Addressing the Needs of Persons with Epilepsy:
Recommendations for a Plan of Action for the State of New Jersey

New Jersey Epilepsy Task Force
Final Report
November 30, 2016
The New Jersey Epilepsy Task Force Report is dedicated to Clayton Myers who tragically lost his battle with Epilepsy on August 4, 2012.

Until Epilepsy does not take one more life, or affect the quality of life, we will push forward.
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November 30, 2016

Honorable Chris Christie  
Governor, State of New Jersey

Honorable Stephen M. Sweeney  
New Jersey State Senate President

Honorable Vincent Prieto  
Speaker of the New Jersey General Assembly

Dear Governor Christie, Senate President Sweeney and Speaker Prieto:

On July 29, 2010 Governor Christie signed P.L. 2010, c.48 establishing the New Jersey Epilepsy Task Force in the Department of Health. The Task Force worked throughout 2011 to develop recommendations and comply with the law. At the end of the Task Force's term it was decided that the Task Force needed more time to study the complex issues facing individuals with epilepsy in New Jersey, thus Governor Christie signed into law P.L. 2013, c.66 which amended the previous law and essentially extended the term of the Task Force and required the issuance of an interim and final report. Attached for your review are the New Jersey Epilepsy Task Force Interim and Final Reports. The Interim and Final Reports are submitted together to provide a chronology of the two year process of public input, study and findings that resulted in the final recommendations. The Task Force understood its charge to: develop recommendations to educate the public and health care professionals about screening, diagnosis, and treatment of epilepsy and its complications; and develop recommendations to address psychosocial issues faced by persons with epilepsy, such as, depression, stigmatization, and discrimination. The members developed recommendations based on what they determined were the needs of New Jersey residents who are affected with epilepsy. Although the recommendations reflect the consensus of the appointed members of the Task Force, some of the recommendations would require additional authority or other administrative or legislative change; therefore, the
recommendations expressed in this report do not necessarily reflect the views or policy of any state agency.

Sincerely,

[Signature]

Cathleen D. Bennett
Commissioner
New Jersey Epilepsy Task Force Members

Ann Marie Bezuyen  
**Director of Special Projects**  
**The Anita Kaufmann Foundation**

Ann Marie Bezuyen is an Agency Representative on this Epilepsy Task Force, and the Director of Special Projects for The Anita Kaufmann Foundation (AKF), whose mission is to educate the public not to fear epilepsy and seizures. They are a global sponsor for the largest epilepsy awareness initiative in the world, “Purple Day.” Her programs include “Heads Up For Vets!” in collaboration with the Department of Veterans Affairs Epilepsy Centers of Excellence. Ms. Bezuyen received her degree in education from William Paterson University, and has been an epilepsy advocate and educator since 1995. She is extremely passionate about eliminating stigma through educational awareness programs and to that end maintains memberships on many boards, consortiums and this Task Force. She works daily with persons with epilepsy and their families on an individual basis. Ms. Bezuyen is an invited local radio and public television guest, as well as the author of several research papers and magazine and newspaper articles.

Ann Carletta  
**Patient Advocate**  
**Vice Co-Chair, New Jersey Epilepsy Task Force**

Ann is one of the public members on the Epilepsy Task Force. Diagnosed at 8 years old and spending years trying unsuccessfully to get seizures under control, she eventually opted for neurosurgery and has been seizure-free since then. She has been a volunteer for FACES, Finding a Cure for Epilepsy and Seizures, since 2006 and consults with people who are considering neurosurgery as an option to control their seizures. Ms. Carletta has published articles on her experience living with seizures and undergoing the 2-stage neurosurgery.

Eric B. Geller, MD  
**Director, Adult Comprehensive Epilepsy Center**  
**Institute of Neurology and Neurosurgery at St. Barnabas**  
**Vice Co-Chair, New Jersey Epilepsy Task Force**

Dr. Geller serves as an Agency Representative on this Epilepsy Task Force. He is the Director of the Adult Comprehensive Epilepsy Center at the Institute of Neurology and Neurosurgery at Saint Barnabas in Livingston, NJ since 1998. He is a board member of the Epilepsy Foundation of New Jersey and Family Resource Network of New Jersey, and a member of the Saint Barnabas Medical Center Bio-Ethics Committee. Dr. Geller has 20 years of experience in treating difficult seizure problems, and has been an investigator or co-investigator in trials of new epilepsy treatments and in the NIH-funded Epilepsy Phenome-Genome Project. He has published multiple peer-reviewed articles and book chapters on epilepsy, with a focus on epilepsy surgery. He is board-certified in Neurology with Added Qualifications in Clinical Neurophysiology (American Board of Psychiatry and Neurology) and by the American Board of Clinical Neurophysiology. He has been annually named a Top Doctor in New Jersey and New York since 2004.
Marilyn Gorney-Daley, DO, MPH  
Senior Public Health Physician  
Director of Special Child Health and Early Intervention Services  
Designee for Cathleen D. Bennett  
Commissioner of Health

Dr. Marilyn Gorney-Daley serves as Health Commissioner Cathleen D. Bennett’s designee. Dr. Gorney-Daley is the Director of Special Child Health and Early Intervention at the New Jersey Department of Health, with over 10 years experience working with special-needs populations, especially children with special healthcare needs. She is a board-certified public health and preventive medicine physician and is a member of the American College of Preventive Medicine and the Association of Maternal and Child Health Programs.

Nicole Hartmann  
Public Member

Nicole Hartmann is an affected public member on the New Jersey Epilepsy Task Force. She was diagnosed with epilepsy at age 15 and has been very involved with the epilepsy community ever since. Nicole began as an intern with the Epilepsy Foundation of New Jersey (EFNJ) following a scholarship win in her senior year of high school. Soon after, she became the founding member of the New Jersey Epilepsy Youth Council. At age 20, she became part of the National Epilepsy Youth Council and was recently elected as the Vice Chair. Nicole received her Bachelor of Science degree in Biology from Elmira College in 2011 and her Master of Biomedical Science Degree from UMDNJ in 2012. Currently, she works as a medical scribe in an oncology practice in Howell, NJ while applying for entry to medical school. Her hopes are to become a pediatric neurologist.

Eric M. Joice  
Executive Director  
The Epilepsy Foundation of New Jersey

Eric Joice is the Executive Director of The Epilepsy Foundation of New Jersey, a statewide health organization. Eric has held this position since 1983. Prior to that, he was Associate Director of the Mental Health Association of New Jersey. Eric Joice has been a member of the Governor’s Task Force on the Prevention of Child Abuse and Neglect and the Governor’s Committee for the Prevention of Mental Retardation and Developmental Disabilities. He has served on the New Jersey State Rehabilitation Council and the Governor’s Committee on Voluntarism. He has also chaired the New Jersey State Employee Charitable Campaign, and was President of the NJ Voluntary Health Agencies (now CHC). He is a recipient of awards from the Community Health Law Project, Exceptional Parent Magazine, the United Way and the Epilepsy Foundation of America.
Roopal M. Karia, MD
Pediatric Neurologist
Associate Director, Pediatric Neurology & Pediatric Epilepsy
Jersey Shore University Medical Center
Department of Pediatrics
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Neptune, NJ 07754

Dr. Karia is board-certified in Neurology with Special Qualification in Child Neurology, board-certified in Clinical Neurophysiology by the American Board of Clinical Neurophysiology, and board-certified in Neurodevelopmental Disabilities. She has participated as a sub-investigator and principal investigator in numerous clinical trials for epilepsy medications. Dr. Karia has also served on a NICHQ (National Initiative for Children’s Healthcare Quality) project to improve access and care for persons with epilepsy.

Marcelo E. Lancman, MD
Director of the Epilepsy Programs
Hackensack University Medical Center, Hackensack, NJ (Level IV epilepsy center)
Atlantic Health System, Summit, NJ (Level IV epilepsy center)
White Plains Hospital Center, White Plains, NY (Level IV epilepsy center)
Jersey City Medical Center, Jersey City, NJ

Dr. Lancman serves as a Neurologist on this New Jersey Epilepsy Task Force. He is an Associate Professor of Neurology at New York Medical College. Dr. Lancman is board-certified with the American Board of Psychiatry and Neurology, Inc. and American Board of Clinical Neurophysiology, Inc. (epilepsy). He has served as a past ad hoc reviewer for *Epilepsia, Neurology*, and *Electroencephalography and Clinical Neurophysiology* scientific journals. Dr. Lancman is Chairman of the Special Interest Group (Private Practice Epilepsy) of the American Epilepsy Society and is the author of approximately 50 scientific publication/book chapters, including “What You Need to Know if Epilepsy Has Touched Your Life: A Guide in Plain English” (in press). He has served as Principal Investigator of several scientific grants and has received the Best Doctors of America award from 2007 until present. Dr. Lancman is a member of the professional advisory Board of the Epilepsy Foundation of CT, past member of the Epilepsy Foundation of NYC and the Epilepsy Society of Southern NY.

