

### Introduction

In September of 1997 the Center for Disease Control (CDC), American Epilepsy Society, National Association of Epilepsy Centers and the Epilepsy Foundation of America convened the Living Well with Epilepsy conference. The goal of that conference was to create a public health agenda that would fulfill three objectives: (1) to assess what was currently known about epilepsy and seizures; (2) to identify critical gaps in research that would enable better recognition and treatment; and (3) to determine strategies for surmounting barriers to optimal health and functioning. The conference groups were focused around three areas of public health: policy development (Early Detection and Treatment), assessment (Epidemiology and Surveillance), and assurance (Living Well with Epilepsy). In July of 2003 a follow-up conference (Living Well II) was held to review the progress that had been made since 1997; identify gaps in research, early recognition, diagnosis, and treatment; and to develop policies and strategies for overcoming barriers to optimal health and functioning.

While progress has been achieved on the national goals and objectives set forth by *Living Well with Epilepsy* and *Living Well with Epilepsy II*, the Epilepsy Foundation of Michigan recognized a critical need for these goals to be adapted and implemented at the state level. To this end, the Foundation funded a year long Michigan Epilepsy Strategic Planning Initiative to create a broad public health agenda for addressing epilepsy in Michigan.

### Impact of Epilepsy

Seizures and epilepsy affect 2.7 million Americans of all ages at an annual cost of \$15.5 billion in direct and indirect costs.<sup>1</sup> It is estimated that one percent of the population is living with epilepsy; three percent of the population aged 75 and older develop epilepsy; and ten percent of the population experience at least one seizure in their lifetime.

While treatments are now currently available that allow for a life free from seizures and side effects for the majority of persons with epilepsy, nearly 40% continue to have frequent and unpredictable seizures.<sup>2</sup> In addition others must live with debilitating side effects of the condition or its treatment such as attention and memory problems, mood disorders, unemployment, and social isolation.

### Data from the Epilepsy Foundation highlight the breadth of the impact of epilepsy<sup>3</sup>

- Epilepsy is the third most common neurological disorder in the United States...and is equal in prevalence to cerebral palsy, multiple sclerosis and Parkinson's disease combined.
- Epilepsy strikes most often the very young and the very old...it currently affects more than 326,000 children under age 15 and more than 90,000 of them have severe seizures that cannot be adequately controlled.
- The number of cases in the elderly is beginning to soar as the baby boom generation approaches retirement age. Currently more than 570,000 adults age 65 and above in the U.S. have the condition.
- This year another 200,000 people in the U.S. will be diagnosed with epilepsy and an estimated 25,000 to 50,000 will die of seizures and related causes, including status epilepticus (non-stop seizures), sudden unexpected death in epilepsy (SUDEP), drowning and other accidents.
- Thirty to forty percent of people with epilepsy are severely affected and continue to have seizures despite treatment.
- Of the major chronic conditions, epilepsy is among the least understood even though one in three adults knows someone with the disorder.
- Lack of knowledge about proper seizure first aid exposes affected individuals to injury from unnecessary restraint and from objects needlessly forced into the mouth.
- The leading non-medical problem confronting people with epilepsy is discrimination in education, employment and social acceptance.

