



Bill of RIGHTS

for People Living with Epilepsy





Bill of Rights for People Living with Epilepsy

The Bill of Rights for People Living with Epilepsy was created and developed by the Epilepsy Foundation of Greater New York in partnership with Novartis Pharmaceuticals Corporation, along with a number of leaders in the epilepsy community including epileptologists, neurologists, nurse practitioners, social workers and most importantly, people living with epilepsy. The Epilepsy Foundation affiliates of Greater Chicago, Los Angeles and South Florida also contributed extensively to the development of the document.

The Bill of Rights for People Living with Epilepsy is designed to inform people affected by epilepsy about issues related to healthcare, health insurance coverage, life at school and life in the workplace. People with epilepsy are encouraged to take an active role in managing their healthcare; however, any and all treatment decisions must be made together with their healthcare team. Those who are informed will gain the greatest benefit from the existing system.

The Bill of Rights for People Living with Epilepsy is not a legal document. These 10 rights are aspirational goals that the epilepsy community is striving to achieve. None of the information should be construed as medical or legal advice and recipients of this document should not make decisions or take actions based on the information contained in this document without obtaining appropriate medical or legal counsel from a qualified, licensed professional.

In January, 2005, Harris Interactive® conducted a survey online on behalf of Novartis Pharmaceuticals Corporation among 507 adults with epilepsy and 149 parents of children (under age 18) with epilepsy.

1. **People with epilepsy have the right to be treated fairly and with respect.**

- People with epilepsy should be able to live without facing stigma, in a society that understands epilepsy as a medical condition. To correct the lack of knowledge and prevent discrimination, members of the epilepsy community should seek to raise the public dialogue about the condition to educate as wide an audience as possible.
- People with epilepsy should be treated fairly, with compassion and understanding by law enforcement officers and other first responders (e.g., emergency medical technicians, firefighters, public transit workers and school personnel, etc.). First responders should be trained to know the difference between a person who is confused or disoriented because of a seizure or their medications, and a person who is intoxicated. First responders should also be trained to properly administer first aid to a person who is having a seizure and should be able to recognize most types of seizures. Many Epilepsy Foundation affiliates offer such training programs for first responders in their communities.

2. **People living with epilepsy have the right to receive comprehensive, understandable information about epilepsy and its treatment.**

- People living with epilepsy and their families should receive easy to understand and up-to-date information about the condition, including information about treatment options related to their specific seizure type and current research. This information should be given at the initial diagnosis and during the treatment process.
- People living with epilepsy are encouraged to ask their doctor to review, explain and interpret their medical tests (e.g., MRI, blood tests, EEG, etc.) with them so they will become more informed about their condition.
- Non-English speaking people living with epilepsy are encouraged to ask for information from their healthcare provider in their native language.

3. **People living with epilepsy have the right and responsibility to be active members of their healthcare team.**

- Many people living with epilepsy work with a healthcare team to treat their condition. They should feel comfortable asking for the qualifications of the people taking care of them.
- The healthcare team may include (but is not limited to) primary care doctors, neurologists, epileptologists, nurses, physician's assistants, speech and language pathologists, physical and occupational therapists, social workers, pharmacists and emergency personnel.
- People living with epilepsy are encouraged to share their treatment and quality of life goals with their healthcare team and ask for these to be considered and incorporated into their healthcare plan. They are also encouraged to ask for accurate information about their condition on an ongoing basis.
- People living with epilepsy have the right to seek a second opinion from another doctor and to ask for a copy of their medical records to provide to the new doctor. However, insurance policies vary so a visit to a new doctor may not be covered for certain individuals.
- People living with epilepsy can ask their healthcare providers and insurance company about the financial costs of medical tests and treatments.

*Oscar Gonzalez,
living with
epilepsy and
contributor to
the Bill of
Rights.*



4.

People living with epilepsy have the right to know and understand all of the treatment options that are available to them.



Maureen Lowry-Fritz, parent and advocate for her daughter who has epilepsy. Maureen was a contributor to the Bill of Rights.

- People living with epilepsy are encouraged to work with their healthcare team so they can make informed decisions about their own care.
- People living with epilepsy have the right to ask for comprehensive information about anti-epileptic drugs (AEDs), including potential short-term and long-term side effects.
- People living with epilepsy have the right to ask for information about which medications are appropriate for treatment of their condition and which have been approved by regulatory agencies.
- People living with epilepsy have the right to ask for information about any medication prescribed to them, whether it's for day-to-day use or in a hospital setting.
- People living with epilepsy can ask if a doctor has changed or a pharmacist has substituted a prescription for a brand name drug with a generic drug.
- People living with epilepsy have the right to ask their doctor whether their epilepsy can be treated with a single medication.
- People living with epilepsy have the right to ask for information about other available treatments, such as surgical options and diet.
- People living with epilepsy can access publicly available information about the availability of and eligibility criteria for clinical trials with investigational drugs and other interventions. People interested in clinical trials should talk to their doctors and/or visit www.clinicaltrial.gov.

