



JustOneMoreDay.org

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Just One More Day for Love, Hope & a Cure

March 19, 2009

Dear ODAC Members:

We, the Board members of Just One More Day, are writing to urge the Committee to recommend approval of Avastin as a single agent in recurrent glioblastoma multiforme.

Just One More Day is a non-profit foundation formed by parents to help other parents whose children have been diagnosed with pediatric diffuse intrinsic pontine gliomas ("DIPG"), a cancerous tumor which invades the brainstem. DIPGs are almost always terminal, with most children dying within one year of diagnosis. In thirty years, and despite a number of different trials, no chemotherapy has been found to be effective against DIPG. With Avastin, however, there is hope.

Although DIPGs are generally considered inoperable, DIPG lesions were biopsied as part of a recent French study. The study revealed that the vast majority of DIPGs are high-grade gliomas, with many being glioblastoma multiforme.

In our network of parents we have seen many of our children with DIPGs stabilize with Avastin. In fact, we have recently been overjoyed by dramatic regression of the DIPG in Andrew, son of one of our Board members, after he received a single cycle of Avastin. Avastin has provided a spark of hope in the dismal world of diffuse intrinsic pontine gliomas.

We realize that the question before the committee is whether to recommend approval of Avastin as a single agent in recurrent glioblastoma. Unfortunately, the call for written testimony did not indicate whether the question addresses both adults and children or only adults. Regardless, we believe it is important that our voice be heard on the matter. We are directly impacted by what is being done for adults with brain tumors, as treatments are usually not approved for children until they pass through the approval process for adults. Articles such as ***Antiangiogenic Therapy Using Bevacizumab in Recurrent High-Grade Glioma: Impact on Local Control and Patient Survival*** (J. Neurosurg. 2009 Jan; 110(1): 173-80) are encouraging and reflect what we are seeing with our children.

We ask that the committee pause and reflect on the impact of this recommendation to the entire brain tumor community – including our children. Previously there has been so little hope for children with DIPGs. Even a little more time with our children – even, as our name reflects, just one more day – is incredibly precious to us. Please help the flame of this hope continue to burn and, we hope, to grow even brighter.

None of our board members have financial conflicts regarding the approval of Avastin.

Thank you for your time and consideration.

Directors

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