



Developing Infrastructure for Pediatric Oncology in India:

India Pediatric Oncology Initiative
Experience

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March 23, 2009





Current Infrastructure for Pediatric Oncology in India

Enumeration of the work force

Where are childhood cancers treatable/ treated?

Resources:

- **Clinicians: Oncologists – Paed, Surg, Radiation**
 - expertise in special tumor types, e.g. retinoblastoma
- **Diagnosticians: Path & imaging**
- **Wards**
- **Drugs**
- **Supportive care**
- **Registry: what type of cancers, age groups, stages, treatments and outcomes**



For whom?

- **For the patients and their families**
 - **For health professionals**
 - **Oncologists**
 - **Paediatricians**
 - **Nurses, Pharmacists, Social workers**
 - **Registry staff**
 - **For policy makers**
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26 Regional Cancer Centers

1. Kamla Nehru Memorial Hospital, Allahabad
2. Regional Cancer Centre, Trivandrum
3. Chittaranjan National Cancer Institute, Kolkata
4. **Kidwai Memorial Institute of Oncology, Bangalore***
5. **Cancer Institute (WIA), Adyar, Chennai***
6. Gujarat Cancer Research Institute, Aswara, Ahmedabad
7. MNJ Institute of Oncology, Hyderabad,
8. Dr. B.B. Cancer Institute, Gopinath Nagar, Guwahati
9. Acharya Harihar Regional Cancer for Cancer Research & Treatment, Manglabag, Cuttack
10. Regional Cancer Centre, Indira Gandhi Medical College, Shimla
11. **Tata Memorial Hospital, Parel, Mumbai ***
12. Cancer Hospital & Research Centre, Mandre Ki Mata, Gwalior
13. Indira Gandhi Institute of Medical Sciences, Sheikhpura, Patna
14. **Institute Rotary Cancer Hospital, (A.I.I.M.S), New Delhi ***
15. Acharya Tulsi Regional Cancer Research Institute (RCC), S.P. Medical College, Bikaner, Rajasthan
16. R.S.T. Cancer Hospital & Research Centre, Nagpur, Maharashtra
17. Pondicherry Cancer Care Society, JIPMER, Pondicherry
18. Regional Cancer Centre, Pt. B.D. Sharma Post Graduate Institute of Medical Sciences, Rohtak, Haryana
19. Pt. J.N.M. Medical College & RCC, Raipur, Chhattisgarh

*Current or Past site for an INCTR protocol sites

Five New Regional Cancer Centers Were Recognized in 2005

- 20) Sanjay Gandhi Post Graduate Institute, Lucknow, Uttar Pradesh
- 21) Post Graduate Institute of Medical Education and Research, Chandigarh
- 22) Sher-i-Kashmir Institute of Medical Sciences, Srinagar, Jammu and Kashmir
- 23) Arignar Anna Memorial Cancer Research Institute and Hospital, Kancheepuram, Tamil Nadu
- 24) Regional Institute of Medical Sciences, Imphal, Manipur



Who is treating children with cancer?

- **Physicians**
 - **Adult Oncologists**
 - **Pediatricians**
- **Nurses**
 - **Majority are not trained in chemotherapy administration or infection control**
- **Chemotherapy Administration**
 - **Pharmacists mix the chemotherapy regimens**
 - **Given by the Nurse or Resident Doctor**



