

are limited and outdated. We aimed at evaluating the diagnostic interval time(DIT) for Canadian children, and identifying factors possibly associated with prolonged DIT. **METHODS:** Using the CYP-C database, we analyzed data from children <15 years, diagnosed with CNS tumors between 2001–2015. DIT was defined as time in weeks, elapsed from the first contact with a healthcare provider to confirming diagnosis. We described DIT according to patient's demographics, socioeconomic, geographic factors as well as tumor-related criteria. **RESULTS:** Patients from all Canadian provinces, except Ontario, had available timepoints to calculate DIT. The cohort included 842 patients. Mean DIT for all patients was 11.7 weeks (median 1.4). Gliomas had the longest mean DIT and embryonal tumors had the shortest (14.6 and 3.6 weeks $p<0.01$). ATRT and medulloblastoma had a mean DIT of 1.3 and 4.3 weeks respectively. DIT for HGG was shorter than for LGG (6.4 versus 16.1 weeks, $p<0.01$). Metastatic disease, infratentorial tumors, or age ≤ 36 months had significantly shorter DIT (5.6 vs 12.4 vs 18.4, 7.4 vs 13.1 and 8.6). Sex, annual income(QAIPPE), and distance from tertiary center did not influence DIT. **CONCLUSION:** The current diagnostic interval time for pediatric CNS tumors in Canada is 11.7 weeks (median 1.4 weeks). These results only reflect the healthcare system's contribution toward diagnosis confirmation, but not the patient interval before seeking medical attention.

EPID-07. A GLOBAL PERSPECTIVE ON THE BURDEN OF PEDIATRIC CENTRAL NERVOUS SYSTEM TUMORS

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Although approximately 90% of pediatric cancer cases exist in low- and middle-income countries, the magnitude of the global burden of pediatric central nervous system (CNS) tumors remains poorly quantified. **METHODS:** Data from International Incidence of Childhood Cancer-3 and CONCORD-3, which include observed incidence and survival from population-based cancer registries (PBCR), and from GLOBOCAN 2018 and Global Burden of Disease 2016, which produce burden estimates from observed and modelled data, were used to analyze epidemiologic characteristics and correlations for CNS tumors globally. Data from The World Bank were used for national macroeconomic variables. **RESULTS:** The majority of countries are not covered by PBCR, with information on incidence and survival available for 37% and 27% of countries, respectively. Survival data is not available for any low-income country. The incidence of CNS tumors varies markedly, from 0.4 to 49 $\times 10^6$ person-years, the greatest variability in pediatric cancer subgroups. Modelled data suggests that approximately 40,000 incident cases and 19,000 deaths occur from CNS tumors worldwide. When country-level data are segregated based on World Bank groups, a difference in incidence and survival exists ($p<0.05$). A higher national health expenditure correlates with both an increased incidence and survival of CNS tumors, while the inverse is true for under-5 mortality ($p<0.05$). **CONCLUSIONS:** Scarce facts are available, but this analysis establishes a link between national income and epidemiologic parameters for CNS tumors. In this context, carefully designed initiatives, focusing on a health-systems approach are critical to meet the global challenge of pediatric CNS tumors.

EPID-08. FINDING THE NEEDLE IN THE HAY STACK – POPULATION-BASED STUDY OF PREDIAGNOSTIC SYMPTOMATIC INTERVAL IN CHILDREN WITH CNS TUMORS

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PURPOSE: Delay in diagnosis of central nervous system (CNS) tumors in children is well documented. The aims of this study were to characterize the symptomatology of CNS tumors and the time to diagnosis in a large pediatric hospital in Canada. **METHODS:** Retrospective chart review of children diagnosed with a CNS tumor between 2000 and 2016 in Vancouver, British Columbia, Canada was performed. Data collected included demographics, symptomatology, tumor type, age at diagnosis, known visits to healthcare professionals, neuroimaging, therapy and post treatment relapse or progression. **RESULTS:** 148 children with complete medical records were reviewed. The average age at diagnosis was 87.8 months (standard deviation (SD) = 59.7; median = 72). 50.7% of patients had posterior fossa tumors and 49.3% had supratentorial tumors. 30% of patients were diagnosed after a single visit to a health care provider. 7.7% of children needed more than 4 visits. Median total time to diagnosis (PSI) was 62 days (range = 0–2047 days). The longest prediagnostic interval was first symptom

