

Minutes of meeting of STAKEHOLDERS on CHD


Venue- NHM Conference Hall

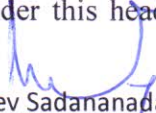
Date- 13th January 2017

Participants

- Shri. Rajeev Sadananadan IAS, Additional Chief Secretary (Health)
- Shri. Keshvendra Kumar IAS, SMD-NHM
- Dr. B Ekbal, Planning Board Member, Kerala
- Dr. Arun Kumar Singh, National Advisor-RBSK, MOH&FW
- Dr. R Ramesh, DHS Kerala
- Dr. RamlaBeevi DME Kerala
- Dr. Krishnakumar, Prof&Head, Dept of Pediatric Cardiology, AIMS, Cochin.
- Dr. Balu Vaidyanathan, Professor, Dept of Pediatric Cardiology, AIMS Cochin
- Ms. Bistra Zheleva, Vice President (Programs), Children's HeartLink
- Ms. Adriana Dobrzycka, International Programs Manager, Children's HeartLink
- Dr. Jayakumar, Cardio Thoracic Surgeon, Superintendent Government Medical College, Kottayam
- Dr. Ramesh, Cardio Thoracic Surgeon Government Medical College, Calicut.
- Dr. Arun, District Programme Manager, Alappuzha
- Dr. Rani, SNO – RBSK, Kerala
- Dr. Amar Fettel, SNO Arogya Kiranam
- Dr. Riyaz, IAP President Kerala
- Dr. Zulfikar Ahamed, Prof. & Head, Dept of Pediatric Cardiology, SAT
- Dr Baiju, Addl. Prof. & In Charge Head, Dept of CTVS, SCTIMST Thiruvananthapuram
- Dr. Jawahar, Superintendent/RMO, SCTIMST
- Dr. Jagadeesh, Deputy Direct Planning, DHS Kerala Mr. Suresh, State HR & Administrative Manager, NHM
- Ms. Veeralakshmi Rajasekhar, In Country Consultant, Children's HeartLink
- Ms. Rajashree Panicker, Monitoring & Evaluation Consultant, Children's HeartLink
- Dr Sreehari M., State RMNCH+A consultant UNICEF Kerala

The meeting started with the introductory remarks from Shri. Keshvendrakumar IAS, State Mission Director NHM Kerala. In his remarks, he reinstated the commitment of Government of Kerala for further reduction of IMR to single digit and briefed their efforts in line with SDG targets set by Kerala. He also briefed on the ongoing activities partnering with UNICEF, IAP, KFOG and other professional bodies for improving standard of care during delivery and newborn care by setting new quality standards formulated based on local evidences. Also affirmed that budget will not be a problem for taking up initiatives under this head and


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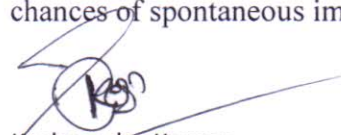
NHM will be giving focused planning and implementation of activities in this line in coming years.

Dr B. Ekbal, Former Vice Chancellor of Kerala University and Present Planning Board Member congratulated all those involved in this effort for acknowledging the relevance of the issue and supporting the states for their efforts to further reduce IMR as a model to the whole nation. He expressed all his support to the plan of action proposed out of the workshop and for the future of this program.

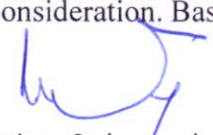
Following this there were presentations from experts from different domains on topics related to management of congenital Heart Disease.

