

NEED ASSESSMENT AND IMPLEMENTATION OF DIGITAL STORYTELLING TO
OFFER VARIOUS FORMS OF SUPPORT FOR SUFFERERS OF AND AWARENESS
FOR SYSTEMIC EXERTION INTOLERANCE DISEASE, OR S.E.I.D., FORMERLY KNOWN
AS CHRONIC FATIGUE SYNDROME, OR C.F.S.

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Accompanying Research of Creative Project

Telecommunications: Digital Storytelling

Submitted by David R. Smith

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Running head: DIGITAL STORYTELLING FOR SYSTEMIC EXERTION INTOLERANCE
DISEASE (SEID)

Need Assessment and Implementation of Digital Storytelling to Offer Various Forms of Support
for Sufferers of and Awareness for Systemic Exertion Intolerance Disease, or SEID, Formerly
Known as Chronic Fatigue Syndrome, or CFS.

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Abstract

Project explores need assessment and implementation of knowledge base platform to offer a
wide range of resources and support for those afflicted by what was, in spring 2015, renamed
Systematic Exertion Intolerance Disease (SEID), formerly known as Chronic Fatigue Syndrome

(CFS) and Myalgic Encephalomyelitis (ME)—a condition from which this researcher has personally suffered for many years as do millions worldwide. Shockingly, no single website currently offers a well-rounded database of personal narratives, medical research, or accessible resources for practical help, presented in such a way with the SEID sufferer as the target audience—something this researcher had been looking for early on in his medical journey.

Project analyzes secondary research—published literature on internet technology use and communications preferences of those living with chronic illness or disease—to ultimately determine which platform of digital storytelling (website, video, commercial, social media, etc.) is most effective in achieving desired awareness of and support for the disease, while specifically accommodating those with the disease. Project concludes with launch of fully functional multimedia platform deemed most effective medium for achieving these desired goals.

Project contains compilation and annotation of research—a cohesive narrative based on research through assessment of scholarly databases and study of both peer-reviewed journal articles and popular/non-peer-reviewed sources—in addition to launch of actual knowledge base platform itself.

Keywords: systemic exertion intolerance disease, SEID, chronic fatigue syndrome, CFS, myalgic encephalomyelitis, ME, digital storytelling, coping with chronic illness / disease, Internet technologies, mobile technology, communication preferences, medical support group

INTRODUCTION

What is Systematic Exertion Intolerance Disease (SEID)?

Systematic Exertion Intolerance Disease (SEID), as it was recently renamed in the spring of 2015, is a debilitating and often disabling chronic disease affecting multiple systems of the body. It is characterized by profound fatigue, cognitive impairment, pain, un-refreshing sleep and other symptoms that are made worse by exertion and do not improve with rest. Symptom flare-up follows physical and cognitive exertion, hence the name Systemic Exertion Intolerance Disease.

"In my experience, [SEID/ME/CFS] is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages." -Dr. Daniel Peterson, described as a "pioneer" in the treatment of SEID/CFS/ME

There are a number of different names for this disease. In the United States, it is referred to as Chronic Fatigue Syndrome or "CFS" since a hallmark feature of the disease is an inability to produce sufficient energy to meet daily demands, Post-Viral Fatigue Syndrome or "PVFS" since it often follows a severe viral or bacterial infection, and Chronic Fatigue Immune Dysfunction Syndrome or "CFIDS" since it is believed to be caused by an impaired immune system. In Europe, it is referred to as Myalgic Encephalomyelitis or "ME," with myalgia referring to "muscle pain" and encephalitic referring to "inflammation of the brain." Regardless of which name used, it is sometimes paired or partnered with Fibromyalgia.

Symptoms

According to the Centers for Disease Control and Prevention (CDC), the fatigue of SEID is accompanied by characteristic symptoms lasting more than 6 months. These symptoms include:

- Increased malaise (extreme exhaustion and sickness) following physical activity or mental exertion
- Problems with sleep
- Difficulties with memory and concentration
- Persistent muscle pain
- Joint pain (without redness or swelling)
- Headache
- Tender lymph nodes in the neck or armpit
- Sore throat

The symptoms listed above are the symptoms used to diagnose SEID. However, many SEID patients experience other symptoms, including:

- Brain fog (feeling like you're in a mental fog)
- Difficulty maintaining an upright position, dizziness, balance problems or fainting
- Allergies or sensitivities to foods, odors, chemicals, medications, or noise
- Irritable bowel
- Chills and night sweats
- Visual disturbances (sensitivity to light, blurring, eye pain)
- Depression or mood problems (irritability, mood swings, anxiety, panic attacks) (Centers for Disease Control and Prevention)

According to the National Organization for Rare Disorders (NORD), additional symptoms that may occur include headaches, muscle weakness, neck pain, a sensation of tingling, and burning

or numbness of the extremities (paresthesia), and cardiovascular abnormalities (National Organization for Rare Disorders).

A characteristic or hallmark symptom of [SEID] is marked fatigue, sickness, and symptom flare-up that follows physical and cognitive exertion (known as post-exertional neuroimmune exhaustion or post-exertional malaise). Normal activities of daily living can cause severe physical or cognitive fatigue, which can last for days, weeks, or even months. A 24-hour delay in the onset of post-exertion is fairly common. Affected individuals develop a lack of stamina that causes a considerable reduction in activity level. Even mild exertion through normal, daily activities is typically associated with worsening of other symptoms (National Organization for Rare Disorders).

Causes

While there is no official known cause of SEID, there are many theories, including: viral or bacterial infections; immune disorders; stress; trauma such as an operation or accident; chemical exposure; toxins; or a combination of these.

Many cases, including my own, were preceded by a viral infection, usually a flu-like or upper respiratory illness. In my case, it was flu-like in

"It is an acquired immune deficiency, beyond a shadow of a doubt."

-Dr. Judy Mikovitz, researcher

nature. This onset is usually rapid (acute), but gradual onsets are also reported. Affected individuals may have an infectious disease with an incubation period of approximately four to seven days; and these individuals do not recover from the initial infection, but instead progress to the second phase known as the chronic phase (National Organization for Rare Disorders).

This second phase usually occurs two to seven days after the initial infection and is characterized by measurable widespread (diffuse) changes in the central nervous system, which are thought to be the result of an infection invading the nervous system (encephalitis), or the immune system attacking the brain (autoimmune encephalitis). A number of recent studies demonstrate that this process is a result of brain inflammation, which damages or destroys the nerve cells and/or the support tissue in the brain. Brain inflammation is encephalitis, so [SEID] does appear to be a form of encephalitis (National Organization for Rare Disorders).

Controversy and Debate Over the Name

Understanding the above theorized causes of SEID are critical to understanding the controversy and debate to the various names given to the disease.

The first outbreak of Myalgic Encephalomyelitis was in 1934 and the term Myalgic Encephalomyelitis first appeared in the medical literature in 1956. Myalgic Encephalomyelitis is recognized and has been classified as a specific neurological disorder by the World Health Organization (WHO) since 1969. The criteria for classification focuses on the encephalitic (inflammation of the brain) features of the disorder. Since it is theorized that an infection (viral or bacterial) is invading the nervous system and brain (encephalitis) and a major symptom is muscle pain (myalgia), one can see the genesis of the name: Myalgic Encephalomyelitis, meaning “brain and spinal cord inflammation with muscle pain” (National Organization for Rare Disorders).

The term CFS was first used in the medical literature during the 1980s in the United States. The criteria focused more on fatigue than the encephalitic (inflammation of the brain) features of the disorder. This was unfortunate, since there is more than sufficient robust evidence, which illustrates the underlying biological process involving the central nervous system, immune system, energy metabolism and stress system. Consequently, the emphasis on fatigue unfortunately led to defining the disorder being seen as a psychiatric illness. Because little was known about the cause or physiology of CFS, a wide range of patients were diagnosed with CFS even though they may have had a variety of conditions and experienced different symptoms. CFS eventually evolved into a larger disease designation that overlapped with myalgic encephalomyelitis. Consequently, some researchers, patients, government organizations, and other organizations began to use the terms interchangeably or with the combined acronym ME/CFS, creating a broad disease category (National Organization for Rare Disorders).

To further complicate matters, the disease is sometimes referred to as Post-Viral Fatigue Syndrome or (PVFS), because it is believed the illness is caused by a persistent viral infection such as cytomegalovirus (CMV/HHV-5), Epstein Barr virus (EBV/HH-4), parvovirus B19, herpes simplex virus (HHV-1 or HHV-2), human herpes virus (HHV 6 or 7), and certain bacterial infections. It is not known whether these viruses caused ME, or whether they developed due to an impaired immune system. And since the immune system could be the culprit, the disease is sometimes referred to as Chronic Fatigue Immune Dysfunction Syndrome or (CFIDS).

And lastly, on February 10, 2015:

The Department of Health and Human Services (HHS), the National Institutes of Health, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Food and Drug Administration, and the Social Security Administration asked the Institute of Medicine (IOM) to convene an expert committee to examine the evidence base for ME/CFS. In [the report], *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, the committee proposed new diagnostic criteria that will facilitate timely diagnosis and care and enhance understanding among health care providers and the public (National Academics of Sciences, Engineering, and Medicine).

The Institute of Medicine's expert committee also recommended that the illness be renamed Systemic Exertion Intolerance Disease, to reflect what patients, clinicians, and researchers all agree is a core symptom: a sustained depletion of energy after minimal activity, post-exertional malaise, and the fact that symptoms flare-up following physical and cognitive exertion. My doctor, Dr. Lerner, was a member of this committee.

