

Executive Summary
India Pediatric Oncology Initiative
Meeting

India **Pediatric**
Oncology Initiative™

FIRST ANNUAL MEETING

January 24-25, 2009

Le Meridien Hotel
New Delhi, India

Jiv Daya Foundation

2/2/2009



Date/ Location:

Saturday, January 24 - Sunday January 25, 2009 - Delhi, India

First annual meeting of Jiv Daya Foundation's "India Pediatric Oncology Initiative"

Participants:

Moderators & Advisory Board

Vinay Jain (President, Jiv Daya Foundation, TX, US)

Murali Chintagumpala (Texas Children's Cancer Hospital, TX, US)

Amar Gajjar (St. Jude Children's Medical Research Hospital, TN, US)

Vikram Kanwar (Albany Medical Center, NY, US)

Sadhana Shankar (Glaxo Smith Kline, PA, US)

Attendees:

Pankaj Abrol (Post Graduate Institute of Medical Sciences, Rohtak, Haryana)

Brijesh Arora (Tata Memorial Hospital, Mumbai, Maharashtra)

Sandeep Agarwala (All India Institute of Medical Sciences, New Delhi, India)

Poonam Bagai (CanKids...KidsCan, New Delhi, India)

Sameer Bakhshi (All India Institute of Medical Sciences, New Delhi, India)

Shweta Bansal (Tata Memorial Hospital, Mumbai, Maharashtra)

Anita Chandra (Sri Ramachandra Institute of Medical Sciences, Chennai, Tamil Nadu)

Girish Chinnaswamy (Christian Medical College, Vellore, Tamil Nadu)

Sanjeev Digra (Government Medical College, Jammu, J & K)

Mona Gajre (Lokmanya Tilak Municipal General Hospital, Mumbai, Maharashtra)

Raman Kataria (Jan Swasthya Sahyog, Bilaspur, Chattisgarh)

Shailesh Kavinde (Deenanath Mangeshkar Hospital, Pune, Maharashtra)

Rizwan Khan (Aligarh Muslim University, Aligarh, Uttar Pradesh)

Purna Kurkure (Tata Memorial Hospital, Mumbai, Maharashtra)

Archana Kumar (Chhatrapati Shahuji Maharaj Medical University, Lucknow, Uttar Pradesh)

P. Kusumakumary (Regional Cancer Center, Trivandrum, Kerala)

Vijay Linga (Nizam Institute of Medical Science, Hyderabad, Andhra Pradesh)

Amita Mahajan (Apollo Hospital, New Delhi, India)

Mamta Manglani (Lokmanya Tilak Municipal General Hospital, Mumbai, Maharashtra)

Ram Kumar Marwaha (Postgraduate Institute of Medical Education and Research,

Chandigarh, Punjab)

Manjusha Nair (Regional Cancer Center, Trivandrum, Kerala)

Digumarti Raghunadharao (Nizam's Institute of Medical Sciences, Hyderabad, Andhra Pradesh)

Lakshmi Srinavas Malladi (Cancer Institute (WIA), Chennai, Tamil Nadu)

Lalit Sharma (Bhagwan Mahaveer Hospital & Research Center, Jaipur, Rajasthan)

MEETING SUMMARY:

The Inaugural meeting of the India Pediatric Oncology Initiative was held in New Delhi in January of 2009. Attended by over 40 delegates, this 2 day meeting was well received and supported by oncologists from all over the country. The meeting was a forum for current strategies to be reviewed and new ideas for Jiv Daya Foundation to become involved in pediatric oncology efforts in India. Areas of need presented themselves with potential projects for the Foundation to support. Participants were able to network with one another and learn how others in the field have overcome the same challenges that are prevalent in pediatric oncology today. Success stories, patient data, infrastructure needs and methods for providing treatment and attaining positive results were shared among the group. The second day was filled with individual reporting sessions from current grant projects as well as potential grant recipients. The *'Practical Handbook for Nurses in Pediatric Oncology'* written by Dr. Gauri Kapoor, was distributed to all delegates, as the Foundation had provided a grant to pay publishing a majority of these manuals.

IPOI 2009 brought together faculty and delegates from the USA and India to address common challenges in pediatric oncology and learn from one another. The meeting was

a great success and established new firsts for the partnership with Jiv Daya Foundation and institutions in India to work towards the improvement of pediatric oncology. Several projects for nurse training, salary support for staff and textbooks were brought to light for future projects that can be supported by the Foundation.

