

# News from here and there

## India launches Sickle Cell Anaemia guidelines and third phase of Thalassaemia Bal Sewa Yojana

Sickle cell anaemia and thalassaemia are diseases that are being targeted by the government. On 8 May 2023, in observance of World Thalassaemia Day, Dr Bharati Pravin Pawar, the Union Minister of State for Health and Family Welfare, unveiled the Standard Treatment Workflow Guidelines for Sickle Cell Disease, a project that has been developed by the Indian Council for Medical Research (ICMR). Simultaneously, she inaugurated the third phase of the Thalassaemia Bal Sewa Yojana (TBSY) and introduced the Thalassaemia Bal Sewa Yojana Portal.

According to the guidelines, the following groups will be screened to determine sickle cell anaemia: antenatal mothers or pre-pregnancy planning; newborns; and population screening of a patient of any age. The guidelines also encompass procedures for medical disease counselling, genetic counselling, preconception care counselling, pre-test and post-test support for families, and cascade screening.

The guidelines emphasize specific indications for hospitalization or referral to a higher-level healthcare facility; the indications include persistent temperatures exceeding 38 °C, pain that is not adequately relieved by home remedies, notable respiratory symptoms (cough, shortness of breath, chest pain) or hypoxia, abdominal pain, distention, acute enlargement of the spleen, and 'significant' vomiting and diarrhoea, among others.

The Coal India Limited (CIL) has provided support to TBSY as part of their commitment to corporate social responsibility (CSR).

An innovative effort known as the Haematopoietic Stem Cell Transplant (HSCT) programme has been offering financial assistance to thalassaemia patients with compatible sibling donors who have financial constraints. The funding for HSCT has been provided by CIL since 2017.

Over the course of the first two phases of the HSCT programme, 356 bone marrow transplants have been facilitated across 10 designated hospitals. These hospitals include the All India Institute of Medical Sciences (AIIMS), New Delhi; Christian Medical College and Hospital (CMC), Vellore; Tata Medical Centre (TMC), Kolkata; Narayana Hrudayalaya, Bengaluru; CMC, Ludhiana; Kokilaben Dhirubhai Ambani Hospital, Mumbai; Municipal Council Greater Mumbai Hospital (MCGM), Mumbai; Post-Graduate Institute of Medical Education and Research (PGIMER), Chandigarh; Rajiv Gandhi Cancer Institute, New Delhi; and Sanjay Gandhi Postgraduate Institute of Medical Sciences (SGPGI), Lucknow.

In the programme's third phase, CIL will extend a financial support package of ₹10 lakh (1 million) for each HSCT, benefiting both thalassaemia and aplastic anaemia patients. This financial package will be directly transferred to the institution performing the HSCT.

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## Disgraced surgeon, Paolo Macchiarini, receives 30-month prison term

On 21 June 2023, the Svea Court of Appeal in Stockholm found Paul Macchiarini, the once acclaimed and charismatic pioneer of regenerative medicine, guilty of gross assault against three of his patients. He was handed a 30-month prison sentence by the five-judge panel.

The Appeals Court has given this ruling a year after a Swedish district court gave Macchiarini a suspended sentence. It found him guilty of causing bodily harm in two of the three cases.

Both the prosecution and Macchiarini's defence team appealed against that ruling. The prosecution wanted a 5-year sentence whereas the defence wanted all charges to be dismissed.

During 2011–2012, while working at the Karolinska Institute in Stockholm, Macchiarini performed surgeries on at least three patients to replace their damaged trachea with synthetic trachea containing stem cells that were obtained from the patients' own bone marrow. The idea was that the stem cells would multiply and provide a long-lasting replacement. However, the transplants were a complete failure and all three patients died due to complications. The first patient died just 4 months later due to massive bleeding. The second patient died 2.5 years later and the third patient died around 5 years later. Both suffered from devastating and painful complications.

As per *Science.org* (<https://www.science.org/content/article/disgraced-italian-surgeon-convicted-of-criminal-harm-to-stem-cell-patient>), eight of the nine patients that Macchiarini treated are dead.

