

## Minutes of meeting of STAKEHOLDERS on CHD


Venue- NHM Conference Hall

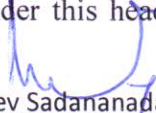
Date- 13<sup>th</sup> January 2017

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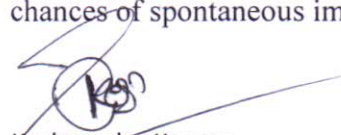
NHM will be giving focused planning and implementation of activities in this line in coming years.

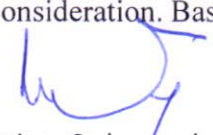
Dr B. Ekbal, Former Vice Chancellor of Kerala University and Present Planning Board Member congratulated all those involved in this effort for acknowledging the relevance of the issue and supporting the states for their efforts to further reduce IMR as a model to the whole nation. He expressed all his 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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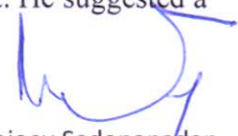
  
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on the guidelines there is a categorization of cases into three classes, (1) General agreement exists that the treatment is useful and effective, (2) conflicting evidences or divergence of opinion or both about the usefulness/ efficacy of treatment, (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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