onset to first healthcare provider visit (PSI1, median 37 days). Patients with posterior fossa tumors, presence of metastases, and symptoms of ataxia and paresis were associated with shorter PSI. **CONCLUSIONS:** CNS tumors in children continue to pose a diagnostic challenge with significant variability in time to diagnosis. Our population-based study found that median time from symptoms to seeking medical advice by parents was over a month. It is essential to uncover the reasons for delay and address them where possible.

EPID-09. THE INCIDENCE OF PRIMARY BRAIN TUMORS IN CHILDREN IN JAPAN BASED ON 2016 NATIONAL CANCER REGISTRY IN JAPAN

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The national cancer registries began in January 2016 and the actual number of cancer patients in 2016 including primary brain tumors in Japan was released as a preliminary report in January 2019. According to the report, 667 incidence of pediatric brain tumors were reported in aged 0–14 years (boy: 382; girl: 285), of them 537 patients underwent surgery, chemotherapy, or radiation therapy (diagnosis: 516, undiagnosed: 21), and 130 patients were followed up without any treatments. The breakdown of tumor types was 279 Neuroepithelial tumors, 73 Embryonal tumors (61 Medulloblastomas), and 63 Germ Cell Tumors (GCTs). The crude rate per 100,000 population in 2016 was 4.23 for all pediatric brain tumors, 1.77 for Neuroepithelial tumor, 0.39 for Medulloblastoma, and 0.40 for GCTs. In comparison, the United States CBRUS2019 (2012–2016) reported that the age-adjusted incidence rates per 100,000 population in the United States was 5.74 for all pediatric brain tumors, 4.15 for Neuroepithelial tumors, 0.48 for Medulloblastoma, and 0.22 for GCTs. The age-adjusted incidence in Japan based on the US population in 2000 was 4.21 for all pediatric brain tumors, Neuroepithelial tumor 1.77, Medulloblastoma 0.39, and GCTs 0.39, suggesting that the incidence of Neuroepithelial tumor and Medulloblastoma is lower whereas that of GCTs is approximately twice comparing to the US. By taking advantage of the national cancer registry data, which was publicly opened to researchers in 2019, we report the incidence of primary brain tumors and its comparison worldwide based on the re-classification criteria of primary brain tumors including benign tumor.

EPID-10. EPIDEMIOLOGY STUDY OF UNCOMMON CHILDHOOD BRAIN TUMOURS IN ASIAN CHILDREN

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Our local registry identified 656 brain tumours from Jan 1999 to Dec 2018, (incidence: 29.8/yr/million). Other from Glioma, Medulloblastoma/PNET, Germ Cell tumours, Ependymoma, the remaining rarer tumours accounted for 18% (n=118). The 7 more common groups are: craniopharyngioma(n=28); ATRT(n=18); choroid plexus papilloma/CA(n=12); Ganglioglioma(n=11); ETMR(n=7); DNET(n=7); meningioma(n=6). Their respective incidences are 1.27; 0.81; 0.55; 0.5; 0.32; 0.32 0.27/yr/million. For craniopharyngioma, M:F=15:13 and median age was 7.4yrs (2mons-16.5yrs). 12/28 children had surgery alone and 13/28 had focal RT post-surgery with better outcome. 3 underwent intra-cystic interferon-beta also stable. For ATRT, M:F=7:8 and median age was 2.3yrs (4mos-14.2yrs). 2 had metastatic disease and 7/18 patients remained alive. For choroid plexus tumours, there were 7 papilloma, 2 atypia and 3 carcinoma. M:F=5:6 and median age was 1.5yrs (4mos-14yrs). All papilloma, 1/2 atypia and 1/3 carcinoma survived. For ganglioglioma, M:F=7:4 with median age of 5.5yrs (5mos-13.2yrs). They commonly presented with seizure and only one died (brainstem primary). The ETMR includes ependymoblastoma and medulloepithelioma, they had quite different clinical characteristics and outcome. 6/7 DNET had convulsion and M:F=6:1. Median age was 11.5yrs (2.66-14yrs). They all survived even if incompletely resected. For meningioma, 1/6 had germline mutation of NF-2 gene. M:F=3:3 and onset was >8yrs except the NF-2 patient. All survived but the NF-2 had multiple recurrences. 4 patients developed secondary meningioma due to irradiation but they were >18yrs so excluded. In summary, rarer forms of childhood brain tumours only accounted for <20% of all brain tumours and they had diverse presenting features and outcome.

