

NEW BEST PRACTICES TO KNOW UPON DIPG DIAGNOSIS

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- The most important first step is radiation to start relatively quickly (to preserve as much function as possible during the honeymoon period that many patients have, or to improve any functional loss before its permanent) – for some children with less symptoms this might be less critical.
- There is no documented difference between proton or photon radiation for DIPG/DMG, so whatever can be offered sooner should be considered. Radiation is standard of care used for many years and can generally be performed at most hospitals safely.
- Steroids should be weaned as quickly and safely as possible – when and how much to use depends heavily on the clinical presentation and should be discussed with your team. Consider with your team whether it is necessary to start steroids proactively. Steroids do not inhibit the tumor from progressing, steroids help alleviate symptoms caused by inflammation surrounding the tumor. Learn the pros and cons of steroids early.
- Biopsy should be performed by someone who has experience with the procedure. If a patient is critically ill and needs to start radiation therapy quickly, a biopsy can also be performed after completion of radiation therapy. Biopsies are necessary to confirm the diagnosis and determine the specific DIPG subtype. Having tissue available is becoming more and more important as many trials require information from the biopsy or actual tissue for enrollment. Be sure that the tissue is used for relevant testing – often the tissue is fairly limited. Data generated from the tissue can easily be shared with others.
- Some clinical trials start WITH radiation, but most clinical trials start after radiation – all trials are listed on clinicaltrials.gov but be sure to discuss these options also with your team. It is challenging to sort through the different options alone.
- Ask for a second opinion if you want to – it is highly recommended to get second opinions from different centers with experience treating DMG, as centers have different options to offer. Some trials are only available in certain places and providers have variable levels of comfort taking care of ALL diagnoses, including DIPG.
- If your insurance is not covering all needs, talk to your social worker about secondary insurance options (i.e. Medicaid).
- Palliative care is often a helpful resource in the beginning to coordinate care, provide emotional support, etc. and palliative care can be activated WHILE on therapy in pediatric and plays a different role than classic “HOSPICE” end of life care in adults. Palliative care teams can really make your life much easier.
- We will make more progress when working as a team– data sharing for a rare disease like DIPG is critical. One example is the DMG ACT. This group combines researchers around the globe to develop the best next therapies for children with DIPG. Anyone can join and we aim to make data available as soon as possible to enhance research further. Consenting to share data with the Children’s Brain Tumor Network allows researchers to learn from DIPG patients to drive treatments.