5. Special populations of people with epilepsy (e.g., children, adolescents, women of child-bearing age, people with developmental disabilities, the elderly, etc.) have the right to ask about treatment and information appropriate to their specific needs.

- Women living with epilepsy have the right to ask about the effects of seizures and AEDs on contraception, fertility, family planning, pregnancy, breast feeding and menopause.
- Parents have the right to ask which medications and other treatments are appropriate for use in children with epilepsy.
- People living with epilepsy who are taking medications for other conditions (e.g., people with developmental disabilities and the elderly) are encouraged to ask which AEDs are appropriate to take in combination with those medications.

6. People living with epilepsy have the right to understand all of the options and legal protections for accessing healthcare benefit coverage available to them.

- People living with epilepsy are encouraged to seek easy-to-understand, timely information regarding health plan benefits, exclusions, appeal and appeal denial procedures and to advocate for an appropriate resolution. For more information contact your local Epilepsy Foundation affiliate or other epilepsy support agencies.
- People living with epilepsy have the right to ask about the specific rules governing insurance policies and other health systems (e.g., Medicaid, Veterans Administration, etc.) for the state where they live. For more information, contact your local Epilepsy Foundation affiliate or visit www.epilepsyfoundation.org.
- People living with epilepsy have the right to know that in certain situations the Health Insurance Portability and Accountability Act of 1996 (HIPAA) may provide certain protections in regards to pre-existing conditions. For more information visit www.cms.hhs.gov/hipaa.

A majority, eight in ten adults (79 percent) and nine in ten parents (91 percent), say that they would like to receive specific information about the rights of people with epilepsy.

7.

People with epilepsy have the right to know that healthcare providers will hold personal and medical information confidential.

- Maintaining patient confidentiality is a basic responsibility and ethical obligation of healthcare providers. Patients are entitled to communicate in confidence with their healthcare providers.

8.

Children with epilepsy may have the right to receive special education and related services at school; parents have the right to advocate for such services.

- Parents of children with epilepsy need to know that there are laws in place designed to protect the rights of children with disabilities in school. Epilepsy may or may not be classified as a disability, depending on a number of factors that vary among individuals. To learn more about this, visit www.epilepsyfoundation.org.
- Adult students in post-secondary education programs that receive federal funding may also be entitled to accommodations.
- People living with epilepsy and parents of young children with epilepsy are encouraged to alert teachers and other staff (e.g., school nurses, principals, etc.) to their condition and any medications they may be taking. Both epilepsy and AEDs can have a pronounced effect on a person's cognitive abilities, thus affecting performance in school. Additionally, schools should be encouraged to offer training to their staff on how to properly administer first aid to a person who is having a seizure and properly respond to other issues associated with epilepsy.



Dr. Blanca Vazquez, director of Clinical Trials and Out-Patient Services at New York University Epilepsy Center, and contributor to the Bill of Rights.

9. People with epilepsy have the right to know that there are federal and state laws that may provide them with protections in the workplace.

- People with epilepsy need to know that there are many federal and state laws in place that may provide them with protections in the workplace, such as The Americans with Disabilities Act (ADA). To learn more about these laws, contact your state Equal Employment Opportunity Commission or visit www.eeoc.gov.

10. People with epilepsy have the right to access help and support that will assist them in making informed decisions about living with epilepsy.

- The Epilepsy Foundation, with affiliates throughout the country, and other epilepsy support agencies have up-to-date educational materials on epilepsy and are poised to help patients, family members and others concerned about epilepsy to understand the condition, its treatment options, and its effect on quality of life. The Foundation has several support programs to help families through the many aspects of living with epilepsy. Each Epilepsy Foundation affiliate can provide information on local comprehensive epilepsy centers and social support services to help each person and family living with epilepsy access the best care and support available.

Adults and parents say they primarily rely on their doctor (55 percent and 60 percent respectively) and the Epilepsy Foundation (55 percent and 45 percent respectively) for information about their/their child's legal rights.

Bill of Rights for People Living with Epilepsy Partners

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Methodology

Harris Interactive® conducted the survey online on behalf of Novartis Pharmaceuticals Corporation between January 7–17, 2005 among 507 adults with epilepsy and 149 parents of children (under age 18) with epilepsy. Both the adults with epilepsy surveyed and the children of the parents surveyed took prescription medication to control their condition. Figures for age, sex, race/ethnicity, education, income and region were weighted where necessary to bring them into line with population proportions. Propensity score weighting was applied to adjust for respondents' propensity to be online.

In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a statistical precision of plus or minus 5 percentage points for the U.S. adults with epilepsy sample and plus or minus 8 percentage points for the parents of children with epilepsy sample. This online sample was not a probability sample.





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The Bill of Rights program is conducted by the Epilepsy Foundation and Novartis Pharmaceuticals Corporation