

PUBLIC INTEREST LITIGATION NO. 28 OF 2019

Joaquim Sebastian D’Costa)
Aged 63 years, Occupation: Social)
Worker, residing at Pavwalla)
Building No. 6, Room No.11)
1st Floor, Thakurdwar,)
Mumbai – 400 002) .. Petitioner

Versus

1. Union of India, Through)
its Chief Secretary,)
Ministry of Health and)
Family Welfare, Government)
of India, Nirman Bhavan,)
C-Wing, Maulana Azad Road,))
New Delhi – 110 011)
 2. The State of Maharashtra)
(through government pleader)))
High Court, Mumbai.)
 3. Public Health Department &)
Family Welfare, State of)
Maharashtra, Through its)
Chief Secretary, 5th Floor,)
Main Building, Mantralaya,)
Mumbai – 400 032.)
- .. Respondents

Mr. Manmohan Amonkar for Petitioner.

Ms. P. H. Kantharia, Govt. Pleader with Mr. Abhay Patki,
Addl. Govt. Pleader for Respondent Nos.2 and 3.

**CORAM: NITIN JAMDAR, ACTING CJ. &
ARIF S. DOCTOR, J.**

DATE: 19 JULY 2023

JUDGMENT (Per Acting Chief Justice):

. The Petitioner has filed this Petition seeking a direction to frame independent regulation/policy and establish programs/schemes for mandatory screening of Inborn Errors of Metabolism (IEM) in newborns in government hospitals in the State of Maharashtra and other States in India, creating awareness about IEM, establishing a newborn screening registry for IEM and expanding the Rashtriya Bal Swasthya Karyakram to include IEM. The Petitioner seeks to bring to the notice of this Court the absence of newborn screening programs for IEM in government hospitals in India (excepting few States.

2. The annexures to the Petition are research papers published in scientific journals. These are -Indian Pediatrics, Volume 47, dated 17 March 2010, titled "*Newborn Screening in India*. Another paper published in Indian Pediatrics, Volume 50, dated 15 July 2013. An article from the Indian Journal of Clinical Biochemistry. Printout from a web magazine on Newborn screening. A paper published in the International Journal of Health Sciences and Research, *Screening*

of Inborn Errors of Metabolism – use of Current and Future Technology in Indian Scenario. Abstract from a paper published in the Indian Journal of Psychological Medicine – *Communication Impairments in Children with Inborn Errors of Metabolism: A Preliminary Study.* Another paper titled "*Newborn Screening in India*" by the National President of the Indian Academy of Pediatrics. Then there are applications filed under the Right to Information Act, 2005, which are filed by the Petitioners Advocates and not by the Petitioner. A notice issued by the Petitioner's Advocate is annexed.

3. The research paper "*Inborn Errors of Metabolism: Review and Data from a Tertiary Care Center*" would show the expertise required to fully appreciate the issue to find a solution. The paper states, and we borrow the extract, that inherited metabolic disorders are a heterogeneous group of genetic conditions mostly occurring in childhood. They are individually rare but collectively numerous, causing substantial morbidity and mortality. Review of total of eight hundred and sixty-nine cases with different age groups that had been referred from several diagnostic centres and hospitals of India to the Department of Metabolism in Narayana Hrudayalaya show cases suspected with inborn errors of metabolism. Advanced techniques applied to diagnose the disorders of inborn errors of metabolism indicates occurrence of several metabolic disorders. The research paper then gives scientific details such as —

Inborn errors of metabolism (IEM) individually are rare but collectively are common. In IEMs single gene defects are responsible for the abnormalities in the synthesis or catabolism of proteins, carbohydrates or fats by way of defective enzymes or transport proteins, resulting in a block of metabolic pathway. The male to female ratio is 1:1 for X-linked dominant if transmission is from mother to child (1). Effects are due to toxic accumulations of the substrates before block, intermediates from alternative metabolic pathways, defects in energy production and use caused by a deficiency of products beyond the block or a combination of these metabolic deviations. Figure 1 shows the theoretical consequences of metabolic disorders. Nearly every metabolic disease has several forms that vary in age of onset, clinical severity and often mode of inheritance. Proper history from parents has a role in suspecting IEM. Parental consanguinity increases the chance of autosomal recessive IEM (2).

For evaluating an IEM the following five important aspects should follow:

- 1. History/ Family History – We should note whether the neonate was born to a consanguineous parent or not and also check previous history of older sibling like fatal deaths or miscarriages or genetically affected siblings and also note the pedigree for about two generations.*
- 2. Physical examination like dermatitis, alopecia, facial dysmorphism, cataract etc.*
- 3. Initial screening tests includes Complete blood count, Electrolytes level, Glucose, Ammonia, Lactate, Lactate/ Pyruvate ratio, Reducing substances, organic acids, Amino acids, Ketones.*
- 4. Advanced screening tests: The test is performed on the basis of clinical context which includes*

long chain fatty acids, MPS separation and speciation, quantitation of amino acids, organic acids, carbohydrate and other metabolites.

5. *Definitive diagnostic tests: To confirm the disorder detected, a specific enzyme assays in leucocytes, plasma/serum or red cells, immunoassays and DNA/ Mutation based analysis will be tested.*

The diagnosis of metabolic disorders is challenging because of: 1. The episodic nature of metabolic illness. 2. The wide range of clinical symptoms that is also associated with more common conditions. 3. The low incidence of these disorders. 4. The consequent lack of experience among the pediatric sub-specialties and 5. The need for specialty testing (3).