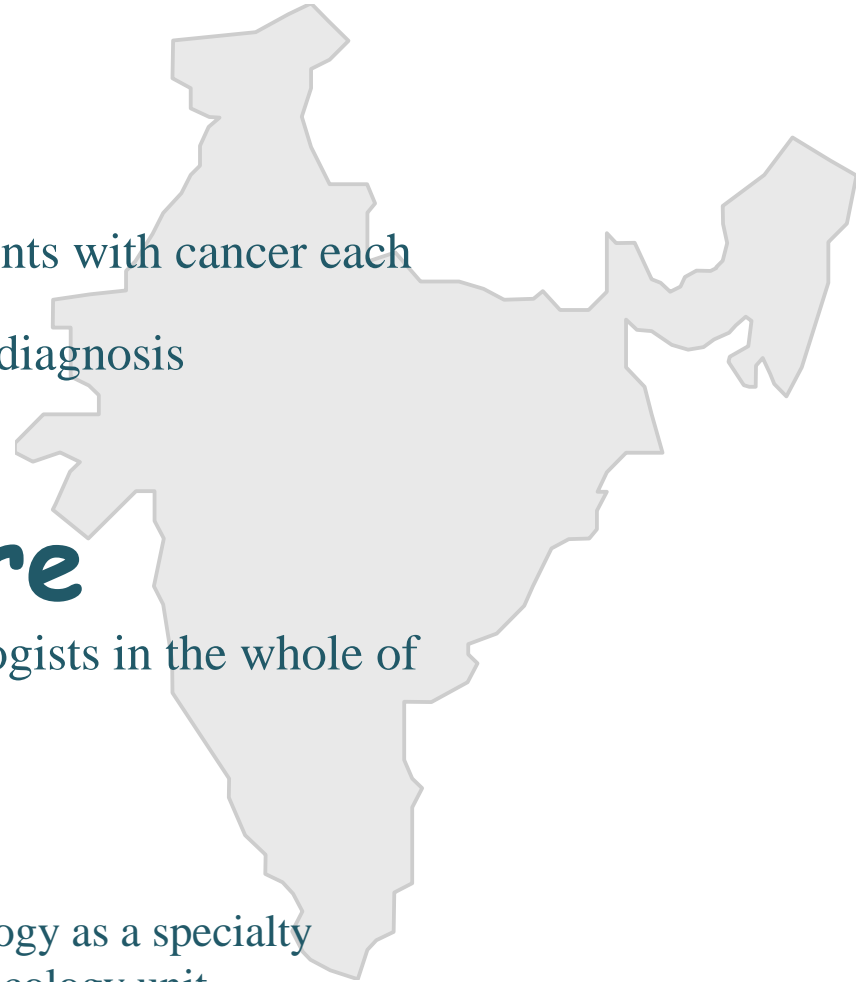
The Pediatric Oncology Workforce

The Situation

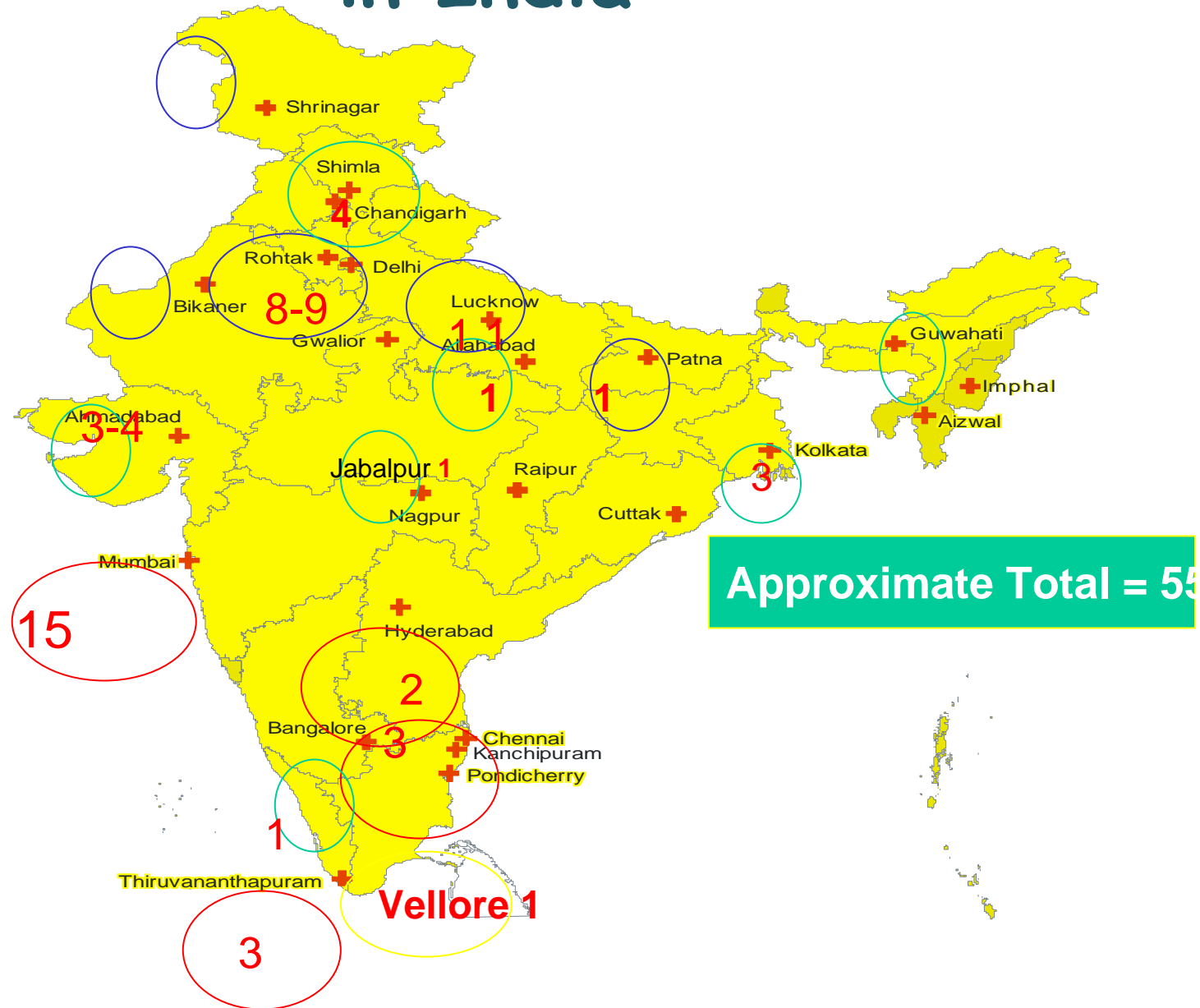
- 25% of childhood cancers occur in India
- Approximately 40,000 new pediatric patients with cancer each year
- 70% of patients have advanced disease at diagnosis
- Cure rates vary between 10% – 25%

The Infrastructure

- Approximately 55 trained pediatric oncologists in the whole of India
- 26 Regional Cancer Centers
- 172 Oncology Departments
- 265 Medical Colleges
 - Medical Colleges do not recognise Oncology as a specialty
 - Most *do not* have a dedicated pediatric oncology unit
 - Most do provide *some* care to children with cancer
 - Most diagnose and refer



Practicing Pediatric Oncologists in India



Professionalising the Workforce

Professionalizing the Workforce

- **India National Training Projects exist for Practical Pediatric Oncology & Hematology**
 - (NTP – PPH & NTP – PPO): very few paediatricians in training ever attend it
- **Objective – Workshops to train pediatricians across the country in early diagnosis, management and shared care of cancer & blood disorders in children.**
 - Each 2 day workshop is aimed at training 25-30 physicians
- **National Board Fellowship Program = Not MCI recognised**
 - **Three month training program**
