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THE IMPACT OF EPILEPSY AND THE EVOLUTION OF A NONPROFIT:
“THE EPILEPSY CONNECTION”

By
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A thesis submitted to the faculty of the University of Mississippi in partial fulfillment of
the requirements of the Sally McDonnell Barksdale Honors College

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Approved By

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DEDICATION

This thesis is dedicated to everyone who guided and encouraged me throughout the year.

Thank you.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to Dr. Richard Buchholz, my advisor, for his invaluable proofreading, guidance, and recommendations. Without his assistance, this endeavor would not have been possible. I would like to extend my sincere appreciation to my readers and chair for allowing me this opportunity and providing their expertise. Additionally, I could not have undertaken this journey without the support of the Sally McDonnell Barksdale Honors College.

Words cannot express my gratitude to the members of The Epilepsy Connection, who inspired and helped to make our service club successfully acknowledged on UM campus. I am also extremely grateful to my peers, the Ole Miss faculty and staff, and the Oxford community for helping The Epilepsy Connection meet their goals during successful fundraisers and awareness events.

Lastly, I would like to acknowledge my wife, Anna Katherine, and my family, especially my parents, who encouraged and supported me throughout this process. Their consistent belief in me never wavered. I would also like to recognize all of the peers and teachers who impacted me profoundly along the way.

ABSTRACT

THE IMPACT OF EPILEPSY AND THE EVOLUTION OF A NONPROFIT: “THE EPILEPSY CONNECTION”

This thesis examines the diagnosis, symptoms, and consequences of epilepsy along with the author’s personal journey that promoted the creation of a successful epilepsy service club on the University of Mississippi campus, later evolving to a nonprofit organization off campus. Epilepsy is defined as having at least two seizures without a known trigger that are recurring and may include uncontrollable jerking of muscles or staring blankly with significant risk for short-and long-term consequences. These consequences include social isolation, problems at school, reduced physical activity, increased risk for injuries, social stigma, anxiety, depression, attention issues, and other consequences. An independent online search by the author sought to discover epilepsy-based organizations among universities that had 10,000 or more students enrolled among eleven Southern states. Out of 105 universities found in the eleven states, three universities, the University of Mississippi, the University of Central Florida and the University of South Florida, published information about epilepsy-based service clubs on their campuses. This search accounted for 2.9% prevalence of epilepsy-based college service club organizations across eleven Southern states. Based on these findings, additional follow up is necessary to search in other U.S. regions to see if the results are similar and to identify prevalence of epilepsy service organizations in a wider population. The prevalence of epilepsy service club organizations nationwide is not known.

Keywords: epilepsy, seizure, consequences of epilepsy, impact of epilepsy, epilepsy college service club, epilepsy treatment, epilepsy social stigma, epilepsy nonprofit, The Epilepsy Connection

PREFACE

The desire for this thesis came from my long personal journey with epilepsy and my passion to seek out and assist peers with epilepsy. I have a strong belief that social relationships help to unite us and make us stronger as a society. This thesis aims to convince readers that through education and awareness they can help to reduce stigma against people with epilepsy.

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LIST OF ABBREVIATIONS

UM- University of Mississippi

TEC- The Epilepsy Connection

RSO- Registered Student Organization

AED- Anti-Epileptic Drugs

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INTRODUCTION

Epilepsy carries a social stigma that may be due to the public's lack of knowledge about the causes and consequences of this disorder. Stigma is described as “an attribute that is deeply discrediting” and there is a social perception that individuals with epilepsy are different from what is perceived as normal in society (Austin, et al., 2022; England et al., 2012; World Health Organization, 2023). Furthermore, stigma and negative attitudes towards epilepsy have been shown to affect an individual's quality of life by reducing opportunities for “education, employment, and social relationships” (Austin, et al., 2022). Through education and disseminating knowledge to the public, the hope is that social stigma against epilepsy can be reduced. This thesis will define epilepsy along with its biological basis and short-and long-term consequences, include personal experiences, the creation of a college campus student group, and discuss the expansion to a nonprofit organization for epilepsy.

CHAPTER ONE

Epilepsy is not a rare disorder (Epilepsy Foundation, 2020). It is described with specific symptoms mostly occurring from seizures, and there are three common types of seizures associated with epilepsy. Today, there are a variety of treatments available in the United States for epilepsy. Unfortunately, even with treatment, epilepsy has short-and long-term consequences. Children and adults, especially those with uncontrolled seizures, face many challenges.

A Review of Epilepsy

-Occurrence

Epilepsy is a common neurological disorder found in 1 in 26 individuals in the United States at some point in their lives with an estimated 150,000 new cases diagnosed each year in the United States (Epilepsy Foundation, 2020). A global estimation of 70 million people worldwide has been reported to be affected by epilepsy (Thijs et al., 2019). In addition, individuals with epilepsy include all ages, socioeconomic backgrounds, ethnic groups, and both genders (Epilepsy Foundation, 2020).

