% of cases.

4] GS: So much for our wasted efforts of "High risk pregnancy & high risk baby follow up Clinics". In spite of all efforts, Preterm births are not decreasing & we are missing the cerebral palsies occurring in full term births[25% of cases] & therefore prevention of cp is not possible
AH: Only 40% of cp cases are due to Preterm births & we need to look at antenatal , intra & perinatal care more closely. Even in antenatal check ups, it is not enough to look at macro parameters like nuitritional deficiencies of Iron & thyroid. We need to recognize factors like family history of neurological disorders, thrombophilia & factor V leiden deficiency & polycythaemia to prevent infantile hemiplegias & moyamoya & MELA syndromes which are increasingly being recognized as causes as well as genetic syndromes presenting with primary motor delay. Placental non infective inflammation & not infections of the TORCH group alone need to be identified. Micro environment of the pregnant mother which includes stress, fatigue, inadequate rest, interpersonal relationships, smoking, alcohol& drugs need to be looked into. If we evolve a **comprehensive ANC model covering all these aspects**, I am sure prevention of cerebral palsy will certainly ensue.

GS: Some of these factors are not under the control of doctors like for example genetics & stress. We tend to put them as causes after a disability results. A small country like Turkey in an almost perfect model of Neuroepidemiological study has shown that many neurological disorders particularly Epilepsy, mental retardation & cerebral palsies are common in some communities. We are yet to have any such studies & without adequate statistical figures, cannot even think of anticipatory guidance of families. Consanguinity is a social custom in many parts of our country & even PVL of pre maturity is supposed to be more in certain combination of gene clones. We are way behind in implementing Positive eugenics. All these need more energetic preventive measures that are not entirely in the domain of health services as on today & therefore I assert prevention is not possible.

AH: While the genetic cases & the no due to consanguinity are small, we need to look at the over all picture in a more positive way & send a very positive message. Antenatal screening is the only answer & we need to direct our efforts towards this. We need to take serious note of the recent times magazine report that what happens to the mother is

going to affect the fetus in a much bigger way than we all have believed.

GS: An offshoot of such an approach will be again an excuse for blame game on Obstetricians. It took almost 6 decades for the National Perinatal Collaborative project to prove William Little's theory of natal causation of cerebral palsy as wrong & even today , breech & forceps delivery by the Obstetricians are blamed as causes while in reality it is the abnormal fetal kinetics& altered pattern of general movements due to damaged brain are the cause. Many families are told that IUGR is preventable & the fault was of the treatment by the Obstetrician. While true negligence may occur in extremely few cases, majority cases are truly not preventable by any single measure. This again is a reason for for my argument that in today's social& health scenario, primary prevention of cerebral palsy is not possible.

AH- I do not share the negativistic thinking of my senior colleague .While I agree that true negligence by Obstetricians is a rarity, we as responsible health professionals need to work towards minimizing the ignorance pervading professional as well as public minds. We need to concentrate on a more proactive approach of meticulous records, documentation & health education of women at large at every available opportunity. Prevention of disability almost parallels with empowerment of women with adequate knowledge regarding health & reproduction which unfortunately has been missed in he previous generation. We need to learn from these mistakes, concentrate on integrated women & child health services & importantly on HEALTH EDUCATION OF PROSPECTIVE PARENTS either at school ,college level or at the post marriage phase by compulsory anticipatory guidance. We need to learn from the experience of Indian Epilepsy association & believe in covering corporation & municipality schools & not just the high income English medium schools. I MUST ASSERT EDUCATION IS THE BEST PREVENTIVE STRATEGY IN MEDICINE.

GS- One of the preventable causes is the recent & increasing trend for methods of assistive reproduction where in multiple fertilization is resorted to increase the success of IVF. We doctors often become obsessed with this self created delusion of playing GODS. Studies have demonstrated the increasing incidence of imprinting disorders among IVF babies. So much of prevention strategies involve putting our own house in order & re educate our own colleagues in these directions. Community education in all these directions is an onerous task & I don't see any easy way unless we involve policy makers & health administrators in a top down information dissemination process & creation of huge human resource & infrastructural expenses. If we try hard enough, at least a few causes can be prevented. But we need to raise these two questions at this juncture -1] Are our members ready to go that extra mile? 2] How do we go about it? I am afraid we are not very sure!

This cynical remark lead to healthy & forceful interactive session where measures to be taken by members for further action by the academy were discussed . This led our president Dr.Johari to announce that the theme for the 2011 national cerebral palsy day will be PREVENTION OF CEREBRAL PALSY. Dr. Shashikala ended the debate by quoting Albert Einstein "Madness is doing the same thing over & again but expecting different results" & exhorted the audience to act differently to make a difference. Dr. Vipul shaw requested all the members to vote for the arguments which incidentally & overwhelmingly was for the motion in true spirit of healthcare providers including Dr.Shashikala raising both her hands & the wide grin of Dr.Anaita symbolized the grit of younger generation. May we all walk the talk!

Ed's note: COMMENTS & OPINIONS FROM READERS ARE INVITED. REFERENCES WILL BE PROVIDED IF NEEDED.