Shelby A. Myers
Public Member - parent of a child with epilepsy
Chair, New Jersey Epilepsy Task Force

Shelby A. Myers was one of the representatives asked to give public testimony for the submission of the Epilepsy Task Force Bill in May 2010. She was nominated to the Task Force and elected the Chair in November 2011. She is a Patient Liaison for The NBN Group and aids in the transition of medically fragile children from facilities to their home. She is the founder and continues in the capacity of Marketing and Public Relations for Clayton’s Hope Organization, a nonprofit that raises awareness and funding for epilepsy research. Most recently, in September 2012, she was named the Epilepsy Advocate of the year by the Epilepsy Foundation of New Jersey/Family Resource Network. Shelby is the proud mother of five children and has been married for 20 years. Her son, Clayton, passed away on August 4, 2012, due to complications of epilepsy.
Jonathan Sabin, LSW  
Designee for Acting Commissioner Elizabeth Connolly  
Department of Human Services
Jonathan Sabin is the Director of the Office on Autism and the Office for the Prevention of Developmental Disabilities at the Division of Developmental Disabilities, which is part of the Department of Human Services. Jonathan has experience working with individuals with disabilities in a variety of settings. He had advocated on behalf of some of New Jersey's most vulnerable citizens while working in the non-profit sector as well as at the Department of Children and Families and the Office of the Child Advocate.

Harry A. Thibodeau, RPh, CCP, FASCP  
Consultant Pharmacist
Harry A. Thibodeau is an accomplished 30-year professional veteran in the field of pharmaceutical consulting. As a Clinical Pharmacist and President of Pharma-Care, Inc., Harry's expertise provides multidisciplinary approaches to assist consumers and families in various facilities and settings, such as mental health, developmental disabilities, sub-acute care, veteran homes, and assisted living, to name just a few. Harry received his degree in Pharmacy from Long Island University, Brooklyn College of Pharmacy. His mission is to promote the most cost-effective services and the highest quality of care for consumers on state, national and international levels, as exemplified by his missions over the last decade to help those in need in third-world countries. With the ever-changing horizon of healthcare, Harry serves on various local, regional, national and international task forces, committees, and boards. Included are the NJPHA (New Jersey Pharmacist Association), ASCP (American Society of Consultant Pharmacist), CMS (Centers for Medicaid and Medicare) Medicare Part D Consortium, CMS PQA (Pharmacy Quality Alliance) workgroup and ASCP's Public Policy and Advocacy and Government Affairs Committees working with Congress to advance healthcare to special-needs populations. Additionally, Harry speaks and sponsors in academia, writes articles and publications, gives presentations, and conducts studies, among others, sharing his passion for the profession of consulting pharmacy. Harry is certainly known for his knowledgeable gift of gab, gentle and caring ways, and supportive nature for those in need.

Administrative Staff

Diane DiGiovacchino  
New Jersey Department of Health  
Administrative Assistant 3
Diane DiGiovacchino has worked for the New Jersey Department of Health, Division of Family Health Services, for 24 years in various capacities. Currently, she is principal assistant to the Director of the Special Child Health and Early Intervention Services Unit, performing and coordinating administrative support services.
Executive Summary

On November 22, 2011, we, the Epilepsy Task Force convened for our initial meeting. Adhering to the current statistics, over 450,000 individuals in the United States have received a newly diagnosed form of epilepsy since our first meeting. One in 26 people in the United States will be diagnosed with epilepsy at some point in their lifetime and one in 10 will develop a seizure (without an epilepsy diagnosis). On a personal level, at least two patients overseen by Neurologists on the Task Force have lost their lives due to Sudden Unexpected Death in Epilepsy (SUDEP), and the son of our chairperson lost his life due to complications of epilepsy on August 4, 2012. These statistics speak for the urgency for programs and legislation to take place within our State.

Our work has only addressed the top layer of a multitude of issues that face our residents and, in turn, impact all residents within the state, including social, financial and legal effects (to name a few).

Within our summary, one will find outlined recommendations based upon the information collected, surveys submitted (via online surveys submitted by the residents within the State of New Jersey), public testimony (via public hearings that were conducted during our term), recommendations for proposed legislation and examples of programs currently in place. Upon collecting the data, the amount of statistics and corroborating evidence that we could use to finalize our findings became apparent. It was also apparent that we would not be able to address each issue that equally should be included within our report. We therefore have addressed key issues that were collectively voted upon by the members of the Epilepsy Task Force. Our hope is that these recommendations will be a starting point for future legislative action, which will in turn create programs and solutions.

Some of the recommendations outlined within the Final Report include a statewide epilepsy initiative to include the areas of psychological, medical and educational awareness; discontinued substitution of generic seizure medications; and, a recommendation that any person who deals with the general public will have seizure awareness training (much like that already in place for cardiopulmonary resuscitation [CPR] training). Also, we are recommending that New Jersey be the 45th state to not require physician reporting to the Motor Vehicle Commission (MVC). We, with the help of state representatives, established the first Epilepsy and Seizures website for the State of New Jersey. This website will aid the general public in accessing pertinent information related to resources and their care. The website, to many of us, is our greatest achievement within our term although it will need to be maintained to give the most accurate and up-to-date information; thus, an epilepsy volunteer group would aid in its longevity and reliability.

We have each held our positions on the Task Force in the highest of regard. Our meetings were made a priority and put first on our professional schedules. We have each worked
diligently to provide a comprehensive summary of recommendations to you. It is our hope that these recommendations will become policy within the State of New Jersey and set a precedent for other states to adopt. It is not only our honor to present this to you, but our obligation, as we are the voice for those living with the effects of epilepsy. We thank you for developing this Task Force and look forward to the changes that these recommendations will produce.

Ann Carletta
Eric B. Geller, MD
Eric M. Joice
Roopal M. Karia, MD
Marcelo E. Lancman, MD
Shelby A. Myers
Harry A. Thibodeau, RPh, CCP, FASCP
Marilyn Gorney-Daley, DO, MPH, Commissioner of Health Designee
Jonathan Sabin, LSW, Commissioner of Human Services Designee
Glossary of Terms

**Advocacy** - The act or process of advocating or supporting a cause or proposal. [http://www.merriam-webster.com](http://www.merriam-webster.com)

**AEDs** - Antiepileptic drug(s): A medication used to control both convulsive and nonconvulsive seizures; sometimes called an anticonvulsant. [http://www.epilepsy.com](http://www.epilepsy.com)

**Automatic Movements** - Automatic, involuntary movement during a seizure; may involve mouth, hand, leg, or body movements; consciousness is usually impaired; occurs during complex partial and absence seizures and after tonic-clonic seizures. [http://www.epilepsy.com](http://www.epilepsy.com)

**Brand Name Drug** - Medication manufactured by a major pharmaceutical company; the drugs are often expensive, but tend to be uniform in the amount of drug and the method of preparation. [http://www.epilepsy.com](http://www.epilepsy.com)

**Cerebral Palsy** - A condition with various combinations of impaired muscle tone and strength, coordination, and intelligence. [http://www.epilepsy.com](http://www.epilepsy.com)

**Certified First Responder** - A person who has completed a course and received certification in providing pre-hospital care for medical emergencies. [http://www.merriam-webster.com](http://www.merriam-webster.com)

**Cognitive** - Pertaining to the mental processes of perceiving, thinking, and remembering; used loosely to refer to intellectual functions as opposed to physical functions. [http://www.epilepsy.com](http://www.epilepsy.com)

**Complex Partial Seizure** - An epileptic seizure that involves only part of the brain and impairs consciousness; often proceeded by a simple partial seizure. [http://www.epilepsy.com](http://www.epilepsy.com)

**Comprehensive Epilepsy Centers** - A center that provides an accurate diagnosis of seizure type and seizure syndrome, epilepsy education for you and your caregivers, appropriate treatment specific to your diagnosis, and surgical treatment or access to it if indicated. [http://www.naec-epilepsy.org](http://www.naec-epilepsy.org)

**Depression in Epilepsy** - People with epilepsy may be more likely than other people to experience emotional changes. [http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

**Developmental Disability** - A physical or mental disability (as mental retardation) that becomes apparent in childhood and prevents, impedes, or limits normal development including the ability to learn or to care for oneself. [http://www.merriam-webster.com](http://www.merriam-webster.com)