-Definition and Types

Epilepsy is defined as having recurring and unprovoked seizures, or at least two seizures without a known trigger happening within 24 hours apart (Centers for Disease Control and Prevention, 2020; Stafstrom & Carmant, 2015). A seizure occurs when there are chemical changes in neurons that cause uncontrollable and excessive firing of neuronal activity through the brain (Stafstrom & Carmant, 2015). Seizures can cause temporary changes in an individual's muscle tone or movements. For example, an individual may become stiff, twitch, or go limp during a seizure. Also, seizures can cause

abnormal sensations or states of awareness. Causes for epilepsy can be genetic, head trauma, tumors, stroke, or unknown causes. An electroencephalogram is the most commonly used method to diagnose epilepsy (Stafstrom & Carmant, 2015).

There are three common types of epileptic seizures: generalized, focal onset impaired awareness, and focal onset awareness.

Generalized Seizures. These begin with sudden abnormal electrical activity in one or both hemispheres of the brain (Center for Disease Control and Prevention, 2020; Stafstrom & Carmant, 2015). Examples of generalized seizures are bilateral convulsive movements of all limbs lasting three to five minutes also known as tonic-clonic convulsions or grand mal seizures. During a convulsive seizure, the limbs stiffen followed by jerking movements and there is a loss of consciousness. There are other forms of generalized seizures, however, that may not be convulsive, such as absence seizures, or staring seizures, which may last only five to twenty seconds (Center for Disease Control and Prevention, 2020; Stafstrom & Carmant, 2015). When the absence or tonic-clonic seizure ends, the individual initially wakes up confused but will resume normal conversation or activity shortly. These non-convulsive seizures are brief episodes and can easily be missed.

Focal Onset Impaired Awareness. Formerly known as complex partial, these begin in one area of the brain and cause altered awareness during some or all of the seizure (Center for Disease Control and Prevention, 2020; Stafstrom & Carmant, 2015). The individual shows involuntary movements like minor shaking or rubbing of hands. The individual can also display a chewing motion or feel confused.

Focal Onset Awareness. Formerly known as simple partial has uncontrollable neuronal activity specifically in one sensory or motor area of the brain (Center for Disease Control and Prevention, 2020; Stafstrom & Carmant, 2015). The individual is aware of what is happening and may notice unusual sensations or movements. Focal seizures are controlled by the function of the brain area in which they occur.

-Treatments

Despite more than 20 anti-epileptic drugs (AEDs) available today, 36% of those diagnosed with epilepsy live with uncontrolled seizures (Janson et al., 2020; Singh & Verma, 2019). Non-pharmaceutical treatments for epilepsy include: dietary changes, neurostimulation, and surgery. The use of a ketogenic diet is a diet high in fats and low in carbohydrates, with potential side effects including dehydration, constipation, and nutritional deficiencies (Kossoff, 2017). Neurostimulation includes devices that analyze brain activity patterns to detect seizures as they start and deliver an electrical charge or drug to stop the seizure (Amin & Benbadis, 2017). Vagus nerve stimulation is used for intractable (also called refractory) epilepsy. A wire is connected to the left vagus nerve in an individual's neck and sends bursts of electrical energy to the brain (Amin & Benbadis, 2017). Mild initial side effects include insomnia, coughing, or headaches. Deep brain stimulation includes implanting electrodes into a specific area of the brain. The electrodes are connected to a generator in the chest, which sends electrical pulses to the brain at timed intervals (Amin & Benbadis, 2017). The last option is invasive surgery to remove a small well-defined area causing seizures if it does not interfere with speech, motor, vision, or hearing (Amin & Benbadis, 2017).

-Consequences

Short-term. Children who have uncontrollable seizures are particularly at risk for developing poor self-esteem, problems at school with learning, grades, and school experiences, as well as issues with interacting with their peers, behavioral problems, and a lack of social skills (Epilepsy Foundation, 2022). Behavior problems can arise from their frustration, impulsive behaviors, and lack of organizational skills. They may also have problems with memory and concentration along with attention issues. Due to a fear of social rejection, seizures may decrease engagement in physical and social activity. This reduction in activity level promotes more social isolation.

Furthermore, seizures cause short-term physical effects. These effects include uncontrollable jerking and shaking of muscles and becoming stiff. The physical effect may include losing conscious awareness, staring blankly, and inability to talk. They may show repeated blinking of eyes, or their eyes may move side to side or upwards. They may be unable to move or have a loss of muscle tone and fall forward. They may also repeat movements called automatisms like lip-smacking, wringing hands, playing with buttons, walking or running. The individuals with epilepsy may continue motor movements in an activity they were performing before the seizure started. There may be a loss of urine or bowel control. Individuals with epilepsy also report strange sensations such as a “rising” feeling in their stomachs, or unusual smells or tastes. They can also report dizziness, sweating, headache, or nausea. In addition, some report a tingling feeling in their arms or legs or a change in skin color such as paleness. Other physical symptoms may include biting of tongue due to clenching teeth during a seizure, difficulty breathing, or heart racing. They may feel thirsty, tired, or sleep after the seizure. There

could also be a general weakness of one part or side of the body. Injuries such as bruising or cuts may also have occurred during the seizure (Schachter, 2022).