IACP Working Committees

1. **MEMBERSHIP & CREDENTIAL COMMITTEE**
   Chairperson: Dr. M.S.Mahadeviah.
   Co- chairperson: Dr. Aniruddh K.Purohit.
   Members: Dr. Asha Chitnis & Dr. Bhale Rao
2. **WEBSITE COMMITTEE**
   Chairperson & web master: Dr. Vipul Shah.
   Co-Chairperson: Dr. A.N.Johari.
   Members: Dr. G.Shashikala & Mr. K.D.Mallikarjuna.
3. **NEWS LETTER, BROCHURE & PUBLICATION COM.**
   Chairperson: Dr. G.Shashikala.
   Co-chairperson: Dr. A.N.Johari.
   Members: Mr. K.D.Mallikarjun & Dr. Madhavi Kelapure.
4. **ACADEMICS , CONFERENCE & CME COMMITTEE**
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   Co-chair person: Dr. G.Shashikala
   Members:
   Dr. A.K.Purohit {Surgery}
   Dr. Pradeep Dubey { Dev.Paediatrics }
   Dr. Asha Chitnis {Physiotherapy}
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   Mrs.Usha Dalvi {Speech Therapy}
   Dr. Sanjay Marwah {Adult disability & Life span care}
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   Members: Dr. Anaita Hegde & Dr. Bhale Rao.
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   Co -Chairperson: Dr. Ranjit Aurora.
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   Co -chairperson: Dr. Gaurav Kochar.
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   Chairperson : Dr. Anaita Hegde
   Co-chairpersons: Dr. A.N.Johari & Dr. G.Shashikala
   Members: Dr. Dhruv Mehta & Mr. K.D.Mallikarjuna.

IACP Election Notice

***Dear Membesrs*,**
The Election **for the following posts 2012-14** will be held either unanimously or by ballot (if necessary) at the General Body Meeting to be held on **Saturday, 5th November 2011** at IACP Conference Venue, Kolkatta.

S.No.	Posts	No. of Vacancies	Term of Office
1	President	Dr. A.K.Purohit	Three Years
2	Vice Presidents	1. Dr. G.Shashikala	
		2. Dr. K.D. Mallikarjuna	
3	General Secretary	One - To be elected	
4	Joint General Secretary	One – To be elected	
5	Treasurer	One - To be elected	
6	Joint Treasurer	One - To be elected	
7	Executive Members	Four – To be elected	

Note:
As per constitution only Dr.A.K.Purohit, Dr.G.Shashikala & Mr.K.D.Mallikarjun are among founder members left to occupy the position of Presedent in 2011, 2014 & 2017. Hence it is suggested that Dr.G.Shashikala & K.D.Mallikrjun be elevated to the posts of Vice Presidents 1 & 2. In case of Mr.Mallikarjun it is preferable that President &General Secretary are not from same city and institution as we need broad based all India representation for the important positions of President & General Secretary. Further having served two terms as Treasurer and rendering exemplary service to IACP Mr.Mallikarjun should be an automatic choice for the post of 2nd Vice President to be in line to take over as President of IACP in 2017.

Eligibility:
Election Criteria :1.Eligibility of the contestants for EB needs to be scrutinized by the election committee. Only Life Members can contest after having served at least one term as a Member on the Executive body before applying for the post of General Secretary / President, or Vice-President and there shall be good representation on the EB from the following specialties. a)Surgical o**Non-Surgical** b)**Therapy** c)**P.M.R.** d)**Psychosocial / Education.**
2.All members for any post for election should be of good moral character and have no criminal cases pending and if so during the term / tenure his / her posts gets automatically cancelled. The term of the executive body will be for a period of three years. Normally members of the EB shall not hold the same post for more than one term of three years though succession to the next higher post is permitted. However in the case of President there is no higher post in the academy.
3."In order to retain continuity of purpose of academy the Founder Members who have worked for enhancement and growth of organization will be given the chance to be elevated to higher post without elections. Elections can be held only for other remaining vacant posts. In the event of extra ordinary performance or situations the tenure of the President can be extended for a period of not more than one more year by a majority vote. In such an extended term of office the President has the prerogative of retaining the existing core working group of the EB or seek new members.
Interested candidates should send their nomination to the **General Secretary/Election Officer** IACP on or before 15/09/2011. Nominations received after 15/09/2011 will not be considered valid. If no nomination is received within the stipulated time **Secretary/Election Officer** will call the nominations from the floor of the General Body and the post will be filled up with suitable candidate.

Provisional Life Members are not eligible for contesting.

Nomination Paper duly filled-in and addressed to the **General Secretary/Election Officer** IACP, at the official address of IACP **NOT LATER THAN Thursday, 15th September 2011.**

"IACP ELECTION - 2011 SCHEDULE"
(Subject to change under unforeseen circumstances)
Last date for filing nomination Thursday, 15th September 2011
Last date for withdrawal of nomination Wednesday, 5th October 2011
Scrutiny of nomination papers

Kindly note that IACP records made on or before
1st June 2011 will be accepted and will be considered as valid for the purpose of IACP Election 2011.

CANVASSING IN ANY MANNER IS PROHIBITED.

Indian Academy of Cerebral Palsy Nomination Form

for the Post of _____ Election for Term 2012-2014

1. Contestant

I, Dr ..... here by submit the nomination for the post of ..... of **IACP** for the election **2012-2014** for which nomination has been filled as per proforma. I do not have any dues to our Association. I am Permanent Life Member of the Academy since ..... I here by declare that all informations given by me is correct and I own the responsibility for the same.

Membership. No: ..... Signature: .....

Date: ..... Full Name: .....

Postal Add: ..... Telephone: .....

..... Email Id: .....

2. Proposer

I here by propose the name of Dr ..... of (place) ..... of **IACP** for the election **2012-2014**. I do not have dues to our Association.

Membership. No: ..... Signature: .....

Date: ..... Full Name: .....

Postal Add: ..... Telephone: .....

..... Email Id: .....

3. **Seconder**

Name of ..... is seconded by me, for the post of ..... I do not have any dues to our Association.

Membership. No: ..... Signature: .....

Date: ..... Full Name: .....

Postal Add: ..... Telephone: .....

..... Email Id: .....

Please note Important Dates:

- Completed nomination form to
  General Secretary /Election officer before 5.00 P.M Thursday, 15th September 2011.
- Last date of Withdrawal 5:00 P.M. Wednesday, 5th October 2011.