**Epilepsy** - A disorder characterized by transient but recurrent disturbances of brain function that may or may not be associated with impairment or loss of consciousness and abnormal movements or behavior.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Epileptologist** - A neurologist with specialty training in epilepsy.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Generalized Absence Seizure** - A primary generalized epileptic seizure, usually lasting less than 20 seconds, characterized by a stare sometimes associated with blinking or brief automatic movements of the mouth or hands; formerly called petit mal seizure.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Generalized Seizure** - A seizure that involves both sides of the brain and causes tonic and clonic movements (primary or secondary generalized) or another type of primary generalized epilepsy (e.g., absence or atonic seizure).  [http://www.epilepsy.com](http://www.epilepsy.com)

**Generalized Tonic-Clonic Seizure** - A convulsion; newer term for grand mal or major motor seizure; characterized by loss of consciousness, falling, stiffening, and jerking; electrical discharge involves all or most of the brain.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Generic Drug** - A drug that is not sold under a brand name; for example, carbamazepine can be obtained as a generic drug or as Tegretol or Carbatrol, its brand names.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Genetic disorder** - A disease caused by a different form of a gene called a variation, or an alteration of a gene called a mutation.  [http://www.webmd.com](http://www.webmd.com)

**Infantile Spasms** - Infantile spasms consist of a sudden jerk followed by stiffening.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Intractable** - Difficult to alleviate, remedy, or cure; for example, intractable seizures are difficult to control with the usual antiepileptic drug therapy.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Ketogenic Diet** - A high-fat, low-carbohydrate diet used to control seizures in some children with seizures that are difficult to control with medications.  [http://www.epilepsy.com](http://www.epilepsy.com)

**Major Depressive Disorder** - A mood disorder having a clinical course involving one or more episodes of serious psychological depression lasting two or more weeks each with no intervening episodes of mania.  [http://www.merriam-webster.com](http://www.merriam-webster.com)

**Modified Atkins Diet** - A liberalized ketogenic diet in which only carbohydrates are restricted. The amount of calories, fat, fluids and protein is unrestricted, although fat intake is encouraged.  [http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

**Monitoring** - Video-EEG monitoring: A technique for recording the behavior and the EEG of a patient simultaneously; changes in behavior can be correlated with changes in the EEG; useful for making the diagnosis of epilepsy and localizing the seizure focus.  [http://www.epilepsy.com](http://www.epilepsy.com)
MRI - Magnetic resonance imaging (MRI): A scanning technique that creates pictures of the inside of the body and the brain; uses a strong magnet (does not use x-rays); more sensitive than CT.  http://www.epilepsy.com

Myoclonic Seizure - The level of muscle contraction present during the resting state; with increased tone there is stiffness and rigidity; with decreased tone there is looseness or floppiness of the limbs and trunk.  http://www.epilepsy.com


Neurology - The scientific study of the nervous system especially in respect to its structure, functions, and abnormalities.  http://www.merriam-webster.com

Neuropsychologists - A doctor who specializes in the study and practice of neuropsychology and focuses on the relationship between the central nervous system and mental functions such as language, memory, perception, and attention.  http://www.epilepsy.com

Neurosurgeons - A highly trained specialist who has a primary focus of addressing conditions affecting a patient's peripheral nerves and their main nervous system.  http://www.ehow.com

Postictal State - The period of time after the seizure.  http://www.epilepsyfoundation.org

Psychosocial - Involves both psychological and social aspects of relating social conditions to mental health.  http://www.merriam-webster.com

Radiologists  - Someone who interprets imaging that is performed on a patient (such as an EEG).  http://www.ehow.com

Refractory Epilepsy - Epilepsy that is difficult to treat, unresponsive or of limited response to medication.  http://www.epilepsyfoundation.org

Seizure - A sudden, excessive discharge of nervous-system electrical activity that usually causes a change in behavior.  http://www.epilepsy.com

Seizure Disorder - Epilepsy is also called a seizure disorder.  http://www.epilepsyfoundation.org

Simple Partial Seizure - An epileptic seizure that involves only part of the brain and does not impair consciousness.  http://www.epilepsy.com

Status Epilepticus - A medical emergency where an individual experiences prolonged or clustered seizures that sometimes develop into nonstop seizures.  http://www.epilepsyfoundation.org
**Stigma** - The leading non-medical problem confronting people with epilepsy is discrimination in education, employment and social acceptance. [http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

**SUDEP** - Sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause for death can be found, despite thorough post-mortem examination and blood tests. The definition excludes people dying in status epilepticus and those who drown. [http://www.epilepsy.com](http://www.epilepsy.com)

**Traumatic Brain Injury** - A traumatic brain injury (TBI) occurs when a person’s brain is physically injured, usually by sudden force. [http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

**Vagus Nerve Stimulation (VNS)** - A pacemaker-like device, implanted in the upper chest, that stimulates a nerve in the left neck and can reduce seizure activity. [http://www.epilepsy.com](http://www.epilepsy.com)
Legal Authority and Purpose

As per P.L. 2010, c. 48 (S1928), The New Jersey Epilepsy Task Force was established in the Department of Health with the first meeting convened on November 22, 2011. The purpose of the Task Force shall be to: 1) develop recommendations to educate the public and health care professionals about screening, diagnosis, and treatment of epilepsy and its complications; and 2) develop recommendations to address psychosocial issues faced by persons with epilepsy, such as, depression, stigmatization, and discrimination. The Task Force shall report its findings and recommendations to the Governor, and to the Legislature pursuant to section 2 of P.L. 1991, c.164, along with any legislative bills that it desires to recommend for adoption by the Legislature, no later than 12 months after the initial meeting of the Task Force. This act will expire upon issuance of the Task Force report.

As per P.L. 2010, c. 48 (S1928); amended by S2353 (11/29/12), P.L. 2013, c. 66, There is established the New Jersey Epilepsy Task Force in the Department of Health. The purpose of the task force shall be to: 1) develop recommendations to educate the public and health care professionals about screening, diagnosis, and treatment of epilepsy and its complications; and 2) develop recommendations to address psychosocial issues faced by persons with epilepsy, such as, depression, stigmatization, and discrimination. The task force shall report its findings and recommendations to the Governor, and to the Legislature pursuant to section 2 of P.L. 1991, c.164, along with any legislative bills to that it desires to recommend for adoption by the Legislature, as follows: an interim report no later than 12 months after the initial meeting of the task force; and a final report no later than 12 months after the initial report. This act shall take effect immediately and shall expire upon the issuance of the task force's final report.
Epilepsy Background

The State of New Jersey has many opportunities in many areas to impact the lives of people with epilepsy. Some of these areas include emergency medical services, where first responders are called to care for people during or after seizures. First responders may not know how to recognize or manage seizures and may inadvertently cause unnecessary harm. Other areas include the MVC, which can impact a person with epilepsy's ability to drive. Public transportation, Medicaid, and state facilities such as group homes and developmental centers all have an impact on persons with epilepsy and other developmental disabilities. Parents may be navigating a very difficult educational path for their children with epilepsy, as they may face stigmatization and a lack of awareness concerning the condition. Persons with epilepsy may be looking to state agencies for assistance and may have trouble navigating the system. Again, there are many, many areas that could be explored in which to make recommendations to benefit the epilepsy community.

The New Jersey Epilepsy Task Force has spent the past year gathering information and brainstorming possible ways that the State of New Jersey can improve the lives of those affected by epilepsy. Our goal has been to improve what the State already does, or offer new ways to do what only state government is capable of doing. We realize the current fiscal constraints can limit the most well-intentioned goals, and intend that our recommendations have the smallest possible costs.

Background on Seizures and Epilepsy

What are seizures?

A seizure is a sudden surge of electrical activity in the brain that usually affects how a person feels or acts for a short time. According to the National Institute of Neurological Disorders and Stroke (NINDS), doctors have described over 30 different types of seizures, with two major categories of seizures: focal and generalized. It is important to note that not all seizures can be easily defined as focal or generalized though; some people have seizures that begin as focal seizures but then spread to the entire brain.

Focal seizures, also called partial seizures, occur in just one part of the brain. Focal seizures can be described as simple, where the person will remain conscious, but experience unusual feelings or sensations that can take many forms. Focal seizures are also described as complex, where the person has a change in or loss of consciousness. In a complex focal seizure, the person may display strange, repetitious behaviors such as blinks, twitches, mouth movements or even walking in a circle. The symptoms of focal seizures can easily be confused with other disorders. The strange behavior and sensations caused by focal seizures can be mistaken for symptoms of narcolepsy, fainting, or even mental illness. An experienced clinician is needed to diagnose epilepsy and distinguish from other disorders.

Generalized seizures occur on both sides of the brain. These types of seizures can cause a loss of consciousness, falls, or massive muscle spasms. Tonic-clonic seizures, which are also referred to by an older term “grand mal seizures” cause a mixture of symptoms, including a
stiffening of the body and repeated jerks of the arms and/or legs as well as loss of consciousness.

Physical symptoms of seizures can vary greatly, ranging from the subtle to the terrifying. Other seizures more difficult to recognize include the “absence” seizure, in which there is arrest of activity and often blinking, lasting seconds, with no aftermath.

