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DEI-06. IMPROVING ACCESS TO POST-MORTEM BRAIN TUMOR TISSUE DONATION BEYOND THE INPATIENT HOSPITAL SETTING
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Between May 2021 and December 2023, approximately 33% of patients were being treated inpatient at the time of consent for post-mortem tissue donation through Gift From A Child. In the past, a major obstacle preventing families from donating post-mortem tissue was the inability to leave the hospital. Care teams and patient families are often concerned that in order to donate, the patient would have to pass away at the hospital. This creates a situation where the desire to donate comes at the cost of patient care and comfort. Through GFAC, children can pass at home, hospital, or hospice and still donate tissue successfully. The ability to donate post-mortem tissue is independent of patient location, ensuring that the focus of the family and care team remains on the child’s care rather than donation logistics. Additionally, patients can successfully donate tissue independent of status at the time of inquiry (declining, stable, urgent). The ability to quickly access a resource at a low burden to the family has been crucial in allowing tissue donation to happen. This also improves patient equity by eliminating access to hospital resources as a reason for a patient family to be required to live near a hospital. This is oftentimes a tremendous financial difficulty for patient families. Through establishing standard operating procedures and appointing tissue navigators, GFAC has streamlined what was previously an extremely complicated process mired in logistical obstacles. Patient families now have access to an efficient process for tissue donation. Previously, families would need to navigate complicated logistics unsupported, now they (or someone on their behalf) only need to contact GFAC or a Research Center of Excellence via phone or email and consent for donation. This ensures that post-mortem tissue can be donated easily, efficiently, and from wherever the patient family chooses.