Goals of the Meeting

- To accelerate the development & improvement of pediatric oncology in India by:
 - Re-engaging members in the field about treatment needs and tapping into their ability to impact outcomes
 - Emphasizing rationale for improved manpower and training on overall patient survival rates
 - Identifying tangible projects that can provide immediate assistance such as nurse training, support for textbooks and subscriptions to journals, salary support for Physicians, Nurses, Social Workers and Data Managers, etc.
- To gain a better understanding about the landscape of pediatric oncology in India
- To stimulate discussion amongst members in the field to learn from one another and address common issues that are prevalent in pediatric oncology in India.
- To be a forum where current strategies will be reviewed and new ideas for Jiv Daya Foundation to become involved in pediatric oncology efforts
- To identify areas of need and tangible projects for the Foundation to support
- To learn methods to improve cure rates among children with cancer
- To identify champions to transition ownership of future Foundation projects & meetings

Key accomplishments:

1. Renewed understanding and/or awareness of the pediatric oncology landscape in India.
2. Individual reports provided an overview of patient population, infrastructure, training and manpower needs that are prevalent today.
3. Delegates committed to work together and to try to create a pediatric oncology cooperative group in the future.
4. Potential projects for manpower enhancement, training projects and textbook support were tentatively approved by the Foundation (pending formal paperwork).

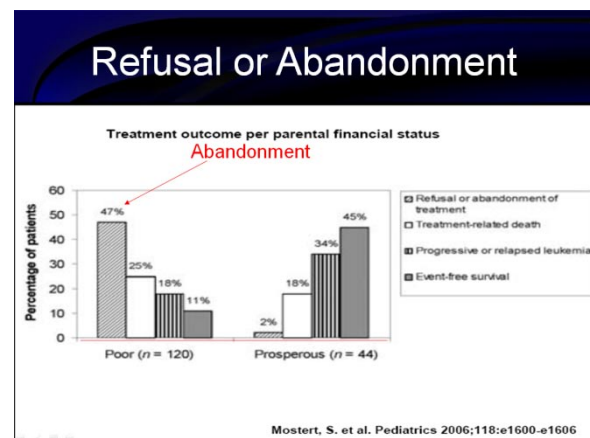
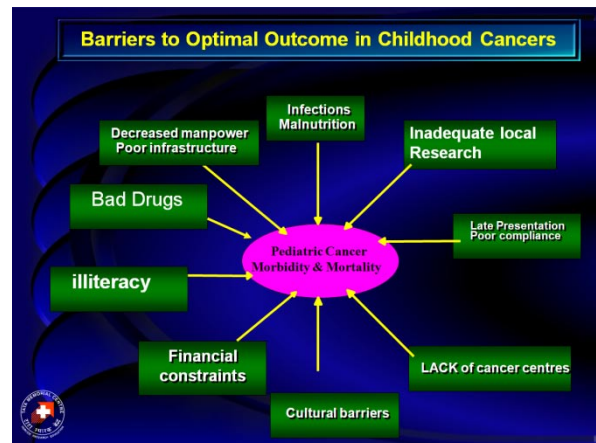
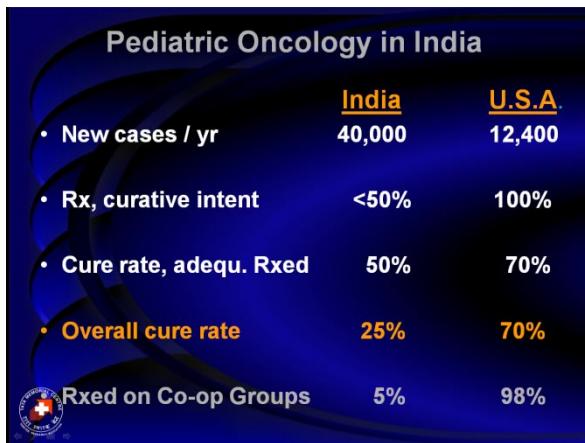
Agenda

Overview and Goals of the IPOI	Vinay Jain
Infrastructure Needs in Pediatric Oncology Care	R.K.Marwaha
The Outpatient Setting in the Delivery of Cancer Care	Sameer Bakhshi
Challenges of Providing Cancer Care in a Tertiary Setting	Brjesh Arora
Improving Leukemia Cure Rates	L. Appaji
Providing Pediatric Oncology in a General Hospital	Mamta Manglani
Building a Pediatric Neuro-Oncology Unit at RCC	P. Kusumakumary
Building a State-Wide Network for Pediatric Oncology	Dirgumarti Rao
Providing Oncology Care in a Primary Health Care setting	Raman Kataria
In a Tribal-Rural area in Central India: Lessons Learned	
Challenges of Implementing Western Medicine in the Indian Context	Girish Chinnaswamy
Public/Private Partnerships in Delivering Pediatric Oncology Care	Sujatha Shankar
Accessing Government Health Care Plans	Murali Chintagumpala Poonam Bagai