Children With Neuro Developmental Disabilities, How Can You Help Them?

Neuro developmental disabilities are a group of brain disorders which occur due to interference in the development of structure & function of the brain in early life. They impair the abilities of children to perform certain functions depending upon the area of brain affected. With adequate help, many compensate for their limitations and can live contributory lives like many of us. Some of you might know some one with such problems. You can help them better if you learn a little more about them.

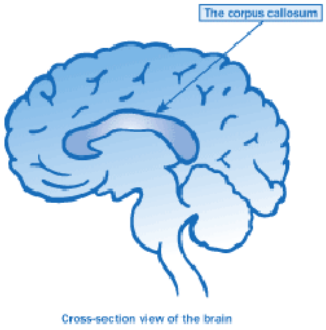
WHY IS BRAIN CALLED THE MASTER ORGAN?

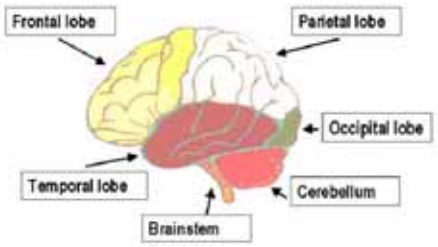
We call the brain as the master organ of the body. It practically controls all our bodily functions starting from the simplest vegetative function of hunger, thirst& walking to more complex functions like memory, learning& emotions and the most complicated but essentially human functions like thinking, speech, reading& writing as well as socialization.

Watson & Crick who discovered DNA which truly is the coil of life, have called the understanding of Brain as the last frontier in Biological Science research that parallels advances in all sciences put together. Even today we are no where near full comprehension of it. Nevertheless, it makes a fascinating & compelling account. So, let us look at the brain & understand its structure, function and what happens if its' development is interfered with briefly.

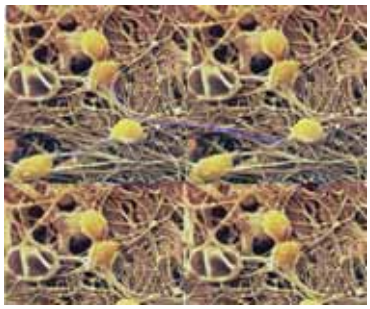
STRUCTURE OF BRAIN- HOW IS IT MADE?

Human brain is a cauliflower like organ cut & connected by a bundle of connecting fibers in the middle. The two walnut shaped halves are called hemispheres and each half controls the opposite side of the body. An adult brain weighs approximately 1.8 kg in men and slightly less in women and is well protected in the human skull surrounded by cerebrospinal fluid. It is richly supplied by blood vessels which facilitates high glucose consumption essential for its very high activity levels. The only time brain partially rests is during sleep. Hence, good eating habits and adequate sleep are very essential to keep your brain healthy



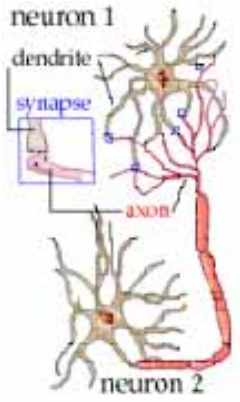


The functional working units of brain are groups of nerve cells called neuronal nets. The integrity & efficiency of brain totally depends on the connectivity among these networks. Each neuron or nerve cell is an octopus like structure which



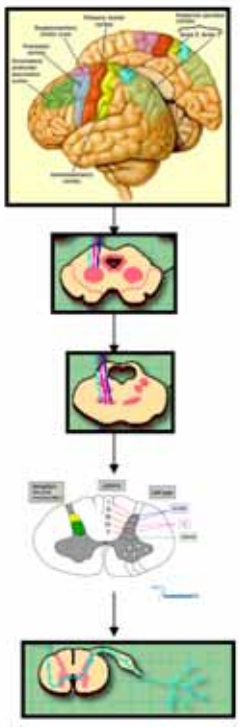
is making connection with innumerable number of neighboring or distant nerve cells through its branches called dendrites and axons which are signal or information transmitting cables at junctions called as SYNAPSES.

An adult brain has about 100 billion cells. If each neuron in the adult brain along with its branches is placed in a square, it is said to occupy an area of 4 square miles! Imagine this wonder of nature being so compactly organized in convolutions & furrows inside our skulls! The story of its connections is still more fascinating! The number of possible connections is calculated to be 10 x10 miles of type written 0's! To appreciate nature's ingenuity, think of this. Such a vastly complicated organ is formed by the innumerable number of divisions of a SINGLE ECTODERMAL NERVE STEM CELL! We only use 1/10th of our brain cells as normal persons. Hence, we potentially have a large reserve in case of injury. If we don't use some cells before a particular time, these cells are programmed to die.



HOW DO WE LEARN?

Our brain is the seat of all learning. We really learn to walk, talk, sing and play like we learn so many things at school .All the cells present in a given brain are formed by the end of 5th month of pregnancy. Not a single cell is added later on. Subsequent growth is all due to the increase in connections by formation of new synapses. You must remember that in biological evolution, specialized cells have the least regenerative ability. That is a prize we pay for special abilities of brain! The number of cells and their branches are determined by genes but the number of connections these can make is powerfully influenced by environment.



LEVELS OF BRAIN FOR DIVISION OF LABOUR

Dr. V.S Ramachandran, an eminent Indo American neuroscientist of our times calls the flow of information across these masses of nerve cells constantly in touch with each other as NERVE TALK and quotes the number of permutations & combinations of

activity possible in various brain sites as exceeding the number of elementary particles in the universe!

FORMATION OF THESE NEURONAL NETS IS THE BASIS OF ALL LEARNING.