For the sake of my research and throughout this paper, I will use the combined acronym of SEID/CFS/ME and, for research purposes, present these *diseases* as the same illness.

Diagnosis

Currently, there are no biomarkers for SEID/CFS/ME - no blood tests, brain scan, or lab tests. A SEID/CFS/ME diagnosis requires that a patient have 4 of the 8 symptoms listed above for 6 months or more.

Impact & Affected Populations

SEID/CFS/ME has a major impact on society because, according to the CDC, SEID/CFS/ME affects over 1 million Americans, which is more people in the United States than multiple sclerosis, lupus, and many of forms of cancer (Centers for Disease Control and Prevention). According to the ME Association of the United Kingdom, it is currently estimated that some 250,000 people in Britain are affected by the illness (ME Association). And, finally, according to The National Alliance for Myalgic Encephalomyelitis, it is estimated to affect 17 million worldwide (National Alliance for Myalgic Encephalomyelitis).

In some, the effects may be minimal, but in a large number, lives are changed drastically: in the young, schooling and higher education can be severely disrupted; in the working population, employment becomes impossible for many. For all, social life and family life become restricted and, in some cases, severely strained. People may be housebound or confined to bed for months or years (ME Association).

"...inflammation occurs in the brain and ... patients with this illness experience a level of disability that's equal to that of patients with late-stage AIDS, patients undergoing chemotherapy, or patients with multiple sclerosis."

-Dr. Nancy Klimas, Director of the Institute for Neuro Immune Medicine

CDC studies show that SEID/CFS/ME can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, chronic obstructive pulmonary disease (COPD), and similar chronic conditions (Centers for Disease Control and Prevention).

Treatment

There is currently no accepted cure and no universally effective treatment for SEID/CFS/ME.

Those treatments that have helped reduce particular symptoms in some have unfortunately proved ineffective or even counterproductive in others. What we do know, is that an early diagnosis, together with adequate rest, during the acute phase, or during any relapse, appear to bring the most significant improvement (ME Association).

Treatments include:

- Antiviral Therapy
- Immune System Modulation Inhibitors
- Anti-Inflammatory Medication
- A combination of Antiviral, Immune, and Anti-Inflammatory Medications
- Acupressure, Massage, and Bodywork (often classified under “Alternative” or “Holistic Treatments.”)
- Mind-Body Programs that "Retrain the Brain."

Managing [SEID/CFS/ME] can be as complex as the illness itself. There is no cure, no prescription drugs have been developed specifically for [SEID/CFS/ME], and symptoms can vary a lot over time. – Center for Disease Control and Prevention

Each of these treatments will be explained in further detail in the knowledge base platform.

Prognosis

According to the ME Association, most people with SEID/ME/CFS fall into one of four groups:

1. Those who manage to return to completely normal health, even though this may take a considerable period of time. The percentage falling into this category is fairly small.

2. The majority, who tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or exacerbations are often precipitated by infections, operations, temperature extremes or stressful events. **"We consider [SEID/CFS/ME] to be in the category of serious or life threatening diseases." –U.S. FDA**
3. A significant minority, who remain severely affected and may require a great deal of practical and social support.
4. A few, who show continued deterioration, which is unusual in SEID/ME/CFS. When this occurs, a detailed medical assessment is advisable to rule out other possible diagnoses (ME Association).

According to the CDC:

The severity of [SEID/CFS/ME] varies from patient to patient. Some people can maintain fairly active lives. For most patients, however, [SEID/CFS/ME] significantly limits their work, school, and family activities for periods of time.

While symptoms vary from person to person in number, type, and severity, all [SEID/CFS/ME] patients are limited in what they can do to some degree. CDC studies show that [SEID/CFS/ME] can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, chronic obstructive pulmonary disease (COPD), and similar chronic conditions.

[SEID/CFS/ME] often affects patients in cycles: patients will have periods of illness followed by periods of relative well-being. For some patients, symptoms may diminish or even go into complete remission; however, they often recur at a later point in time. This

pattern of remission and relapse makes [SEID/CFS/ME] especially hard for patients to manage. Patients who are in remission may be tempted to overdo activities when they're feeling better, but this overexertion may actually contribute to a relapse.

The percentage of CFS patients who recover is unknown, but there is some evidence to indicate that patients benefit when accompanying conditions are identified and treated and when symptoms are managed. High-quality health care is important (Centers for Disease Control and Prevention).

About the Researcher

My Story

I was born and raised in the Midwest, in Indiana; but spent a significant amount of time in Tennessee, where my family has a second home. Driving back and forth gave me zest for life, traveling, people, and cultures, and a love for nature and the outdoors. I have always considered myself a Type A, driven personality, and have always enjoyed life “on the go.” I excelled in school, graduating valedictorian of my class, and received a full-ride academic scholarship upon completing high school. While life was always hectic, but I seemed to thrive on stress.

My journey with SEID/CFS/ME began in 2003, at the age of 20, as I was finishing up my sophomore year of undergraduate studies at Indiana University. With semester-long projects submitted, I had just a few days to prepare for my final exams. It had been a long semester of late nights, poor nutrition, limited sleep, and intense stress. What I thought was food

Among those afflicted by SEID are Laura Hillenbrand, Best-Selling Author of *Unbroken* and *Seabiscuit*. Her journey also began with an onset she describes in her memoir titled, “A Sudden Illness.”

poisoning from a late night pizza delivery while studying, turned out to be the most severe flu-like illness I had ever experienced. So severe, that it required a two-day hospitalization due to severe dehydration and dangerously low vitals. Following my hospitalization, I vividly remember lying in bed, feeling as if my head were going to explode! I remember telling my mother that it felt like my “brain was going to pop through my skull.” It was so severe, that I specifically remember imagining the relief it might bring if I were somehow, someway, safely able to drill a hole in my head to give the pressure a means of escape. I remember tossing and turning in bed in miserable agony for 24 hours from this cranial pressure, while my body felt it was enduring the worst flu possible.

I remained at home that summer, but the fatigue from that "flu" seemed to persist and linger over my traditional summer activities of intense traveling and hard work. By fall, returning to college seemed impossible. I took the fall semester off, but spent the majority of that time in bed, sleeping 15-20 hours a day.

My family suspected I was suffering from severe depression, so they encouraged me to stay as busy and active as possible. I transferred to a small, private University close to home, where I would go on to finish my undergraduate degree. During those two and a half years, I was very active socially, but academically, I struggled to maintain the grades I had always historically earned. I also struggled with energy, but attributed that to being in my 20s and no longer a teenager.

Immediately after college, in 2006, I opened my own business while working a physically intense part-time job. While strong each morning, I quickly and easily tired as the day progressed. Soon, waking up each morning, I began to feel as though I had inherited "energy

deficits" from the previous day despite having slept 8 hours the night before. I noticed soreness and achiness in my muscles, but attributed this to my physically intense part-time job. In addition to a business and part-time job, I was also dealing with major stress from a family crisis and a toxic relationship.

By 2008, I had left my job, closed my business, and decided to further my education with a master's degree in the Ball State University Telecommunications Digital Storytelling Program. As always, I hit the ground running, but soon felt like I was "running on fumes." Midway through grad school, my symptoms became so severe, that it felt reminiscent of that summer and fall following my hospitalization in 2003. In addition to the flu-like ache in my muscles, pain in my bones and joints, un-refreshing sleep, and excruciating fatigue that would not improve with rest, I begin to notice devastating brain fog and cognitive impairment that had an embarrassing affect on my abilities as a student. In the morning, I taught three classes as a teaching assistant, and did so with flying colors—receiving very high reviews from my students at semester's end—but after lunch, I felt crippling intolerance to any form of physical or mental exertion. Always passionate about school, I struggled to stay awake and focus in my afternoon classes.

In the fall of 2010, after two years of graduate school, I was diagnosed with Chronic Fatigue Syndrome. While receiving an actual diagnosis was a relief, it seemed to create more questions than answers. At that time, the medical community was just transitioning SEID/CFS/ME from a psychosomatic disorder to a physical disease. Despite these advances, I was told there was no cure, no treatment, and no known cause. I felt alone, discouraged, and terrified.

While I had started a thesis for my graduate program, I made the painful decision to walk away from school and spent the next four years on medical odyssey--traveling, researching, and

working with anyone who might help with my condition. I spent one year under the care of a treatment facility in Ohio that specialized in SEID/CFS/ME. My improvement was minimal, so I then worked with doctors in California, Texas, and Florida; experimenting with numerous vitamins, supplements, and nutritional regimens. Before long, my bedroom began to look like a pharmacy and medical library. Nothing seemed to help my condition, and my world seemed to pile up around me. While the rest of the world was moving forward, I felt trapped within the overwhelming confinements of my increasing mental and emotional “fog.” I was in a state of total despair.