Key Discussion Points:

1. Pediatric Oncology in the Indian Context

The presentations and discussion highlighted the current scenario of pediatric oncology status in India. Delegates discussed existing barriers to attaining optimal outcomes; i.e., lack of infrastructure, insufficient staff, lack of training, economic restraints and other challenges related to the delivery of care. The common issue expressed was the constant influx of patients, inadequate beds to see them all and not enough staff to treat them.



Snapshot of Daily Patient Load:

Daily OPD Rates are very high:

- AIIMS - Daily OPD is 70 -80/day
- TMH - Daily OPD is 180/day
- Kidwai- Daily OPD 60 patients/day

2. Areas of need were identified for Jiv Daya Foundation to make an impact:

A) Nurse Training Opportunities:

Nurses should be trained in pediatric oncology basics and able to administer chemotherapy drugs.

- JDF can provide scholarships for nurses to train at Tata Memorial Hospital and All India Institute of Medical Sciences to provide travel grants for accommodations, travel, per diem.
 - Projects Proposed:
 - LTM Hospital, Mumbai - Send 4 nurses to train at Tata Memorial
 - PGIMS, Rohtak - Send 3
- JDF can provide scholarships for nurses on our active grant projects to attend the India ONS (Oncology Nursing Society) meeting to network and learn from other nurses in the field.

B) Retaining Staff in Pediatric Oncology:

- Jiv Daya Foundation can provide a grant to incentivize health care professionals to stay committed to pediatric oncology.

Example: NIMS - we have given money to be an incentive for nurses to stay on board and it has worked. This has been in conjunction with the medical center and their approval.

C) Alternate Training Methods:

- JDF can provide grants to purchase:
 - Pediatric oncology textbooks
 - Subscriptions to important journals such as "Pediatric Blood & Cancer"
 - Printing of manuals created by physicians in India.

i.e. We provided a grant for the printing of 500 copies of Gauri Kapoor's Pediatric Oncology Nursing Manual which were distributed at this meeting.



D) Training for Data Managers:

- a. They need to have an understanding of pediatric oncology
 - b. They need to know what format to enter data
 - c. They need to know how to analyze the data
2. JDF promoted the IndiaPOD on Day 2 to feedback from the participants about changes that should be made and how they can best make use of it.
 3. IDEA: Doctors should be appointed to help Data Managers understand the terminology, case records and pediatric oncology for data entry.
 4. Data management courses are available in India.
 - a. If sites can identify and hire a Data Manager, then The Foundation can provide support for their training.
 5. Clean data is needed to help institutions benchmark and analyze their data.

E) Support for Physicians:

- a. The Foundation is willing to provide salary support for physicians, nurses, social workers, data managers and field workers who are dedicated to pediatric oncology.

3. Alternate Resources for Economic Assistance:

- Fact: The majority of patients in India are of low socio economic status
 - Opportunity:
 - Prime Minister's Relief Fund
 - Chief Minister's Relief Fund
 - Dr. Reddy's Foundation
 - Local NGO's and donors (such as CanKids, based in Delhi)

4. Reports from Current Grant Projects:

- Each site presented on the status of their respective grant projects. This highlighted the number of staff hired, patient data, benefit made on outcomes and future plans for improvement. The purpose of this reporting was to assess the added benefit that was made with Foundation assistance and to show others what is possible.

Commitment to Care:

Vinay Jain asked key questions that focused on building capacity for treatment at each site. The feedback from these questions helps Jiv Daya Foundation to understand the need of each site and their thoughts on how outcomes can be improved.

Some of the immediate projects which were suggested include:

1. PGIMER, Chandigarh – Salary support for 1 Data Manager & 1 Social Worker
2. LTM Hospital, Mumbai – Support for nurse training, textbooks and journals
3. Government Medical College – Physician training in pediatric oncology at a neighboring tertiary center

Future Steps:

1. To follow up on the potential projects mentioned during the meeting to evaluate the potential for maximum benefit to building capacity and increasing outcomes at a center.
2. These potential projects will undergo proper review by JDF staff and board
3. To keep members engaged and support efforts to generate interest, awareness of and knowledge of pediatric oncology.

