



Neuroblastoma in India: Closing the Gap

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In low- and middle-income countries (LMIC), there is a paucity of childhood neuroblastoma (NB) cases diagnosed in contrast to the expected number, and this pattern is also seen in India.¹ The incidence of NB is notoriously hard to ascertain, given that >30% of patients with NB may have the disease form that is surgically resectable or self-involuting. Patients who have aggressive NB may be confused with other malignancies in the absence of adequate pediatric oncology care services. The concept of “incidence gap” in childhood cancers is well recognized, but is especially problematic in a LMIC.² While the expected number of annual cases of NB in India is around 3000, we estimate that under 1,000 children are diagnosed each year; approximately a third of that reported from the Surveillance, Epidemiology, and End Results (SEER) program.³ These data are derived from the International Incidence of Childhood Cancer report, with data from 7 Indian population-based cancer registries representing 4% of the Indian population.

In addition, for patients with NB who are diagnosed in India, there are gaps in knowledge about biology, presentation, and outcomes. To better understand the landscape of NB in India, we launched the India Neuroblastoma Registration and Biology Study (InPOG-NB-18–01, CTRI/2020/01/023088) to prospectively collect NB registry and biology data across India.⁴ Several barriers impacted accrual, including reluctance of Institutional Ethics Committees to permit centralized genomic analysis, difficulties in prospectively consenting as well as capturing registration data in busy pediatric oncology clinics, and the recent pandemic.⁵ As a result, after 2 years of effort we had registered less than

a dozen cases. In 2021, we made the decision to amend the study, closing down the biology component, and only collecting retrospective anonymized data on NB patients for each center.

In the 6 months since study amendment, we now have data on 90 patients from four centers, with 8 sites expressing an interest and waiting for Ethics Committee Approval. We should reach our target of 400 patients by the end of this year. The initial data gathered is a small sample of the ultimate total but reveals some interesting findings, which will need to be confirmed once all the sites submit data. As expected, there is a male predominance (53/90), and the majority had metastatic (47/90) or unresectable (24/90) disease. Only a minority underwent urine vanillylmandelic acid (VMA) testing (17/90) and/or Iodine-123 metaiodobenzylguanidine (MIBG) testing (10/90). This is presumably due to the difficulty in accessing these tests, since positron emission tomography-computed tomography was still performed in the majority of patients (60/90). Once we accrue data from more patients, we will look at survival outcomes of NB.

If this current approach in data sampling is successful, we will apply it to other childhood tumors, such as rhabdomyosarcoma and Wilms tumor. While this will still not give us an accurate estimate of the incidence of these uncommon childhood cancers in India, the acquired data on presentation and outcomes will help us optimize the required clinical management for the same.

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Conflict of Interest

None declared.

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