

Medicine, Indianapolis, IN, USA, <sup>2</sup>University of Nottingham, Nottingham, United Kingdom, <sup>3</sup>Akron Children's Hospital, Akron, OH, USA, <sup>4</sup>Nationwide Children's Hospital, Columbus, OH, USA, <sup>5</sup>Riley Hospital for Children, Indianapolis, IN, USA

**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

Karina Ribeiro<sup>1,2</sup>, and Sidnei Epelman<sup>1</sup>; <sup>1</sup>Santa Marcelina Hospital, Department of Pediatric Oncology, Sao Paulo, SP, Brazil, <sup>2</sup>Faculdade de Ciências Médicas da Santa Casa de Sao Paulo, Department of Collective Health, Sao Paulo, SP, Brazil

**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

Muriel Hart<sup>1,2</sup>, Amy Mellies<sup>3</sup>, Alina Beltrami<sup>1,2</sup>, Ahmed Gilani<sup>1,4</sup>, and Adam Green<sup>3,5</sup>; <sup>1</sup>Morgan Adams Foundation Pediatric Brain Tumor Research Program, Aurora, CO, USA, <sup>2</sup>Biomedical Sciences Program, University of Denver, Denver, CO, USA, <sup>3</sup>University of Colorado Cancer Center, Aurora, CO, USA, <sup>4</sup>Department of Pathology, University of Colorado School of Medicine and Children's Hospital Colorado, Aurora, CO, USA, <sup>5</sup>Morgan Adams Foundation Pediatric Brain Tumor Research Program, Department of Pediatrics, University of Colorado School of Medicine and Children's Hospital Colorado, Aurora, CO, USA

**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

Allison P. Heath PhD<sup>1</sup>, Yuankun Zhu BS<sup>1</sup>, Michele Mattioni PhD<sup>2</sup>, Bailey Farrow BS<sup>1</sup>, Jena Lilly MS<sup>1</sup>, Yiran Guo PhD<sup>1</sup>, Jo Lynne Rokita PhD<sup>1</sup>, Phillip B. Storm MD<sup>1,3</sup>, Samuel L. Volchenbom MD, PhD<sup>4,5</sup>, Javad Nazarian PhD<sup>6</sup>, Nicole Vasilevsky PhD<sup>7</sup>, Jack DiGiovanna PhD<sup>2</sup>, Melissa Haendel PhD<sup>7,8</sup>, Robert L. Grossman<sup>4</sup>, Brandi Davis-Dusenbery PhD<sup>2</sup>, Deanne M. Taylor PhD<sup>1,9</sup>, Vincent Ferretti PhD<sup>10,11</sup>, and Adam Resnick PhD<sup>1,3</sup>; <sup>1</sup>Children's Hospital of Philadelphia, Philadelphia, PA, USA, <sup>2</sup>Seven Bridges Genomics, Cambridge, MA, USA, <sup>3</sup>Department of Neurosurgery, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA, <sup>4</sup>Center for Research Informatics, The University of Chicago, Chicago, IL, USA, <sup>5</sup>Department of Pediatrics, Biological Sciences Division, The University of Chicago, Chicago, IL, USA, <sup>6</sup>Children's National Medical Center, Washington, DC, USA, <sup>7</sup>Oregon Health & Science University, Portland, OR, USA, <sup>8</sup>Oregon State University, Corvallis, OR, USA, <sup>9</sup>Department of Pediatrics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA, <sup>10</sup>Ontario Institute of Cancer Research, Toronto, ON, Canada, <sup>11</sup>CHU Sainte-Justine Research Center, Montreal, QC, Canada

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

Marianne Torontali, Renee Doughman, Brooklyn Chaney, Katie Black, Anthony Asher, Andrew Rupert, Christine Fuller, James Leach, Blaise Jones, Maryam Fouladi, and Mariko DeWire; Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

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