

ABSTRACT

Non-Communicable Diseases (NCD) – Establishment of a Registry for Type-I Diabetic Children and Adolescents to monitor their treatment and continuum of care – Orders issued.

Health and Family Welfare (EAP II /1) Department

G.O.(Ms.)No.323

Dated: 27.09.2023 சோபகிருது, புரட்டாசி -10 திருவள்ளுவர் ஆண்டு 2054

Read:

From the Mission Director, National Health Mission-Tamil Nadu, letter No.1470/NCD/P14/2022, dated 29.06.2023.

ORDER:

The Hon'ble Minister (Health & Family Welfare) has made the following Announcement No.73 on the Floor of the Tamil Nadu Legislative Assembly, while moving the Demand No.19 of the Health and Family Welfare Department on 18.04.2023:-

"குழந்தைப் பருவ நீரிழிவு நோய் (Type-l Diabetes) சிகிச்சை மற்றும் மேலாண்மைக்காக மாநில அளவிலான பதிவேடு உருவாக்கப்படும்".

- 2. In the letter read above, the Mission Director, National Health Mission—Tamil Nadu has stated that the data from the International Diabetes Federation (IDF) Diabetes Atlas, 2021 indicates that India has the World's highest number of children and adolescents suffering from Type-I Diabetes Mellitus. T1DM affects approximately 1.2 million children and adolescents worldwide in the age group of 0 19 years, with 149,500 new cases being diagnosed every year. In the absence of a nationwide T1DM registry, it is difficult to estimate exact numbers. However, Registry of Youth Onset Diabetes (YDR) in India has enrolled 5546 patients among which Type 1 Diabetes was most prevalent (63.9%).
- 3. The Mission Director, National Health Mission Tamil Nadu has further stated that disease registries are a collection of secondary data related to patients, about their specific condition and diagnosis, and they play an essential role in surveillance studies. These registries will help to understand the demographic and socioeconomic details, clinical characteristics, biochemical profile, associated complications, and treatment in the above said conditions. The registries also help clinicians and policymakers to make targeted decisions during the management of disease conditions in a Government setup. Registries play a pivotal role in the health system to assess the quality of care delivered to chronic conditions such as diabetes, which require continuous long-term care. One of the central components of the "chronic care model" is the use of registries to improve patient outcomes.

- 4. The Mission Director, National Health Mission Tamil Nadu has also stated that the children and adolescents living with Type-1 Diabetes (T1DM) in India face multitude of challenges including lack of structured diabetes education and counseling. Absence or disruption of standard care affects the physical and mental well-being of these children. Ensuring long term sustainable interventions so as to improve survival and quality of life of children and adolescents suffering from T1DM is the need of the hour. With this aim, the Honorable Minster for Health and Family Welfare had made the announcement in the Tamil Nadu Legislative Assembly on 18.04.2023 to establish the Registry for Type-I Diabetic Children and Adolescents to monitor the treatment and continuum of care. The announcement will ensure prompt capturing of a structured data in the form of a registry for T1DM which is implementable, deliverable, replicable, scalable, and pharmacoeconomically viable.
- 5. The Mission Director, National Health Mission-Tamil Nadu has furnished the Objectives and Roles of the Type-I Diabetes Registry and requested the orders of the Government:-

Objectives of Registry:

- To promote awareness about the magnitude of problem among health professional and public.
- Assessing the trend of distribution of Type-I Diabetes across the districts.
- To improve Health Care system with aim of providing "minimal care" to all the Type-I Diabetes patients without fail.

Roles of T1DM Registry:

- Maintaining the district wise data of T1 diabetic patients.
- Allows policy makers to set public health priorities and also help them in evidence based policy making.
- To facilitate research in areas of basic, clinical, epidemiological, genetic and molecular levels pertaining to Type I diabetic patients.
- Providing Comprehensive health care services at out-patient department (OPD).
- Detection and management of disease and complications.
- Planning of requirement of Insulin (Newer analogues) and other consumables (insulin pens, insulin pumps).
- Appropriate referral.
- Provision of counselling services, training of available human resources, and capacity building at the community level.
- Children and their caregivers will also have access to telephonic contact with trained program coordinator for emergency management.
- Helps the physician to track the patient, increases the follow-up rate and identifies high risk patients.
- The treatment details will be recorded and updated in the form of initial, monthly and annual visits for proper follow-up of patients ensuring decreasing complications, morbidity and mortality of patients.

- 5. The Government, after examination, have decided to accept the proposal of the Mission Director, National Health Mission—Tamil Nadu and issue the following orders:-
 - The Mission Director, State Health Society / National Health Mission—Tamil Nadu, Chennai is permitted to establish a Registry for Type-I Diabetic patients to monitor their treatment and continuum of care.
 - The Institute of Child Health and Government Hospital for Children, Egmore, Chennai is designated as State Nodal Centre for coordination and reporting of data.
 - iii. The Paediatric and General Medicine Departments, Institutes of Diabetology and District Early Intervention Centres (DEICs) of all Government Health Care Facilities are permitted to collect the following data from the Type1 Diabetic patients using a digital platform:
 - a. Basic Demographic Details with ID proof (Aadhar)
 - b. Family Details
 - c. Clinical Information including anthropometry
 - d. Biochemical Parameters, and
 - e. Treatment History
 - iv. The following Private Centres of Medical Excellence are requested to share the data to the Government health facilities listed below for digitalising of data through State owned Makkalai Thedi Maruthuvam Line list portal:-