EPID-11. ESTABLISHING A BASELINE TIME-FRAME FOR SYMPTOM ONSET TO DEFINITIVE DIAGNOSIS FOR CHILDREN WITH NEWLY-DIAGNOSED CNS TUMORS: AN EXPANDED, MULTI-INSTITUTIONAL COLLABORATIVE STUDY

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BACKGROUND: We have previously documented the presence of diagnostic delays in children with central nervous system (CNS) tumors in the United States. This study serves to expand and validate the previously established baseline from symptom onset to definitive diagnosis in children with newly-diagnosed CNS tumors. **DESIGN:** The medical records of children with newly-diagnosed CNS tumors were retrospectively reviewed from January 2004 to December 2017 at Nationwide Children's Hospital, Akron Children's Hospital and Riley Hospital for Children at IU Health. Records were reviewed for age, gender, tumor type, presenting symptoms, number of healthcare visits prior to diagnosis, time interval (in months) from onset of symptoms to definitive diagnosis and any associated genetic syndromes. **RESULTS:** Of the 768 patients with newly-diagnosed CNS tumors, the median time interval from symptom onset to definitive diagnosis was 40.5 days while the mean symptom interval was 144 days (range < 1 to 5,475 days). The median age of diagnosis was 7 years, with a male predominance (57%). This expanded cohort continues to reveal that pediatric brain tumor patients most often seek care at the primary care level, although many patients were seen in various multiple subspecialty clinics prior to diagnosis. **CONCLUSIONS:** This multi-institutional cohort study updates our previously documented single state time interval and provides a consistent Midwest "benchmark" to improve awareness for children with brain tumors through the adaptation of the UK 'HeadSmart,' now renamed 'BrainFirst.' Additionally, future work could include a prospective registry to better examine potential risk factors for delays in diagnosis.

EPID-12. TEMPORAL AND GLOBAL GEOGRAPHIC VARIATION IN THE INCIDENCE OF PEDIATRIC CNS TUMORS, 1998–2012

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AIMS: To describe the temporal and geographic variation in the incidence of pediatric CNS malignancies worldwide, presenting analyses by sex, period, region, and histological subtype between 1998 and 2012. **METHODS:** Data were extracted from volumes IX to XI of the Cancer Incidence in 5 Continents, covering the periods 1998–2002 (1), 2003–2007 (2), and 2008–2012 (3). We pooled data from 44 countries, classifying them into 6 regions (Africa (AF), Asia (AS), Oceania (O), Europe (E), Central/South America (CSA), North America (NA)). Age-standardized incidence rates (ASIR per million, 0–19 years) were calculated and temporal variation was evaluated using incidence rate ratios (IRR) (95% CI). **RESULTS:** The highest incidence (Period 3) was observed in NA (34.0 and 30.2 for males and females, respectively). Astrocytic tumors were predominant in all regions, with percentages ranging between 24.5% (E, females) and 45.6% (NA, females). Increasing trends (Period 3 x 1) were observed in AS (IRR=1.15, 95% CI 1.06–1.25), CSA (IRR=1.25, 95% CI 1.01–1.55), and NA (IRR=1.05, 95% CI 1.03–1.07), for males and in AS (IRR=1.15, 95% CI 1.05–1.26) and NA (IRR=1.08, 95% CI 1.06–1.11) for females. Geographic discrepancies in time-trends were observed for astrocytomas, ependymomas, medulloblastomas, other embryonal tumors, and other specified tumors. Reductions in the incidence of unspecified tumors from period 1 to 3 were noted in E, AS, and NA, ranging from -20% (E, females) to -66% (AS, females). **CONCLUSIONS:** Heterogeneous trends and improvement in the registration of histological types were noted. Geographic variation can help to raise hypotheses to investigate etiologic factors.