In the fall of 2014, I read of an 85-year-old researcher and medical doctor by the name of Dr. A. Martin Lerner. Once having SEID/CFS/ME himself, Dr. Lerner had recovered and devoted his career to researching the disease. Specializing in infectious diseases, Dr. Lerner theorized that SEID/CFS/ME was the result of a persistent viral infection. His blood work concluded that I, indeed, had a chronic level of the human herpesvirus 6 (HHV-6). Dr. Lerner explained that this was a common virus, affecting upwards of 80% of the population and that I had mostly acquired the virus before the age of two- possibly through saliva by someone kissing me as a baby. As a healthy youth and adolescent, my healthy immune system kept the virus at bay, so the virus lay dormant in my body--similar to how the chicken pox virus remains dormant with a healthy immune system. When I became ill at IU in 2003, my immune system was compromised and that dormant virus reactivated, much like the dormant chicken pox virus can reactivate into shingles later in life. My story now coincides almost perfectly with the theory set forth not only by Dr. Lerner, but by the National Organization for Rare Disorders (NORD) mentioned in the previous “Causes” section:

This second phase [for me, returning home from the hospital in 2003] usually occurs two to seven days after the initial infection and is characterized by measurable widespread (diffuse) changes in the central nervous system, which are thought to be the result of an infection invading the nervous system (encephalitis), or the immune system attacking the brain (autoimmune encephalitis). A number of recent studies demonstrate that this process is a result of brain inflammation, which damages or destroys the nerve cells and/or the support tissue in the brain. Brain inflammation is encephalitis, so [SEID/ME/CFS] does appear to be a form of encephalitis (NORD).

Perhaps this explains the feeling of my “brain wanting to pop out of my skull.”

This viral theory reinforces why the disease is sometimes referred to as Post-Viral Fatigue Syndrome or (PVFS), because it believed the illness is caused by a persistent viral infection such as cytomegalovirus (CMV/HHV-5), Epstein Barr virus (EBV/HH-4), parvovirus B19, herpes simplex virus (HHV-1 or HHV-2), human herpes virus (HHV 6 or 7), and certain bacterial infections. However, it is not known whether these viruses caused SEID or whether they developed due to an impaired immune system in affected individuals (NORD).

Because the virus manifests itself in the neurological tissue of the brain and central nervous system, perhaps this is why the symptomology mimics that of a neuro-autoimmune disease. Perhaps this explains why the symptomology of SEID/CFS/ME is similar to those seen in multiple sclerosis, lupus, Lyme disease, narcolepsy, mononucleosis, multiple chemical sensitivities, Gulf Ware Syndrome, and chronic Epstein Barr infection.

As a sufferer, I, personally, prefer to refer to the first few months following the initial infection of the infectious agent as “Post Viral Fatigue Syndrome.” This time is very critical, and should

be deemed a “medical emergency.” It was during this time that, if not in bed, I was still pushing myself too hard. Had my doctors given me a proper diagnosis, I could have rested during this time, and, based on the stories of others, potentially made a full recovery. After reading *numerous* personally stories on those affected by SEID/CFS/ME, which suggest that after the first 3-6 months after the initial infection, the infected body passes the critical time of potential healing, and the body enters full-blown SEID/CFS/ME. I call it the “point of no return.”

Those who do make full recoveries, including Ryan Prior- the director, Co-writer and producer of the 2015 documentary on SEID/CFS/ME, *Forgotten Plague*- seem to have been properly treated during this critical interval. The ME Association seems to understand this as well, stating:

What we do now, is that an early diagnosis together with adequate rest during the acute phase, or during any relapse, appear to bring the most significant improvement (ME Association).

This is why high-quality health care and early detection are so important!

As the National Organization for Rare Disorders previously pointed out, the infectious agent triggers brain inflammation, which damages or destroys the nerve cells and/or the support tissue in the brain. Perhaps this *damage* is what makes a “cure” so difficult.

My Treatment

In May 2010, Dr. Lerner published a study titled “Subset-Directed Antiviral Treatment of 142 Herpesvirus Patients with Chronic Fatigue Syndrome,” which tested the effectiveness of Dr. Lerner’s antiviral treatment protocol.

A summary of this study is provided in the following official release abstract:

Purpose: We hypothesized that chronic fatigue syndrome (CFS) may be caused by single or multiple Epstein–Barr virus (EBV), cytomegalovirus (HCMV), or human herpesvirus 6 (HHV6) infection. To determine if CFS life-altering fatigue and associated findings including muscle aches, tachycardia at rest, chest aches, left ventricular dysfunction, syncope, and elevated herpesvirus serum antibody titers are reversed by long-term subset-directed valacyclovir and/or valganciclovir.

Patients and methods: Data were collected at physician visits every 4–6 weeks from 142 CFS patients at one clinic from 2001 to 2007. To be included in this study, patients had to be followed for at least six months. The data captured included over 7000 patient visits and over 35,000 fields of information. Severity of fatigue was monitored by a validated Energy Index Point Score® (EIPS®). Baseline and follow-up serum antibody titers to EBV, HCMV, and HHV6, as well as coinfections with *Borrelia burgdorferi*, *Anaplasma phagocytophila*, *Babesia microti*, and antistreptolysin O, 24-hour ECG Holter monitors, 2D echocardiograms, cardiac dynamic studies, symptoms, and toxicity were captured and monitored. International criteria for CFS plus a specifically designed CFS diagnostic panel were used.

Results and conclusions: The Group A herpesvirus CFS patients (no coinfections) returned to a near-normal to normal life ($P = 0.0001$). The long-term EIPS value

increased (primary endpoint, $P < 0.0001$) with subset-directed long-term valacyclovir and/or valganciclovir therapy. Secondary endpoints (cardiac, immunologic, and neurocognitive abnormalities) improved or disappeared. Group B CFS patients (herpesvirus plus coinfections) continued to have CFS (Lerner, Beqaj, Fitzgerald, Gill, Gill, & Edington, 2010).

Dr. Lerner's complete study is available in Appendix 1.

In November 2014, I began Dr. Lerner's treatment protocol in the form of biweekly intravenous infusions of a powerful antiviral drug. Mondays consisted of blood work in my hometown of Muncie, Indiana. On Tuesday, the blood work was sent electronically to Dr. Lerner while I was driven four hours north to a suburb of Detroit, Michigan. Wednesday morning, I checked in to the Beaumont Hospital of Royal Oak Infusion Center, where I was administered the 6-hour infusion. Thursday morning, I would see Dr. Lerner at his Beverly Hills, Michigan clinic, where I would receive additional blood work to ensure treatment safety. Initially, Dr. Lerner ordered 6 infusions (3 months of treatment), but because of my high viral levels, ordered 4 additional infusions for a total of 5 months in treatment. The 5 months of treatment were an extremely exhausting cycle of road trips, needles, tests, and insurance claims. Dr. Lerner insisted that I would "feel worse, before I would feel better" and I trusted his expertise. He was right, but I remained strong.

Following the treatment, I had 3 follow-up visits with Dr. Lerner, in which he helped me transfer supervision of my case to my local Primary Care Provider. Dr. Lerner also graduated me to antiviral pills, to take indefinitely, as a preventative to keep the virus from returning and to allow my body and immune system time to heal.

Dr. Lerner passed away October 5, 2015, at the age of 86. Sadly, his clinic was closed and the building was sold. Dr. Lerner's contributions to the SEID/CFS/ME community are detailed greatly in his obituary:

Dr. A. Martin Lerner attended Washington University at age 16. Upon completing medical school and his internship, Dr. Lerner worked at the National Institute of Health in the Lab of Infectious Diseases researching epidemiology, influenza, immunity, and viral tissue work where he published the first of several papers in leading medical journals. Following his years of residency at Barnes Hospital and Boston City Hospital, Dr. Lerner attended Harvard University as a National Institute of Health Fellow in Infectious Diseases. He then attended M.I.T as a Fellow in Molecular Biology. Dr. Lerner's innovative and landmark research led him to publish more than 28 papers by the time he left Boston.

Arriving in Detroit in 1963 as the Head of Infectious Diseases at Wayne State University and Detroit Receiving Hospital, Dr. Lerner led training programs and laboratories for virus studies. He published several ground-breaking papers on Herpes Encephalitics, pneumonia, cardiomyopathy, and immunology. Dr. Lerner's brilliance in research and medicine has been recognized by many, including the Royal Northern Hospital in London, England; as a recipient of the Fifth Annual Award for Academic Achievement by the Probus Club of Detroit; as a recipient of the Phi Lambda Medical Fraternity, Omicron Chapter, for Outstanding Contribution to Research, Teaching and Academic Medicine; the State of Israel's Maimonides Award; as Governor of the American College of Physicians, Michigan Chapter; recipient of the Alumni Achievement Award from Washington State University School of Medicine; recipient of the Laureate Award from

the American College of Physicians; recipient of the Heart Award by Mothers Against Myalgic Encephalomyelitis (The Ira Kaufman Chapel, 2015).

Giving Back and Moving Forward

As of October 2016, when I wrote this research paper, I am one year and six months out of treatment. Dr. Lerner advised that I would “feel worse before I felt better” during treatment, and that I probably would not see many results until at least one year after treatments. Following the ME Association’s previously mentioned criteria, I would now classify myself into the second category of prognosis:

The majority, who tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or exacerbations are often precipitated by infections, operations, temperature extremes or stressful events (ME Association).

I experienced such a relapse this past January, when we experienced bitterly cold weather in combination with a personal stressful event. I am currently six months out of my one-year recovery trial, and just now regaining enough energy, clarity, and focus to return to complete my master’s degree, as the Ball State University Telecommunications Department and Graduate School were very gracious in allowing me to return. While I had originally intended to write a thesis, SEID/CFS/ME happened, circumstances changed, and what better way to prove my “Digital Storytelling” skills than to share my journey with SEID/CFS/ME as a final project.

As someone who has experienced the disease first hand, I feel my voice is unique and powerful, because I understand just how overwhelming it can be to manage life with this illness. On my

health journey over the last 6 years, I have met with numerous professionals, physicians, and specialists, as well as other sufferers, their families, and others dealing with chronic disease—giving me a unique story to tell.

