



## ABSTRACT

National Health Mission – Tamil Nadu – Establishment of Centre of Excellence for Prevention and Management of Genetic Disorders in Institute of Child Health and Hospital for Children attached with Madras Medical College, Chennai, Government Coimbatore Medical College and Hospital, Coimbatore and Government Madurai Medical College and Hospital, Madurai with an initial cost of Rs.8,19,00,000/—Orders issued.

### Health and Family Welfare (EAP.II/1) Department

G.O.(Ms.).No.63

Dated 11.03.2024.

சோபகிருது, மாசி - 28 ,  
திருவள்ளூர் ஆண்டு 2055

### Read:

1. G.O.(Ms.).No.311, Health and Family Welfare (EAP.II/2) Department, dated 30.07.2018.
2. From the Mission Director, National Health Mission –Tamil Nadu letter No.930/NHM/P20/2022, dated 01.07.2022 and 02.09.2022.
3. From the Engineer-in-Chief and Chief Engineer (General), Public Works Department, letter No.AEE/T3/NHM/2022, dated 04.11.2022.
4. From the Mission Director, National Health Mission – Tamil Nadu letter No.930/NHM/P15/2022, dated 23.12.2022, 03.01.2023, 02.05.2023 and 24.07.2023.

### ORDER:

The Hon'ble Minister (Health & Family Welfare) has made the following announcement (Announcement No.84) on the Floor of the Tamil Nadu Legislative Assembly while moving the Demand No.19 of the Health and Family Welfare Department on 29.04.2022:-

"மரபியல் சார்ந்த நோய்கள் மற்றும் மரபுசார் பிற அரிய வகை நோய்களுக்கான மருத்துவத் துறையை மூன்று ஒப்புயர்வு மையங்களாக சென்னை எழும்பூர் குழந்தைகள் நல மருத்துவமனை, மதுரை மற்றும் கோயம்புத்தூர் அரசு மருத்துவக் கல்லூரி மருத்துவமனைகளில் ஏற்படுத்தித் முதற்கட்டமாக ரூபாய் 8.19 கோடி மதிப்பீட்டில் திட்டமிடப்பட்டு செயல்படுத்தப்படும்".

2. In the letter second read above, the Mission Director, National Health Mission has stated that the detection of chromosomal abnormalities is of great importance in current medical management. In

SRS 2020, it has been reported that the Infant Mortality Rate (IMR) in Tamil Nadu is estimated at 13 deaths per 1,000 live births and under-five mortality rate (U5MR) is estimated to be 16 deaths per 1,000 live births. Out of the total 10,000 deaths recorded per year, 6% deaths were attributed to multiples congenital anomalies and 8% contributed to congenital heart diseases. With such higher incidence of birth defects and congenital malformations, 602 children of under-five age group died due to birth defects and more than 1500 children live with disability. The number of such patients reaching out to a Tertiary Hospital are roughly about 100-150 per week and they end-up only at the preliminary stage of diagnosing without complete evaluation of the underlying genetic disease. The data is implying that the underlying genetic disorders remain the important cause of morbidity and mortality and warrant the need for the services of a genetic diagnostic testing laboratory. She has further stated that there is no genetic testing or genomic analysis available easily at an affordable cost for such patients and the health care team is therefore unable to assess, counsel and offer treatment. The establishment of a genetics department and complete molecular genetic diagnostic testing facility is essential for the work-up of a spectrum of constitutional disorders as well as malignancies. Identification of an abnormality enables appropriate corrective treatment measures to be undertaken in a timely manner so that the devastating impact of inherited conditions could be reduced. Hence, there is a dire need to establish a molecular genetic testing laboratory in the area of Human Genetics (Biochemical Genetics, Cytogenetics, Molecular Genetics, Clinical Genetics and Comprehensive Clinical Care) and screening of pregnant women and newborn babies for diagnosis of inherited genetic diseases in all the districts to provide comprehensive clinical care. The Centres will specialise in the following specific genetic disorders:-