Several of Macchiarini's colleagues at Karolinska Institute had complained against him. Yet, the institute quelled these complaints. It was only after these individuals' informed journalists from Swedish television and a three-part investigative TV series on Macchiarini, *Experimenten*, was broadcast in early 2016, did the world get to know that he was a quack and that his engineered tracheas were a sham. Subsequently, Karolinska Institute fired him amid charges of fraud and misconduct. It also wanted several of his papers to be retracted.

An investigation into the three cases, previously discontinued, was reopened in December 2018 by Mikael Bjork, the Director of Public Prosecution in Sweden. The prosecution obtained additional written evidence and conducted interviews with individuals in Sweden, Spain, Belgium, Great Britain and the USA.

Based on these investigations the Swedish prosecution found that the operations conducted by Macchiarini were in conflict of both science and proven experience. The three operations were considered an aggravated assault, and he should bear criminal responsibility.

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### **National Medical Council to unveil ‘One nation, one registration platform’ for doctors**

The National Medical Commission (NMC) is set to launch its ‘One nation, one registration platform’ for doctors across India. The NMC, on 10 May 2023, had issued a gazette notification titled ‘Registration of Medical Practitioners and Licence to Practice Medicine Regulations, 2023’ to this effect under section 31 of the NMC Act that was introduced in August 2019 ([www.nmc.org.in/ActivitiWebClient/open/getDocument?path=/Documents/Public/Portal/NmcGazette/DOC-20230514-WA0038\\_230514\\_120545.pdf](http://www.nmc.org.in/ActivitiWebClient/open/getDocument?path=/Documents/Public/Portal/NmcGazette/DOC-20230514-WA0038_230514_120545.pdf)). As per this gazette notification, a common National Medical Register (NMR) will be maintained by the Ethics and Medical Registration Board (EMRB) of the NMC for all the registered medical practitioners in the country.

The EMRB will generate a Unique Identification (UID) number for all doctors in the country and thereby grant the practitioner, registration in NMR as well as eligibility to practise medicine in India. All the existing medical practitioners enrolled in the Indian Medical Register or the State Medical Register, and who do not possess the UID as per these Regulations are required to update the web portal of the EMRB within a period of 3 months of publishing of these Regulations and obtain the UID as a one-time measure. The licence so generated shall be valid for a period of 5 years from the date of issuance.

The NMR will have entries of the registered medical practitioners of all state registers (maintained by the State Medical Councils) and will also have information regarding the

medical practitioner such as date of registration, medical qualification/s, speciality, year of passing, the name of the institute/university from where the qualification(s) were obtained and the place of work (name of hospital/institute). This information will be made available to the public by placing it on the website of the NMC ([www.nmc.org.in](http://www.nmc.org.in)). The NMR is intended to be a dynamic register, where registered medical practitioners can keep updating details of their qualifications, fellowships and other details.

This gazette notification also provides details regarding the process of registration of additional qualifications, renewal of licence to practise medicine, transfer of licence to practise, removal and restoration of registration, transitory provisions, denial of licence to practise, fee structure, timelines, among others.

A pilot study has already been conducted in four medical colleges each from the government and the private sectors across the country. The NMC is in the process of consulting stakeholders to finalize the process. Licence to practise and the prevailing system of registration shall continue till such time that these regulations and appropriate sections are in force. This measure is expected to eliminate duplication of information and reduce logistic delays. By allowing the public to access information on any physician working in India, the NMR hopes to facilitate transparency.

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*The National Medical Journal of India* is looking for correspondents for the ‘**News from here and there**’ section. We are particularly interested in getting newswriters from the north and northeast regions of India as well as from other countries. By news, we refer to anything that might have happened in your region which will impact on the practice of medicine or will be of interest to physicians in India. The emphasis of the news items in this column, which are usually from 200 to 450 words, is on factual reporting. Comments and personal opinions should be kept to a minimum if at all. Interested correspondents should contact SANJAY A. PAI at [sanjayapai@gmail.com](mailto:sanjayapai@gmail.com) or [nmji@nmji.in](mailto:nmji@nmji.in)