We begin to learn as early as 4weeks of intrauterine age & we already have the hard ware for learning even before we enter our kindergarten schools. Does that surprise you? The richer the environmental inputs at home, better is our pre school learning. We all learn easily in the first five years of life which happens to be the best & sensitive phase of brain growth. There is also a critical phase beyond which learning certain skills is difficult and hence this policy of "Teach them young "so as to help maximal & easy learning. This is the best way to learn how to learn well. Academic training at schools is only adding some soft ware to this already existing scaffold or basic support structure.

HOW DOES THE BRAIN WORK?.

The Brain operates on a highly organized principle of DIVISION OF LABOR. Different areas are earmarked to do different jobs but all jobs are extremely interconnected & fine tuned with control systems operating at each level. Information is processed as a whole and executed with extraordinary local expertise. We call the brain as a chemical soup operating like an electronic model just like a super, super computer, a super hologram {a three dimensional picture created by laser beams}. Nobel laureate Gerald Edelman has postulated a system of ANGLED MIRRORS [in combination with PRISMS?] to explain all the information processing that occurs in our brain as a result of the interaction between body function & environment. The formation of new neuronal networks after these interactions is called NEURO PLASTICITY. Like the cells, these connections are also pruned if necessary. New connections sprout if some are damaged.

BRAIN DAMAGE SHOULD NOT SURPRISE YOU.

After reading about these intricacies of brain, it should not surprise you that this complex organ is likely& vulnerable to damage and some loss of function depending upon the site. In reality, it is damaged so in frequently and therefore most of us happen to be so called NORMALS! Sometimes, such a thing occurs during pregnancy, during birth or soon after birth or early childhood.

Very early damage gets compensated fairly well and such children are practically like you & me but for their small functional differences. One such problem is CEREBRAL PALSY where children's walking system is predominantly involved. Such children may walk differently. They may not be able to run or climb stairs or use walking aids like crutches, Frames or even wheel chairs. Some of these children have Fits. Some kids have difficulty in speech & communication. They may not be able to make friends on their own and are in their own world. We call them as children with AUTISM. Some may have only difficulty in reading & writing and are called as children with LEARNING DISABILITY. Some others have difficulty in attention & inhibition and have a problem known as ATTENTION DEFICIT HYPERACTIVITY DISORDER. Some children have problems in all these areas together and this is known as MENTAL RETARDATION.

There are other disabilities concerned with seeing, Hearing and orthopedic problems or due to inadequate muscle development or infections like poliomyelitis These kind of problems occur in about 15% of children which means they are very common and you should be aware of them.

WHAT CAN YOU DO?

1. These children are NOT SICK OR DULL & BORING! They are just DIFFERENTLY ABLED. ACCEPT them if they are in your school or neighborhood primarily as children like all of you.
2. Their problems are only a small part of their personalities. Most of them are warm hearted, lovable kids who are good enough to be your friends. Befriend them & help them in school work or in the play field
3. Appreciate their courage & don't label them or equate them with their problems. .DON'T PITY THEM WITH SYMPATHY BUT SHOW EMPATHY which means understanding others in emotionally appropriate ways.
4. Don't make fun or bully them or keep victimizing them for things done by other able bodied children who are more disabled behavior wise. Stand by them, protect them & support them in ways you can with a genuine spirit of friendship.
5. Visit their homes & invite them and their siblings to your homes. Many parents of these children are extraordinarily nice people you will remember for a lifetime.
6. Last but not the least, remember many people with disability have been & are great achievers. Try & see how many names you can enlist. Believe me, that list will surely surprise you! Some of the greatest people in the world had & have some are the other disability. That is sure to keep you inspired to do better & bigger things in life.
7. NONE OF US ARE PERFECT IN ALL ASPECTS. It is this imperfectness that should make us humble, vulnerable yet strong and worthy, aspiring human beings. Join these children in a walk or see them perform on October3rdduring the celebration of National Cerebral palsy day and cheer them and show your solidarity with them. An organization by the name of Indian Academy of Cerebral Palsy works for the welfare of these children. We celebrate this day in memory of our founder president Late. Dr. Perin Kavas Mullaferoze , the first lady orthopedic surgeon who pioneered treatment of these children in our country.

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Prognostication in cerebral palsy: How far can we go? Implications for Counseling Families and Planning Intervention

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Robert Palisano,ScD,
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Doreen Barlett, PhD, Ellen Wood, MD, MSC,
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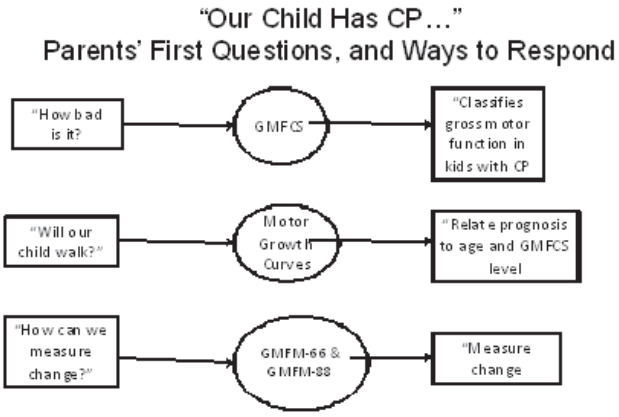
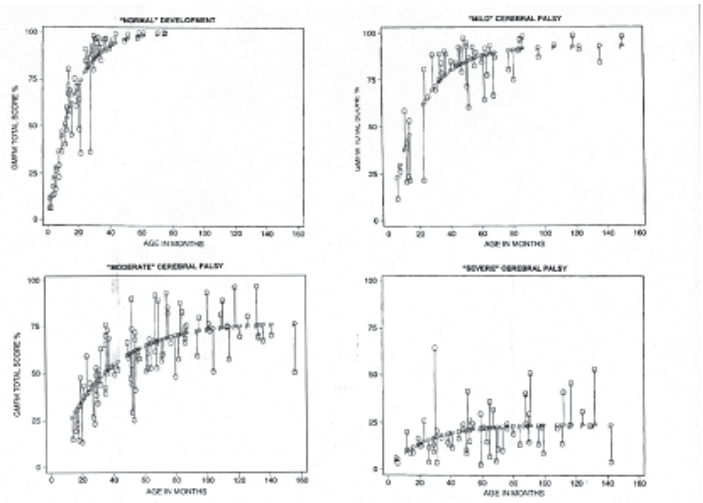
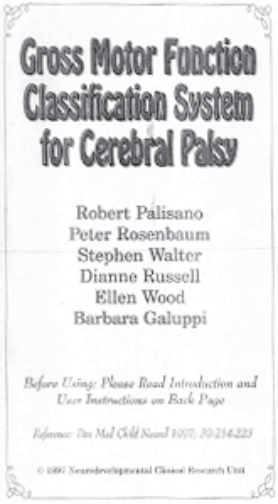