Dr Arun Kumar Singh, National Advisor, RBSK in his presentation on RBSK and Management of children with CHD (Potential for Kerala) pointed out the need for Kerala to set new targets and show the way to others as they have no role model as on date to achieve the goals dreamed of. He appreciated the efforts the state has undertaken and congratulated all involved in the efforts and expressed all possible supports to this endeavor. He said that Kerala needs to explore all possibilities out of RBSK in their future plans and for that it is essential to go in line with RBSK strategy of GoI. He reinstated the need to have universal screening of newborn for birth defects in Kerala with focus on visible and functional Birth defects before extending metabolic screening to more centers. He pointed out that CHDs as one of the leading cause of IMR in Kerala needs to be addressed with special focus by taking it up along with the birth defect screening program and standard protocols, guidelines and procedures globally available may be customized and used in the delivery points and followed by the universal RBSK screening program in AWC up to 6years, planned twice a year and confirmation through DEICs. He pointed out that as per the available statistics prevalence of CHD is around 5/1000 and that of critical congenital heart disease in India is about 3/1000, and unfortunately only 3% of them receive treatment in time. He also reinstated the essentiality of empaneling more private institutions in the state before going for an extensive screening program to accommodate surgery for those children affected and identified to have critical CHD along with strengthening public health facilities in Kerala to take care of more of that kind in near future itself. He suggested planning accordingly while preparing PIP for the coming year under RBSK.

Dr Arun Kumar Singh insisted on following the national guidelines for managing cases with CHD with due consideration to the fact that each case needs individualized care plan based clinical judgement and exceptions may be made. The national guidelines are very clear on documentation of the pre-operative investigations which are mandatory for preauthorization for surgery, ideal age for intervention or timing of surgery, cases where surgery is not indicated and chances of spontaneous improvement and by which age for the case under consideration. Based



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on the guidelines there is a categorization of cases into three classes, (1) General agreement exists that the treatment is useful and effective, (2) conflicting evidences or divergence of opinion or both about the usefulness/ efficacy of treatment, (3) Evidence and/or general agreement that the treatment is not useful and in some cases, is harmful. He also suggested to form a committee which would help: A) On guidance regarding the type of intervention, its usefulness, effectiveness, alternate provisions, etc. over-e-mail B) Study the existing centers and recommend ways to improve the facilities C) Develop more DM pediatric cardiology centers in the state and increase the seats of the already existing ones D) Develop short term courses for various health personals.

In his presentation on 'Significance of CHD from public health perspective and the economics of managing CHD', Pediatric Cardiologist, Dr. R. Krishnakumar, AIMS Kochi, gave a public health perspective to the management of CHDs and pointed out that Congenital Heart Disease surfaced as IMR declined in Kerala and the thought for affordable surgery options started since 90's. Among the different types of CHD, mortality in percentage if uncorrected before 1 year age is as follows for, Tetralogy of Fallot (25%), Transposition (72%), Persistent Truncus arteriosus (75%), Total anomalous pulmonary venous connection (90%), Duct dependent Pulmonary atresia (~100%), Duct dependent systemic circulation (~100%), Single ventricle variants(75%). He suggested to consider all three forms like Infant and newborn heart surgery, Catheter interventions and Medical management in the options while planning. Dr Krishnakumar in his presentation very well narrated the components of a comprehensive cardiac care program which should have a pediatric cardiology, Pediatric Cardiac Surgery and intensive care wing along with support from neonatology, general paediatrics and pediatric surgery, nephrology, gastroenterology, child development, etc. He said skilled and committed caregivers, coherent teamwork, robust infrastructure, quality equipment, supportive administration, well-developed and mature referral base, favorable economics and human development in the region, a system for charitable care, sustainable systems and services: education and training, nursing and ethical practice environment that is not totally profit driven are very much essential for developing a pediatric cardiac service in a hospital.

Dr. Balu Vaidyanathan, Pediatric Cardiologist from AIMS, Kochi proposed making fetal heart evaluation a must for all pregnancies (within the 20 weeks gestation period) and to have it as part of the anomaly scan in Kerala where there is 100% access to antenatal care and institutional births (99.5 %). In his presentation, pointed out that 25% of the IMR in Kerala is contributed by CHD and 60% the children with critical CHD die before the first birthday. He also described the RACHS system of classification for CHD ie, simple, Major, Complex and More complex for pointing out the varying treatment provisions and for clearly understanding the need for prenatal diagnosis and the management provisions based on that. He suggested a