A lack of understanding about the many different types of seizures can be a tremendous problem for persons with epilepsy. As per the NINDS’s report “Seizures and Epilepsy: Hope Through Research,” people who witness a non-convulsive seizure may find it difficult to understand that behavior that looks deliberate may not be under the person’s control. In some cases, this misunderstanding can lead to affected persons being arrested or mismanaged.

What is epilepsy?

Anyone’s brain can seize under the right physical stress – alcohol withdrawal, high fevers, chemical imbalances in sodium or calcium in the blood, or with certain medications. “Epilepsy” is the term for conditions that cause seizures spontaneously, randomly and recurrently. Because of the social stigma attached to the word “epilepsy,” many use the phrase “seizure disorder,” which means the same thing.

Who has seizures and epilepsy?

Seizures are extremely common. The World Health Organization’s (WHO) October 2012 Epilepsy Fact Sheet states that up to 10% of people worldwide will have a seizure during their lifetime. The Institute of Medicine’s (IOM) 2012 Report, “Epilepsy Across the Spectrum” notes that 2.2 million people in the U.S. and more than 65 million people worldwide have epilepsy and one in 26 people in the U.S. will develop epilepsy at some point in their lifetime. Children and older adults are the fastest-growing segments of the population with new cases of epilepsy, although all ages can be affected. The IOM 2012 Report also notes epilepsy is the fourth most common neurological disorder in the U.S. after migraine, stroke, and Alzheimer’s disease.

What causes epilepsy?

The causes vary by age of onset. Children may develop epilepsy due to genetic diseases or a birth defect such as cerebral palsy. Seizures are particularly common in children and adults with autism. Older adults are more likely to have acquired brain insults such as strokes, brain tumors or neurodegenerative diseases such as Alzheimer’s. Traumatic brain injury affects all ages, and is one of the common causes of epilepsy.

How is epilepsy diagnosed?

The first step is recognizing there is a problem. Generalized tonic-clonic seizures are obvious, and are quickly brought to medical attention. Absence and complex partial seizures are much harder to recognize, and are often mistaken for inattention or behavioral problems in children or the elderly. Once the problem is identified, testing requires taking a careful history and physical examination, sometimes blood tests and MRI (magnetic resonance imaging) of the brain. Electroencephalography (EEG) is the key diagnostic test. It uses wires attached to the scalp to record the brain’s electrical activity and searches for abnormal brain waves.
Most people with seizures are initially seen by a generalist, such as a pediatrician, primary care doctor, or by an emergency room physician. Most patients will eventually see a neurologist, a physician who specializes in brain diseases. Epileptologists are neurologists with special training and interest in epilepsy. Comprehensive Epilepsy Centers are medical facilities with a wide range of expertise, such as neurologists, neuropsychologists, neurosurgeons, radiologists, and EEG technologists. These facilities offer diagnosis and treatment for the most difficult cases, such as those requiring brain surgery, experimental treatments, or complex medical issues such as pregnancy. In the past, New Jersey residents had to travel out of state for specialized care, but in the past 15 years there has been a growing number of epilepsy centers in our State providing the highest-level care.

**How is epilepsy treated?**

Seizure medications are the mainstay of treatment. A 2012 IOM Committee on epilepsy recommended that the term seizure medication be used to replace anti-epileptic drugs (AEDs), as the term “epileptic” may have a negative connotation. There are over 20 medications available, with new ones arriving almost annually. Unfortunately, about one in three people with epilepsy do not achieve full control with medication alone. For these people, options may include brain surgery to remove the region causing seizures, various electrical nerve stimulators, or special diets (the ketogenic diet and the modified Atkins diet).

**What do seizures do to people?**

Seizures can be dangerous. People sometimes fall, causing fractures, smashed teeth, or other injuries. Even very mild seizures that are not physically violent can cause severe injuries if they occur at inconvenient times – driving a car, bathing, climbing a ladder, using a power tool, or cooking at a stove. Prolonged, uncontrolled seizures (status epilepticus) can damage all organs of the body and can result in death.

People who have lived with seizures and taken seizure medications for many years may accumulate less visible injuries. However, medications can damage the liver, blood cells, and the kidneys; cause osteoporosis; and interfere with other medications such as blood thinners and oral contraceptives. Memory loss is an extremely common complaint, as repeated seizures may damage the brain’s memory circuits over time. Other seizure medication side effects can include psychiatric changes including suicidal thoughts, sedation, weight gain, tremors, and skin and hair changes.

**What is it like to live with epilepsy?**

This subject will be developed in the rest of this report. Excerpts of the public testimony submitted to the Task Force will put a human face to the condition. People with epilepsy experience stigmatization and discrimination in social situations ranging from the home to school to the workplace. The potential to have seizures may prevent driving a car. Having epilepsy can mean becoming a frequent visitor to a doctor’s office or the hospital; taking medication several times a day; struggling financially to make ends meet when paying for medication and medical expenses; fighting with insurance companies to cover necessary testing and treatments; and/or unpredictably losing bodily control in public.
Epilepsy History

New Jersey and Epilepsy Treatment: A Historical Perspective

New Jersey has a well documented history with individuals with epilepsy since the middle of the 19th century. In New Jersey “epileptics” were kept at the State Lunatic Asylum at Trenton through the 1860s. Physicians noticed at that time that housing both the “insane” and “epileptics” was detrimental to both groups.

In 1877, the Legislature took up the issue of building a separate facility to house persons with epilepsy. Approval did not come until 20 years later. In 1898, the New Jersey State Village for Epileptics opened in Skillman, Montgomery Township, New Jersey with seven patients.

In 1911, an involuntary sterilization law for specific groups of persons including epileptics was passed, but by 1913 it was declared unconstitutional, Smith v. Board of Examiners.

Life at the New Jersey State Village for Epileptics could be difficult. During the Depression Era the New Jersey State Village for Epileptics became overcrowded as families were encouraged to bring children to the Village for treatment. Facilities were severely overcrowded. After the First World War, influenza swept the country. It swept the New Jersey State Village for Epileptics as well, killing scores of residents. Ultimately, a scandal about conditions at what one newspaper
called "the snake pit of New Jersey", as well as new, more effective pharmaceuticals, led to the closure of the New Jersey State Village for Epileptics in 1952.

After the Village closed, the state developed the New Jersey Consultation Service for Convulsive Disorders (later the NJ Consultation Service for Neurological Diseases). This service provided consultation to local hospitals around the State and was administered by the New Jersey Department of Health. During the 1960s, the Department of Health also conducted public education programs for students and the general public about epilepsy. The Department published its Directory of Epilepsy Services in 1962 and updated the document in 1969.

New Jersey passed landmark legislation in 1972 entitled the New Jersey Law Against Discrimination (LAD), making it unlawful to subject people to differential treatment based on disability. The law named epilepsy as an example of a condition covered by the legislation.

In 1985, the New Jersey Division of Mental Retardation\(^1\) was redirected and became the Division of Developmental Disabilities. The Division was to address the needs of those with a severe chronic disability manifest before age 22, likely to continue and which resulted in substantial functional limitation. Epilepsy was listed as one of the conditions included in the definition.

The New Jersey Division of Developmental Disabilities asked the Epilepsy Foundation of New Jersey, a voluntary health organization founded in 1970, to undertake a year-long study of the needs of residents with epilepsy. The resulting document, completed in 1986, called for increased awareness, civil rights protections, service programs, mental health services and prevention activities. It also called for the creation of a standing State task force on epilepsy.

In 2010 P.L. 2010, c. 48 established the New Jersey Epilepsy Task Force.

In 2013, the Governor extended the New Jersey Epilepsy Task Force to meet for an additional year. (P.L. 2013, c. 66)
The State of New Jersey Should Make Efforts to Better Understand the Burden of Epilepsy Among State Residents

The burden of epilepsy affects all people in New Jersey. A person with epilepsy will directly pay the costs of his or her disease while residents of New Jersey bear the costs indirectly through taxation to support government-funded programs. The Centers for Disease Control and Prevention (CDC) estimates that one in 26 people in the United States will be diagnosed with epilepsy at some point in their lives. The IOM 2012 Report, “Epilepsy Across the Spectrum” notes epilepsy is the nation’s fourth most common neurological disorder, after migraine, stroke, and Alzheimer’s disease. According to 2012 CDC statistics, epilepsy affects about 2.3 million adults and 467,711 children 0-17 years of age. Epilepsy results in an estimated annual cost of $15.5 billion in medical costs and lost or reduced earnings and production.