- Haemoglobinopathies viz., Thalassemia and Sickle Cell Anaemia
- Chromosomal Disorders
- Spinal Muscular Atrophy (SMA)
- Duchenne Muscular Dystrophy (DMD)
- Other Neuro-Muscular Disorders
- Lysosomal Storage Diseases (LSD)
- Mucopolysaccharidosis (MPS)
- Congenital Adrenal Hyperplasia (CAH)
- Congenital Hypothyroidism
- Glucose-6-Phosphate Dehydrogenase (G-6PD) Deficiency
- Cystic Fibrosis

3. The Mission Director, National Health Mission-Tamil Nadu has further stated that the following activities will be undertaken by the Molecular Diagnostic Testing Laboratories:-

#### **A. Prenatal testing for genetic disorders such as:**

- i. Thalassemia Beta Thalassemia, Alpha thalassemia, Sickle cell disease and other Hemoglobinopathies.
- ii. Chromosomal aberrations Down syndrome Turners syndrome.

- Neural tube Defects and other an euploidies.
- iii. Chromosomal instability Duchenne Muscular Dystrophy, SMA, Fragile-X.
- iv. Developmental delay disorders and dysmorphisms.
- v. Other Genetic disorders prevalent at a relatively higher rate for which antenatal testing methods are provided if unavailable.

**B. Newborn Screening for relatively common treatable genetic metabolic disorders including:**

- i. Congenital Hypothyroidism and Congenital Adrenal Hyperplasia
- ii. Glucose-6-phosphate dehydrogenase (G6PD) and pyruvate kinase deficiency
- iii. Congenital Fanconi Anaemia.
- iv. Galactosemia
- v. Other treatable genetic metabolic disorders prevalent at a relatively higher rate in the region.

**C. Infertility and Disorders of Sexual Development (DSD) – Primary amenorrhea, ambiguous genitalia, gonadal dysgenesis.**

**D. Paediatric and Adult immunodeficiency disorders: -**

- i. Paroxysmal Nocturnal haemoglobinuria (PNH),
- ii. X-linked agammaglobulinemia, Common Variable immunodeficiency (CVID), Severe combined immunodeficiency (SCID)

**E. Haematological malignancies both Acute and chronic conditions of leukemia, lymphoma as well as the solid tumors.**

**F. Genetic Counselling of pregnant mothers carrying fetuses with high risk of genetic disorders.**

4. The Mission Director, National Health Mission has also stated that he over all scope of the Centres will be as follows:-

- a. Diagnostic testing of inherited Genetic disorders.
- b. Screening of pregnant women and new-borns in all Districts.
- c. Genetic counseling to the pregnant mother carrying foetus with high risk of genetic disorders and to the parents who were identified for the presence of Genetic diseases.
- d. Strengthening of infrastructure and the resources, periodical training of technical staff and faculty from trained centres.

5. The Mission Director, National Health Mission-Tamil Nadu has also stated that the cost needed for the establishment of three (3) Centres of Excellence will be met out from the initial cost of Rs.8.19 crores approved by the Government of India in ROP2022-24 under the FMR RCH 3-31 (2) for the screening of Congenital Hypothyroidism and Congenital Adrenal Hyperplasia among all new-borns delivered in Government Hospitals.

A proposal in this regard placed before the 42<sup>nd</sup> Executive Committee of National Health Mission-Tamil Nadu and the same was approved.