My distinctive strategies to tell my story originate from a course I took in my undergraduate studies, just prior to becoming ill, titled “Medicine, Magic, & Mortality,” that focused on narratives of the dying and/or those living with life altering illnesses. Primarily geared toward nursing and medical students, the course helped me better understand what it is like to suffer from a chronic illness by hearing others’ stories—both in person and through reading autobiographies. By connecting with others through their storytelling, I gained a greater appreciation of life and a deeper understanding of the human spirit with regard to suffering, healing, living, and dying. In this class, we discussed how people often use storytelling as a coping device in the form of art, music, interpretive dance, writing, and personal reflection. These diverse methods of storytelling enable the storyteller to connect with his or her audience on a significantly deeper emotional and spiritual level. It is no surprise that this particular course sparked my initial interest as a storyteller and would later inspire me to become a “digital storyteller” through graduate school. And what better platform to tell my story, than through the SOLID storytelling skills I have now acquired through Ball State’s Telecommunications Digital Storytelling Program.

Why I am Passionate about this Cause

While we are still uncertain of what causes SEID/CFS/ME, there is no cure, and we are still determining an effective treatment; as mentioned earlier, we do know this:

An early diagnosis, together with adequate rest, during the acute phase, or during any relapse, appear to bring the most significant improvement (ME Association).

To quote the blog of a devoted mother whose combat veteran son fell ill with SEID/CFS/ME:

If I only knew 10 years ago what I know today, so many lives would be changed and more might be saved.

The shock and awe of watching somebody you love get eaten up by a mystery illness is overwhelming and frightening (Rachel, 2012).

As a sufferer myself, I know the loss and devastation I have faced as a result of this disease. I cannot help but ponder what my life might be like today, if I had known more about this illness early on, and how to properly react in those critical first stages. While I cannot change my past, I am hoping I might “pay it forward” and save someone else by changing his or her future for the better. To quote a line from one of my favorite stories, *The Starfish Story*, adapted from the poem *The Star Thrower*, by Loren Eiseley: “It made a difference to that one!”

PROJECTED STATEMENT OF OBJECTIVE:

I would like to create a knowledge base platform, unlike any others currently available, richly employing digital storytelling to offer a wide range of resources and support for those afflicted by what was recently renamed Systemic Exertion Intolerance Disease (SEID), and commonly known as Chronic Fatigue Syndrome (CFS).

Projected Objectives to Define my Creative Project:

1. Implementation of a knowledge base platform employing digital storytelling to offer a wide range of resources and support for those afflicted by SEID/CFS/ME.
2. Scholarly research on SEID/CFS/ME summarized for the average reader is crucial because many sufferers do not have access to this crucial information given their condition.
3. Providing general/broad information on SEID/CFS/ME based on the most current medical conversation. There is a lot information out there, and with so many advancements in the past 2 years—some of it is useful, but much of it is outdated or inaccurate.
4. A unified knowledge base that will save time for people who do not have the mental energy to do their own research or present their case to non-believing, non-supportive family members.
5. Major advancements have been made VERY RECENTLY that need better coverage and exposure: including the protocol used to treat me and even a NEW treatment protocol. Also, with the unexpected passing of my doctor on October 5, 2015, I feel the need to raise awareness of his research.
6. I will be compiling research, annotating this research, and creating a cohesive narrative based on the research by accessing scholarly databases and studying peer-reviewed journal articles, in addition to popular or non-peer-reviewed sources. An annotated bibliography of scholarly sources would be useful to the average SEID-afflicted person or friend/family member, because many sufferers do not have access to these peer-reviewed journals – reinforcing my case for a need for this project. Also, by working with my late

doctor, A. Martin Lerner, I have been made aware of a lot of current medical research, some of which has not been widely published yet.

Perceived Need Prior to Research:

Shockingly, no single website currently offers a well-rounded database of personal stories, medical research, or accessible resources for practical help, **with the SEID sufferer in mind**—something I had been looking for early on in my CFS journey, and is something I hope I can provide now.

Aside from the illness itself and the lack of information on research and possible treatments, my most difficult challenge was validating my illness to those closest to me. With it being an invisible illness, it often required faith to believe. I feel the pinnacle of my knowledge base would be using diverse mediums of digital storytelling to equip SEID/CFS/ME sufferers with tools to educate their families on the illness and provide these families with the information they need to become a stronger support network for their ailing family members. This would fulfill a gap in SEID/CFS/ME resources that is previously unexplored.

- **Videos**
- **Photos**
- **Personal stories**
- **Printable Brochureware**

Careful attention will be given to the proper name used for the illness. As previously mentioned, there are 3 different names used to describe the illness, creating a bit of confusion. I will use all 3 names, but strategically, to optimize and enhance searchability, while being mindful of the name(s) valued most by the SEID/CFS/ME community.

Finally, as someone who has experienced the disease first hand, I understand just how overwhelming it can be to manage life with this illness. I can put together a knowledge base that applies sound design principles, is easy to navigate, and features only the most critical and relevant information. When you are ill, the last thing you want to do is navigate through pages and pages of information. My knowledge base would be built with a person suffering from SEID/CFS/ME in mind.

Identifying My Target Audience

While I am a SEID/CFS/ME sufferer myself, it is imperative that I to use secondary sources to identify my target audience.

According to the CDC, more than one million Americans have SEID/CFS/ME. This illness strikes more people in the United States than multiple sclerosis, lupus, and many forms of cancer.

- [SEID/CFS/ME] occurs four times more frequently in women than in men, although people of either sex can develop the disease
- The illness occurs most often in people in their 40s and 50s, but people of all ages can get [SEID/CFS/ME]
- [SEID/CFS/ME] is less common in children than in adults. Studies suggest that [SEID/CFS/ME] is more prevalent in adolescents than in younger children

- [SEID/CFS/ME] occurs in all ethnic and racial groups and in countries around the world. Research indicates that [SEID/CFS/ME] is at least as common among African Americans and Hispanics as it is among Caucasians
- People of all income levels can develop [SEID/CFS/ME]
- [SEID/CFS/ME] is sometimes seen in members of the same family, but that does not indicate that it's contagious. Instead, there may be a familial or genetic link. Further research is needed to explore this possibility (Centers for Disease Control and Prevention)

According to PEW Research, statistically speaking, chronic disease is associated with being:

- Older
- Living in a lower-income household
- Reporting a lower level of education (Fox & Duggan, The Diagnosis Difference, 2013)

Understanding my Target Audience:

According to the CDC, common difficulties for SEID/CFS/ME patients include problems coping with:

- The changing and unpredictable symptoms
- A decrease in stamina that interferes with activities of daily life
- Memory and concentration problems that seriously hurt work or school performance
- Loss of independence, livelihood, and economic security

- Alterations in relationships with partners, family members, and friends
- Worries about raising children

Feelings of anger, guilt, anxiety, isolation and abandonment are common in [SEID/CFS/ME] patients. While it's OK to have such feelings, unresolved emotions and stress can make symptoms worse, interfere with prescription drug therapies, and make recovery harder (Centers for Disease Control and Prevention).

METHODOLOGY

In addition to the project itself, I will submit a document outlining the research required for the development of the platform. Realizing the time and resources needed for Human Subject Participation approval from Ball State's Institute Review Board (IRB), I felt it was unwise to involve human participants at this time given the time allotted for this project. With the approval of my committee, I chose to limit my work to secondary research only, involving a review of previous published literature related to the topic.

Review of Previously Published Literature

“Chronic Disease and the Internet.” Fox, Susannah & Kristen Purcell. Pew Research Center. March 24, 2010.

This study provides valuable statistical and demographic data on US adults living with chronic illness or disease. Includes statistical data on how those with chronic disease and illness access

information, both online and offline, including Internet technology access and use, as well as communications preferences.

This report is the result of collaboration between the Pew Internet Project and the California HealthCare Foundation.

- *The Pew Internet & American Life Project is an initiative of the Pew Research Center, a nonprofit “fact tank” that provides information on the issues, attitudes and trends shaping America and the world. The Project is nonpartisan and takes no position on policy issues.*
 - *The California HealthCare Foundation is an independent philanthropy committed to improving the way health care is delivered and financed in California.*
- All quantitative, numerical data is based on a December 2008 national telephone survey conducted by Princeton Survey Research Associates International (PSRAI).*
- *PSRAI is an independent firm dedicated to high-quality research providing reliable, valid results for clients in the United States and around the world. Evans Witt and Jennifer Su guided the quantitative research, overseeing interviews of 2,253 respondents, age 18 and older, in both English and Spanish, including 502 cell phone interviews.*

All stories and quotes from consumers are based on qualitative surveys fielded in the summer and fall of 2009 on PatientsLikeMe and HealthCentral.

“The Diagnosis Difference.” Fox, Susannah & Maeve Duggan. Pew Research Center.

November 26, 2013

Follow-up study to “Chronic Disease and the Internet.” This study provides updated statistical and demographic data on US adults living with chronic disease or disease. Includes information about Internet technology access and use, communications preferences of those living with chronic illness or disease, and how those living with chronic disease track and monitor those conditions.

The results reported here come from a nationwide survey of 3,014 adults living in the United States. Telephone interviews were conducted by landline (1,808) and cell phone (1,206, including 624 without a landline phone). The survey was conducted by Princeton Survey Research Associates International. Interviews were done in English and Spanish by Princeton Data Source from August 7 to September 6, 2012. In this survey there are 1,498 respondents who are living with one or more chronic health conditions.