S.No	Private Centres of Excellence	Reporting Government facility- DEICs/Institute of Diabetology
1.	Dr.Mohan Diabetic Research Foundation, Chennai	Madras Medical College, Chennai
2	Prof. M.Viswanathan Diabetes Research Centre, Chennai	Stanley Medical College, Chennai.
3	Dr.A.Ramachandran Hospital for Diabetes, Egmore, Chennai	Kilpauk Medical College, Chennai.
4	Dr.V.Seshiah Diabetes Research Institute, Aminjikarai, Chennai	Kilpauk Medical College, Chennai.
5	Kanchi Kamakoti Child Trust Hospital, Chennai	Omandurar Government Estate, Chennai.
6	PSG Institute of Medical Sciences & Research, Coimbatore.	Coimbatore Government Medical College, Coimbatore.
7	Sri Ramachandra Medical College, Chennai.	Chengelpettu.
8	SRM Institute of Science and Technology, Chennai.	Medical College, Chengelpettu.
9	Saveetha Medical College, Chennai.	Chengelpettu Governmen Medical College, Chengelpettu.

10	Chettinad Hospital and Research Institute, Kelambakkam, Kanchipuram.	Chengelpettu Government Medical College, Chengelpettu.
11	Trichy Diabetes Speciality Centre, Thiruchirappalli.	K.A.P.Visvanathan Government Medical College, Thiruchirappalli.
12	Kovai Diabetes Speciality Centre & Hospital, Coimbatore.	Coimbatore Government Medical College, Coimbatore.
13	Arthur Asirvatham Hospital, Madurai.	Madurai Medical College, Madurai.

- v. The Directorate of Public Health and Preventive Medicine, Chennal is directed to coordinate in the following aspects:
 - a. Rashtriya Bal Swasthya Karyakram (RBSK) Medical Officers should identify the Type 1 Diabetic School students and aid in submitting the data to District Early Intervention Centres on a weekly basis.

b. The follow up monitoring of these patients may be provided through the field staff at Health Sub Centre level.

c. Fixing responsibilities of medical officers, staff nurses and Rashtriya Bal Swasthya Karyakram teams to aid in formulation of Type-I Registry.

- The Directorate of Medical and Rural Health Services, Chennai is directed to Vi. coordinate in the following aspects:
 - a. Providing the data of known Type-I Diabetic Patients and referring the patients with signs and symptoms to the District Early Intervention Centres / Medical Colleges concerned for confirmation of diagnosis
 - b. A Nodal Medical Officer (probably a Pediatrician / General Medicine) may be assigned in each District Headquarters Hospital who may visit the District Early Intervention Centres on a periodical basis and report to the Joint Director of Medical and Rural Health Services concerned, so as to aid in data collection.
- The Directorate of Medical Education and Research is directed to coordinate in vii. the following aspects:
 - a. Nomination of one nodal unit with one Nodal Officer each in Department of General Medicine and Pediatrics in all Medical College Hospitals to aid in data collection and monitoring of their Type-I Diabetic patients.
 - b. The Assistant Professor in the nodal unit may visit the District Early Intervention Centres on a periodical basis and report to the Director of Medical Education and Research which will help in guiding and monitoring of the District Early Intervention Centres in Medical Colleges to ensure confirmation of diagnosis.

c. Nomination of one Nodal Unit with State level Nodal Officer in the Institute of Child Health and Government Hospital for Children, Egmore, Chennai to aid and coordinate in data analysis, research and publication of data from

the Registry.

- viii. The Project Director, Integrated Child Development Services, Chennai is directed to instruct the concerned Anganwadi Workers under Integrated Child Development Services (ICDS) Project to assist the Village Health Nurses in identifying the patients among the Children coming to the respective Anganwadi and reporting to Rashtriya Bal Swasthya Karyakram Medical Officers.
- ix. The Indian Medical Association, Association of Physicians of State, Indian Academy of Pediatrics and Diabetology Associations like Diabetes Association of India (DAI), Research Society for Study of Diabetes in India (RSSDI), Madras Medical College Diabetologists' Alumni Association (MMCDAA) etc., are directed to contribute the data of patients attending private clinics to any nearby medical colleges and aid in data collection through Type-1 Diabetes Registry.

(BY ORDER OF THE GOVERNOR)

GAGANDEEP SINGH BEDI PRINCIPAL SECRETARY TO GOVERNMENT

To

The Mission Director, National Health Mission-Tamil Nadu, Chennai-600 006.

The Project Director, Integrated Child Development Services, Chennai-600 113.

The Director of Public Health and Preventive Medicine, Chennai-600 006.

The Director of Medical and Rural Health Services, Chennai-600 006.

The Director of Medical Education and Research, Chennai-600 010.

The Director, Institute of Child Health and Government Hospital for Children, Egmore, Chennai-600 008.

Copy to:

All Sections of Health and Family Welfare Department, Chennai-600 009.

All Head of Departments of Health and Family Welfare Department.

All Departments of Secretariat, Chennai-600 009.

The Special Personal Assistant to Hon'ble Minister (Health and Family Welfare) Department, Chennai-600 009.

The Senior Private Secretary to Principal Secretary to Government, Health and Family Welfare Department, Chennai-600 009.

The Senior Private Secretary to Secretary to Government, Social Welfare and Women Empowerment Department, Chennai-600 009.

The Special Programme Implementation Department, Chennai-600 009.

The Health and Family Welfare (P / S / Data Cell) Department, Chennai--600 009.

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SECTION OFFICER