Additionally, seizures can impact mobility and automobile driving for adolescents and adults. Each state has regulations about the eligibility of people who drive with medical conditions. Usually for those who have epilepsy and seizures, there is a certain period of time for individuals to be seizure-free before they are legally allowed to drive. The regulations can be found on each state's department of motor vehicle website.

Long-term. Seizures lead to social stigma, which produces a long-term psychosocial impact reducing interaction with peers. Individuals with epilepsy and seizures feel lonely and may develop fewer friendships or lack social support. It has been reported that 25% to 55% of individuals with epilepsy also have depressive symptoms (Kwon & Park, 2014; Shafer & Vosburgh, 2018). Additionally, anxiety symptoms are reported in approximately 20% of individuals living with epilepsy (Wang et al., 2019; Hingray et al., 2019). Unfortunately, Mula and Sander (2013) reported that suicide is three times more likely in those living with epilepsy compared with those who are not. In addition, Rheims and Auvin (2021) reported that as high as 70% of individuals who are diagnosed with refractory or difficult to treat epilepsy are also diagnosed with attention deficit/hyperactivity disorder.

Generally, individuals with epilepsy have more physical problems such as fractures and physical injuries related to seizures. These injuries can include falls and burns. Individuals with active epilepsy are at risk for drowning and head injuries. The risk of premature death in individuals with epilepsy is up to three times higher than in the general population (World Health Organization, 2023).

Additionally, a seizure lasting more than five minutes, or having more than one seizure within five minutes is called status epilepticus, which is a medical emergency. The mortality rate for individuals with the first episode of generalized convulsive status epilepticus is between 16% to 20% (Wylie et al., 2022). Medical complications from status epilepticus can include cardiac damage, respiratory failure, and aspiration pneumonia. There can also be permanent neurological damage in the brain (Wylie et al., 2022).

Furthermore, according to 2014 data, convulsion-type seizures led to more than 1 million emergency department visits and 280 thousand hospital admissions (American Journal of Managed Care, 2020). The estimated direct costs of epilepsy have been reported to be \$28 billion per year. A significant portion of these costs is related to uncontrollable epilepsy (American Journal of Managed Care, 2020).

Adults living with active epilepsy usually have a lower annual household income and vocational issues (Kobau et al., 2014). Uncontrollable seizures may contribute to their lack of employment, and Shafer (2014) mentioned that there is inequality in workplace policies, which can lead to discrimination. Additionally, unemployment is reported to be greater in adults with active epilepsy and approximately 32% are reported to be unable to work (Epilepsy Foundation, 2020). In addition, 13% may have to limit the type of work positions or the amount of work due to epilepsy (Kobau et al., 2014).

In summary, epilepsy is a common neurological disorder worldwide that involves seizure activity with approximately a third of individuals living with uncontrolled seizures. With three common types of seizures, treatment includes anti-seizure medications, ketogenic diet, neurostimulation, and surgery. However, epilepsy has

significant short- and long-term consequences. At an early age, I embarked on the following personal journey that over years gave me a deeper understanding of the consequences and daily struggles that occur while living with epilepsy.

CHAPTER TWO

When I was 4 years old, I told my mother that I had special powers. She assumed this proclamation was based on my role-playing of Power Rangers, toy superheroes. However, these special powers meant that I saw white circles constantly during the day, which changed colors and moved at night. My parents were not informed of the extent to these special powers until my mother saw a seizure occur for the first time. Upon questioning more about my special powers, my parents were able to interpret symptoms that I had been experiencing. Fortunately, after undergoing magnetic resonance imaging, my parents and I learned that I did not have a brain tumor or brain structure abnormality. However, I was diagnosed with generalized epilepsy and absence seizures, which started my family and me on a journey that would take years to understand.

Beginning Personal Impact of Epilepsy and Symptom Description

Initially, a pediatric neurologist at the University of Mississippi Medical Center told my parents that before diagnosis, I probably experienced more than 100 seizures a day, each one lasting between six to twelve seconds approximately. My kindergarten teacher had not reported any issues, which is common for these types of seizures to get overlooked. At that time, my seizures were like staring spells. However, my parents informed the teacher that I most likely had not heard the majority of what she had taught, which my end of the year low scores reflected. I repeated kindergarten to relearn the information after being placed on medication for my seizures. When I entered elementary school, my head would roll back and my eyes would go upward to the left during most seizures, still lasting for seconds. Although, these episodes were easier to notice than staring episodes.