 - In-service pediatricians with an interest in the pediatric oncology
 - Training program for nurses:
 - Nursing manual developed by Dr. Gauri Kapoor or Dr. Anupam Sachdeva, which can be distributed throughout India
- **INCTR Handbook for Pediatric Supportive Care Guidelines**

Training Opportunities

Training Programs for Pediatric Oncology:

1. AIIMS:

- Formal 2 yr training course for Master's Course in **Oncology Nursing**
- Diploma in Nursing is a formal training for one year
- Infectious Disease and chemotherapy administration have 1 month training courses

2. Tata Memorial Hospital:

- 6 month pediatric oncology training program = not recognised anywhere

3. Kidwai Memorial Institute of Oncology:

- Starting a 6 month pediatric oncology fellowship
- Two year full fellowship will be launched soon

4. PGIMER:

- 3 year fellowship
- Planning a 1 year or 6 month course on basics in pediatric oncology in conjunction with AIIMS

Barriers to Optimal Outcomes in Childhood Cancers

- Barriers to the Delivery of Care:
 - Lack of manpower
 - Poor infrastructure
 - Advanced disease at presentation & poor compliance
 - Co-morbidities: Hep B, TB, Malaria, HIV
- Barriers to Access of Care:
 - Illiteracy & Cultural Barriers
 - Financial constraints
 - Lack of cancer centers and trained professionals

How Can We Get There?