“Rare Diseases and Online Resources.” Fox, Susannah. Pew Research Center. February 11, 2009.

Brief article addresses the gap of social networking sites and those living with a rare disorder.

Written by Susannah Fox, author of two previous studies, who serves as the Chief Technology Officer of the U.S. Department of Health and Human Services (HHS) with personal mantra: “I help people navigate health and technology.”

“Family Caregivers are Wired for Health.” Fox, Susannah, Maeve Duggan, & Kristen Purcell. Pew Research Center. June 20, 2013.

A collaboration of all 3 authors of the previously mentioned 3 studies, this study provides valuable statistical and demographic data on different segment of those affected by chronic

disease: the caregivers. Includes essentially the same statistical data on how information is accessed, both online and offline, including Internet technology access and use, as well as communications preferences, but from the perspective of the caregivers, and not the chronically ill themselves.

The results of this study come from The 2012 Health Survey, sponsored by the Pew Research Center and the California HealthCare Foundation, were obtained by telephone interviews with a nationally representative sample of 3,014 adults living in the United States. Telephone interviews were conducted by landline (1,808) and cell phone (1,206, including 624 without a landline phone). The survey was conducted by Princeton Survey Research Associates International. Interviews were done in English and Spanish by Princeton Data Source from August 7 to September 6, 2012

“How Do We Know that Social Media is Important to Health Care?” Fox, Susannah. Pew Research Center. October 21, 2013

Susannah Fox addressed the use of “social tools” in health care, social media’s use in medicine, and how various forms of digital storytelling (including text messaging and video) are effective as health tools.

“Mobile Solutions for Chronic Disease Management.” Seth, Ashish. Online: Sandhill Business Strategy. January 28, 2014.

Ashish Seth, Co-founder & Head of Mobile Services InnovationM, is emphasizing the need for patients and care providers to be better connected to each other for better management of chronic diseases through the mobile technology in healthcare and technology that is “beyond mobile.”

“Research Shows Patients with Chronic Diseases Want More Mobile Solutions.” Essany, Michael. Online: mHealthWatch.com. November 15, 2015.

This story appeared in Ball State University’s *News About Mobile Media* by Mike Hanley. Highlights a study released by mobile engagement provider, Mobiquity, that exposes the gap between patients demand for taking control of their own health and the accessibility or availability of digital and mobile tools to manage chronic disease.

“Social Networks a Lifeline for the Chronically Ill.” Miller, Cain Miller. The New York Times. March 24, 2010.

New York Times story using Susannah Fox’s 2008 study to share personal accounts of how those with chronic diseases are using social network and the vital role community plays in improving their lives.

“U.S. Smartphone Use in 2015.” Smith, Aaron. Pew Research Center. April 1, 2015.

This study describes the phenomenon of smartphone adoption and how Americans rely to some degree on a smartphone for accessing online services and information and for staying connected to the world around them — either because they lack broadband at home, or because they have few options for online access other than their cell phone. The study also provides statistical data on the types of information and services people access through their smartphones.

The survey was conducted by Princeton Survey Research Associates International (PSRAI) nationally representative sample of 2,002 adults living in the continental United States. (Fox, Rare Diseases and Online Resources, 2009) (Fox, Duggan, & Purcell,

Family Caregivers are Wired for Health, 2013) (Miller, 2010) (Fox, How Do We Know that Social Media is Important to Health Care?, 2013)

FINDINGS

Since there has not currently been a study on the needs and wants of the specific SEID/CFS/ME community, I have chosen to use the research of Suzannah Fox and associates with Pew Research Center. Their findings are not SEID/CFS/ME specific, but they are of the nation's other leading chronic diseases. Fox reports that nearly half of U.S. adults (45%) report that they live with one or more chronic conditions, such as high blood pressure, lung conditions, diabetes, heart disease, or cancer. Likewise, as previously mentioned, CDC studies show that CFS can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis, heart disease, end-stage renal disease, chronic obstructive pulmonary disease (COPD), and similar chronic conditions. With this overlap, I feel Fox's research fits my project. The population in Fox's study can be categorized as follows:

- 25% say they are living with high blood pressure.
- 13% say they are living with asthma, bronchitis, emphysema, or other lung conditions.
- 11% say they are living with diabetes.
- 7% say they are living with heart disease, heart failure, or heart attack.
- 3% say they are living with cancer.
- 16% say they are living with any other chronic problem or condition.

One in four adults (24%) is living with one condition; one in five adults (20%) is living with two or more chronic health conditions (Fox & Duggan, The Diagnosis Difference, 2013).

Given Fox's credentials as Chief Technology Officer of the U.S. Department of Health and Human Services (HHS), having participated in numerous studies on health and technology, her personal mantra of *"I help people navigate health and technology,"* and the representative samples used in her studies--her research is well-qualified to defend my position. My only reservation in using the work of Fox is that her initial research, *"Chronic Disease and the Internet,"* was conducted in 2008 and published in 2010. Luckily, *"The Diagnosis Difference"* updated this research to 2012 and was published in 2013, which is why I have chosen to use her research as the core of my project. This national survey by the Pew Research Center, supported by the California HealthCare Foundation, explores how adults with chronic conditions gather, share, and create health information, both online and offline. The Pew Research Center has identified what we call a "diagnosis difference," or "gap" in these behaviors between someone who is chronically ill and someone who is not. By understanding this "gap," I will better understand my target audience, and consequently, develop a more effective project. I will present Fox's data in cross-comparison fashion and demonstrate how her data will determine the content and delivery of my knowledge base.

Figure 1. Choosing the Right Platform to Assemble Information

"72% of U.S. adults living with chronic conditions use the internet." –Fox (2013)

Accessing the need:

Fox (2010):

Online health resources play a supporting role in many people's lives as they pursue better health and navigate the health care system, either as passive recipients of advice or as active "partners in their care." Disease-specific patient networks, which have been called "the chicken soup of the internet," present an opportunity for people to harness social media tools not only for emotional support but to find practical tips and to weigh treatment options. There is also a significant investment being made in the Nationwide Health Information Network, which is meant to bring together streams of medical information and ensure its secure exchange between health care consumers and providers. However, the question remains: Are online health resources reaching the population most in need? (Fox & Purcell, Chronic Disease and the Internet, 2010)

"Living with a chronic condition is independently associated with key health-related activities"

Fox (2013):

If someone living with a chronic condition has access to the internet, [having a diagnosis] is tied to certain online behaviors. When controlling for age, income, education, ethnicity, and overall health status, internet users living with one or more conditions are more likely

than other online adults to:

- Gather information online about medical problems, treatments, and drugs.
- Consult online reviews about drugs and other treatments.
- Read or watch something online about someone else's personal health experience (Fox & Duggan, The Diagnosis Difference, 2013).

“People living with chronic conditions are more likely than others to fact check with a medical professional what they find online”

While online information is important, it does not fully replace information, advice, and care from a medical professional.

Fox (2013):

Thirty-one percent of U.S. adults living with chronic conditions say they have gone online specifically to try to figure out what medical condition they or someone else might have. They are more likely than other “online diagnosers” to talk with a clinician about what they find:

- 60% of online diagnosers living with chronic conditions say they talked with a medical professional about the information they found online, compared with 48% of online diagnosers who report no conditions.
- About half of online diagnosers living with chronic conditions say that a clinician

confirmed their suspicions, either completely or in part. About one in five say that a clinician offered a different opinion (Fox & Duggan, *The Diagnosis Difference*, 2013).

Implementation:

My *Projected Statement of Objective* states my desire to create a knowledge base platform, unlike any others currently available, richly employing digital storytelling to offer a wide range of resources and support for those afflicted by SEID/CFS/ME. As the title of Fox's initial study, "*Chronic Disease and the Internet*," suggests, my knowledge base should be "online" by utilizing the Internet. **Since 72% of U.S. adults living with chronic conditions have access to the internet, and it is presumed by Fox that this 72% uses the internet** (Fox & Duggan, *The Diagnosis Difference*, 2013), **it is essential that I have an online presence.** Furthermore, as indicated by the research data, when controlling for age, income, education, ethnicity, and overall health status, internet users living with one or more conditions are **more likely** than other online adults to:

1. Gather information online about medical problems, treatments, and drugs.
2. Consult online reviews about drugs and other treatments.
3. Read or watch something online about someone else's personal health experience.

While online information is important, it does not fully replace information, advice, and care from a medical professional. Since the chronically ill are more likely than other "online diagnosers" to talk with a clinician about what they find, we understand that online information is not replacing professional medical advice, but *supplementing* it.

By understanding the online and off-line behaviors of the chronically ill, it is clear to me

that I need an online presence. And what better way to have an online presence, then through a website? As a digital storyteller, a website will create a platform for me to collect and organize a diverse assortment of digital media: videos, photos, personal stories, charts, diagrams, and printable features. However, based on Fox’s research, **“Will a website be *enough*?”**

Figure 2. Availability and Accessibility– Understanding Online Activities of the Chronically Ill to Enhance Usability

“The Internet gap creates an online health information gap.”

Fox (2013):

People living with chronic conditions are significantly less likely than other adults to have internet access:

- 72% of adults living with chronic illness have Internet access.
- 89% of adults who report no chronic conditions have Internet access.