My seizures occurred in both brain hemispheres. Motor functions continued during a seizure, but I could not access the language and communication areas of my brain. For example, if I was chewing gum when I had a seizure, then I would continue to chew. If I was walking or running when I had a seizure, I would continue to walk or run. I could not communicate during a seizure and I was not conscious. Therefore, there was a risk for injury when I had seizures.

Also, during school when I had a seizure and the teacher was talking, I would exit the seizure and the teacher was talking about something differently. I always felt like I lost time and information. In addition, during a seizure, there was a chance of urinary incontinence, which was unpredictable, but I experienced this effect from seizures usually on a daily basis. This problem was devastating as a young child and presented as much of a disability as my unpredictable seizures.

Personal Treatment and Additional Epilepsy Diagnosis

My treatment consisted of increased dosages from a variety of medications. However, after the first three AEDs failed to control my seizures, by age seven, I was also diagnosed with refractory epilepsy, sometimes called intractable epilepsy or uncontrolled, drug-resistant epilepsy. Due to the high dosage of more than one medication, I could hardly put together a sentence and lagged behind my peers.

My parents sought additional recommendations and treatment at Johns Hopkins University in Baltimore, a renowned pediatric neurology department, to enhance my quality of life and hopefully reduce the number of daily seizures. Johns Hopkins did individualize medical treatment and I participated in an experiment to provide data to

help other children with difficult to treat epilepsy. I also participated in their ketogenic diet protocol for a while.

Consequently, my pediatric neurologist at Johns Hopkins helped to reduce the number of seizures overall during most days, but the treatment did not control the seizures. I continued to have approximately 75 seizures a day with an occasional good day of 30 to 50 seizures a day. My seizures were unpredictable although getting hot and/or losing sleep were especially triggers that increased the likelihood and number of seizures.

Johns Hopkins continued to treat me, as well as a local provider. However, when I was near puberty, my seizures began to change and lasted longer than usual. My pediatric neurologist at Johns Hopkins gave a last option to combine two medications. It was understood that I would have increased side effects due to use of an older generation medication, which I experienced vomiting and vertigo for at least six months.

Accommodations at School

Along with treatment for seizures from Johns Hopkins, my parents sought to obtain accommodations at school. My school did not have a resource center at that time, so my parents advocated for me and provided education about epilepsy to the school. With accommodations, I was able to have more time on tests and obtain tutor assistance. I was allowed to use a private bathroom at school since I changed disposable underwear because of urinary incontinence from the seizures.

Personal Consequences and Learning Disability

Before my diagnosis, I had played Little League baseball and soccer, which I had to discontinue including all sports. I became a quiet child and withdrew from others. I felt

like I was different and could not share information about my problems. Before my diagnosis, I was a happy and social boy, but after the diagnosis, I was sad and told my parents that I could not participate in school events and extracurricular activities because of my seizures or the fear of having a seizure; the school usually agreed. I apologized to people around me after having seizures and lacked self-confidence. Academically, my grades suffered because I had problems with memory, attention, organization, and reading, which created a learning disorder due to the seizures and medications.

Like most children with epilepsy, I chose not to tell others in the community about my seizures because I did not want to be seen as weird, stupid, or different and I did not want children to make fun or avoid me. However, I was called “seizure boy” at school sometimes, which embarrassed me and made me feel like I was not smart. I felt isolated and frustrated with difficulty connecting to others. I did not want to be defined by epilepsy. My parents sought to improve my quality of life and help me to overcome my obstacles. Fortunately, my parents found the Epilepsy Foundation of MS, the only office in Mississippi that supported children and adults with epilepsy.

Epilepsy Foundation of Mississippi Summer Camps

They had a small office, but I credit the Epilepsy Foundation of Mississippi as one of the greatest influences, along with my parents’ influences and medical treatment, in my life. I went to a summer camp when I was eight years old and it changed my outlook on life. For the first time since I had been diagnosed, I was at a place with people who understood epilepsy and they were not afraid of it. In addition, all the children at the camp had epilepsy. I was the only one with uncontrollable absence seizures, but I saw that other children had worse seizures than me. They also had urinary incontinence when

they had seizures, which helped me not to feel alone. In fact, I created friendships that summer that lasted for years.

The camp scheduled activities for the campers including swimming, canoeing, and a high ropes course to help the campers to overcome fear and to become more independent. There were themed events including a talent show. In addition, there were camp counselors that assisted with activities to help campers learn how to talk about and overcome their issues. I participated in all of the events and activities, realizing that I could still do things even with epilepsy. I became happier and more social after experiencing summer camps. Even though there were still many challenges along the way, with my parents' support and my willingness to overcome my obstacles, I learned how to grow emotionally and physically while living with epilepsy.

Overcoming Personal Obstacles

Because I could not play sports, my parents provided me an opportunity to learn to play the trombone and guitar to help me to create extra-curricular activities. I also participated in beginning band. In addition, I participated in Boy Scouts with the help of my father. My mother also assisted me during school events as well as continued to educate school officials about epilepsy to help build their resource program. In addition, my parents paid for additional tutor sessions as needed outside of the school program. My parents worked diligently to place me in opportunities that would help me to succeed.

