

Glioblastoma Bill of Rights

We the patients have the right to:

- ☐ **1** **Personalized care plan**
A custom plan developed before initial treatment - tailored to you and your tumor. Discussion of all options and every FDA-approved treatment (including Tumor Treating Fields).
- ☐ **2** **Timely tumor testing & storage**
Tumor biomarker testing (individual makeup, including mutations) before treatment begins. Fast-tracked analysis. Tissue from initial surgery frozen for potential use.
- ☐ **3** **Second opinion**
A second opinion before treatment and again at any point. A good doctor will welcome this and a good healthcare system will enable it.
- ☐ **4** **Access to clinical trials**
Up-to-date, accurate, and personalized information about emerging treatments. Help with related travel and expenses. Clinical trials offered at diagnosis and if the tumor recurs.
- ☐ **5** **Specialist care**
Tumor removed by a neuro-surgeon. Treatment guided by a neuro-oncologist. Access to specialists like radiation oncologists and neuro-pathologists. Coordinated and communicative care team.
- ☐ **6** **Quality of life support**
Psychological help (care partners too) and support groups. Palliative care - to ensure good quality of life, minimize suffering, and manage pain. Hospice care - comfort rather than curative treatment (when appropriate).
- ☐ **7** **Affordable high quality care**
Access to affordable and effective treatment. Transparency about outcomes. Help with insurance, benefits, housing, and transportation. Information about workplace rights (short and long-term disability, accommodations).
- ☐ **8** **Easy access to records and ability to donate data**
Ease in obtaining health records - including fast-tracked MRI results - and transporting own data. Ability to donate data and tissue for research.
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