- Establish dedicated pediatric units in every one of the 26 regional cancer center
 - Increase the number of trained, dedicated pediatric nurses
 - Train more nurses in pediatric oncology
 - Ensure and document compliance of patients with complete treatment plan
 - Track, enter and analyze data
-

Methods to Improving Infrastructure in Pediatric Oncology

Developing leaders to become local champions to improve the standard of care for children with cancer

Promoting alliances between cancer centers, hospitals and health professionals within India and between India and the US to maximize benefit from the available expertise

Emphasizing **long term collaborations** with medical institutions and physicians throughout India by **Networking**

Expanding pediatric oncology care and training for health care providers, improve staffing in pediatric oncology, and build capacity for treatments

Tracking patient data to understand barriers of attaining remission

Utilizing Social Workers to **connect families to financial assistance**

Goal: Improve overall survival rates of children with

**ISMPO XI Biennial
Conference, NIMS, Hyderabad**

27-29 Jan 2001

**Formation of a Childhood Acute
Lymphoblastic Leukemia study group**

**Prof Magrath and the MCP 841
participants**

Best so far

**Paediatric Oncology Subdivision of the
Indian Academy of Paediatrics**

**Funds up to 6 workshops a year:
Literature, workbooks, faculty, lunch and
snacks**

Held at NIMS in 2003

Results of the workshop

- **We offered free registration for all faculty and Paediatrics Fellows for the *entire state***
 - All medical colleges and children's hospitals
 - Nearly 16 students per year x 3 = 48 in all
 - 32 registered, 28 attended, 20 remained for tea
 - Dr. Bharat Agarwal, Prof Poorna Kurkure
- **Are paediatricians really interested in a sub-specialty training in oncology???**

Reasons for poor uptake of treatment:

Poverty?

- **Delay in diagnosis**
- **Poor knowledge of availability of services**
- **Logistics: dropout rate**
- **Loss of wages**
- *Lack of follow up: both for continuing treatment and for survival*

Solution: Networking

- **Identify paediatricians, physicians, oncologists interested in treating childhood cancer in:**
 - **Medical Colleges, Districts HQ & Large Towns**
 - **Assess their capabilities & resources**
 - **Build capacity at all levels: MD & Nurse**
- **Finish initial treatment & refer for continuing therapy closer home**
- **Started with the Telangana Districts**