**Table 1. Michigan Epilepsy Taskforce Members**

**CO-CHAIRS**

**Carol Callaghan**, Director, Division of Chronic Disease and Injury Control, Michigan Department of Community Health

**Gregory L. Barkley**, MD, Vice Clinical Chair, Neurology Department, Henry Ford Hospital

**EARLY RECOGNITION, DIAGNOSIS, AND TREATMENT**

**Jules Constantinou**, MD, Henry Ford Hospital, Department of Neurology

**Mary Beth Bolton**, MD, Health Alliance Plan, Medical Director

**Christina Kryger**, St. Mary's Mercy Medical Center Epilepsy Monitoring Unit

**Christine Farrell**, RDH, PA, MSA-MDCH, Program Specialist

**Jayne Martin**, DO MSU College of Osteopathic Medicine, Department of Neurology

**Michael Wolske**, Advocate, adult with epilepsy

**Arlene Gorelick**, MPH, Epilepsy Foundation of Michigan, President

**George Baker Jr.**, MD, MDCH, Children's Special Healthcare Services

**SELF-MANAGEMENT**

**Brien Smith**, MD, Henry Ford Hospital, Department of Neurology

**Tony Kim**, MD, Community Living Services, Medical Director

**Russell Derry**, MPH, Epilepsy Foundation of Michigan, Director of Education

**Kenneth Podell**, PhD, Henry Ford Hospital, Neuropsychologist

**Sarah Minarek**, BSN, RN, Children's Hospital of Michigan, Pediatric Neurology

**Lara Thomas**, University of Michigan School of Public Health, Center for Managing Chronic Disease

**Toya Williams**, Advocate, parent of child with epilepsy

**Rochelle Hurst**, MDCH, Division of Chronic Disease and Injury Control

**QUALITY OF LIFE**

**Don Dees**, Department of Labor and Economic Growth (DLEG) Michigan Rehabilitation Services, Site Manager

**Suzanne Howell**, DLEG Michigan Rehabilitation Services

**Tamyra Torok**, DLEG Michigan Rehabilitation Services

**Elaine Simmons**, DLEG Michigan Rehabilitation Services, Counselor

**Frank Bublitz**, St. Clair County CMH, Ombudsman

**Leslynn Angel**, United Cerebral Palsy Metro Detroit, President and CEO

**Don Trap**, Shiawassee Regional Education Services District

**Peggy Brey**, Office of Services to the Aging, Deputy Director

**Charlyss Brandon**, MDCH Bureau of Community Mental Health, Specialist for Services and Supports for Persons with Developmental Disabilities

**Nancy Grosso**, RN, FNP, Henry Ford Hospital, Nurse Practitioner Specialist

**Sandy Winchell**, Advocate, parent of child with epilepsy

**Karen Huszarik**, Advocate, parent of child with epilepsy

**Marc McWilliams**, Michigan Protection and Advocacy Services, Advocate

**Mia Cooke**, MSW, Epilepsy Foundation of Michigan, Health Educator

**Michael Nigro**, DO, Michigan. Inst. for Neurological Disorders

**Cynthia Archer-Gift**, MDCH Community Mental Health Services

**EPIDEMIOLOGY AND SURVEILLANCE**

**Ann Rafferty**, PhD MDCH Division of Epidemiology

**Michael Paustian**, MS, MDCH-Children's Special Healthcare Services, Epidemiologist

**Joan Durling**, Shiawassee County CMH, Consumer Outreach

**Sharon Leenhouts**, Medical Data Solutions, LLC, Consultant

**Tyler MacEachran**, MPA, Epilepsy Foundation of Michigan, Vice President

**Richard Wimberley**, MDCH Division of Chronic Disease, Manager

**Michael Dabbs**, Brain Injury Association of Michigan, President

**Jeffrey Loeb**, MD, PhD, Wayne State University, Department of Neurology/Center for Molecular Medicine and Genetics

## Public Health Implications

Epilepsy has broad public health implications. Elimination of seizures and prevention of side effects is possible for many people living with epilepsy, but most do not have access to the comprehensive epilepsy treatment needed to achieve optimal quality of life. Epidemiological and surveillance data are limited and additional research is considered necessary to understand the causes of epilepsy and how it impacts diverse age groups, races and communities. Evidence suggests that earlier detection and treatment of epilepsy increases the chances for positive outcomes in seizure control, mental health and cognitive function, and self sufficiency. Preventable problems, such as inappropriate medication due to misdiagnosis of syndrome, cause increased health costs in hospitalizations and treatments for uncontrolled seizures.