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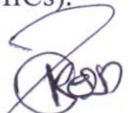
two-prong approach, Screen everyone or Targeted study- high risk cases only, keeping in mind that 10-20% of CHD occur among high risk pregnancies. Then he explained the ideal timing for fetal heart evaluation as 14-20 weeks gestation pointing to the MTP act and its relevance in this context and the need to combine fetal heart screening with anomaly scan. Following recommendations are put forth to make Fetal heart evaluation mandatory component of all targeted anomaly scans with timing of scan: 16-20 weeks' gestation. Further educate regarding the standard protocol for conduct and reporting of scan and referral of cases which fail screening to higher level of expertise. Following this a core advisory group of experts from fields of cardiology, Obstetrics, Radiology and Fetal Medicine may be formed to prepare a training module and organise workshops in Govt medical colleges/academic institutions/district hospitals and an advanced training for selected doctors who wish for higher level of expertise(ToTs). It is also advisable to maintain a database of all records, follow-up of pregnancy and neonatal outcomes for medicolegal, academic and research purpose.

Following is the suggested downstream plan if an anomaly is detected; (1)a system for referral to the nearest pediatric cardiology expert, (2) Counseling and pregnancy management planning,(3) Option of planned delivery for correctable, critical problems,(4) Support for heart surgery after birth.


He presented a plan to train OBGs and Radiologists in Kerala to develop their skills to perform the fetal heart evaluation. This would include keenly observing the 4-chamber view (through the 3-view technique) and outflows of the heart to identify the anomalies.

Dr. Zulfikar Ahamed, Pediatric Cardiologist from SAT, spoke about post natal screening of newborns in Kerala for critical CHDs using a combination of pulse oximetry and physical examination. He felt it was a feasible, reproducible, and low cost (&accurate) technology that could play a significant role in lowering the IMR. He also pointed out that the system is almost ready to be piloted in some major delivery points in the state especially in Medical Colleges, which can be easily replicated in all delivery points across Kerala with minimum expertise, infrastructure and logistics.

Ms. Bistra Zheleva, Vice President of International Programs at Children's HeartLink (CHL),presented on seeing congenital heart disease from a population health or public health perspective. She presented on the findings and recommendations in Children's HeartLink's recently published reportseries, 'The Invisible Child: Childhood Heart Disease and the Global Health Agenda'. The reports address the need for more data, resources and improved health systems and training to address the needs of children with heart disease. Ms. Zheleva advocated for a multi sectoral approach towards improving access to care for children with heart disease and elaborated on the work that CHL has done in this area in low and middle income countries (LMICs).



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Dr. Baiju, Consultant Thoracic Surgeon, SCTIMST pointed out some major difficulties that they were facing like the high number of waiting list cases and deficiencies with regard to record keeping causing delay in providing care to all those require surgery. He emphasized the need to strengthen a public facility towards the northern Kerala pointing to the difficulties public faces based on their experience. He requested the Additional Chief Secretary to provide some critical HR so that they can improve upon the number of surgeries currently doing as they have surgeons and operation theatre available to do at least one more case per day. He along with the Medical Superintendent pointed out that there is a huge backlog of funds to be provided from NHM for the cases already operated under RBSK.

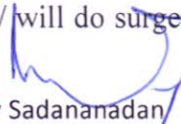
Dr. Jayakumar, Superintendent and Cardio Thoracic Surgeon MCH Kottayam said that they have already started doing cases and expect to complete more than 100 cases this year before December 2017 and the major difficulty they are facing are constraints in providing separate OT and ICU for pediatric cases. He pointed out that a detailed proposal for improving the facilities in MCH Kottayam is already submitted to DME and will be submitting a revised one immediately.

Dr. Ramesh, Cardio Thoracic Surgeon MCH Calicut, representing HOD and Superintendent submitted that Cardio Thoracic Department MCH Calicut is already doing pediatric cases, but not in large numbers. He also pointed out that they do not have back up support for newborn care to take Critical CHD in young patients. He welcomed the suggestion by the SCTIMST team that the readiness to come to Calicut and support the Department to take up cases considering the merit and feasibility to do the operations at Calicut so that to improve the capacity of the team there in Calicut.