According to the Department of Human Services’ website, Medicaid’s Fiscal Year 2012 budget will cost New Jersey’s taxpayers $5 billion. In 2011, there were 245,268 adults and 674,094 children on New Jersey Medicaid and New Jersey Family Care (Medicaid expansion program). There are 162,500 people with disabilities covered by Medicaid in New Jersey. New Jersey spent $20,584 on each Medicaid recipient with a disability in 2007. Seventeen percent of all people covered by Medicaid in New Jersey have a disability. New Jersey spends 45% of its Medicaid funds on services for people with disabilities. Epilepsy is prevalent among those with other disabilities, such as autism (25.5%), cerebral palsy (13%), Down syndrome (13.6%), and mental retardation (25.5%)—while 40% of people who have both cerebral palsy and mental retardation also have epilepsy. We can attempt to lessen the number of people with epilepsy from qualifying for Medicaid by allowing them to remain gainfully employed, which is often difficult to achieve due to revocation of drivers’ licenses under current law.

The costs of medications for this disease vary greatly. One medication is not a substitute for another, and a generic is not always effective as the name brand it substitute for without a guarantee that the same generic is available. Costs of some medications have skyrocketed, such as Acthar Gel (used for infantile spasms), which previously sold for $50 a vial and was selling for $28,000 a vial per a New York Times December 2012 article. While some older generic drugs are available inexpensively, many of the newer drugs still under patent are several hundred dollars per month each, and often people with epilepsy take multiple medications at the same time. It would be easy for an uninsured person with epilepsy to be spending in excess of $1,000 per month on medications.

The association between epilepsy and depression is strong. Patients with epilepsy are more likely to suffer from psychiatric illnesses, more specifically depressive disorders (9%-22%), than the general population. Despite the clinical significance of depression, it often goes unrecognized and untreated in patients with epilepsy. Fears of antidepressants lowering seizure thresholds, coupled with potential adverse interactions between antiepileptic and antidepressant medications, have strongly contributed to the undertreatment of this population. Studies and research regarding the treatment of depressive disorders in epilepsy are needed.
According to the CDC, each year another 150,000 people in the United States will be diagnosed with epilepsy. Each year, additional New Jersey residents seek varying levels of support, and the New Jersey Epilepsy Task Force hopes to see a program in place that will enable those people to get the support they need.
Public Forums

Summary

On April 13 and May 22, 2012, two public hearings were held from 10 a.m. to noon at the Department of Human Services, Division of Developmental Disabilities in Hamilton, New Jersey. These forums were held by the New Jersey Epilepsy Task Force in order to receive input from the public affected by epilepsy. This input was graciously received and was an informative and a moving testament to the importance of the actions of this Task Force. The testimonies came from people with epilepsy who were diagnosed at different points in their lifetime. Ages ranged from adults in their fifties to an 11-year-old girl who suffered from febrile seizures and deals with the struggle of her persistent epilepsy every day. Verbal and written testimonies were also provided by parents and friends of individuals living with epilepsy.

Persistent themes existed through much of the testimony and reiterated the importance of topics discussed during Task Force meetings. The most frequently mentioned issues are awareness and education. A sense of fear is felt by people with epilepsy and their parents who must rely on the knowledge of strangers if a seizure occurs in a public setting. The testimony received supports the implementation and expansion of education programs for people of all ages – particularly those in the police and emergency response fields. Ensuring the public’s awareness of epilepsy and seizure first aid makes the world a safer place for those whose seizures may not be under control. Current driving laws and dealing with epilepsy in the workplace were common ideas throughout the testimony. Other areas covered in these hearings were education with service dogs, disability benefits, and identification of resources.

The public forums were an integral part of the process for making our recommendations. The testimony emphasized the importance of the Task Force. Each letter or statement has provided a unique point of view on the actions that should be taken. The stories shared were extremely personal and took great courage to reveal. The Task Force is grateful for the time and individual strength that each person gave to help improve the lives of those living with epilepsy in New Jersey.

Quotes/Excerpts from Public Testimony

"Sometimes I find myself crying at just the thought of what could happen to him if he had a seizure while taking a shower, walking down 3 flights of stairs from his apartment, or walking across the busy road to the bus...We need public awareness and more funding for research to help the one in ten people who will experience a seizure in their lifetime."

—Parent of a person with epilepsy
"Encourage people or family members who are affected by epilepsy to be willing to share about their experiences with others in their social circles and churches."

-Person with epilepsy

"It would be great to have some kind of workshop or class for our teachers and staff to learn about epilepsy and seizure disorders. Show them the signs so other kids won't have to wait so long to be diagnosed."

-Person with epilepsy

"Not having a driver's license makes one dependent on others. I live in central/southern New Jersey and the public transportation system in these areas is very limited. Many people with epilepsy have encountered problems with their employers or schools due to the inability to drive or dependence on others. Perhaps if there were more epilepsy education and awareness, employers would be more understanding or flexible."

-Person with epilepsy

"My epilepsy has limited my ability to participate in a variety of social activities...and further limited my ability to pursue social and career opportunities."

-Person with epilepsy

"...I continued to have complex partial seizures. They occurred at work, on the bus, subway, at home, when I slept or when I was awake. My epilepsy was a result of head trauma from a car accident four months prior to my high school graduation."

-Person with epilepsy

"I asked to speak today for the other members of our special society that have found they are drowning in a system that is designed to help us but falls short time after time."

-Person with epilepsy

"...I must emphasize that my life would be far easier if I left my home each day believing that the Police, 911 operators and Health Officers were knowledgeable about the State and Federal Laws applicable to Service Dogs and their Handlers."

-Person with epilepsy

"Epilepsy has such a wide range of frequency, presentation, and symptoms thus making it more difficult to understand/recognize, therefore focused attention is needed to address the lack of knowledge."

-Parent of a child with epilepsy
"Many people realize that anti-convulsants have dramatic side-effects that will drastically affect the user’s life in multiple ways."
   —Person with epilepsy

"Hopefully this Task Force will make the necessary recommendations to Governor Christie and the legislators..."
   —Former New Jersey State employee

"Our insurance covers her medications. But, one of her medications cost the insurance $1400 per month... We could be at the hospital up to 10 days. This is very costly to us. The travel expenses, parking, eating, days off from work are sometimes deducted from the salary."
   —Parent of a child with epilepsy

"This is an opportunity for New Jersey to focus on the important issues of improving access to patient-centered care that meets the complex range of physiological, psychological, cognitive, and social needs of people with epilepsy; improving access to community resources and quality of life for people and families living with epilepsy; and promoting better public awareness and understanding of epilepsy."
   —Liza Gundell, Deputy Director, Epilepsy Foundation of New Jersey

"On Thursday, March 29, 2012 three fifth grade students from Pleasantdale Elementary In West Orange assisted a restaurant patron having an unforeseen seizure with knowledge gained from a school presentation of seizure first-aid by the Epilepsy Foundation of New Jersey (EFNJ). This is just one example of why Epilepsy education should be incorporated into health curriculum."
   —Andrea Racioppi, Associate Director, Epilepsy Foundation of New Jersey
Detailed Recommendations and Summaries:

Section A: Serving the Epilepsy Community: Educating the Public and Health Care Professionals and Addressing Psychosocial Issues

First Responder Training

**Recommendation:** First Responders, including police, fire, and emergency medical technicians should be trained in seizure recognition and first-aid. Anyone who is required to have a CPR certification should also have seizure training.

Seizures are considered emergencies, and a 911 call is typical. A seizure may occur at any time — walking down the street, shopping, at home, or at work. While a convulsive seizure is obviously a medical problem, other seizure symptoms may be harder to recognize. Complex partial seizures may make people unresponsive or partially responsive; they may appear confused, and may not cooperate with the authorities. The postictal state is a period of time after a seizure before full recovery, and may cause confusion and disorientation as well. Someone who had a seizure may be bleeds, look disheveled, and be uncooperative, and may be mistaken for being intoxicated or mentally ill. While seizures do not cause violence, during or after a seizure a person might react more violently to being touched or ordered to do something. These concerns are not theoretical. There are New Jersey residents who, instead of receiving medical aid, have been arrested, injured and subsequently died in police custody because their medical condition was not recognized.

**Villanueva v. Township of Bloomfield (NJ Superior Court, filed May 14, 2003), Docket No. ESX-L-3286-03 (settled 2008)**

**Summary:** As alleged in this lawsuit, Santiago Villanueva, 35, a native of the Dominican Republic, who lived in New York, was experiencing a seizure on April 16, 2002, when he was arrested at the garment factory where he worked. According to Bloomfield, NJ police reports, officers and emergency medical technicians responding to a 911 call deemed Villanueva combative and, at times, unresponsive to simple verbal commands — common signs of certain types of seizures. The responders acknowledge using some force to bring Mr. Villanueva under control. The police restrained Mr. Villanueva by placing pressure on his back and neck, despite insistence by his co-workers that such force was unnecessary. Mr. Villanueva stopped breathing at one point during the incident, but started again before reaching the Columbus Hospital in Newark, where he died. The medical examiner determined the cause of death to be homicide by mechanical asphyxiation.