## Closing the Gap

Despite the existence of new approaches to treating epilepsy and successful strategies for overcoming the mental health and educational challenges that may be associated with epilepsy, many are still not benefiting from recent advances. To begin closing the gap between what is being done and what can be done for epilepsy treatment and quality of life, Epilepsy Foundation of Michigan established the Michigan Epilepsy Taskforce.

## The Michigan Epilepsy Taskforce

Multiple stakeholder groups from various communities across Michigan including physicians, neurologists, schools, universities, public and mental health systems, and people experiencing epilepsy were assembled to collaborate on the development of a state strategic plan. This Taskforce was charged with evaluating the nationally established Living Well II goals and developing feasible strategies for implementation of those goals within Michigan.

## Task Force Members

The Epilepsy Foundation of Michigan identified stakeholders from various communities across the state and invited them to participate in the Michigan Epilepsy Taskforce. Carol Callaghan, Director of the Chronic Disease and Injury Control Section of the Michigan Department of Community Health (MDCH), and Dr. Gregory Barkley of the Department of Neurology at Henry Ford Hospital were identified as co-chairs of the taskforce and provided expertise during taskforce discussions.

Taskforce membership was subdivided into four topic areas based on Living Well II: Early Recognition; Diagnosis and Treatment; Epidemiology and Surveillance; Self-Management; and Quality of Life. The groups were comprised of the members at left.

## Review of Current Research and Projects

Prior to convening the taskforce, current progress on Living Well II goals in Michigan was identified through a literature review and survey. Epilepsy Foundation of Michigan staff conducted a literature review of progress at both the national and state level. Taskforce members were then surveyed to ascertain if any programs or projects were being implemented on the national and state level. Taskforce members were asked 1) if they had knowledge of any current projects addressing epilepsy across the four topic areas, 2) if they could recommend someone as an epilepsy resource, 3) if they could recommend seminal papers or recent literature reviews on epilepsy, and 4) if they were aware of potential funding sources for addressing epilepsy. Information collected through the literature review and survey was compiled and provided to all taskforce members prior to the initial taskforce meeting.

## Michigan Epilepsy Taskforce Kick-off

Forty-two participants attended the taskforce kick-off at the James B. Henry Center in Lansing on September 11, 2007. The full-day meeting opened with a plenary session featuring presentations that provided background on the complexity of epilepsy treatment and the challenges of navigating the healthcare system from the perspective of an individual living with epilepsy.

In the afternoon, the four workgroups (described above) were convened and asked to address the following:

- 1) Review and discuss Living Well II topic area goals
- 2) Identify 2-3 goals for implementation on a state or local level within Michigan
- 3) Develop possible strategies to address identified goals
- 4) Prioritize strategies based on the following criteria:
  - a. Impact
  - b. Feasibility
  - c. Cost

Neutral facilitators ensured progress in addressing the workgroup charge. Group consensus and the opportunity for equal input from each participant were encouraged through a structured voting system.

## Workgroup Follow-up Meetings

Goals identified at the kickoff meeting were further developed during additional workgroup meetings. Each group defined objectives and strategies that could be implemented in a short time frame (less than three years). Long term strategies (3 to 5 years) were also developed through group discussion. Groups were asked to prioritize objectives based upon the presumed impact and feasibility of implementation. Participants identified resources, partners, leaders, and next steps to begin implementing strategies for each objective.

## QUALITY OF LIFE

*The Quality of Life group was charged with reviewing the following **Living Well** goals:*

- Improve the assessment and treatment of the mental health needs of people with epilepsy through professional education and research.
- Enhance resources and infrastructure necessary to improve access to social services and enhance quality of life of people with epilepsy.
- Improve understanding of risks and consequences of epilepsy and its treatment.
- Improve understanding of the impact of seizures and epilepsy on learning and cognition and ways to lessen and prevent these effects.
- Enhance efforts to combat stigma in epilepsy.