Following the presentations, a discussion ensued regarding the needs in Kerala. The following decisions were taken in the meeting with Additional Chief Secretary:-


- Public Hospitals need to increase Surgical Capacity:
 1. Need to strengthen the facilities in MCH Kottayam, in order to cater to more CHD patients from southern part of Kerala. MCH Kottayam is directed to submit a detailed proposal for strengthening of cardio-thoracic surgery department including HR (pediatric cardiologist, intensivist and trained nurses) through DME and in turn to Government for consideration.
 2. Need to strengthen the ICU in SAT Hospital, Tvm, and add more staff nurses in the ICU and there should be a proper linkage with DEIC and CDC.
 3. Decided to train one specialist from MCH Kozhikode at SCTIMST for better cardiac care services at MCH KKD, and SCTIMST specialist will consult the clients/ will do surgery



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once in a week at MCH KKD if needed considering the logistics, administrative support, infrastructure and feasibility.

4. It is also decided to take up the requirements proposed by the superintendent and Dr Baiju from SCTIMST, regarding the scope of increasing number of surgeries in case if additional human resource is provided and the State Mission Director NHM is requested to review the proposal once it is officially submitted by the Director SCTIMST and report to Government for further action.
 5. It is also decided to speed up the process of empanelling more institutions and complete the process to do more surgeries, until the capacity of public health facilities to take care of all those children born with Critical CHD is improved. Technical inputs for preparing the guidelines and establishing the processes may be sought from CHL considering their expertise in the field.
- Fetal Heart Screening:
 1. Need to train all Sonologists and Obstetricians doing ante natal scanning based on a detailed module for CHD detection during anomaly scanning of ante natal mothers, In this regard it is necessary to train all the related specialists including Gynecologists sand Pediatricians.
 2. Decided to start mandatory fetal heart screening (4 chamber view) during anomaly screening for antenatal mothers. For this training need to organize for all Gynecologist and Sonologist, a detailed guideline and check list is needed for the same. Technical expertise in this regard for preparing guidelines, adopting global evidences and documents,teaching module, etc. may be sort from CHL.
 3. Need to initiate urgent steps to standardize equipments being used for anomaly screening of ante natal mothers at Govt Hospitals.
 - Neonatal Screening:
 1. Decided to start RBSK-linked visible and functional birth defect screening at all major delivery points.
 2. Decided to train all nurses at Delivery units and ICUs on Pulse Oximetry and combine that with Physical examination for the early identification of CHD and birth defects. CHL is requested to share documents and evidence based guidelines with global experiences for adopting the same after validation to apply in our context.

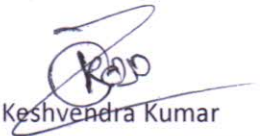

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3. Decided to prepare and disseminate guidelines and manuals for cardiac screening. Post graduate Training: Post graduate students (MD-Gyni,,MD Radiodiagnosis, DM-Cardiac) are to be trained at SCTIMST for 1 month before completing the course.
 4. It is also suggested to have some training programs for pediatricians and adult cardiologists across Kerala on diagnosis and management of critical CHD so that an improved care is provided to such infants and newborn. Modules and training materials already developed with the support of CHL by AIMS may be used for this.
- Funding:
 - It is decided that wherever there is shortage of funds for CHD surgeries under RBSK, funds under Arogyakiranam may be used after obtaining necessary Government orders.
 - Funds for capacity building including infrastructure, equipment, any other for improving the patient care activities may be estimated and detailed proposal may be submitted to Government through Director of Health Services and Directorate of Medical Education and all possible support shall be done through National Health Mission in the next PIP.

Others:

1. Representatives from Children's HeartLink were asked to explore the possibilities of extending support to Government of Keralain building capacity of public sector hospitals and to submit their response once the minutes were made available. They were requested to submit a report on all possible areas where they can support this endeavor by means of technical expertise and advice.
2. Decided to prepare a line list of CHD cases from SCTIMST waiting list by using DEIC facility, and children admitted in ICU/NICU/SNCU/ICCU are to be screened at DEIC by DEIC team before they get discharged from hospital.


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