Because first responders are likely to encounter someone with epilepsy, it is critical that they are trained appropriately. The Epilepsy Foundation and the CDC have developed a free, web-
based training curriculum for police and medical personnel
(http://www.cdc.gov/epilepsy/projectstraining/law-enforcement.htm). The website states:

In response to the need for educational information in a format that is easy to access and
allows for flexible scheduling, the law enforcement training curriculum is now available online.
This approximately 45-minute course aims to train law enforcement on seizure recognition,
correct response to seizures, and awareness of the unique needs of people with epilepsy who
might be taken into police custody. The training is free, and the user can receive a certificate
of completion.

More Information

• Information about the First Responders Training Program is available online
(http://www.epilepsyfoundation.org/livingwithepilepsy/firstresponders/index.cfm). To
access the Law Enforcement Training
Curriculum: https://www.centrelearn.com/login_epilepsyfoundation.asp

• Information about epilepsy and the national campaign is available from the Epilepsy
Foundation by telephone (800-332-1000) or online
(http://www.epilepsyfoundation.org).

Information in Spanish is available by telephone (866-748-8008) or online:
(http://www.fundacionparalaepilepsia.org).

Responsibility for Epilepsy Issues in State Government

| Recommendation: | Epilepsy-related issues should be addressed by all appropriate areas of State government. |

Currently, the Department of Human Services, Division of Developmental Disabilities (DDD) is
the only State entity tasked with providing resources to people with epilepsy. The Task Force
does not find this ideal for a number of reasons. While those with developmental disabilities
have higher rates of epilepsy than the general public, they are not exclusively affected.
Additionally, there are many other issues including driving privileges, transportation, medical
insurance coverage, unemployment, social stigmatization and discrimination that should be
addressed. Many potential resources or sources of information for the epilepsy community are
housed in many different agencies including the Motor Vehicle Commission, the Department of
Transportation, the Department of Banking and Insurance, and others. The elderly in particular
are a growing population with a high risk of epilepsy. They are often cared for in state-
regulated facilities, from assisted living to rehabilitation centers to nursing homes. Women of
child-bearing age also may have difficulty accessing appropriate neurological and obstetrical
care. School children and adolescents face difficult issues with stigmatization in school and a
lack of education on epilepsy. Resources and information to address these issues should be
available to the epilepsy community.
**Recommendation:** Maintain and update the current website for Epilepsy and Seizures developed within the Department of Health.

No one State department can look out for all the issues surrounding epilepsy. For this reason, the Task Force worked together with the New Jersey Department of Health to set up a website for Epilepsy and Seizures, which is now up and active.

**Education of the Public and Professionals**

**Recommendation:** Increase outreach programs for schools, teacher organizations, and professional organizations to raise epilepsy awareness. Anyone who is required to have a CPR certification such as, but not limited to, health care paraprofessionals, coaches, daycare employees, should also be certified in seizure recognition and its first-aid.

Epilepsy is a devastating chronic disease that affects millions of people. It encompasses diverse and heterogeneous manifestations of the same disease process that can span a lifetime. Epilepsy can start in the neonatal period with focal seizures or present in the elderly as either focal seizures or generalized tonic-clonic seizures. Other seizure types include absence, myoclonic, and atonic seizures. Moreover, a person can have a single seizure in their lifetime that may not require treatment or go on to have refractory epilepsy that may require multiple medications. Other treatment options for refractory epilepsy include the implantation of the vagal nerve stimulator or epilepsy surgery.

Because there are so many seizure types and so many treatment options, it is very important for public education regarding this topic. Some seizures can be very subtle and the patient may go undiagnosed for several years affecting school work, home life, social life, and their professional work. An area that needs attention is educating the public and professionals about the different seizure types. One of the ways we can educate the public in recognizing true seizures is by offering more information about this topic on the New Jersey State website. Outreach programs, such as those provided by nonprofit agencies as well as government entities, such as the CDC, raise awareness of epilepsy. We believe that more outreach programs need to be in place to not only include New Jersey school districts, but also first responders, emergency room nurses and physicians, parents, teachers, school bus drivers and coaches. We recommend mandatory certification by professionals who help epilepsy patients to complete a webinar on seizure recognition and first-aid for seizures. They can become certified when they renew their professional license.

Epilepsy education benefits the lives of many individuals. According to an April 2012 Epilepsy Foundation of New Jersey press release, three fifth grade students had attended an epilepsy education assembly and were able to help a woman having a seizure in a restaurant. We recommend that the New Jersey Education Association (NJEA) include a brief seminar on seizure recognition and first aid for teachers who have epileptic students. This could be done at the NJEA annual convention.
Section B: New Jersey Legislation and Driving Law

Medication Substitution

**Recommendation:** The Task Force supports legislation that prohibits the substitution of prescribed epilepsy drugs by pharmacists without prior notification to and written consent of physician and patient.

Different patients respond differently to seizure control medications. For anticonvulsant drugs, small variations in concentrations between Food and Drug Administration (FDA) equivalent-rated drugs can cause toxic effects or seizures when taken by patients with epilepsy. Anticonvulsant drugs for the treatment of epilepsy differ from other classes of drugs in several ways that make therapeutic or generic interchange of agents problematic. In most patients, controlling seizures with medication requires a slow and precise dosage regulation of one or several medications. Changing from one formulation of a drug to another can usually be accomplished, and risks minimized, if physicians and patients monitor blood levels, seizures, and toxicity. Pharmacists do not have access to the patient’s complete medical history and may not know why a particular drug product was prescribed.

**Recommendation:** The Task Force supports legislation that requires a physician to include an epilepsy or seizure diagnosis on a prescription for an antiepileptic drug that is prescribed for epilepsy or seizures.

If a new prescription for a brand name drug is not marked “do not substitute,” but the previous prescription for the same drug was marked “do not substitute,” a generic drug shall be dispensed pursuant to section 8 of P.L.1977, c.240 (C.24:6E-7). If the pharmacy does not stock the prescribed drug from the same manufacturer as most recently dispensed by that pharmacy to the patient, or as indicated by the physician on the prescription, and the pharmacist knows the patient to have an epilepsy or seizure diagnosis based on the physician’s coding on the prescription, the pharmacist shall dispense a generic drug substitute and, within 24 hours, provide the prescribing physician with oral or written notification of, at a minimum, the name and manufacturer of the generic drug substitute dispensed to the patient, and the name and manufacturer of the most recent drug dispensed by that pharmacy to the patient prior to the dispensing of the generic drug substitute.

The members of the New Jersey Epilepsy Task Force agree with the Epilepsy Foundation’s drafted White Paper “Epilepsy Prescription Protection Legislation” and we also believe that additional recommendations are required:

1) The burden of responsibility for consumer protection must be shared by both the attending physician and the dispensing pharmacist.
2) The attending physician must write an indication for use (i.e., seizures) on the original prescription (whether paper or electronic) alerting the dispensing pharmacist that the medication to be issued is for a seizure disorder.

3) Medications for the treatment of seizure disorders may not be substituted without the informed consent of the attending physician and the patient or the patient’s guardian.

4) All pharmacies, regardless of location or type, mail order, internet, institutional pharmacies and community (independent/chain) pharmacies must be required to follow the same regulations with regard to substitution.

**New Jersey Driving Law**

**Recommendation:** Repeal the New Jersey Driving law (N.J.S.A. 39:3-10.4) making New Jersey the 45th State in the United States that does not require physician reporting.

New Jersey is one of only six states that still require reporting. *New Jersey’s law (N.J.S.A. 39:3-10.4) requires physicians to report patients to the Motor Vehicle Commission within 24 hours after determining that the patient experiences:*  
- recurrent convulsive seizures;  
- recurrent periods of unconsciousness or impairment; or  
- loss of motor coordination due to conditions such as, but not limited to, epilepsy in any of its forms, which persist or recur despite medical treatment.

The Task Force finds it discriminatory that the condition of epilepsy is singled out in the statute, and suggests the term be removed. Epilepsy covers a broad range of people with varied seizure disorders. A person can have epilepsy and be seizure-free. The Task Force believes a person can have seizures and be fully capable of driving, and further believes the true issue of concern is if a person repeatedly has a loss of consciousness with no warning signs.