The Quality of Life group met in September and October of 2007 and March of 2008 to determine the goals, objectives and strategies that the taskforce should address. The group focused on the following goals and objectives:

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**QL GOAL 1:** Improve the assessment and treatment of the mental health needs of people with epilepsy through professional education and research.

**OBJECTIVE:** Improve access to psychiatric care by building bridges between mental health and epilepsy communities.

**GAP:** People with epilepsy are likely to experience mood disorders and other mental health issues. Up to 30% of persons living with epilepsy experience depression, and the risk of suicide is ten times that of the general population.<sup>4</sup> Currently most neurologists do not screen for mental health issues among their epilepsy patients and rarely refer patients for mental health services.

**STRATEGIES:** (QL1a) Educate neurologists, and other professionals, about the importance of evaluating for mental health issues through implementation of an ongoing professional outreach campaign. (QL1b) Integrate physical and mental health care for persons with epilepsy experiencing co-occurring mental health issues

These strategies will close the gap by integrating physical and mental health care for persons with epilepsy and co-occurring mental health disorders, increasing the number of patients receiving optimal care and improving quality of life.

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**QL GOAL 2:** Improve understanding of the impact of seizures and epilepsy on learning and cognition and ways to lessen and prevent these effects

**OBJECTIVE:** Develop professional education programs and best practices that address neuro-developmental disorders affecting learning and cognition.

**GAP:** Children with epilepsy experience developmental and neuro-developmental delays at a far higher rate than the general population. Roughly 40% of children with epilepsy have one or more neurological disorders and nearly 50% have learning disabilities.<sup>5</sup> These disorders and delays are due to organic changes in the brain from seizure trauma or the side effects of anticonvulsant medication. Parents and schools are often overwhelmed by the needs of a student with epilepsy. Improved communication between parents and schools is critical for children with epilepsy to receive appropriate educational services that enable them to be successful in school.

**STRATEGIES:** (QL2a) Develop a template for parents that will help them prepare to communicate with schools about their children's educational needs; (QL2b) Establish a state-wide protocol for addressing needs of children with epilepsy in schools similar to that developed for asthma; and (QL2c) Expand epilepsy awareness of school personnel and students.

These strategies will close the gap by ensuring that children with epilepsy are receiving the education services needed to be successful in school and in life.

**GAP:** The earlier delays are identified and addressed, the more likely it is that children will reach their optimal development. It is important that all children with epilepsy are referred for developmental screening and assessment at time of diagnosis, which may not be standard practice for neurologists.

**STRATEGY QL2D:** Educate physicians and neurologists to encourage evaluation of children with epilepsy for cognitive impairments at the time of diagnosis.

This strategy will close the gap by increasing the number of cognitive problems that are identified and addressed early so that children with epilepsy can reach their optimal potential.

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**QL GOAL 3:** Enhance efforts to combat stigma in epilepsy.

**OBJECTIVE:** Develop mechanism to track and address stigma.

**GAP:** Children and adults with epilepsy can suffer socially, emotionally and financially from the stigma associated with living with epilepsy. Adolescents with epilepsy are more likely to suffer from social anxiety, inability to experience pleasure and low self esteem.<sup>6</sup> Lack of knowledge among the general

public results in an inaccurate understanding of what epilepsy is, and a corresponding fear of those with epilepsy.

**STRATEGY QL3A:** Engage in a collaborative public campaign with the MDCH to reduce the stigma associated with epilepsy.

These strategies will close the gap by increasing the knowledge of the public about epilepsy which will reduce stigma, thereby increasing positive life experiences for persons with epilepsy.

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**QL GOAL 4:** Improve employment prospects for adults with epilepsy in Michigan

**OBJECTIVE:** Develop educational efforts aimed at vocational rehabilitation specialists and adults with epilepsy.

**Gap:** Adults living with epilepsy have much higher rates of unemployment (34%) than the general population (9%)<sup>7</sup>. Employers can be unwilling to hire a person with epilepsy due to concerns about an employee experiencing a seizure in the workplace and fears about liability. Adults with epilepsy often struggle to find employment due to these fears and concerns.