Childhood cancer study group

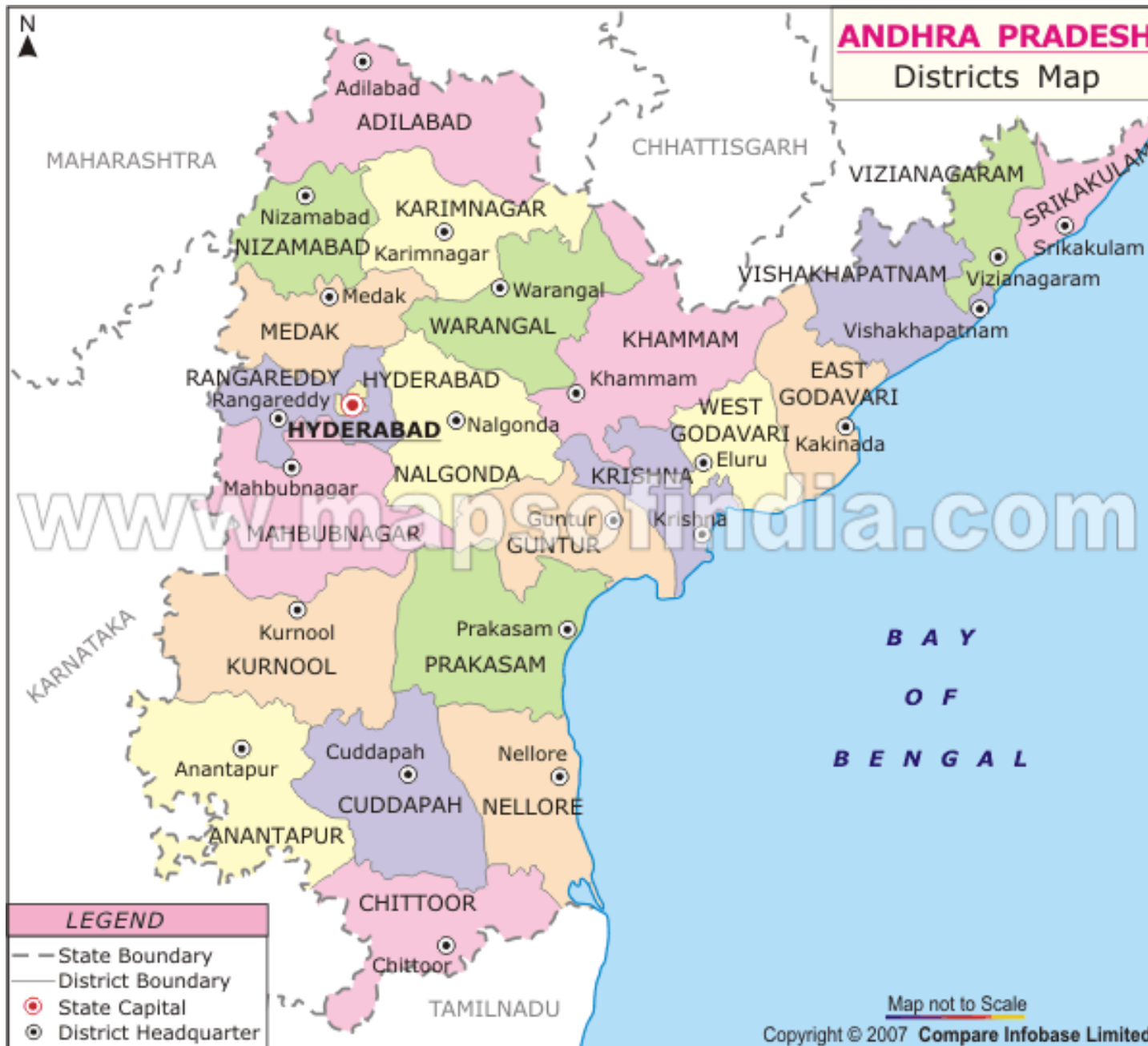
27th October 2007 Time: 9.30 am – 4.00 pm

- 1) Assuring continuity of care for pediatric cancer patients**
- 2) Panel discussion of problems and solutions in pediatric cancer care**
- 3) Management of Wilm's tumor, Osteosarcoma, Rhabdomyosarcoma**
- 4) Acute Lymphoblastic and myeloid leukemia**
- 5) Formation of the Children's Cancer Study group of Andhra Pradesh**

Faculty:

Dr. Murali Chintagumpala

Dr. Yaddanapudi Ravindranath



Cancer Services, AP

- **Hyderabad**
- **Karimnagar**
- **Warangal**
- **Kurnool**
- **Guntur**
- **Nellore**
- **Visakhapatnam**
- **Kakinada**
- **Rajahmundry**
- **Bhimavaram**
- **Vijayawada**
- **Tirupati**

All government medical colleges have a Cobalt machine, none a surgical or medical oncology dept

Over 35 radiation centers, 15 in Hyderabad alone

Arogyasree scheme

- **Launched 2 years back in the state**
- **A medical insurance scheme for those below poverty line**
- **Cancer therapy is included**
- **Any hospital with over 35 beds can enroll**
- **Cashless facility**
- **Has lots of teething troubles...**