This is partly tied to the fact that, as a group, they are older than the general population and have less education – both of which are associated with being offline. Still, the Pew Research Center has identified what [they] call a “diagnosis difference” [that is, a “gap” in the behaviors between someone who is chronically ill and someone who is not].

Holding other variables constant (including age, income, education, ethnicity, and overall health status), living with a chronic disease has an independent, negative effect on someone's likelihood to use [(or have access to)] the internet. [In other words], chronic disease seems to play an independent role. Logistic regression analysis indicates a "diagnosis difference" that is tied to several aspects of health care and technology use.

Holding other variables constant (including age, income, education, ethnicity, and overall health status), the fact that someone has a chronic condition is independently associated with being offline.

Chronic disease is statistically associated with advanced age and lower education, which are also strongly associated with low internet access, and indeed, that connection is reflected in this study. Fully 75% of U.S. adults age 65 and older are living with a chronic condition, for example, and that age group is the least likely to use [(or have access)] to the internet (Fox & Duggan, The Diagnosis Difference, 2013).

As Fox clarified in 2010:

Lack of internet access, not lack of interest in the topic, is the primary reason for the gaps. In fact, when demographic factors are controlled, **internet users living with chronic disease are slightly more likely than other internet users to access health information online** (Fox & Purcell, Chronic Disease and the Internet, 2010).

Analysis:

It is clear that people living with chronic conditions are significantly less likely than other

adults to have internet *access*. However, having *access* to the internet does not guarantee *use* of the internet- as *use* would be an issue of usability and functionality. Fox's intermittent uses of the terms "internet use" and "internet access," make her findings on this particular statistic slightly confusing for the reader to understand. After reading *both* her 2010 and 2013 study, it is clear that *access* equates to *use*. **So, as mentioned in Figure 1, it is presumed by Fox that the 72% of U.S. adults living with chronic conditions have access to the internet also use the internet** (Fox & Duggan, The Diagnosis Difference, 2013).

I would be curious to see the statistics if data were collected that differentiated between *access* and *use*. While someone with a chronic disease may have *access* to the internet, they may not be able to *use* the internet as much as they like because of their illness and the level of disability and functionality the illness creates. By unlocking this information, it would be possible to better adapt technology to increase usability and *use* among the chronically ill.

In terms of both *access* AND *use*, how do we bridge this "gap" and make the Internet more *available/assessable* and easier to *use* to those with chronic disease, primarily those with SEID/CFS/ME? First, we must understand technology use among the chronically ill:

"Lower uptake of technology among people living with chronic conditions"

Fox (2013):

People living with chronic health conditions continue to lag behind other U.S adults when it comes to information and communications technology adoption. Of those who are living with chronic health conditions, 72% say they have access to the internet. By comparison, 89% of those who report no significant health problems say they have access.

This 17-point gap echoes previous studies. In 2008, for example, Pew Research Center data showed that 62% of adults living with one or more chronic conditions used the internet, compared with 81% of adults reporting no health problems, a 19-point gap.

Pew Research Center studies also show that education and age are strongly correlated with having internet access. Yet when age and education are held constant, living with a chronic disease independently increases the likelihood that someone will *not* have internet access.

The more conditions people are managing, the less likely they are to have internet access: 80% of adults living with one condition have internet access, compared with 61% of those living with 2+ conditions.

There is also a gap when it comes to cell phones: 78% of U.S. adults living with chronic health conditions said they own a cell phone at the time of the survey, compared with 91% of those who report no conditions. This ratio has not changed significantly since 2008, when 76% of adults living with chronic conditions reported that they own a cell phone, compared with 89% of those who do not have any chronic conditions.

Living with a chronic condition is not a significant factor in predicting someone's likelihood to own a cell phone. Statistical analysis shows that the gap is better explained by the fact that people with significant health challenges are more likely to be older, living in lower-income households, and reporting a lower level of formal education. Age, income, and education level are all strongly correlated with cell phone ownership (Fox & Duggan, The Diagnosis Difference, 2013).

Analysis:

It is clear that people living with chronic health conditions continue to lag behind other U.S. adults when it comes to information and communications technology adoption, both with internet technology and cell phone use. As we learned above, **lack of internet access, not lack of interest in the topic, is the primary reason for these gaps.** When demographic factors are controlled, internet **users living with chronic disease are slightly more likely than other internet users to access health information online.**

Why then, is there also a gap when it comes to cell phones? 78% of U.S. adults living with chronic health conditions said they own a cell phone at the time of the survey, compared with 91% of those who report no conditions. While age, income, and education level are all strongly correlated with cell phone ownership, the survey does not investigate if the "cell phone gap" is due to financial/socioeconomic reasons (high medical costs making it financially infeasible to own a phone), or if the chronically ill are unable to use a cell phone because of their disabilities and level of functionality.

Furthermore, when Fox's research mentions "cell phones," it does not specify if it is

referring to a basic cellular phone (with on internet access), or a smartphone (a cellular phone that has the added benefit of internet access), or BOTH.

Why this is important:

Fox's research was conducted in 2012. Since then, we have had an increasing adoption of a major technological advancement: the smartphone (a cellular phone that has the added benefit of internet access).

According to another Pew Research study, titled *U.S. Smartphone Use in 2015*, 64% of American adults now own a smartphone of some kind, up from 35% in the spring of 2011 (Smith, 2015).

The progressive adoption of the smartphone solves the two issues addressed earlier by making the Internet both more accessible/available and usable. Here's how:

My personal story:

I was raised in a rural area in Indiana where internet service was not provided or even available. When I transitioned from a traditional cellular phone (flip phone) to a smartphone, high-speed Internet became available to me for the first time in my home. Coincidentally, I became ill right around this time, and while I did not feel up to sitting at a desk at my computer, I did feel up to lying in bed and accessing information from my new smartphone. The technology upgrade was essentially a win/win in that it made the internet both assessable/available and easily usable by accommodating my condition.

My story is validated by *U.S. Smartphone Use in 2015*, because this study found that:

- 10% of Americans own a smartphone but do not have any other form of high-speed internet access at home beyond their phone's data plan.
- Using a broader measure of the access options available to them, 15% of Americans own a smartphone but say that they have a limited number of ways to get online other than their cell phone (Smith, 2015).

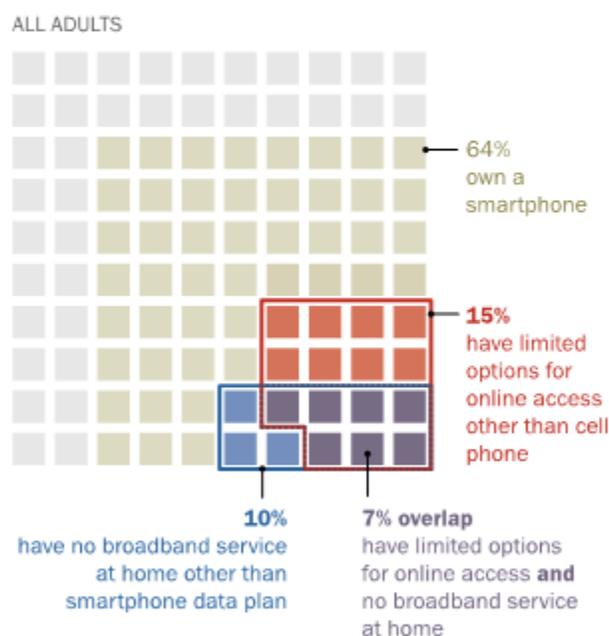
In all, one-in-five American adults (19%) indicate that at least one of those conditions apply to them, and 7% of the public says that both of these conditions apply — that is, they do not have broadband access at home, and also have relatively few options for getting online other than their cell phone (Smith, 2015). The study refers to this latter group as “smartphone-dependent” users.

Also, according to the smartphone study:

Smartphones are used for much more than calling, texting, or basic internet browsing.

The “Smartphone-Dependent” Population: 7% of Americans Rely Heavily on a Smartphone for Online Access

% of U.S. adults who have a smartphone, but lack other broadband internet service at home, and/or have limited options for going online other than their cell phone



Pew Research Center American Trends Panel survey, October 3-27 2014.

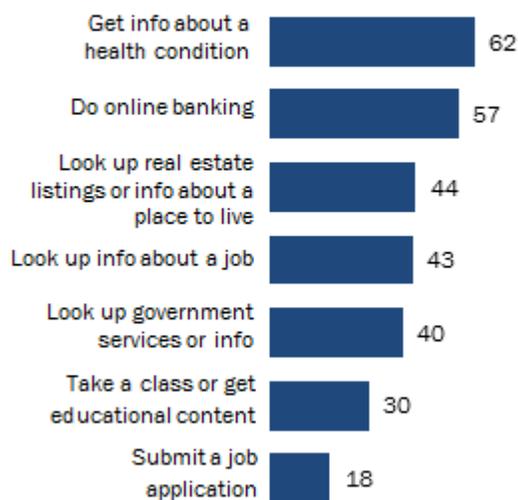
PEW RESEARCH CENTER

Users are turning to these mobile devices as they navigate a wide range of life events:

- **62% of smartphone owners have used their phone in the past year to look up information about a health condition.**
 - 57% have used their phone to do online banking.
 - 44% have used their phone to look up real estate listings or other information about a place to live.
 - 43% to look up information about a job.
 - 40% to look up government services or information.
 - 30% to take a class or get educational content.
 - 18% to submit a job application
- (Smith, 2015).

More than Half of Smartphone Owners Have Used Their Phone to get Health Information, do Online Banking

% of smartphone owners who have used their phone to do the following in the last year



Pew Research Center American Trends Panel survey, October 3-27 2014.