6. In the letter fourth read above, the Mission Director, National Health Mission – Tamil Nadu has stated that as the above project is the first of its kind in the State, the Human Resources are absolutely needed to set up the Centre of Excellence. Most of the Genetic Lab diagnostic procedures are included in the Chief Minister's Comprehensive Health Insurance Scheme while others involve out-of-pocket expenditure. There is no genetic testing or genomic analysis available easily at an affordable cost for patients and the health care team is therefore unable to assess, counsel and offer treatment to their families. Establishment of Genetic Lab will give ownership to the Institution, continuum of genetic services, acquisition of skills and technology and benefit Post Graduate education for all allied health sciences. In terms of cost effectiveness, currently in Institute of Child Health and Hospital for Children, the testing is out-sourced for TSH/CAH@Rs.150 per test. Out-sourcing a part of the testing or a part of the procedure has its disadvantages viz., the equipment is not our own; no skill transfer; dependency on the hiring source for the service and hence there is no empowerment of our laboratory department. The testing cost will also be reduced by 20-30% when the tests are carried out in our own laboratory. Hence, establishing genetic labs in the Public Sector will reduce the out-of-pocket expenditure and aid in research, diagnosis and treatment of genetic diseases in the Government sector.

7. Additionally, the provisions and resources from the Multidisciplinary Research Unit (MDRU) under the Department of Health Research (DHR) of Government of India may also be used to technically support and sustain each of the three Centres of Excellence in the long run. Currently, a Multidisciplinary Research Unit has already been established at Madras Medical College and steps should be taken in a similar way to establish Multidisciplinary Research Units at Coimbatore and Madurai to conduct research and sustain the Centres' routine activities. The funds allotted to Multidisciplinary Research Unit every year by the DHR (Department of Health and Research) can therefore be utilized for the consumables at the discretion of the Dean of the concerned institutions to ensure the continual smooth functioning of the lab without any interruption of work for want of funds. This will also be beneficial to supplement the activities undertaken by the Centres of Excellence as the Department of Health and Research guidelines permit to use the different provisions of a Multidisciplinary Research Unit facility for upkeep and development of Genetic Labs.

8. The Mission Director, National Health Mission-Tamil Nadu has further stated that the post of Medical Officer, who will be the Genetic Lab Coordinator, has not been included in the proposal as it falls in the regular cadre and will not require additional funding. The post of Lab Technician and Data Entry Operator will be managed on diversion basis from the District Early Intervention Centres. But, separate manpowers action is necessary for Senior Lab Technician and Lab-cum-Store Assistant posts and the mode of appointment will be on contract basis only. She has also informed that the Department of Genetics is one of the evolving fields in modern Medicine and

Lab. The proposed Centre of Excellence is the first of its kind in the Government Sector and there are no existing prequalified Genetic Senior Lab Technicians / Lab Technicians in the Government Institutions and the Lab Technicians among others will be specifically trained in the field of Genetic such as Molecular Genetics, Cytogenetic and others. Hence, the Mission Director, National Health Mission has stated that following posts are vital to run these Genetic Labs and suggested the duties and responsibilities of the posts.

Sl.No.	Name of the post	No of posts
1.	Senior Lab Technician	3 (each one post for each institution)
2.	Lab Cum Store Assistant	3 (each one post for each institution)
3.	Lab Technician	3 (each one post for each institution)
4.	Data Entry Operator	3 (each one post for each institution)

9. The Mission Director, National Health Mission – Tamil Nadu has therefore, requested to permit her to establish Centre of Excellence for Prevention and Management of Genetic Disorders at Institute of Child Health and Hospital for Children, Egmore, Chennai attached with Madras Medical College, Chennai, Government Medical College and Hospital, Madurai and Government Coimbatore Medical College and Hospital, Coimbatore with an initial cost of Rs.08.19 crore as detailed below:

Sl. No	Name of Activity	Cost per Centre (Rs.In lakhs)	Total Cost for 3 Centres (Rs.In Lakhs)
1.	Civil Modification Works	10.00	30.00
2.	Equipment/ Instruments	250.00	750.00
3.	Training	4.20	12.60
4.	Human Resource	8.80	26.40
	Total -	273.00	819.00

10. In the letter third read above, the Engineer-in-Chief and Chief Engineer (General), Public Works Department, Chepauk, Chennai has stated that only after getting funds for equipment, estimate for the civil modification works could be prepared. Hence estimate for the above work may not be possible at this juncture. Therefore, Public Works Department agrees to execute the work within the sanctioned amount of Rs.10.00 Lakhs for each hospital for the work "Upgrading the Genetic Departments of Institute of Child Health and Hospital for Children, Chennai, Madurai Medical College Hospital and Government Coimbatore Medical College Hospital as Centre of Excellence for Prevention and Management of Genetic Disorders in Tamil Nadu."