**Strategies:** (QL4a) Convene an Epilepsy and Employment Summit of diverse stakeholders to identify barriers for people with epilepsy seeking employment and identify systemic areas of opportunity, collaboration and best practice; (QL4b) Educate adults with epilepsy about the resources available to them and their rights under the Americans with Disabilities Act.

These strategies will close the gap by increasing the opportunities for more persons with epilepsy to gain employment and live independently.

## EPIDEMIOLOGY AND SURVEILLANCE

*The Epidemiology and Surveillance group was charged with reviewing the following **Living Well** goals:*

- Develop and enhance the capacity and infrastructure for surveillance and epidemiological studies of persons with epilepsy.
- Develop surveillance systems to examine health care utilization and resources for people with epilepsy.
- Expand research on mortality and epilepsy to increase understanding of the causes of death in epilepsy.
- Expand research on co-morbid conditions with epilepsy.

The Epidemiology and Surveillance group met in October and November of 2007. The group focused on the following goals and objectives:

**ES GOAL 1:** Develop and enhance the capacity and infrastructure for surveillance and epidemiological studies of persons with epilepsy.

**OBJECTIVE:** Utilize a measure of health-related quality of life (HRQOL) to monitor health status in the epilepsy population, track changes to better understand the natural history of epilepsy, and evaluate effectiveness of interventions from a personal health perspective.

**OBJECTIVE:** Assess people with epilepsy (not just new onset) to capture information on demographic characteristics, epilepsy types and syndromes, long term effects of treatment and impact of epilepsy as a co-morbid condition.

*The following strategies address both of the above objectives.*

**GAP:** There are little data available on the prevalence of epilepsy within Michigan or the disparities in services and treatment especially for those who are geographically isolated, impoverished, underinsured/uninsured, and minorities. In 2005, Epilepsy Foundation of Michigan funded the addition of five questions on epilepsy to the Behavioral Risk Factor Survey (BRFS). Data from that survey indicated that 1.8% of the population surveyed was diagnosed with epilepsy or seizure disorder. However, quality of life issues were not thoroughly addressed in the 2005 survey, and data are needed to clearly identify the magnitude of service gaps and needs, barriers to employment, transportation.

**STRATEGIES:** (ES1a) Continue the epilepsy questionnaire included in the BRFS and expand to include a follow up survey to acquire information on quality of life issues. The Center for Disease Control has encouraged the Epilepsy Foundation of Michigan and MDCH to continue to collect this information and has offered to assist with the creation of an epilepsy specific follow up interview. (ES1b) Develop a Michigan Epilepsy Research Consortium to: (1) increase communication amongst researchers; (2) increase coordination and collaboration on research projects; (3) increase funding for epilepsy research in Michigan; and (4) prioritize areas of local epilepsy research to document areas of need, disparities in quality of care, and quality of life for those living with epilepsy in Michigan.

These strategies will close the gap by creating a collaborative body for research on epilepsy to improve care and quality of life for persons in Michigan with epilepsy.

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**ES GOAL 2:** Develop surveillance systems to examine health care utilization and resources for people with epilepsy.

**OBJECTIVE:** Identify and track patterns of care, treatment, and prevention efforts to detect disparities, barriers, gaps, and quality of epilepsy care.

**GAP:** People living with epilepsy can experience a wide range of co-morbidities that impact health and quality of life including depression, anxiety and other mental health disorders; sleep dysfunction; poor physical fitness; and debilitating migraines.<sup>8</sup> Little is known on a state level about the costs associated with epilepsy and its treatment and co-morbidities, patterns of care, referral patterns, and cost efficiencies in treatment. Limited data are collected via the state Medicaid system, but data are unreliable and do not include consumers served by private insurers. Currently there is no surveillance system for epilepsy and epilepsy co-morbidities in Michigan.