(of course – we didn't start in this order!)



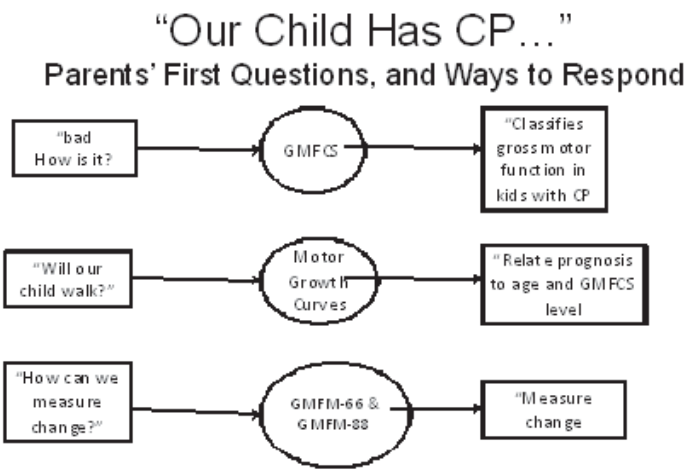
- Q.1: "How bad is it?"
- With colleagues from around the world, we created a reliable system to describe the motor function aspects of CP.
- This introduced a common language about 'severity'of cerebral palsy.
- The system is now used internationally
- To obtain it free go to http://www.canchild.ca/portals/o/outcomes/pdf/GMFCS.pdf.



Reliability of the GMFCS

- There is considerable evidence that the GMFCS is reliable
- Between professionals…
- Between professionals and parents
- Over time…

Palisano et al. DMCN 39:214,1997



Wood & Rosenbaum DMCN 42:293-6,2000
Palisano et al. DMCN 48:424-8,2006

Parents' First Questions, and Ways to Respond

- Q.2: "Will our child walk?"
- Needed an evidence based way to answer parent' questions.
- To address this question we needed to follow children forward in time and observe them systematically(i.e. with serial measures of motor function)

Rosenbaum et al. JAMA,288:157-63,2002

Purpose of the OMG Study

- To create "motor development" curves that document the prognosis for gross motor function in children with CP by 'severity'as described by the 5-level Gross Motor Function Classification System(GMFCS)

Design of the Study

- Prospective longitudinal assessments of gross motor function9GMFM-88) over several years by trained, reliable assessors.
- Children < 6 were assessed ~Q 6 M
- Children ? 6 were assessed ~Q 9-12M
- GMFCS DONE AT EACH ASSESSMENT

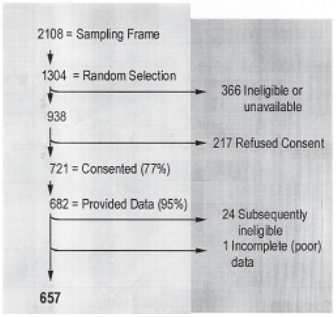
Setting

- 18 publicly funded regional children's rehabilitation programs across Ontario,plus one affiliated community hospital based rehabilitation program
- Each centre sees the large majority of children with disabilities in their own community

Participants

- Random selection of children,stratified by age and GMFCS level
- Children with CP or 'developmenta motor impariment' aged 2-13 years at the start of the study(mid -1996)
- 77% consent by selected families

Figure 1: Sample Selection and Recruitment

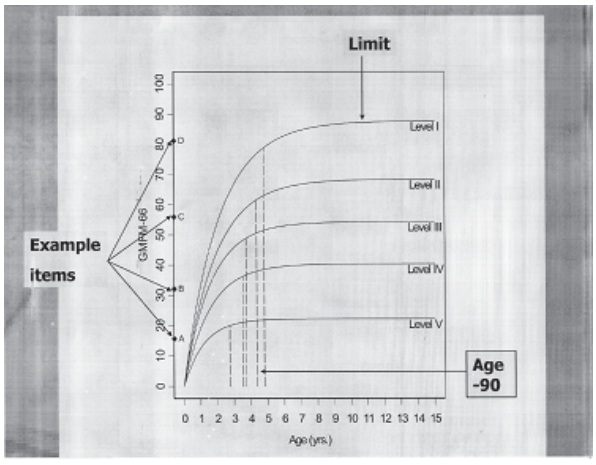


Measures

- Gross Motor Function Measure(GMFM-88)- now also available in a 66 - item interval - scaled version
  Russel et al. The Gross Motor Function Meausre. GMFM-66 and GMFM-88(Users'Manual). Clinics in Developmental Medicine, #159.2002 MKP(CUP)
- GMFCS - a reliable, validated 5- level classification of mtor function in CP
  Palisano et al.DMCN,39; 214-223,1997.