Fortunately, over some time, my epilepsy condition became stable and I stopped having absence seizures. When I stopped having seizures and eventually was able to wean off medications, I was able to play in the high school performance band, perform show choir on stage, and participate in other student activities. Getting off the AEDs

greatly assisted me to be able to think and process quicker and more clearly. With great effort, I was able to join the honors society at school, which gave me increased pride in my accomplishments.

Although I stopped having absence seizures, my threshold is lower than a person who has never had seizures. So, I have an increased risk for seizures depending on the right circumstances. The “perfect storm” of circumstances (loss of sleep with significant stress) has occurred twice and I had seizures. So, even though I have overcome my obstacles, my journey with epilepsy continues. Moreover, my personal journey and challenges gives me a deeper understanding about what people experience with epilepsy. With my journey, I also developed a strong desire to help others with epilepsy to accomplish their goals and overcome their obstacles.

Interest and Desire to Help Others Overcome Obstacles

Summer camp was the first turning point in my life to want to help others with epilepsy. I learned to listen to others’ problems and identified with their struggles. As a group, we were able to openly discuss the challenges of epilepsy, seizures, and medications. I improved and saw how my fellow peers improved with the camp counselors’ assistance. I also tried to encourage others during the camp experiences, and as a teenager, I became a camp assistant. Summer camp was an opportunity to empower children and increase their self-esteem and confidence. With this opportunity, I also obtained a strong desire to help my fellow peers.

Another turning point to assist others occurred when my mother became a board member at the Epilepsy Foundation of MS. She volunteered to create and promote fundraising events. My parents and I realized that the public needed increased education

about epilepsy and seizures. Through learning in our journey, we could help others. My mother scheduled for me to speak during news programs at local television stations and radio stations. I was able to talk about my experiences and encourage others who had epilepsy throughout my high school experiences. One of my greatest highlights was receiving the Heroes Among Us award by the Epilepsy Foundation of Mississippi for my volunteer work to assist others with epilepsy.

Then, after arriving as a college student at the University of Mississippi (UM), I continued to be interested in how I could assist others with epilepsy. I felt that college students also have challenges with epilepsy. They may choose not to tell other students about their issues for reasons similar to those I had experienced. They may feel isolated and that others do not understand. My personal journey with epilepsy, summer camps, and volunteer experiences only deepened my desire to help others with epilepsy. Therefore, as a college freshman, I sought a way to assist students on campus who have epilepsy.

CHAPTER THREE

In 2019, in my quest to find a way to assist college students with epilepsy, I discovered that out of 396 organizations on the UM campus, no epilepsy service club or organization existed. There was a clear need for an epilepsy service club to be created. Agarwal et al. (2013) reported lower retention and graduation rates from students with disabilities compared to students without disabilities due to social isolation, negative attitudes, and lack of social support, but encouraging social integration on campus was reported to have a positive effect. In addition, Morris (2016) indicated that students who participated in extracurricular activities and developed social interactions were more likely to stay in college due to building relationships and support from their peers. Furthermore, Soria and Thomas-Card (2014) reported that service-learning and community service participation increased self-confidence, a sense of belonging, greater awareness of cultures, and a feeling of responsibility to help others. Therefore, the goal to create an epilepsy-based service group on the UM campus began.

Beginning of Epilepsy-Based Service Group

First of all, an epilepsy-based service group at the UM began with the development of a constitution and an officer committee. The officer committee included five officers: President, Vice President, Treasurer, Secretary, and Marketing/Communications. Each officer had an independent responsibility in service to the organization. Secondly, the initial duties of the officer committee were to write the constitution, create a logo (Figure 1), and recruit up to ten additional members, as required by the UM Student Union. Finally, once the requirements were fulfilled, The



Figure 1: *The Epilepsy Connection Logo:* Figure 1 depicts the logo designed for the student service organization The Epilepsy Connection.

Epilepsy Connection (TEC) was officially enrolled as a Registered Student Organization (RSO) as of January 2020.

TEC Mission/Objectives

The purpose of The Epilepsy Connection (TEC) was to be an on-campus service club for students who would support individuals with epilepsy as well as provide education about epilepsy. It was an organization that promoted engagement with peers in a non-judgmental atmosphere where students with epilepsy or seizure disorders can be proactive about their conditions. TEC's objectives included developing and implementing social and community service activities to build a campus community that supported individuals with epilepsy, but members without epilepsy could also join as well as students with other disabilities. TEC was a link among students on campus with epilepsy or seizure disorders partnering with the student disability services office. Additional objectives were to increase student involvement involving the needs of students with epilepsy or seizures and develop fundraisers to reach goals to support those with epilepsy.