**STRATEGY ES2A:** Develop a surveillance system that will identify and track patterns of care, treatment, and prevention efforts to detect disparities, barriers, gaps and quality of epilepsy care in order to increase understanding of how patient care impacts quality of life.

This strategy will close the gap by collecting reliable data to inform politicians, physicians and other service providers about the state of services available to persons with epilepsy in Michigan which will lead to system changes to address access to care and services which will improve quality of life.

## SELF-MANAGEMENT

*The Self-management group was charged with reviewing the following **Living Well** goals:*

- Enhance behavioral and social science research of people 'living with epilepsy' and self-management of epilepsy.
- Facilitate the development and testing of self-management models that incorporate critical components for epilepsy.
- Ensure that programs recognize the spectrum of epilepsy and tailor content appropriately to people with well controlled, refractory, and new onset seizures.
- Promote self-management and self determination principles and programs in the care and services for people with epilepsy.

The Self-management group met in September of 2007 and March of 2008. The group focused on the following goal and objectives:

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**SM GOAL 1:** Promote self-management and self-determination principles and programs in the care and services for people with epilepsy.

**OBJECTIVE:** Encourage the adoption of approaches and attitudes that support epilepsy self-management and self-determination by health care providers, the public health community, and families that are tailored to geographic areas and cultural differences.

**OBJECTIVE:** Identify, evaluate and promote usage of epilepsy self-management tools, including generic chronic disease self-management tools.

*The following strategies address the above objectives:*

**GAP:** There are very few epilepsy-specific self-management models available for persons living with epilepsy. Improving self-management can reduce seizures and improve overall quality of life.

**STRATEGIES (SM1A):** Explore the use of epilepsy and chronic disease self-management tools such as the CDC/ Emory University model and other models. Identified web-based modules could be used in conjunction with the PATH model and would allow access to those who cannot attend the PATH trainings because of transportation or geographic barriers. Emory University and the CDC will be launching a web-based self-management tool specific to adults with epilepsy in 2008.<sup>9</sup> In addition, the effectiveness of disseminating printed educational materials on epilepsy self-management could be explored.

**(SM1B):** Promote usage of identified effective self-management tools within Michigan. Disseminate identified self-management tools through existing education programs and points of contact for persons with epilepsy.

These strategies will close the gap by increasing access to evidence-based self-management models and tools for adults with epilepsy, thereby improving health outcomes and quality of life.

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**SM GOAL 2:** Facilitate the development and testing of self-management models that incorporate critical components for epilepsy.

**OBJECTIVE:** Pilot test one or more models of epilepsy self-management for use in Michigan.

**GAP:** Many people living with epilepsy also suffer from other co-occurring chronic health disorders that also need to be addressed in conjunction with epilepsy for optimal health and to reduce health care costs.<sup>10</sup> Improving self-management of co-occurring chronic disorders can reduce seizures and improve overall quality of life.

**STRATEGY SM2A:** Partner with MDCH and the Office of Services to the Aging to provide the PATH program to adults with epilepsy in Michigan. Design and implement an epilepsy-specific module to address specific needs of persons with epilepsy to be used in conjunction with the PATH curriculum. The Stanford Chronic Disease Self-management Program<sup>11</sup> is an evidence-based six-week workshop imple-

mented in community settings. Participants in the program have been documented to have reductions in hospital use and other health services, improved symptom management and reduced health costs. In Michigan, the Stanford model is implemented as Personal Action Toward Health (PATH) and has been utilized by the MDCH and the Office of Services to the Aging for populations with other chronic diseases.

This strategy would close the gap by increasing the availability and access to evidence-based self-management models and tools for adults with epilepsy thereby improving health outcomes and quality of life.

