

Glioblastoma Bill of Rights

Glioblastoma is an aggressive, deadly brain tumor that currently has no cure. People living with GBM deserve quality care and the ability to make informed decisions.

Now is the time for a GBM Bill of Rights. Developed by patients, alongside our families and advocates, this is the road map to patient power and a brighter future.

We, the patients, have...

THE RIGHT TO

1 Patient-centered care

An equal and collaborative patient/doctor relationship with personalized treatment that includes genomic and genetic testing, and tumor analysis.

THE RIGHT TO

2 A second opinion

A second opinion offered at appropriate stages of diagnosis and treatments.

THE RIGHT TO

3 Clarity of information

Up-to-date, accurate information about all potential treatment options; transparency about treatment centers and their outcomes.

THE RIGHT TO

4 Specialist care

Access to a coordinated medical team — brain tumor specialist, neurosurgeon, neurooncologist, radiation oncologist, and others.

THE RIGHT TO

5 Access to trials and experimental treatments

Up-to-date, accurate information about new drugs, treatments, and clinical trials, including international options.

THE RIGHT TO

6 Psychological support

Comprehensive psychological help for us and our carers.

THE RIGHT TO

7 Money-blind treatment

Best treatment regardless of personal financial situation.

THE RIGHT TO

8 Fast-tracked treatments

Fast-tracked MRI results, treatments, and ER visits.

THE RIGHT TO

9 Patient-owned data

Ownership of and access to our health data, and the ability to transport and donate our data and tissue for research.

THE RIGHT TO

10 Best end-of-life care

Access to pain management, palliative care, and hospice.

THE RIGHT TO

11 Brain donation

Information provided to us and our families about no-cost brain donation for scientific research.



OurBrainBank

An initiative of OurBrainBank
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