TEC's mission was also not to conflict with applicable local, state or federal laws, or the UM's policies and procedures. Hazing and harassment practices were prohibited.

Membership was open to all students at the UM and did not discriminate based on race, sex, handicap, age, sexual orientation, or political or religious affiliation. A goal of TEC was to maintain at least 15 enrolled UM students as members. All members of TEC had equal rights and privileges for membership and to hold an office and were expected to be in good standing with UM. Additional individuals on campus such as faculty, staff, administrators, and alumni were welcome to attend meetings, perform volunteer tasks, and participate in activities and events. A full-time UM staff advisor was responsible to cosign for TEC's bank account and sign checks as needed to assist with the financial management of the campus organization. The staff advisor was the main signatory on TEC's bank account since the elected treasurer changed each year.

Descriptions for elected officers were initially drafted and then voted on by members. Elected officers were to be strong examples of Ole Miss students to include having a passion and desire to serve students through TEC with an understanding of TEC's vision and purpose. Officers were required to have a minimum 3.0 cumulative grade point average at the time of application for a particular officer role and throughout their tenure in office. Each officer was expected to carry at least 12 credits for coursework each semester. In addition, the officers were required to attend all mandatory TEC meetings. No officer of TEC could hold more than one office at a time and the president of TEC could not hold a similar position in another organization on campus registered with the Office of Student Activities. TEC's Executive Board provided applications in March of each year to be used for interviews and elections for

new officers. The outgoing TEC President notified the Office of Student Activities about the results of the elections by May 1 via the on-line club officer registration form.

TEC Service Club History

Because TEC was officially accepted at the UM's Student Union in January 2020, it has remained in good standing with the University. TEC began with 15 members including the officers. Each year the organization had an annual growth of 15 to 20 members, and by January 2022, TEC had 55 members enrolled. Every semester included three social events and three member meetings. The social events included movie watch parties, ice cream socials, and board game nights. In addition, TEC held a fundraising event in the fall and an awareness event in the spring.

Since its founding, three fundraising and two awareness events have occurred. The focus of the fundraising events was to combine efforts from the UM community and the Oxford community while sharing a common goal of helping individuals with epilepsy. For example, "Craving for a Cause" (Figure 2) was a successful 2021 event where food vendors in Oxford came to the UM campus to share profits with TEC to help individuals with epilepsy. The awareness events also shared a similar goal of raising awareness of epilepsy and teaching the community how to respond to an individual having a seizure. During the height of the COVID-19 pandemic, TEC promoted all of their events online to encourage and maintain student support.



Figure 2: *Cravings for a Cause Event Poster:* Figure 2 depicts the poster created to represent the “Cravings for a Cause” event that took place in the fall of 2021.

TEC Service Club Accomplishments

Since their inception, TEC as a college student organization has been successful with their events. Additionally, TEC received the “Best New Student Organization of the Year in 2020” UM award for their efforts to help those struggling with epilepsy and create awareness for students with disabilities. In addition, TEC had the privilege of donating \$1000 from their fundraisers to a Mississippi-based nonprofit for children and adults with epilepsy.

During TEC’s history as a service club organization on UM campus, TEC received recognition as a student organization that welcomed students with epilepsy and worked to educate students, faculty, and administration about epilepsy as well as promote

awareness in the Oxford community. TEC had successful fundraising and awareness events. It was also able to carry out elections for officers and recruit new members. As a service organization, it had accomplished its mission and objectives. However, TEC service club outgrew the allocated funding on campus. So, in the spring of 2022, the decision was made that TEC would become independent of the UM's RSO network. This led to the evolution of a nonprofit that could potentially expand funding sources and resources for a continued presence on UM campus as well as service additional colleges in Mississippi and other Southern states.

CHAPTER FOUR

In December 2020, TEC was registered as a corporation through the Mississippi Secretary of State office with the hope to expand services one day outside of the University campus. However, the corporation remained inactive while TEC was a UM service club organization. After the decision was made for TEC to become independent in the spring of 2022, Logan Thomas applied and was granted nonprofit status by the Mississippi Secretary of State office. Thus, TEC, the nonprofit organization, was born.

Beginning as a Nonprofit

Initially, to start the nonprofit, a bank account was created for TEC at Origin Bank in Ridgeland with Logan Thomas, president, and Anna Katherine, treasurer, as signers to assist with the financial management of the nonprofit. A small amount was deposited from donations. Additional board members consisted of a vice-president and a secretary and board meetings were scheduled. Furthermore, TEC's mission and objectives were reviewed for the nonprofit organization to become effective.

TEC Nonprofit Mission/Objectives

As a nonprofit organization, TEC's mission is to support individuals with epilepsy in their communities and on college campuses in Mississippi as well as outside of Mississippi. An objective is to provide awareness and education about epilepsy. Also, TEC wants to promote engagement with peers so that students with epilepsy or seizures can be proactive about their conditions as well as build a social environment. Community service activities and fundraisers are also encouraged to help support the needs of

individuals with epilepsy. Because it is in its infancy, TEC plans to evaluate its objectives in 2023 to modify as needed.