The Task Force believes this law has a significant impact on both physicians and people with epilepsy seeking treatment in the State of New Jersey. Physicians treating people with epilepsy may report patients who are *not* a risk of a loss of consciousness in order to protect themselves from the possibility of being named in lawsuits, should there be an incident. Insurance policies may not cover the physicians in these cases. The Task Force believes many people with epilepsy are unfamiliar with this law and are unaware of the consequence of losing their licenses when they speak to their physicians, falsely expecting the protection of doctor-patient confidentiality. *New Jersey’s regulation suspends a person’s license for six months upon reporting and N.J.A.C. 13:19-5.1 requires a person remain seizure-free for six months before having a license reinstated.* That makes it difficult for a person whose license has been suspended to remain employed. Once people with epilepsy become aware of this penalty, it becomes difficult for them to have honest relationships with their doctors, for fear of retribution from the State. According to the American Academy of Neurology’s position statement of 2007, mandatory reporting may have a strongly negative impact on the patient-physician relationship, and may ultimately provide no greater safety benefits to the public or the patient. The Task
Force believes repealing the law would incentivize people with private insurance to seek treatment within the State, reduce the long-term unemployment rate of people with epilepsy and restore doctor-patient confidentiality. Physicians, medical practices and medical centers in New Jersey would benefit financially, as would the State itself by keeping people with epilepsy in the State. The Task Force believes New Jersey should become the 45th state that does not require physician reporting.

**Recommendation:** Revise N.J.S.A. 39:3-10.5, N.J.S.A. 39:3-10.6 and N.J.S.A. 39:3-10.7 to remove the terms epilepsy and epileptiform seizures.

In addition to physician reporting of medical conditions, State law also requires people with epilepsy to self-report to MVC as follows.

**N.J.S.A. 39:3-10.5 Report by drivers' license applicants subject to epileptiform seizures**

*Each person subject to recurrent convulsive seizures or recurrent periods of unconsciousness or impairment or loss of motor coordination due to conditions such as, but not limited to, epilepsy in any of its forms, shall at the time of his initial application for a driver's license or any subsequent application for a renewal thereof or at such other time as prescribed by the Director of the Division of Motor Vehicles, report the existence of such conditions to the Director of the Division of Motor Vehicles in a manner to be prescribed by the director.*


The Task Force recommends the term epilepsy be removed as it does not address the intended issue, which is the ability to safely operate a motor vehicle.

The Task Force recommends:

- The term epilepsy be removed, as it does not indicate a person currently has seizures.
- Removal of the term "epileptiform seizures" from N.J.S.A. 39:3-10.6 and N.J.S.A. 39:3-10.7. It should be replaced with *recurrent loss of consciousness with no warning signs*.

**Sudden Unexpected Death in Epilepsy (SUDEP)**

**Recommendation:** The Task Force strongly supports education of Medical Examiners on SUDEP and participation in North American SUDEP Registry.

Seizures may cause injury or death in many obvious ways – falls, crownings, and uncontrolled seizures. What is very under-recognized is that many people with epilepsy may die suddenly and unexpectedly, without a clear cause. This may affect young or middle-aged people who otherwise seemed healthy. Up to 17% of epilepsy deaths may be due to SUDEP. Because so little is known about the causes of SUDEP, there are no clear steps that individuals can take to prevent it. A key step in learning more is identifying those who may have died from SUDEP.
Medical Examiners are the key individuals to identify epilepsy-related deaths. However epilepsy is often not mentioned on death certificates. The New Jersey Vital Statistics website lists many causes of death of interest to the public or to researchers, such as Alzheimer’s disease and Lou Gehrig’s disease, but not epilepsy.

The North American SUDEP Registry (www.sudep-registry.org) is a national project designed to collect information on deaths, including tissue donations. This project depends on family members and Medical Examiners to make donation of the medical information and, if possible, tissue for analysis.

The Task Force strongly supports the education of Medical Examiners on issues of SUDEP. It also supports educational efforts to promote participation in the North American SUDEP Registry.
Endnotes

1 The New Jersey State Department of Human Services, Division of Developmental Disabilities (DDD) was established in 1985 pursuant to Title 30 of the Revised Statutes, specifically 30:6D-23. DDD incorporated the then-existing Division of Mental Retardation (DMR) and expanded the population it served to include all persons with developmental disabilities.

2 http://www.state.nj.us/humanservices/dmahs/home/waiver.html


References


Crowley, JS. (2003, March). MANAGING EPILEPSY CARE A guide to optional epilepsy purchasing specifications to ensure managed care contracts provide access to appropriate services. Center for Health Services Research and Policy, School of Public Health and Health Services, The George Washington University Medical Center.


Appendices

Appendix A
P.L. 2010, Chapter 48 - Law establishing the New Jersey Epilepsy Task Force

Appendix B
“Three Students Utilize Seizure First-Aid Training to Help Restaurant Guest”
Epilepsy Foundation of New Jersey Press Release, April 10, 2012

Appendix C
“American Academy of Neurology position statement on physician reporting of medical conditions that may affect driving competence” www.aan.com

Appendix D

Appendix E
New Jersey Epilepsy Task Force Surveys: Results www.claytonshope.org
Interim Report  
New Jersey Epilepsy Task Force  
February 23, 2015

Initial Meeting  
November 22, 2011

Meeting Dates  
February 3, 2012  
April 13, 2012  
May 22, 2012  
June 29, 2012  
September 14, 2012  
October 26, 2012

Final Meeting  
November 19, 2012

Public Hearing Dates  
April 13, 2012 and May 22, 2012

Members of the Epilepsy Task Force  
Ann Marie Bezuyen  
Director of Special Projects  
The Anita Kaufmann Foundation  

Ann Marie Bezuyen is an Agency Representative on this Epilepsy Task Force, and the Director of Special Projects for The Anita Kaufmann Foundation (AKF), whose mission is to educate the public not to fear epilepsy and seizures. They are a global sponsor for the largest epilepsy awareness initiative in the world, “Purple Day.” Her programs include “Heads Up For Vets!” in collaboration with the Department of Veterans Affairs Epilepsy Centers of Excellence. Ms. Bezuyen received her degree in education from William Paterson University, and has been an epilepsy advocate and educator since 1995. She is extremely passionate about eliminating stigma through educational awareness programs and to that end maintains memberships on many boards, consortiums and this Task Force. She works daily with persons with epilepsy and their families on an individual basis. Ms. Bezuyen is an invited local radio and public television guest, as well as the author of several research papers and magazine and newspaper articles.

Ann Carletta  
Patient Advocate  
Vice Co-Chair, New Jersey Epilepsy Task Force  

Ann is one of the public members on the Epilepsy Task Force. Diagnosed at 8 years old and spending years trying unsuccessfully to get seizures under control, she eventually opted for neurosurgery and has been seizure-free since then. She has been a volunteer for FACES, Finding a Cure for Epilepsy and Seizures, since 2006 and consults with people who are considering neurosurgery as an option to control their seizures. Ms. Carletta has published articles on her experience living with seizures and undergoing the 2-stage neurosurgery.
Eric B. Geller, MD  
Director, Adult Comprehensive Epilepsy Center  
Institute of Neurology and Neurosurgery at St. Barnabas  
Vice Co-Chair, New Jersey Epilepsy Task Force

Dr. Geller serves as an Agency Representative on this Epilepsy Task Force. He is the Director of the Adult Comprehensive Epilepsy Center at the Institute of Neurology and Neurosurgery at Saint Barnabas in Livingston, NJ since 1998. He is a board member of the Epilepsy Foundation of New Jersey and Family Resource Network of New Jersey, and a member of the Saint Barnabas Medical Center Bio-Ethics Committee. Dr. Geller has 20 years of experience in treating difficult seizure problems, and has been an investigator or co-investigator in trials of new epilepsy treatments and in the NIH-funded Epilepsy Phenome-Genome Project. He has published multiple peer-reviewed articles and book chapters on epilepsy, with a focus on epilepsy surgery. He is board-certified in Neurology with Added Qualifications in Clinical Neurophysiology (American Board of Psychiatry and Neurology) and by the American Board of Clinical Neurophysiology. He has been annually named a Top Doctor in New Jersey and New York since 2004.

Marilyn Gorney-Daley, DO, MPH  
Senior Public Health Physician  
Director of Special Child Health and Early Intervention Services  
Designee for Mary E. O'Dowd, MPH  
Commissioner of Health

Dr. Marilyn Gorney-Daley serves as Health Commissioner Mary O'Dowd's designee. Dr. Gorney-Daley is the Director of Special Child Health and Early Intervention at the New Jersey Department of Health with over 10 years experience working with special-needs populations, especially children with special health care needs. She is a board-certified public health and preventive medicine physician and is a member of the American College of Preventive Medicine and the Association of Maternal and Child Health Programs.