PEW RESEARCH CENTER

Yes! In 2015, 62% of smartphone owners used their phone in the past year to look up information about a health condition- more than any other search as indicated by these statistics.

The innovations made possible by the adoption of the smartphone are a major advancement, given the limitations Fox mentions in her 2010 study:

...the more an internet user is tethered to a stationary, home internet connection, the less likely they are to venture far and wide online.

While a majority of internet users have wireless internet access, just one-quarter of internet users living with two or more chronic diseases have such access. People living with chronic disease are likely to be advanced in age, living in lower-income households, and lagging behind the general population in technology adoption. Once again, statistical techniques show that in addition to these factors, the presence of chronic disease has a small but significant negative effect on wireless adoption (Fox & Purcell, Chronic Disease and the Internet, 2010)

Because smartphone adoption has been so successful, people are able to access my website that previously could not. As stated in the *Smartphone Use* study, 7% of the public is “smartphone dependent,” - that is, they do not have broadband access at home, but they do have broadband access on their phone (Smith, 2015).

To accommodate the rising use of smartphones, each website on the internet should pair a mobile version of the site to the original site.

A mobile version of a website is an alternate version of a webpage that is paired to the original version. The original version, or “desktop view,” is designed to be accessed from a computer screen and navigated with a mouse and keyboard. The mobile version is designed to be accessed from a mobile device such as a smartphone or tablet and navigated with the touch of a finger. Same content, but different design to improve usability and function.

Mobile versions of website are especially important for websites targeted at the

chronically ill, since the chronically ill require ease of use.

Implementation:

Because of the increased availability/accessibility and usability provided by smartphones, I will pair a mobile version of my website to the “desktop version,” thus increasing both accessibility and availability, while enhancing usability, given my target audience of those suffering with chronic illness. In theory, this could fill the “diagnosis difference,” thus closing “the gap” that keeps those with a diagnosis offline. Those with SEID/CFS/ME will be able to:

- Gather information online about medical problems, treatments, and drugs pertaining to SEID/CFS/ME.
- Consult online reviews about drugs and other treatments for SEID/CFS/ME.
- Read or watch something online about someone else’s personal health experience SEID/CFS/ME; fulfilling the needs outlined by the research in Figure 1.

Figure 3. Content of Platform Determined by Online Behaviors and Health Topic Interests

Online behaviors
<p>Fox (2013):</p> <p>Eight in ten U.S. adults who have sought health information online say they began their</p>

last inquiry at a general search engine like Google, Bing, or Yahoo. This has been a bedrock finding of the Pew Research Center, dating back to their first health survey in 2000, underlining the centrality of search in Americans' online lives.

In order to get a better idea of how people are navigating health online, Pew asked respondents to tell us in their own words which sites or services they use. Federal government health websites were popular among those living with chronic conditions, such as PubMed, CDC.gov, Medline, HHS.gov, and Medicare.gov. Health insurance websites, clinicians' websites, as well as some specific services like iTriage were also frequently mentioned by people living with chronic conditions (Fox & Duggan, The Diagnosis Difference, 2013).

“Few pay for online content.”

Fox (2013):

Thirty percent of online health information seekers living with chronic conditions say they have been asked to pay for access to something they wanted to see online. Eighty percent of those who encountered a pay wall say they tried to find the information somewhere else; 17% gave up; and 2% paid the fee (Fox & Duggan, The Diagnosis Difference, 2013).



Health topics of online interest

Fox (2010):

There is almost a universality of interest in the following health topics, no matter someone's health status. Chronic disease increases someone's propensity to look for information about many of these topics, though not all. In addition, information seeking for many of these topics is driven by key demographic factors such as being female, holding a college degree, having broadband at home. These popular topics are noted in the chart below:

Health Topics

The percentage of internet users who have looked online for information about certain topics.

	No conditions	1+ conditions	2+ conditions
A specific disease or medical problem	65%	69%	69%
Certain medical treatment or procedure	54	55	54
Exercise or fitness	54	49	41*
Doctors or other health professionals	48	43	42*
Prescription or over-the-counter drugs	43	48	53*
Hospitals or other medical facilities	38	38	36
Health insurance	37	37	42
Alternative treatments or medicines	33	38	36
How to lose weight or how to control your weight	33	35	30
Depression, anxiety, stress or mental health issues	28	28	30
Any other health issue not listed above	26	27	31
Experimental treatments or medicines	19	22	23
How to stay healthy on a trip overseas	13	10	12

* Indicates a significant difference between those without chronic conditions and those with chronic conditions.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=1650. Interviews conducted in English or Spanish. Margin of error is ±8%.



(Fox & Purcell, Chronic Disease and the Internet, 2010)

What types of information people are looking for, and how they use this information

Fox (2013):

People living with chronic conditions are more likely than others to fact check what they find online with a medical professional

Thirty-one percent of U.S. adults living with one or more chronic conditions say they have gone online specifically to try to figure out what medical condition they or someone else might have. By comparison, 38% of U.S. adults who report no chronic conditions say they have done so. This difference is related to the fact that people living with chronic conditions are less likely than other adults to have internet access. When we look only at internet users, the two groups are equally likely to say they have gone online for a diagnostic check.

Among online diagnosers, people living with one or more chronic conditions are more likely than others to say that the information they found online lead them to think that it needed the attention of a doctor or other medical professional: 53%, compared with 41% of those living with no chronic conditions.

Among online diagnosers, people living with chronic conditions are also more likely to say they talked with a medical professional about the information they found online: 60% of online diagnosers with one or more chronic conditions did so, compared with 48% of those who report no conditions. And 48% of online diagnosers with one or more chronic conditions say that a medical professional confirmed their suspicions, either completely or in part. Twenty-one percent of online diagnosers with one or more conditions say a medical professional offered a different opinion, in contrast to the information found

online. Twenty-seven percent of online diagnosers with one or more conditions say they did not visit a medical professional in order to get their opinion.

Again, the diagnosis difference likely plays a role: **people with serious health concerns are likely to take their online research seriously** (Fox & Duggan, *The Diagnosis Difference*, 2013).

While online information is important, it does not fully replace information, advice, and care from a doctor or health care professional, friends and family, or support from others with the condition. Just as the chronically ill are more likely than other “online diagnosers” to talk with a clinician about what they find (as indicated in *Figure 1*), we can see how online information is not fully replacing the three sources mentioned above, but *supplementing* them. In the diagram, *Sources, Information, and Chair*, there is a significant number of people who use BOTH online and offline sources in combination with each other. This is a perceived need: I could use my website as a directory or hub, to provide the information these people need to **pursue** these offline leads... **online:**

Sources of Information, Care, and Support

Among all American adults 18+...

The last time you had a health issue, did you get information, care, or support from...



...a doctor or other health care professional.



...friends and family.



...others who have the same health condition.

Total Yes:

1 Chronic Condition

2+ Chronic Conditions

78%

83

65%

67

25%

31

YES	Online	1 Condition	1	1	2
		2+ Conditions	-	1	2
	Offline	1 Condition	66	44	15
		2+ Conditions	77	53	24
NO	Not a Source	1 Condition	21	35	74
		2+ Conditions	15	32	67

Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 2 percentage points for results based on all adults.

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Analysis:

The above diagram shows how there are a significant number of those with chronic conditions who use BOTH online and offline sources. Hence why it is critical for my online presence to understand the integral relationship between using these sources online and offline:

1. *Doctors and health care professionals.* In the 2012 survey, as previously found in the 2008 survey, health professionals dominated the offline information mix: in the 2012 survey, 81% of all adults living with one or more chronic conditions got information, care, or support from a doctor or other health care professional. That is, the majority of those living with chronic illness obtained their information or assistance from a health professional. But as further investigation revealed, the chronically ill used online information in SUPPLEMENT to seeing a medical professional. Therefore, my website will serve as a directory and hub, to network sufferers of SEID/CFS/ME with doctors, honoring the traditional face-to-face interaction with health care providers. Since Fox's research determines that health professionals dominate the information mix, it is critical that a "Find a Physician Near You" feature be added to my website. In researching all the SEID/CFS/ME websites, I discovered a few websites that feature a long list of physicians available around the world. The problem with these lists is that they lack usability- they are not searchable, so the user literally must read through pages and pages of text. By creating my website in the popular web designing tool, Wix, I have discovered a way in which I can create a *SEARCHABLE* directory of doctors by creating a Google document database spreadsheet of the doctors' names with their contact information, and linking the spreadsheet to a table widget in Wix. In doing so, a user will be able to type in his/her location, and my database will generate a list of doctors (when available) for that location. This is completely revolutionary, and not available on any other SEID/CFS/ME site, fulfilling my objective of creating a platform unlike any others currently

available on the web. My online presence will help sufferers not only find a doctor, but equip them the information they will need to make their doctor visit more effective.

- a. *Readers note: For the sake of time available to complete this project, I will include a list of only 25 physicians. I will continue to add to the database following the submission of my project. By asking online users to submit leads to me, my ultimate goal is to have every single physician in the world that deals with SEID/CFS/ME in this database. Because I am unable to screen these doctors, I cannot personally stand behind any of them, which is why I will post an appropriate disclaimer on my website.*

Also, because so many doctors are unaware of SEID/CFS/ME, they are unable to properly diagnose it. I see the need for a way of educating doctors around the world. This could be a brief video, e- brochure, or something else, with the potential of being available for distribution to every doctor in the world. Or, to appeal to the masses, it could be a brief video designed to be shown at medical conventions.

