

# Bridging the Gap in Access to Care for Children With CNS Tumors Worldwide

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With more than 40,000 CNS tumors diagnosed in children and adolescents every year worldwide, CNS tumors are a leading cause of cancer morbidity and mortality in these patients.<sup>1</sup> The complexity of elements needed to provide quality care is substantial, with integration of comprehensive multidisciplinary care comprising accurate pathologic and radiologic diagnosis, neurosurgery, radiation therapy, chemotherapy, rehabilitation, and close monitoring for acute complications and long-term effects. Unfortunately, most children with CNS tumors are diagnosed in low- and middle-income countries (LMICs) where health systems are frequently not adequately equipped to manage such complex cases.<sup>2</sup> In addition, data on the

incidence, survival, and burden of CNS tumors is currently scant at best, even more so than for other childhood cancers.<sup>3</sup>

Although international collaborations to improve the outcomes of children with cancer through the implementation of capacity-building, research, and education is an effective and sustainable strategy, such efforts have historically not prioritized CNS tumors.<sup>4</sup> With increased global support, evidenced by the WHO Global Initiative for Childhood Cancer, special attention must now focus on building capacity to care for children with CNS tumors.<sup>5</sup>

CNS malignancies comprise a widely varied collection of diagnoses with markedly disparate outcomes, from low-grade tumors to incurable neoplasms.<sup>6</sup> Furthermore, advances in genomic medicine have redefined their classification and have impacted treatment in ways that one decade ago were not considered possible. Many CNS tumor types, once thought of as single entities, compose multiple subgroups with distinct clinical and molecular characteristics.<sup>7</sup> However, despite the growing list of molecular aberrations identified in pediatric CNS tumors, proven efficacious molecular based treatments are still limited. Nonetheless, early adoption of these insights could lead to accelerated progress around the world.

To help bridge the gap in outcomes for pediatric CNS tumors in LMICs, St. Jude Children's Research Hospital (St. Jude) launched the first St. Jude Global Academy Neuro-Oncology Training Seminar, which is a blended course in pediatric neuro-oncology with a focus on LMIC needs. The course focuses on teams of specialists who care for children with CNS tumors (oncologists, neurosurgeons, neurologists, radiologists, pathologists, and radiation oncologists) and seeks to provide knowledge and skills that are globally applicable in the context of multidisciplinary care. After systematic creation of the curriculum, course elements were defined by a needs assessment survey that included an evaluation of team dynamics, treatment capacity, and educational goals. The first component was a 9-week online course, and the second was a workshop at the St. Jude campus with 20 participants from seven countries. The workshop, held

in November 2019, sought to consolidate acquired knowledge and, more importantly, to share experiences and start to generate ideas for impactful interventions and collaboration.

During the course, barriers to quality care were discussed extensively among participants from different specialties, geographic regions, and health care contexts. Importantly, systematic evaluations of treatment barriers for children with CNS tumors in LMICs are limited.<sup>8,9</sup> Salient barriers that were discussed included (1) an absence of coordinated multidisciplinary care; (2) an inability to subspecialize or concentrate on neuro-oncologic diseases; (3) limited infrastructure, including neurosurgical, laboratory, radiotherapy, and rehabilitation facilities; (4) delays in referrals between specialties; (5) postsurgical morbidity; (6) insufficient hospital- and population-based data; (7) treatment abandonment; and (8) an increasing discord between recent molecular insights and the current clinical context in LMICs. Understanding such barriers is a first step to reducing them. Workshop participants also noted that past improvements in care were based on (1) establishment of multidisciplinary teams and regular team meetings; (2) the dedication of knowledgeable, passionate individuals; (3) institutional, regional, and international collaborations; and (4) optimization of available resources.

To work toward the goal of providing high-quality care for children with CNS tumors in LMICs, workshop participants formed the Global Alliance for Pediatric Neuro-Oncology (GAP-NO). To our knowledge, this is the first multinational, multidisciplinary group focusing on pediatric CNS tumors in LMICs. The mission of GAP-NO is to improve access to quality care and outcomes for children with CNS tumors globally through multidisciplinary collaboration, education, generation and adaptation of knowledge, and optimization of resources. This alliance can be leveraged to increase advocacy for children with CNS tumors across the world, thus increasing visibility of this disease burden.

Because data and literature that report CNS tumor outcomes from LMICs is largely lacking, this must also be a global priority.

Recognizing the true burden of disease and current outcomes will facilitate identifying the interventions needed to improve survival and quality of life. In addition, understanding the heterogeneity of resources available in different contexts will expedite the development of tailored treatment protocols for differing health systems and hospital infrastructures.

Narrowing the survival gap in LMICs poses an enormous challenge, but partnerships among institutions with the similar challenges can be leveraged to define successful interventions. International and interdisciplinary collaborations and initiatives are needed to improve the outcomes of children with CNS tumors in LMICs. Ultimately, these vulnerable patients must be included in national health agendas as a priority point of action to fully implement change. Cures should be limited only by our understanding of diseases, not by the availability of care.

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### **Authors' disclosures of potential conflicts of interest**

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## References

1. GBD 2017 Childhood Cancer Collaborators: The global burden of childhood and adolescent cancer in 2017: An analysis of the Global Burden of Disease Study 2017. *Lancet Oncol* 20:1211-1225, 2019
2. Ward ZJ, Yeh JM, Bhakta N, et al: Estimating the total incidence of global childhood cancer: A simulation-based analysis. *Lancet Oncol* 20:483-493, 2019
3. Allemani C, Matsuda T, Di Carlo V, et al: Global surveillance of trends in cancer survival 2000-14 (CONCORD-3): Analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries. *Lancet* 391:1023-1075, 2018
4. Rodriguez-Galindo C, Friedrich P, Alcasabas P, et al: Toward the cure of all children with cancer through collaborative efforts: Pediatric oncology as a global challenge. *J Clin Oncol* 33:3065-3073, 2015
5. World Health Organization: Global Initiative for Childhood Cancer. <http://www.who.int/cancer/childhood-cancer/en/>

6. Steliarova-Foucher E, Colombet M, Ries LAG, et al: International incidence of childhood cancer, 2001-10: A population-based registry study. *Lancet Oncol* 18:719-731, 2017
7. Gajjar A, Bowers DC, Karajannis MA, et al: Pediatric brain tumors: Innovative genomic information is transforming the diagnostic and clinical landscape. *J Clin Oncol* 33:2986-2998, 2015
8. Baskin JL, Lezcano E, Kim BS, et al: Management of children with brain tumors in Paraguay. *Neuro Oncol* 15:235-241, 2013
9. Chan MH, Boop F, Qaddoumi I: Challenges and opportunities to advance pediatric neuro-oncology care in the developing world. *Childs Nerv Syst* 31:1227-1237, 2015