EPID-13. A POPULATION-BASED ANALYSIS OF CNS TUMOR DIAGNOSES, TREATMENT, AND SURVIVAL IN CONGENITAL AND INFANT AGE GROUPS

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BACKGROUND: Congenital (<3 months) and infant (3 to 11 months) brain tumors are biologically different from tumors in older children, but epidemiology of these tumors has not been studied comprehensively. Insight into epidemiological differences could help tailor treatment recommendations by age and increase overall survival (OS). **METHODS:** Population-based data from the SEER 18 registries was obtained for 14,493 0-19-year-olds diag-

nosed with CNS tumors between 1990 and 2015. Incidence, treatment, and survival were analyzed using Chi-square and Kaplan-Meier analyses. **RESULTS:** Between the <3 month, 3–5 month, 6–11 month, and 1–19 year age groups, tumor type distribution differed significantly ($p < 0.001$); high-grade glioma (HGG) was most common in the <3-month-olds, while low-grade glioma (LGG) was most common in the other groups. 5-year OS for all tumors was 36.7% (<3 months), 56.0% (<3–5 months), 63.8% (6–11 months), and 74.7% (1–19 years) (log rank $p < 0.001$). OS by tumor type was worst for <3-month-olds with LGG, medulloblastoma, and other embryonal tumors; OS was worst for 3–5-month-olds with ependymoma, <1-year-olds collectively with atypical teratoid-rhabdoid tumor, and 1–19-year-olds with HGG (log rank $p < 0.02$ for all tumor types). <3-month-olds were least likely to receive any treatment for each tumor type and least likely to undergo surgery for all except HGG. <1-year-olds were far less likely than 1–19-year-olds to undergo radiation for embryonal tumors, as expected, but were also less likely to undergo chemotherapy. **CONCLUSIONS:** Congenital/infant CNS tumors differ pathologically, therapeutically, and prognostically from those in older children. Treatment changes could help address poorer outcomes for these young patients.

EPID-14. GABRIELLA MILLER KIDS FIRST DATA RESOURCE CENTER: COLLABORATIVE PLATFORMS FOR ACCELERATING RESEARCH IN PEDIATRIC CANCERS & STRUCTURAL BIRTH DEFECTS

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Since launching to the public in September 2018, the Gabriella Miller Kids First Data Resource Center (DRC) has made an increasing number of pediatric genomic studies available to the research community. Currently, 1.3 PBs of genomic and clinical data drawn from 12,000 participants are available across a variety of pediatric cancer and structural birth defect studies. The DRC has architected a secure, cloud-based platform with over 1,300 users that supports the ability of researchers to not only find, access, and reuse data, but also integrate, collaborate, and analyze data quickly at scale. Users can use integrations with platforms such as Cavatica for bioinformatics workflows and PedcBioPortal for cancer genomic visualizations. Additionally, a set of framework services, powered by Gen3, provide a foundation for interoperability with other large-scale data sources, platforms, and a growing ecosystem of analysis and visualization applications. These integrations allow users to search across both TARGET and Kids First clinical data in one location while allowing data governance to be maintained by the original approvers. The new "explore data" feature allows users to search across all studies in order to identify virtual cohorts. Within the portal, these cohorts can be saved and shared with collaborators for iterative refinement and analysis. With appropriate approvals, the associated genomic data can be accessed and analyzed seamlessly in Cavatica or other platforms with interoperable framework services. Additionally, gene searching capabilities will be available in 2020. Data is free to download and cloud credits are available for analysis support.

EPID-15. THE INTERNATIONAL DIFFUSE INTRINSIC PONTINE GLIOMA (DIPG)/DIFFUSE MIDLINE GLIOMA (DMG) REGISTRY AND REPOSITORY (IDIPGR) EXPANSION

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Established in April 2012, the mission of the IDIPGR is to provide secure integrated data sets including clinical, pathologic, radiologic and molecular genomics to the research community to promote hypothesis driven research. Over 600 data points per patient are securely stored on a CCHMC constructed web resource and domain using the open-source data mart