Nicole Hartmann  
Public Member

Nicole Hartmann is an affected public member on the New Jersey Epilepsy Task Force. She was diagnosed with epilepsy at age 15 and has been very involved with the epilepsy community ever since. Nicole began as an intern with the Epilepsy Foundation of New Jersey (EFNJ) following a scholarship win in her senior year of high school. Soon after, she became the founding member of the New Jersey Epilepsy Youth Council. At age 20, she became part of the National Epilepsy Youth Council and was recently elected as the Vice Chair. Nicole received her Bachelor of Science degree in Biology from Elmira College in 2011 and her Master of Biomedical Science Degree from UMDNJ in 2012. Currently, she works as a medical scribe in an oncology practice in Howell, NJ while applying for entry to medical school. Her hopes are to become a pediatric neurologist.
Eric M. Joice  
Executive Director  
The Epilepsy Foundation of New Jersey  
Eric Joice is the Executive Director of The Epilepsy Foundation of New Jersey, a statewide health organization. Eric has held this position since 1983. Prior to that, he was Associate Director of the Mental Health Association of New Jersey. Eric Joice has been a member of the Governor’s Task Force on the Prevention of Child Abuse and Neglect and the Governor’s Committee for the Prevention of Mental Retardation and Developmental Disabilities. He has served on the New Jersey State Rehabilitation Council and the Governor’s Committee on Voluntarism. He has also chaired the New Jersey State Employee Charitable Campaign, and was President of the NJ Voluntary Health Agencies (now CHC). He is a recipient of awards from the Community Health Law Project, Exceptional Parent Magazine, the United Way and the Epilepsy Foundation of America.

Roopal M. Karia, MD  
Pediatric Neurologist  
Associate Director, Pediatric Neurology & Pediatric Epilepsy  
Jersey Shore University Medical Center  
Department of Pediatrics  
81 Davis Ave, Suite 4  
Neptune, NJ 07754  
Dr. Karia is board-certified in Neurology with Special Qualification in Child Neurology, board-certified in Clinical Neurophysiology by the American Board of Clinical Neurophysiology, and board-certified in Neurodevelopmental Disabilities. She has participated as a sub-investigator and principal investigator in numerous clinical trials for epilepsy medications. Dr. Karia has also served on a NICHQ (National Initiative for Children’s Healthcare Quality) project to improve access and care for persons with epilepsy.

Marcelo E. Lancman, MD  
Director of the Epilepsy Programs  
Hackensack University Medical Center, Hackensack, NJ (Level IV epilepsy center)  
Atlantic Health System, Summit, NJ (level IV epilepsy center)  
White Plains Hospital Center, White Plains, NY (Level IV epilepsy center)  
Jersey City Medical Center, Jersey City, NJ  
Dr. Lancman serves as a Neurologist on this New Jersey Epilepsy Task Force. He is an Associate Professor of Neurology at New York Medical College. Dr. Lancman is board-certified with the American Board of Psychiatry and Neurology, Inc. and American Board of Clinical Neurophysiology, Inc. (epilepsy). He has served as a past ad hoc reviewer for Epilepsia, Neurology, and Electroencephalography and Clinical Neurophysiology scientific journals. Dr. Lancman is Chairman of the Special Interest Group (Private Practice Epilepsy) of the American Epilepsy Society and is the author of approximately 50 scientific publication/book chapters, including "What You Need to Know if Epilepsy Has Touched Your Life: A Guide in Plain English" (in press). He has served as Principal Investigator of several scientific grants and has received the Best Doctors of America award from 2007 until present. Dr. Lancman is a member of the professional advisory Board of the Epilepsy Foundation of CT, past member of the Epilepsy Foundation of NYC and the Epilepsy Society of Southern NY.
Shelby A. Myers
Public Member - parent of a child with epilepsy
Chair, New Jersey Epilepsy Task Force
Shelby A. Myers was one of the representatives asked to give public testimony for the submission of the Epilepsy Task Force Bill in May 2010. She was nominated to the Task Force and elected the Chair in November 2011. She is a Patient Liaison for The NBN Group and aids in the transition of medically fragile children from facilities to their home. She is the founder and continues in the capacity of Marketing and Public Relations for Clayton’s Hope Organization, a nonprofit that raises awareness and funding for Epilepsy Research. Most recently, in September 2012, she was named the Epilepsy Advocate of the year by the Epilepsy Foundation of New Jersey/Family Resource Network. Shelby is the proud mother of five children and has been married for 20 years. Her son, Clayton, passed away on August 4, 2012, due to complications of epilepsy.

Elizabeth Shea, Esq
Designee for Commissioner Jennifer Velez
Department of Human Services
Liz Shea is a Policy Advisor and Special Assistant to the Deputy Commissioner at the New Jersey Department of Human Services. Liz has over 10 years of experience working in the disability field. Prior to her role at the Department, Liz was the Assistant Executive Director at The Arc of New Jersey and the Deputy Director of the Division of Advocacy for Individuals with Developmental Disabilities at the New Jersey Department of the Public Advocate. Liz is a licensed attorney and holds a Masters degree in Public Policy from Rutgers University.

Harry A. Thibodeau, RPh, CCP, FASCP
Consultant Pharmacist
Harry A. Thibodeau is an accomplished 30-year professional veteran in the field of pharmaceutical consulting. As a Clinical Pharmacist and President of Pharma-Care, Inc., Harry’s expertise provides multidisciplinary approaches to assist consumers and families in various facilities and settings, such as mental health, developmental disabilities, sub-acute care, veteran homes, and assisted living, to name just a few. Harry received his degree in Pharmacy from Long Island University, Brooklyn College of Pharmacy. His mission is to promote the most cost-effective services and the highest quality of care for consumers on state, national and international levels, as exemplified by his missions over the last decade to help those in need in third-world countries. With the ever-changing horizon of healthcare, Harry serves on various local, regional, national and international task forces, committees, and boards. Included are the NJPHA (New Jersey Pharmacist Association), ASCP (American Society of Consultant Pharmacist), CMS (Centers for Medicaid and Medicare) Medicare Part D Consortium, CMS PQA (Pharmacy Quality Alliance) workgroup and ASCP’s Public Policy and Advocacy and Government Affairs Committees working with Congress to advance healthcare to special-needs populations. Additionally, Harry speaks and sponsors in academia, writes articles and publications, gives presentations, and conducts studies, among others, sharing his passion for the profession of consulting pharmacy. Harry is certainly known for his knowledgeable gift of gab, gentle and caring ways, and supportive nature for those in need.
Administrative Staff

Diane DiGiovacchino
New Jersey Department of Health
Administrative Assistant 3
Diane DiGiovacchino has worked for the New Jersey Department of Health, Division of Family Health Services, for 24 years in various capacities. Currently, she is principal assistant to the Director of the Special Child Health and Early Intervention Services Unit, performing and coordinating administrative support services.

Summary
On November 22, 2011, we, the Epilepsy Task Force convened for our initial meeting. Since the Epilepsy Task Force was newly established, we spent the initial meetings forming categories for the groundbreaking recommendations. During our initial meetings we realized not only the importance of the recommendations we would propose to Governor Christie, but also the vast amount of information and issues that needed to be addressed. With the last statement being said, our recommendation, is for the Epilepsy Task Force to remain in place. We feel that the continuation of our work is a necessity, not a need, in addressing the countless obstacles faced by residents of the State of New Jersey living with epilepsy. Our work has only addressed the top layer of a multitude of issues that face our residents and, in turn, impact all residents within the State, including social, financial and legal effects (to name a few).

We felt that it was imperative to conduct public hearings – to find the areas of most concern for the residents within the State of New Jersey. Two public hearings were scheduled and the amount of statistics and corroborating evidence that we could use to finalize our findings revealed more areas we did not address. It was also apparent that we would not be able to address each issue that equally should be included within our report. We therefore chose to address key issues that were collectively voted upon by the members of the Task Force and add to these issues during our continuation. Our hope is that these recommendations will be a starting point for the continuation of the Task Force to address and, in turn, create programs and solutions.

In addition to the public hearings, we also created an online survey to aid the residents in partaking in the ability to have their voices recognized. The questions on the survey were aimed at generating responses on those topics we chose to address. Again, the overwhelming response from the citizens of New Jersey led us to conclude that we did not have enough time to properly make recommendations for a final report. We understood not only the importance of our work, but that in order to be the voice for those with epilepsy, a multitude of issues needed to be addressed and investigated. At this point we collectively decided that our main recommendation should be to have the Task Force extended.

We each held our positions on the Task Force in the highest regard. Meetings were put first on our schedules and we diligently worked to provide a comprehensive summary of recommendations to you. We hoped that this work would be able to be completed in a year’s time, but as time progressed, it was evident that this was not possible (in order to give you the recommendations that we felt would best represent those in the State living with epilepsy). It is our hope that the final recommendations will become policy within the State of New Jersey.
and set a precedent for other states to adopt. We understand the importance of our work and that, hopefully, it is not just New Jersey that we are making recommendations for, but more so, the entire country. Our State is the first to form an Epilepsy Task Force, and it is our hope that other states will follow in our path which is the reasoning for the diligence we wish to put into the final report. It is not only our honor to be a part of this Task Force, but our obligation to give you the best of each of us, as we are the voice for those within the State of New Jersey living with the effects of epilepsy.