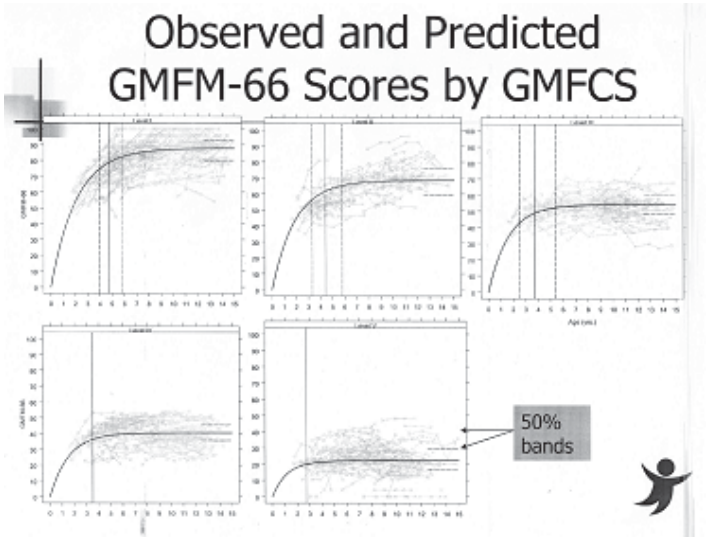
Results 1: Population at Outset

	GMFCS LEVELS					
Age(yr) (N)	I 183	II 80	III 122	IV 137	V 135	Total 657
1-4	63	33	35	42	36	209
5-8	66	29	57	59	68	279
>9	54	1	30	36	31	169
MEAN	**6.90**	**6.16**	**6.88**	**6.81**	**6.76**	**6.76**
MEDIAN	6.82	6.39	6.85	6.71	6.62	6.62



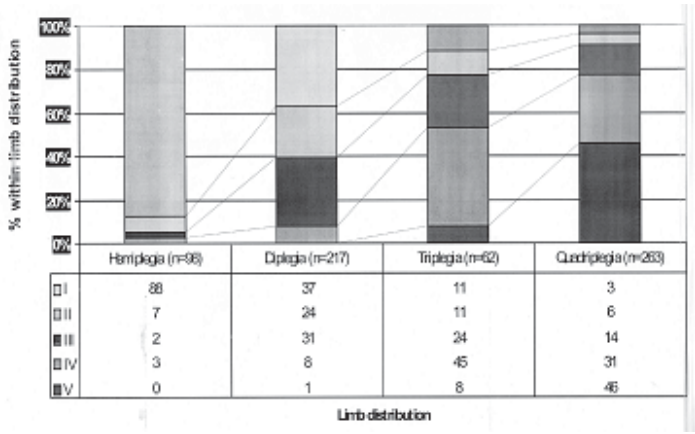
Results 2: Parameters of Motor Development

	GMFCS LEVELS				
	I	II	III	IV	V
Observations/ Subject	4.0	4.4	4.1	3.9	3.8
GMFM-66 LIMIT(95%ci)	87.7 86.0-89.3	68.4 65.5-71.2	54.3 52.6-55.8	40.4 39.1-41.7	22.3 20.7-24.0
Age-90 (95%CI)	**4.8 4.4-5.2**	**4.4 3.8-5.0**	**3.7 3.2-4.3**	**3.5 3.2-4.0**	**2.7 2.0-3.7**



What Else Have we Learned:

- Lack of clear connection between body distribution of CP and GMFCS levels- as shown in the next two slides
  Gorter et al. DMCN 46;461-467

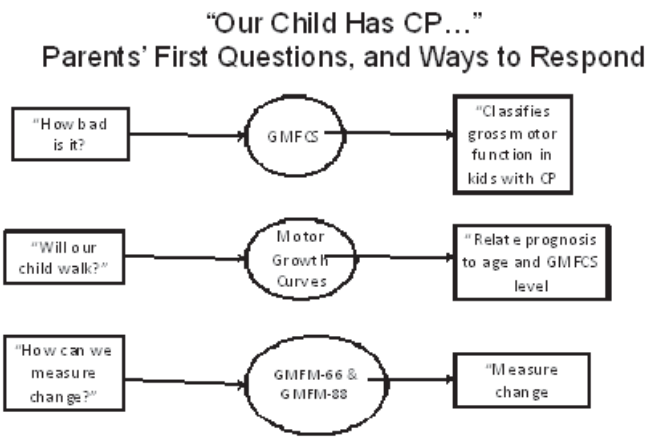


Distribution of CP by GMFCS Level T1
B:Based on GMFCS Level(read **down**)

Distribution	I	II	III	IV	V	Total
Leg dominant (diplegia)	80 (44.0)	51 (63.8)	68 (56.2)	18 (13.5)	2 (1.6)	219 (33.3)
Three-limb dominant(Tri)	7 (3.8)	7 (8.8)	15 (12.4)	28 (21.1)	5 (3.9)	62 (9.6)
Four-limb dom(quad)	9 (4.9)	15 (18.8)	36 (29.8)	84 (63.2)	122 (94.6)	266 (41.2)
Hemisyndrome	86 (47.3)	7 (8.6%)	2 (1.7)	3 (2.3)		98 (15.2)
TOTAL	182 100.0	80 100.0	121 100.0	133 100.0	129 100.0	645 100.0

What Else Have Learned?