## EARLY RECOGNITION, DIAGNOSIS AND TREATMENT

*The Early Recognition, Diagnosis and Treatment group was charged with reviewing the following **Living Well** goals:*

- Support research to evaluate existing best practices and standards of care for persons with epilepsy.
- Improve understanding of seizures and epilepsy and best practices for epilepsy management, including referral to tertiary level of care, particularly for primary care providers.
- Improve early recognition and timely diagnosis of seizures and epilepsy, including rare forms of seizures.
- Improve access to optimal care for persons with epilepsy.
- Improve recognition and use of appropriate seizure first aid.
- Enhance understanding of mortality in epilepsy among all audiences.
- Enhance professional education on seizures and epilepsy, particularly to primary care providers and health care professionals in training.
- Improve systems of care for people with epilepsy.
- Expand health services research to improve access to care.

The Early Recognition, Diagnosis, and Treatment group met in September and November of 2007 and March of 2008. The group focused on the following goals and objectives:

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**ERDT GOAL 1:** Improve understanding of seizures and epilepsy best practice for epilepsy management, including referral to tertiary level of care, particularly for primary care providers.

**OBJECTIVE:** Increase communication and dissemination of standards of care and best practices among health care professionals, the public health community, health plans/insurers, people with epilepsy, and families.

**GAP:** Epilepsy is not a single condition, but actually a compilation of over three dozen different syndromes. Correct diagnosis is crucial as even very similar syndromes respond

very differently to the same treatments. <sup>12</sup> Misdiagnosis causes the wrong treatment to be given, leading to increased health costs from uncontrolled seizures, use of multiple medications and frequent hospitalizations; lower quality of life; and even death.

Misdiagnosis may result from the lack of time spent on epilepsy and its syndromes by neurology residents. Often the only instruction that is given on epilepsy consists of just one or two class sessions.

**STRATEGY ERDT1A:** Develop and implement a curriculum for neurology residents with an epilepsy focus to thoroughly educate residents about the diagnosis and treatment of epilepsy and its syndromes.

This strategy will close the gap by increasing the number of patients receiving the correct diagnosis, improving treatment and quality of life and decreasing health care costs associated with incorrect diagnosis and treatment.

**GAP:** Epilepsy is a complex condition with many co-morbidities and health consequences that need to be taken into consideration for optimal health care services.

Insurers do not currently have a purchasing protocol for epilepsy services in place and may not understand the referral patterns necessitated by epilepsy and its co-morbidities such as earlier onset of osteoporosis due to long term medications and the need for bone density tests far earlier than general population guidelines. Receiving appropriate referrals is crucial to improving health outcomes, lessening health care costs, and improving quality of life for people living with epilepsy.

**STRATEGY ERDT1B:** Encourage insurers to adopt best practices in addressing the complex health issues experienced by persons with epilepsy through adoption and expansion of purchasing protocols. Explore usage of protocols such as the George Washington University Medical Center School of Public Health and Health Services epilepsy purchasing protocol that specifies a referral module from primary care physicians to neurologists to specialists based upon specific criteria and timelines.

This strategy will close the gap by increasing the number of patients receiving appropriate referrals and correct diagnosis and care, thereby lessening the health care costs associated with uncontrolled symptoms and improving quality of life.

**GAP:** The severity criteria used for Children's Special Health Care Services (CSHCS) eligibility for children with epilepsy is out-of-date. Current guidelines only cover newer drugs and not older drugs, such as Phenobarbital and Dilantin, which comprise two thirds of prescriptions, and do not cover those who have controlled symptoms on monotherapy. Children with epilepsy who could benefit from MDCH's CSHCS program may not be covered.

**STRATEGY ERDT1C:** Create an advisory board of pediatric neurologists and clinical nurse specialists to inform CSHCS on recommendations for severity criteria, eligibility guidelines, and necessary coverage of older line drugs. CSHCS has indicated that new guidelines for children with epilepsy are needed and would be adopted if developed and recommended by a panel of pediatric neurologists.