11. The Government, after careful examination, have issue the following orders:-

- i. Centre of Excellence for Prevention and Management of Genetic Disorders is established at Institute of Child Health and Hospital for Children, Egmore, Chennai attached with Madras Medical College, Chennai, Government Coimbatore Medical College and Hospital,

Sl. No.	Name of the post	No. of posts and mode of creation	Remuneration
2	Lab Cum Store Assistant	3 (each one post for each institution) by surrendering 2 posts of Instructor for the Young Hearing Impaired, (Speech Therapist) which were originally created on contract basis in G.O.(Ms).No.311, Health and Family Welfare (EAP.II/2) Department, dated 30.07.2018.	Rs.12,000/- per month per person.

- iv. The Director of Medical Education and Research is directed to divert the Lab Technicians and Data Entry Operators from the District Early Intervention Centre of all the above 3 Institutions to work in the Centre of Excellence for Prevention and Management of Genetic Disorders.
- v. The Medical Officers in the above Centres of Excellence are designated as Nodal Officer / Lab Coordinator and the duties and responsibilities of the above all posts are described in the annexure of this order.
- vi. The Mission Director, National Health Mission-Tamil Nadu is permitted to release Rs.10.00 Lakh per Centre to the concerned Dean / Director to carry out the civil modifications through the Public Works Department for establishment of Centre of Excellence for Prevention and Management of Genetic Disorders, after providing equipment.

10. This order issues with the concurrence of Finance Department vide e-file No.2758419/2022, dated 11.03.2024.

**(BY ORDER OF THE GOVERNOR)**

**GAGANDEEP SINGH BEDI,  
ADDITIONAL CHIEF SECRETARY TO GOVERNMENT.**

To

The Mission Director, National Health Mission-Tamil Nadu, Chennai-600006.

The Director of Medical Education and Research, Chennai-600010.

The Engineer-in-Chief and Chief Engineer (General), Public Works Department, Chennai-600005.

The Principal Accountant General, Chennai-600018.

The Resident Audit Officer,

Office of the Principal Account General, Secretariat, Chennai-600009.

The Pay and Accounts Officers concerned.

The District Treasury Officers concerned.

The Dean of concerned Medical College and Hospitals.

The Director, Institute of Child Health and Government Hospital for Children, Egmore, Chennai-600008.

Copyto:

- All Sections of Health and Family Welfare Department, Chennai-600009.
- All Head of Departments of Health and Family Welfare Department.
- All Departments of Secretariat, Chennai-600009.
- The Special Personal Assistant to Hon'ble Minister (Health & Family Welfare), Chennai-600009.
- The Senior Private Secretary to Additional Chief Secretary to Government, Health and Family Welfare Department, Chennai-600009.
- The Special Programme Implementation Department, Chennai-600009.
- The Finance (Health-I) Department, Chennai-600009.
- The Health and Family Welfare (E/J/S/DataCell) Department, Chennai-600009.
- Stock File / Spare copy.

**//FORWARDED / BYORDER//**

*[Handwritten Signature]*  
 11/08/2024  
**SECTION OFFICER**  
*[Handwritten Initials]*  
 11.08.24

(BY ORDER OF THE GOVERNOR)  
 ADDITIONAL CHIEF SECRETARY TO GOVERNMENT  
 Health and Family Welfare Department  
 Chennai-600009

The Mission Director, National Health Mission, Tamil Nadu is permitted to release Rs.10.00 Lakh per Centre to the concerned District Director to carry out the self-modification through the Public Works Department for establishment of Centre of Excellence for Prevention and Management of Bacterial Diarrhoea, after providing equipment.