- Can relate health/functional status to GMFCS levels -
- Kennes et al. DMCN 44:240-7,2003
- Saigal et al. Q. of Life Res 14:241-55
- We know about the stability of GMFCS classifications in the OMG study
- Palisano et al. DMCN 48:424-8,2006



On behalf of our whole team THANK YOU for your interest in our work

NB: The Motor Growth Curves and GMFCS are downloadable on the CANCHILD web page (www.canchild.ca)

CME on Research Methodology in Development Disabilities

Resource Persons

1) Dr Girish N, Associate Professor of Epidemiology, NIMHANS, Bangalore
2) Dr Ganga Boraiah, Faculty in Community Medicine, Kempegowda Institute of Medical Sciences, Bangalore
3) Dr T Jagadisha, Additional Professor of Psychiatry, NIMHANS, Bangalore
4) Dr Mariamma Philip, Senior Scientific Officer in Bio-statistics, NIMHANS, Bangalore
5) Dr. Sanjiv Lewin, Professor of Pediatrics, Clinical Ethics, Medical Education, HIV Medicine, St. John's Medical College Hospital, Bangalore 560034
6) Dr Srikala Bharath, Professor of Psychiatry, NIMHANS, Bangalore

Family Forum - Learning to live with cerebral palsy

Originally written in Marathi by **Miss. Nupur Pidadi**
Translated to English for publication in Twinkle star

I am a teenager with cerebral palsy. I am told that because I was born prematurely, there has been involvement of some portions of my brain. Therefore, my hands & leg movement control is affected. I move slowly with support of my wonderful mother who is probably the only person who can understand my difficult speech.

I have received good medical care from the age of 3 months, and I continue to do my strengthening exercises even now which keeps me relaxed & learn to do all my daily activities and be as much independent as my body allows me to do. In spite of these difficulties, my parents, my doctor & therapists kept encouraging me to study in a normal school as I have normal intelligence.

I went to a normal English school till 8th standard and I had lot of problems. I had difficulty in understanding English. Though the school tried their best, they really could not get people to help me solve my difficulties. My parents had the good sense to shift me to "Snehangan" where I studied with other physically challenged children who accepted me nicely & I shifted to Marathi which is my mother tongue. All my school difficulties disappeared as I could understand all the concepts better. Added to this, in this school, all children had some or other physical problem but were very helpful to each other. Even the teachers in this school understood my problems well & helped me participate in lot of activities & become confident. I finished my 10th state board exam with a writer, did my 12th class in Yashwanth Rao open university and I am preparing for BA. I am now taking computer training and intend to pursue it as a career.

Because of my experience, I want to say a few things.

1] Even if we receive very good treatment, some of us may not be able to walk independently if our problems are severe. That should not discourage us. We can still do many things if our parents do not give up hope but support us to get educated. But, how can parents predict our educability unless they are helped by professionals? All parents should be made aware of facilities available in our system by professionals like open school system.

2] There should not be insistence in educating children with speech difficulties in English & there should be more schools like Snehangan where we are recognized as children in spite of our limitations.

3] We need opportunities to prove that we also can do many things if we get helping hand from society. Parents, Doctors & therapists as well as teachers should help us to come to terms with our limitations rather than push us to be like other so called NORMAL children. I must say we don't become abnormal just because we are differently abled. It is not enough to give admission to us in regular schools out of sympathy but create a system that supports us with empathy.

4] Lastly, we must get meaningful & appropriate medical help from governmental set ups as some of the recent advances in treatment of cerebral palsy are very costly. My doctor tells me I need to get a pump inserted in to my spinal cord which costs around 5 lakhs. We also require some training to be able to do some jobs & earn on our own to live our life with dignity & you need to think differently to help us in this regard.

I hereby appeal to all concerned especially children to be friends with us at school & in the neighborhood as we have the same right to enjoy schooling & growing up as much as you all do. On October 3rd, we are celebrating National cerebral palsy day in memory of the lady doctor who first started treatment of children with cerebral palsy in India all over the country. Join us & support us in any way you can.

6th Annual Conference of IACP in Kolkata

We are happy to inform that 6th ANNUAL CONFERENCE OF INDIAN ACADEMY OF CEREBRAL PALSY (6th IACPCON) will be held from 4th -6th November 2011 in association with NIOH, Kolkata.

Theme of the Conference

Cerebral Palsy-Womb to Tomb

Invitation

Dear Colleagues,

Accept Seasons Greetings from NIOH Kolkata.NIOH is an apex institute for locomotor disability under the Ministry of Social Justice & Empowerment (Govt. of India). This Institute is having various academic departments e.g. Orthopaedics, PM&R, Physiotherapy, Occupational Therapy, Prosthetics & Orthotics, Socioeconomic Rehabilitation and Rehabilitation Nursing. Apart from various activities of this institute, one of the mandates is to organize/ promote/ sponsor the training programs/CME/ Workshop etc.

In view of this, we have taken up a National Conference of Indian Academy of Cerebral Palsy (IACP) to be organized by NIOH under the aegis of WBOA (West Bengal Orthopaedic Association) as a part of IACP program from 4th – 6th November 2011 at NIOH, Kolkata.

We take immense pleasure in cordially inviting you to join this 6th IACP-CON – 2011 at NIOH Kolkata from 4th – 6th November 2011. The theme chosen for this conference is "Cerebral Palsy – Womb to Tomb". Day – 1 of this conference (4th November 2011) will be dedicated to three different preconference workshops.

The eminent faculties from different fraternity e.g. Orthopaedics, Paediatrics, Neurosciences, Physiotherapy, Occupational therapy, Prosthetics & Orthotics, Rehabilitation Nursing, Socioeconomic Rehabilitation Specialists etc will deliver their presentation. Apart from this galaxy of speakers will be there to cover the topic.

We are assuring you that we will spare no stone unturned to make this conference a memorable one. We take the opportunity to thank Dr. Ashok Johari (President, IACP), Dr. Shashikala (Secretary, IACP) and all the members of IACP for bestowing us with this responsibility to organize this conference.

We are eagerly looking forward to welcome you at NIOH "The Prestigious Institute" in Kolkata "The City of Joy & Cultural Capital of India".