MOFA

- **Hyderabad**
- **Tirupati**
- **Nellore**
- **Vijayawada**
- **Guntur**
- **Visakhapatnam**

**28 members, DM or AB in medical &
paediatric oncology**

Future Plans

- **Networking programs for districts around a MOFA members' place of work**
- **Include regional paediatricians in the totality of care**
- **Train registry staff, chemotherapy nurses and medical social workers**
- **Use the IAP's core curriculum program**

Patient Perspectives



Stay, Food, Transport, Language

- Most have no place to stay
- Lack of good facilities for healthy hygienic food
- Many travel from distant villages regularly with no proper travel facilities
- Expense of frequent inter and intercity travel
- Many are unable to communicate well

Addressing Social Issues to Increase Outcomes

- **Financial support:** Patients can apply for financial assistance from the Government and local donors or NGOs to subsidize treatment costs
- **Food:** Low-cost/free food should be provided in the treatment facility
- Help with **stay in hospital facilities or Dharamshala;** can be liaised with local NGOs (such as CanKids...KidsCan)

Immediate Solutions - Social Workers

- Social Workers
 - Address social needs of families with the help of philanthropic organizations and **facilitate funding support** from the government and local resources
 - **Follow up** with patients about therapy
 - **Connect** patients with support groups and psychological assistance
- Return:
 - Less children lost to follow do to regular contact, place to stay, supplemental finances to allow initiation and eventually completion of therapy

Next Steps for Pediatric Oncology Development

- Develop partnerships with medical institutions in India and the United States for
 - knowledge transfer
 - financial support
 - empowerment for individuals

(Institutions in the US are eager to develop partnerships for training and collaborations with hospitals and centers overseas)

- Build the capacity to provide high quality care to patients
 - Take advantage of opportunities for manpower enhancement & training
 - Work aggressively towards building a dedicated unit of trained support staff:
 - Physicians, Nurses, Social Workers, Data Managers, Social Workers, Pharmacists, Field Workers





Immediate Solutions - For Centers

- Designated space
- Committed physicians
- Dedicated nurses
- Social Workers and
- Data Managers
- Pharmacists



Immediate Solutions - For Patients

- Socio-Economic needs of families can be addressed with the help of
 - philanthropic organizations who can facilitate
 - funding support from the government
- Support Groups, Counselors and Psychologists

Mobilizing Resources
Sources of Funding for Pediatric Oncology

Immediate Solution - Data Managers

- Hire Data Managers dedicated to pediatric oncology:
 - Collect patient data in the clinic
 - Enter data into a database
 - (i.e. Jiv Daya Foundation's IndiaPOD www.indiapod.org)
 - Analyze and interpret data to show trends in cancer incidence, therapy outcomes, etc.
- Return:
 - Empowerment for Institutions to publish their data
 - Collective analysis of
 - Patient demographics
 - Treatment administration
 - Chemotherapy
 - Radiation
 - Transfusion
 - Follow up status

India Pediatric Oncology Database

Current User: indiapod
08TM0099: SHALINI PANDEY Age: 13yrs Registration Date: 5-4-2008

Home

Add New Patient

Patient Search

Patient Demographics

Disease Summary

Therapy Administration

Surgery

Radiation

Chemotherapy

Transfusion

Follow Up

Standard Lists

Administration

User Administration

Reports

Logout

Therapy Administration

Treatment Started Treatment at this Institution Treatment Start Date dd-mm-yyyy Treatment Cessation Date dd-mm-yyyy

-Select -Select

Chemotherapy Status Radiation Status Surgery Status Hospital Admission Date dd-mm-yyyy

-Select -Select -Select

Reason Treatment Ended Reason Treatment Not Given

-Select

Save Therapy Administration Data

**Ensuring Long Term Sustainability
...State-Wide Networks for Pediatric Oncology**

Jiv Daya Foundation

India **Pediatric**
Oncology Initiative™



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