Individual IEM are rare disorders, most having an incidence of less than 1 per 100,000 births. However, when considered collectively, the incidence may approach 1 in 800 to 2500 births. In one review of cases of IEM diagnosed in British Columbia (a predominantly Caucasian population) between 1969 and 1996, estimates of incidence of various classes of disorders were as follows (4):

- *Amino acid disorders (excluding Phenylketonuria) — 7.6 per 100,000*
- *Phenylketonuria — 7.5 per 100,000*
- *Organic acidemias — 3.7 per 100,000*
- *Urea cycle diseases — 1.9 per 100,000 • Glycogen storage diseases — 2.3 per 100,000*
- *Lysosomal storage diseases — 7.6 per 100,000*
- *Peroxisomal disorders — 3.5 per 100,000*

- *Mitochondrial diseases — 3.2 per 100,000*

In another review of cases of IEM diagnosed in the West Midlands of the United Kingdom (where approximately 11 percent of the population is from black and ethnic minority groups), the frequency of selected IEM during 1999 to 2003 were as follows (5):

- *Amino acid disorders (excluding phenylketonuria) — 18.7 per 100,000*
- *Phenylketonuria — 8.1 per 100,000*
- *Organic acidemias — 12.6 per 100,000*
- *Urea cycle diseases — 4.5 per 100,000*
- *Glycogen storage diseases — 6.8 per 100,000*
- *Lysosomal storage diseases — 19.3 per 100,000*
- *Peroxisomal disorders — 7.4 per 100,000*
- *Mitochondrial diseases — 20.3 per 100,000.*

Age for presentation of clinical symptoms varies for individual IEM and variant forms within the IEM. The timing of presentation depends on significant accumulation of toxic metabolites or on the deficiency of substrate. The disorders of carbohydrate or protein metabolism and disorders of energy production tend to present in the neonatal period or early infancy and tend to be unrelenting and rapidly progressive. Less severe variants of these diseases usually present later in infancy or childhood and tend to be episodic. Fatty acid oxidation, glycogen storage and lysosomal storage disorders tend to present insidiously in infancy or childhood. Disorders manifested by subtle neurologic

or psychiatric features often go undiagnosed until adulthood (6).”

4. It is quite evident that the subject will require domain expertise. The Petition is nothing but a copy and paste from this research articles. Therefore, when the Petition came up on board on 21 June 2023, we enquired with the learned counsel for the Petitioner as to whether the Petitioner could explain to us the basic terminology and, for that purpose, whether he could remain present to assist the Court. The learned counsel for the Petitioner submitted that the Petitioner is not aware of the subject at all, and it is not possible for him to remain present and explain. The Petitioner has described himself as a social worker and nothing more. Out of indulgence, we permitted the Petitioner to amend the Petition to join any expert or an organization as a co-petitioner, and the Petition was adjourned by four weeks. Petitioner did not carry out the amendment.

5. Apart from the abundant motivated Public Interest Litigations (PILS), we find that even many of the PILs filed to address social malaise are also being filed with utmost casualness, offering no substantial assistance to the Court. Various problems afflicting society are often intricate and multifaceted. If such causes are to be effectively redressed, the Petitioner must undertake thorough research and preparation to present their case diligently. Petitions are often filed on subjects, especially complex technical matters where the Petitioner has no expertise. The only attachments to the Petition often are documents sourced from the public domain and media.

Filing PILs without proper research or domain expertise or seeking assistance from experts in the issue can lead to the erroneous or inadequate presentation of facts and arguments. Such poorly presented petitions on complex subjects are detrimental to the cause they seek to espouse.

6. There is a distinction between the scrutiny of the cause itself and the manner in which it is brought before the Court. The Court's interest in the Petitioner's domain expertise in the field is not meant to discourage the public interest litigation per se but to ensure that those who approach the Court are genuinely interested in the cause and can assist the Court. It serves as a mechanism to identify Petitioners who may be using PIL as a superficial means to gain attention or further personal interests. The Court's refusal to entertain a poorly presented petition should not be construed as a rejection of the underlying cause. It simply reflects the Court's assessment that the Petitioner may be unable to contribute effectively to resolve the issue. Judicial time is not infinite and should not be squandered by such petitioners.

7. Further, filing a PIL does not absolve the petitioners of their duty to work towards the cause they are advocating. The responsibility of a petitioner extends beyond the act of filing a Petition. It involves a genuine commitment to pursuing the cause and making tangible efforts to effect a change. The Court will rightfully inquire about the petitioner's involvement in practical initiatives to resolve the issue they have raised. Filing a PIL Petition

is one of the steps in addressing a problem of public importance. It is equally vital for the petitioner to complement this legal recourse with on-the-ground work. Ground-level work may involve conducting research, engaging with affected communities, partnering with NGOs or civil society organizations, and advocating for policy changes.

8. In the case at hand, the Petitioner has done nothing except copy and paste material from the public domain or worse, just lent his name to this Petition drafted by advocates. He knows nothing about the subject and, as admitted by the advocate, cannot even explain what is written in the Petition. Neither the advocates can. We place our disapproval on record for the utter casualness with such an important topic brought before the Court. PILs are not to be filed for mere publicity and as a quick way to recognition.

9. With these observations, the PIL is disposed of, leaving the cause open to be considered as and when brought before the Court by any public-spirited individual or an organization well-versed with the subject who can assist the Court. It is out of indulgence that we have not imposed costs on the Petitioner for this misadventure.

(ARIF S. DOCTOR, J.)

(ACTING CHIEF JUSTICE)