10. This order issued with the concurrence of Finance Department vide No. 2754/19022, dated 11.03.2024.

Annexure to G.O.(Ms.).No.63, Health and Family Welfare (EAPII-1)  
Department, dated 11.03.2024.

Duties and Responsibilities of the posts sanctioned to the Centre of Excellence  
for Prevention and Management of Genetic Disorders

**1. Nodal officer/Medical officer/Lab Coordinator:**

- i. This genetic diagnostic testing laboratory will only function as centralised lab for the medical college where it is place and the designated candidate should be responsible to coordinate all the basic techniques and functioning of the lab only for genetic diagnostic testing purpose. Under any circumstances, this genetic lab should not be functioned under any department or speciality. The lab coordinator will oversee the day-to-day functioning of the lab, procure equipment, infrastructure and chemicals, plan and hold review meetings, conduct teaching sessions and will be the signing authority for all the patient reports published from the lab.
- ii. The lab coordinator should undertake the following if any research works or research-based projects are proposed to be done in this genetic lab. After institutional ethics committee approval, a proper Memorandum of Understanding (MOU) should be signed by all the investigators of the research project with the centralized genetic diagnostic testing facility and the incurring costs should only be borne by the investigators by themselves or through separate funding. The running expenses of the molecular genetic tests shall not be incurred by the lab.
- iii. Should take up the complete responsibility as an Administrative Officer in functioning the lab.

**2. Senior Lab Technician:**

- i. Under general supervision, performs routine tests in medical laboratory to provide data for use in diagnosis and treatment of disease, ensuring validity and accuracy of test results.
- ii. Performs quality control on test results, ensuring validity and accuracy.
- iii. Performs calibration and troubleshooting on testing systems and instruments to ensure adherence to established standards of accuracy.
- iv. Practices safety, environmental, and/or infection control methods.
- v. Performs miscellaneous job-related duties as assigned.
- vi. Keeps records and reports on results according to established procedures.

**3. Lab-cum-Store Assistant:**

- i. Collects, processes, and handles blood and /or other biological specimens according to established procedures; instructs patients in the proper collection of samples.
- ii. Conducts blood tests; may draw blood from patient's finger, ear lobe, or vein observing principles of asepsis to obtain blood samples.
- iii. Should do preparation of the equipment, chemicals and other requisites needed to run the basic techniques in genetic tests.



- v. Should coordinate the lab requirements in all the functioning genetic tests, preparation of charts and handling purchase of chemicals, reagents, maintaining stock register, maintenance of equipment register, maintenance of financial records of the lab. Also, should know to work in all basic MS office or similar software in windows / iOS. Should prepare all the patient reports and process the same for despatch.

#### 4. Lab Technician:

- i. Performs routine tests in medical laboratory to provide data for use in diagnosis and treatment of disease, ensuring validity and accuracy of test results.
- ii. Collects, processes, and handles blood and/or other biological specimens according to established procedures; instructs patients in the proper collection of samples.
- iii. Conducts blood tests; may draw blood from patient's finger, ear lobe, or vein observing principles of asepsis to obtain blood samples.
- iv. Should do preparation of the equipment, chemicals and other requisites needed to run the basic techniques in genetic tests.
- v. Performs miscellaneous job-related duties as assigned.

#### 5. Data entry operator:

Should know to work in all basic MS office or similar software in windows/IOS. Should prepare all the patient reports and process the same for despatch. Should be able to communicate effectively the changes in software to the lab coordinator and the reason for delay in turn-around-time to the clinicians.

**GAGANDEEP SINGH BEDI,  
ADDITIONAL CHIEF SECRETARY TO GOVERNMENT**

//TRUE COPY//

*G. Gagandeep Singh Bedi*  
11/03/2024  
**SECTION OFFICER**

*11.03.24*