TEC Nonprofit Awareness Accomplishment

TEC worked with an event in the fall of 2022 at the Oxford Pavilion to promote awareness and education for epilepsy. The ice skating event, “Oxford’s Holiday Festival,” was held for students and the residents of Oxford. TEC promoted college students to buy from food truck vendors at the event for two days. The food truck vendors agreed to donate profits from this event. It was a successful event to promote awareness for epilepsy. From this event and other donations, TEC plans to donate \$1000 to the Batson Children’s Hospital in Jackson by May 2023.

TEC Nonprofit Expansion of Services to College Students

In 2022, TEC continued to focus on college students on the UM campus. However, TEC’s mission is to service additional college campuses. In 2023, as president of TEC, I decided to perform an independent online search to see how prevalent epilepsy organizations were on Southern college campuses so that TEC, as a nonprofit, could potentially expand to provide services outside of Mississippi.

Online Search Methods and Results

The independent online search was performed to address the number of epilepsy-based service club organizations among universities that had 10,000 or more students enrolled in the Southern region of the United States. The search included private and public four-year universities in eleven Southern states: Texas, Louisiana, Mississippi, Alabama, Georgia, Florida, Tennessee, North Carolina, South Carolina, Oklahoma, and Arkansas. I looked at each of the universities’ websites to obtain information about their

service organizations. Out of 105 universities found in the eleven states, three universities were found to have an on-campus organization that supported students with epilepsy.

Discussion of Search Results

The search finding accounts for a 2.9% prevalence of epilepsy-based college service club organizations across eleven Southern States. Aside from the UM, two universities, the University of Central Florida, and the University of South Florida, were found online to have an epilepsy-based service club on their campuses. Except for the UM, no additional college in Mississippi promoted a service club organization on their website. Information is still pending regarding three universities due to a lack of access to student organization information.

I have not conducted any additional searches outside of the eleven states. Therefore, the prevalence of epilepsy college service club organizations nationwide is not known. However, with the identification of only three epilepsy service organizations out of 105 universities, this finding suggests that epilepsy service organizations are not common on college campuses at least in the eleven states that were included in the search. A future search in the Northeast region of the United States could be performed to compare the findings from this search in an attempt to identify the prevalence of epilepsy service organizations in a wider college population.

Future of the Nonprofit Services

TEC is still in its infancy and planning stages at this time for expansion of services outside of the Oxford community and UM campus. With the identification of nine states with no college epilepsy service organization, TEC can begin to identify additional objectives and plan to assist students from other colleges. Initially, TEC plans

to reach out to additional Mississippi colleges to plan promotions of awareness and education. The additional college sites will help TEC to evaluate effectiveness of services outside of the UM campus. This will require additional funding as well as volunteers at each of the college locations and in the communities. Additional sponsors will be solicited and partners will be identified in each of the communities where services are being provided.

Furthermore, TEC is still in the process of achieving 501(c) tax-exempt status from the Internal Revenue Service. With the approval of a 501(c) status, applications will be made to foundations for grants to help fund TEC services. Moreover, TEC has a grant writer on board to assist with grants and administration of grants. Identification of funding sources will not only apply to services for college students but TEC's mission will also include services to younger children and adults.

CONCLUSION

I have discussed epilepsy throughout this work to educate and share with the public so that they can better understand the biological context as well as short-and long-term consequences of epilepsy. With my discussion, I also shared my personal journey with epilepsy and how I overcame obstacles. In addition, my passion to educate the public and help others who suffer from epilepsy led me to create the first epilepsy service club, The Epilepsy Connection, on the UM campus. Due to the club's success on campus, I decided to expand to a nonprofit organization for epilepsy to assist college students from additional college campuses as well as help children and adults in the community.

This project challenged me to review my personal journey and fill in gaps of my past that I had no memory of due to seizures and effects from medications. As a child, I suffered with uncontrolled, drug resistant epilepsy and had unpredictable, daily seizures with urinary incontinence, which created many struggles. However, writing my personal journey gave me increased strength and confidence to show how far I have traveled to get to where I am today as a college student. Furthermore, my passion to help peers with epilepsy has continued during my college experience to provide a nonjudgmental environment where college students with epilepsy can engage socially.

I challenge you as a reader to continue to learn more about epilepsy and become epilepsy aware in our society. Seek out ways to volunteer and donate when you can to epilepsy organizations. Do your part to help end the social stigma attached to epilepsy. Lastly, do not define people as different just because they have epilepsy.

REFERENCES

Agarwal, N., Calvo, B. A., & Kumar, V. (2013). Paving the road to success: A students with disabilities organization in a university setting. University of Texas, El Paso College Student Journal, 34-44.