Dr. Ratnesh Kumar
Organizing Chairman

Dr. Sanjay Keshkar
Org. Secretary

Prof. T.K. Maitra
Executive. Chairman

Prof. N.K.Das
Scientific Chairman

Organizing Committee
Core Committee

Organizing Chairman	: Dr. Ratnesh Kumar
Executive Chairman	: Dr. T.K. Maitra
President, WBOA	: Dr. M.M. Ray
Hon. Secretary, WBOA	: Dr. Amit Guha
Organizing Secretary	: Dr. Sanjay Keshkar
Co-organizing Secretary	: Dr. Rakesh Jhalani
Joint Organizing Secretary	: Dr. Vipul Shah
	: Dr. Rajesh Bhalla
Scientific Chairman	: Dr. N.K. Das

Conference Secretariat:
Room No. 210, NIOH,
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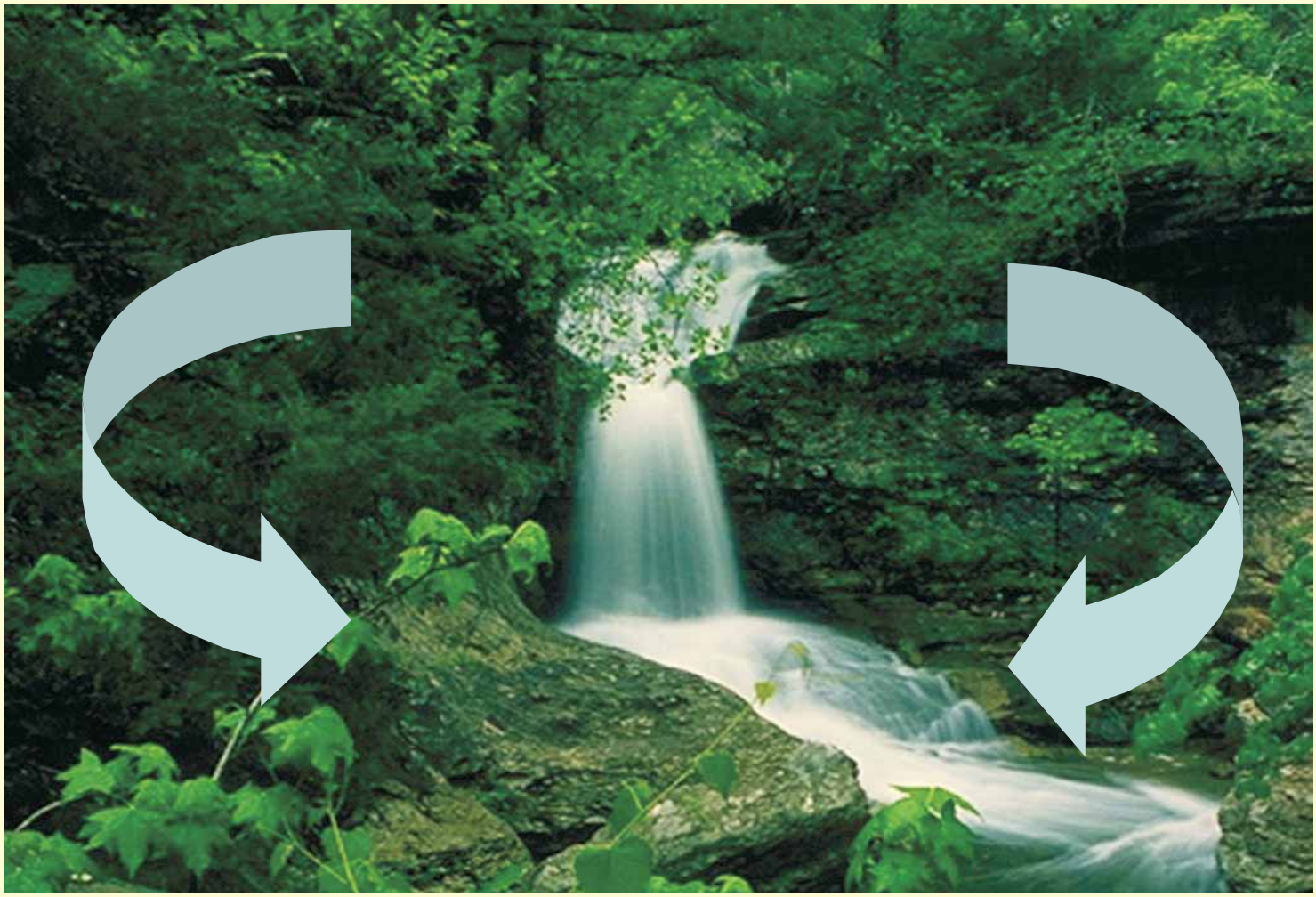
EXCITOTOXIC CASCADE - Confluence of multiple factors - >cumulative neuronal death

O2, Ca, Glucose, Genetics, Iodine, substrate deficits, Maternal health (micro & macro), Fac v laiden, Family history, Natal Antenatal & perinatal care



APPEAL

We request all of you to celebrate
NATIONAL CEREBRAL PALSY DAY on 3rd of October 2011
and send report with photographs to the The General Secretary, IACP. CP Day celebration reports sent before end November will be published in the December newsletter.

For Latest updates in Cerebral Palsy Logon to IACP website

iacp.co.in

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

Be a Member of IACP

Stand united with IACP members, Stay up to date, Grow your professional network, Obtain ongoing support and guidance, Access to quality CME programme, 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 specialty. Promote the specialty to future professionals.

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

Edited, Printed and Published by Dr. G. Shashikala, General Secretary, IACP on behalf of
Indian Academy of Cerebral Palsy, Children's Orthopaedic Centre, Bobby Apartments, Lady Jamshedji Road, Mahim, Mumbai - 400 016.