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OTHR-23. PATIENT DESIRE TO SHARE DATA AND PARTICIPATE IN RESEARCH IN THE DIPG/DMG COMMUNITY
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Direct and reciprocal communication between patient communities and their research and care teams is essential to building trust and ensuring that all essential information is shared. Patient participation in data collection of any sort is often challenging, as patients may be hesitant or unmotivated to share their information. The DIPG/DMG patient community faces the opposite challenge. Because of the frustration of the lack of treatment options and the established trust that exists between patient families and research professionals, DIPG/DMG patient families are both willing and eager to share any information they can. Patient families have seen how their knowledge has helped other families navigate impossible situations and care teams understand how to better support their patients. The information families eagerly provide is crucial to advancing treatment and research. Patient families have repeatedly expressed willingness to participate in quality of life assessments, repeated surveys during and after treatment, and provide their medical and biological information in the hopes that it can aid research. There is a need for a centralized manner for all of this data to be shared by the patient and accessed by care teams and researchers. Patient-led initiatives are addressing this by creating a network of resources. This network helps to guide other patient families through the data-sharing process, address concerns, and find ways to provide what is needed to push research and treatments ahead. There are many benefits to having a centralized data ecosystem for researchers and care teams, such as standardizing data collection and ease of analysis. In the future, this centralized hub could inform personalized care, making options such as n-of-1 trials and matching patients to optimal clinical trials possible in a manner that is effective and efficient.