This strategy will close the gap by increasing the number of children in Michigan with epilepsy who are receiving appropriate care and coverage through CSHCS.

**GAP:** Many professionals in contact with children and adults with epilepsy are unaware of the co-morbidities or special challenges and needs of living with epilepsy.

**STRATEGY ERDT1D:** Explore strategies to increase professional awareness on co-morbidities and special challenges. The Epilepsy Foundation of Michigan may partner with a major health care or academic institution to educate physicians, nurses, teachers, social workers and other professionals. Continuing Education units may be provided as incentive.

This strategy will close the gap by increasing the knowledge about best practices across disciplines and agencies that serve persons with epilepsy thereby improving services, treatment and quality of life for children and adults living with epilepsy.

**OBJECTIVE:** Undertake a campaign to empower people with epilepsy and professionals to work aggressively towards goal of 'no seizures, no side effects'. Incorporate information on patient and family expectations, rights, guidelines and indicators of quality care, how to access care, and community resources for epilepsy education and support.

This objective is being addressed by Self-Management Strategy SM1b and SM2a (page 6)

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**ERDT GOAL 2:** Improve early recognition and timely diagnosis of seizures and epilepsy, including rare forms of seizures.

**OBJECTIVE:** Enhance dissemination of educational materials to those likely to be in contact with people with epilepsy: police, first responders, school personnel, emergency room staff, etc.

See strategy ERDT1D above.

## DEVELOPMENT OF EPILEPSY FOUNDATION OF MICHIGAN ACTION PLAN

The work of the Michigan Epilepsy Taskforce has resulted in a comprehensive action plan to be implemented by the Epilepsy Foundation of Michigan and its partners. For each strategy identified by the Taskforce, the action plan includes a detailed description of strategies, next steps, potential partners, and outcomes to be achieved. The Michigan Epilepsy Taskforce Action Plan will be used to guide the work of the Epilepsy Foundation of Michigan and other stakeholders over the next five years.

### **Additional issues to be addressed by Epilepsy Foundation of Michigan**

While the Action Plan encompasses multiple goals and objectives to close the gap between what is being done and what can be done for epilepsy treatment and quality of life, there are still additional issues to be addressed. Over time the Epilepsy Foundation of Michigan plans to explore the development of strategies to address early recognition of epilepsy and to increase its efforts to improve employment opportunities and access to services for all persons living with epilepsy in Michigan.

**Early Recognition:** The Early Recognition, Diagnosis and Treatment Workgroup felt that misdiagnosis and inappropriate treatment were more pressing issues than early recognition. This decision resulted from group consensus that the onset of seizures is easily recognized, but incorrect diagnosis of the cause of the seizures can lead to ongoing health and

quality of life issues. Epilepsy Foundation of Michigan will explore this issue further to determine if strategies related to early recognition should be added to the Action Plan.

**Employment:** The Epilepsy Foundation of Michigan surveys its members regularly to identify quality of life issues for persons with epilepsy. Employment is an issue continually identified by survey participants. Affordable transportation is crucial and is a major barrier especially for those with driving restrictions. The Quality of Life group discussed barriers to employment for persons with epilepsy but did not have access to the broad group of stakeholders needed to thoroughly address this issue. The Epilepsy Foundation of Michigan will convene a group of stakeholders to identify additional partners and strategies to be in the Action Plan.

**Access to Services:** Barriers to access of care was a common theme among all workgroups. Persons with epilepsy may be unable to access quality services due to geographic distance from specialists and lack of insurance to cover the cost of quality care. Cost of medications is an ongoing issue identified by many who contact Epilepsy Foundation of Michigan. Others have complained of problems when epilepsy medication is switched by insurance companies or pharmacies. Strategies for addressing access to care are not included in the attached plan but will be addressed over the long term as surveillance systems are put in place to collect reliable data on which to create a platform for advocacy.

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#### NOTES

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