American Journal of Managed Care (2020). *Examining the economic impact and implications of epilepsy*. Managed Care & Healthcare Communications, LLC. <https://www.ajmc.com/view/examining-the-economic-impact-and-implications-of-epilepsy>

Amin, U. W., & Benbadis, S. R. (2017). *Neurostimulation in the treatment of epilepsy*. Epilepsy Foundation.

<https://www.epilepsy.com/stories/neurostimulation-treatment-epilepsy>

Austin, J. K., Birbeck, G., Parkso, K., Kwon, C. S., Fernandez, P. T., Braga, P., Fiest, K. M., Ali, A., Cross, J. H., de Boer, H., Dua, T., Haut., Jacoby, A., Lorenzetti, D. L., Mifsud, J., Moshe, S. L., Tripathi, M., Wiebe, S., & Jette, N. (2022). Epilepsy-related stigma and attitudes: Systematic review of screening instruments and interventions – Report by the International League Against Epilepsy Task Force on stigma in epilepsy. *Epilepsia*, 63(3), 598-628.

<https://doi.org/10.1111/epi.17133>

Centers for Disease Control and Prevention (2020). *Types of seizures*.

<https://www.cdc.gov/epilepsy/about/types-of-seizures.htm>

England, M. J., Liverman, C. T., Schultz, A. M., & Strawbridge, L. M. (2012). Epilepsy across the spectrum: promoting health and understanding. A summary of the Institute of Medicine report. *Epilepsy & Behavior*, 25(2), 266–276.

Epilepsy Foundation (2020). *Living with epilepsy*.

<https://www.epilepsy.com/living-epilepsy>

Epilepsy Foundation (2022). *Epilepsy: Impact on the life of the child*

<https://www.epilepsy.com/stories/epilepsy-impact-life-child>

Hingray, C., McGonigal, A., Kotwas, I., & Micoulaud-Franchi, J-A. (2019). The relationship between epilepsy and anxiety disorders. *Current Psychiatry Reports*, 21(40). <https://doi.org/10.1007/s11920-019-1029-9>

Janson, M. T., & Bainbridge, J. L. (2020). Continuing burden of refractory epilepsy.

Annals of Pharmacotherapy, 55(3), 406-408.

<https://doi.org/10.1177/1060028020948056>

Kobau, R., Cui, W., Kadima, N., Zack, M. M., Sajatovic, M., Kaiboriboon, K., & Jobst, B. (2014). Tracking psychosocial health in adults with epilepsy-Estimates from the 2010 National Health Interview Survey. *Epilepsy & Behavior* 41, 66–73.

<https://doi.org/10.1016/j.yebeh.2014.08.002>

Kossoff, E. (2017). *Ketogenic diet*. Epilepsy Foundation.

[https://www.epilepsy.com/treatment/dietary-therapies/ketogenic-diet - What-is-the-ketogenic-diet?](https://www.epilepsy.com/treatment/dietary-therapies/ketogenic-diet-What-is-the-ketogenic-diet?)

Kwon, O.Y., & Park, S. P. (2014). Depression and anxiety in people with epilepsy. *Journal of Clinical Neurology*, 10(3), 175-188.

<https://doi.org/10.3988/jcn.2014.10.3.175>

Morris, D. (2016). Extracurricular activity participation in high school: Mechanisms linking participation to math achievement and 4-year college attendance. *American Educational Research Journal*, 53(5), 1376-1410.

<https://doi.org/10.3102/0002831216667579>

Mula, M. & Sander, J. (2013). Suicide risk in people with epilepsy taking antiepileptic Drugs. *Bipolar Disorders*, 15(5), 622-627.

<https://doi.org/10.1111/bdi.12091>

Rheims, S. & Auvin, S. (2021). Attention deficit/hyperactivity disorder and epilepsy. *Current Opinion in Neurology*, 34(2), 219-225.

<https://doi.org/10.1097/WCO.0000000000000903>

Schachter, S. C. (2022). *What happens during a seizure?* Epilepsy Foundation.

<https://www.epilepsy.com/what-is-epilepsy/understanding-seizures/what-happens->

[during-seizure](https://www.epilepsy.com/what-is-epilepsy/understanding-seizures/what-happens-during-seizure)

Shafer, P. O. (2014). *Employment rights for people with epilepsy- What's new?*

Epilepsy Foundation. [https://www.epilepsy.com/stories/employment-rights-](https://www.epilepsy.com/stories/employment-rights-people-epilepsy-whats-new-~:text=Finding and keeping a job,studies, up to)

[people-epilepsy-whats-new - ~:text=Finding and keeping a job,studies, up to](https://www.epilepsy.com/stories/employment-rights-people-epilepsy-whats-new-~:text=Finding and keeping a job,studies, up to)

[50%25!](https://www.epilepsy.com/stories/employment-rights-people-epilepsy-whats-new-~:text=Finding and keeping a job,studies, up to)

Shafer, P. O., & Vosburgh, S. (2018). *Depression*. Epilepsy Foundation.