Part of my frustration early on, is that I was unable to get the proper diagnosis. I had invested lots of time, money, and resources into pursuing the wrong treatments before I got the right diagnosis. My online presence would enable me to post these resources, so they would be available for sharing and distribution between medical professionals and patients, that not only strengthens the doctor/patient relationship, but strengthens the caliber of information we have

currently have available.

2. *Friends and family.* To accommodate friends and family, my website will feature a button that says “How to Educate Others About Your Illness” that will serve two purposes:
 - a. First, it will provide a convenient way for those with SEID/CFS/ME to educate their loved ones on the disease. (My family was initially non-supportive early on because they did not understand the disease). This button will access information that is designed to quickly and efficiently explain the disease in such way that it encourages others to help.
 - b. Second, since 65% of all adults living with one or more chronic conditions got information or support from friends and family, this section of the site (in addition to the whole website itself) will be available to equip family and friends with the information they need to help their inquiring loved ones who are ill.
1. *Others who have the same health condition.* Since 27% of all adults living with one or more chronic conditions got information or support from others who have the same health condition, it is essential that my website feature the stories of others: both ones that I have had submitted exclusively to my site, in addition to links of those stories featured on other sites. These stories will bring messages of hope, and also share strategies of how to better manage the disease. My platform will also help sufferers of SEID/CFS/ME connect with other sufferers socially, but that will be detailed in *Figure 4. Integration of Social Networking to Facilitate Community.*

Fox's study reveals the information people are looking for, and how they use this information:

1. I can expect users to pull information from my site and fact check it with their medical professional.
2. I can expect users to use my site for a diagnostic check, potentially self-diagnosing themselves with SEID/CFS/ME.
3. I can expect users of my site to be lead to seek the attention of a doctor or other medical professional.
4. I can expect users of my site to talk with a medical professional about the information they found on my website.

Finally, the Health Topics chart above provides a list of the most popular topics that were searched online. If applicable to SEID/CFS/ME, they will determine the content of my website.

Furthermore, to increase the effectiveness of my online presence, I dug deeper, and researched the *offline* sources of information used by those with chronic conditions. In doing so, my online presence can assist user in locating their preferred resources *offline*.

For example, the 2008 survey determined that 56% of those with chronic conditions used books or other printed reference material. This statistic provides my website with a yet another great opportunity: to provides lists and recommendations, as well as helpful tips

in accessing these offline sources such as books and printed materials. My website will feature a list of the top CFS/SEID/ME books based on the feedback from my readers. They will be linked to Amazon, so users of my site can read the reviews of others on Amazon before making their purchase. Similar to my list of physicians, I will have a disclaimer that states I am not responsible for the content of these books, but offering them as a friendly suggestion. Again, my online presence will be a hub to connect users with *offline* sources.

Implementation:

By understanding sources of health information and how adults with chronic conditions gather, share, and create health information, both *online* and *offline*, I can design my platform around these preferences, ensuring my platform has the information needed.

- My website will be enhanced for search engine optimization, since 8 out of 10 U.S. adults begin their search inquiry with a search engine like Google, Bing, or Yahoo.
- My website will feature information from Federal government website such as CDC.gov since these site are popular among those with chronic illness.
- My website will accommodate both *online* and *offline* preferences, because when it comes to information or support, the chronically ill turn to online sources in supplement to their doctors or other health care professionals, friends and family, and other who have the same health condition.

- My website will feature a *searchable* database of doctors worldwide specializing in SEID/CFS/ME, which will be the first of its kind, making my website unique and revolutionary. Not only will my website help people find a doctor, but also provide users with:
 - Provide printer-friendly materials on my website to enable users to print items for review by their medical professionals.
 - Have up-to-date diagnostics from reputable Federal government health websites such as CDC.gov.
 - Provide visitors to the site access to the most comprehensive list of medical professionals who specialize in SEID/CFS/ME in the world, as detailed in the Implementation section of Figure 3.
 - Provide materials specifically geared at facilitation patient-to-doctor discussion.
- My website will feature tools geared at friends and family, since friends and family are an important source of information for the chronically ill.
- My website will allow sufferers of SEID/CFS/ME to connect with others with the same condition, by reading stories and connecting with others through social networking and social media. Share personal stories of those, both in narrative form and video- honoring my original objective of using various forms of digital storytelling.
- My website will feature a list of offline materials, such books on SEID/CFS/ME, making it easy for readers to purchase and receive them quickly from Amazon.com.

Figure 4. Integration of Social Networking to Facilitate Community

Being social about gathering and sharing information

Fox (2013):

The “diagnosis difference” cuts another way, too. This study provides evidence that many people with serious health concerns take their health decisions seriously—and are seriously **social** about gathering and sharing information, both *online* and *offline*.

For example, the last time they had a serious health episode, people living with chronic conditions were more likely than the general population to tap into the help offered by *health professionals, friends and family, and peer patients*. Holding other key variables constant, living with a chronic condition increases the likelihood that someone will seek advice, information, or support from all three sources.

In addition, internet users living with one or more conditions are more likely than other online adults to:

- Gather information online about medical problems, treatments, and drugs.
- Consult online reviews about drugs and other treatments.
- Read or watch something online about someone else’s personal health experience.

Those observations hold when controlling for age, income, education, ethnicity, and

overall health status—all of which are also associated with doing health-related activities online. This echoes the Pew Research Center’s previous work in this area, which showed that, once someone is online, having a chronic disease increases the probability that they will take advantage of **social media** to share what they know and learn from their peers (Fox & Duggan, *The Diagnosis Difference*, 2013).

As mentioned in Figure 2, according to Fox’s research, internet users living with one or more conditions are more likely than other online adults to read or watch something online about someone else’s personal health experience.

In addition, “Video is a viable option for health education particularly among low-literacy populations” (2013, *How Do We Know Social Media is Important to Health Care*).

Sharing stories, finding other people who share the same health concerns

The internet enables people to not only gather health information, but to share it and even create it. We find that, in general, internet users living with chronic conditions are about as likely as those who report no health issues to say they have taken part in social activities related to health, as shown in the table below:

The social life of health information

Among internet users in each group, the % who have interacted with their health online in the following ways

In the past 12 months, have you...	No chronic conditions	1 chronic condition	2+ chronic conditions
	(a)	(b)	(c)
Signed up to receive email updates or alerts about health or medical issues?	8	15 ^a	14 ^a
Read or watched someone else's commentary or experience about health or medical issues online?	25	29 ^c	21
Gone online to find others who might have health concerns similar to yours?	15	19 ^c	13
Downloaded forms online or applied for health insurance online, including private insurance, Medicare, or Medicaid?	11	12	13
Posted a health-related question online or shared your own personal health experience online in any way?	6	9	11 ^a
Used the internet to do any of these	40	45	39

Source: Pew Internet Health Tracking Survey, August 07 – September 06, 2012. N=3,014 adults ages 18+. Interviews were conducted in English and Spanish and on landline and cell phones. Margin of error is +/- 3 percentage points for results based on all internet users.

Note(s): Rows marked with a superscript letter ("") indicate a statistically significant difference between that column and the column designated by that superscript letter. Statistical significance is determined inside the specific section covering each row and column grouping in that row.

Internet users living with chronic conditions stand out from their peers in noteworthy ways: sharing questions online and reading or watching other people's health stories online. Of those who have posted health questions online, eight in ten say they were hoping to reach a general audience of friends and other internet users, compared with just one in ten who say they hoped to get feedback from a health professional. **Peer advice trumps professional advice in certain situations, as previous research has shown.**

When we control other demographic factors, such as age, income, education, race, and overall health rating, we find that **having a chronic condition significantly increases**

the likelihood that someone will take part in any of the following activities:

downloading forms, posting comments, reading or watching someone else's

commentary or experience about health, and signing up for email updates (Fox &

Duggan, The Diagnosis Difference, 2013).

“The social life of chronic disease information is robust.”

Fox (2010):

Interestingly, there are two activities which stand out among people living with chronic disease: blogging and online health discussions. When other demographic factors are held constant, **having a chronic disease significantly increases an internet user's likelihood to say they work on a blog or contribute to an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems.**

Uptake for these activities is low overall, but those who have participated often praise the information they find. For example, one person wrote, “[An] online support group helped me learn about the disease and provided comfort in knowing that my symptoms were not ‘just in my head,’ and helped me take steps to adjust to living with a chronic condition.”

Another shared, “I live in a small town and it is helpful to be able to use the internet to find others that have the same condition as I do.”

Living with chronic disease is also associated, once someone is online, with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts. These resources allow an internet user to dive deeply into a health topic, using the internet as a communications tool, not simply an information vending machine (Fox & Purcell, Chronic Disease and the Internet, 2010).

As the following chart reveals, using a social networking site, reading someone else's blog, using Twitter or another service, creating or working on one's own blog, and participating in an online discussion, all made the list of internet activities for the chronically ill (Fox & Purcell, Chronic Disease and the Internet, 2010).

Internet activities

What internet users reporting 2+, 1+, and no chronic conditions do online

	No conditions	1+ conditions	2+ conditions
Send or read email	90%	90%	91%
Bank online	58*	46	45
Look for info on Wikipedia	51*	38	31
Get financial information	40*	32	28
Use social network site~	39*	25	19
Read someone else's blog	34*	28	26
Use Twitter or another service~	12*	7	7
Buy or sell stocks, mutual funds, or bonds online	12*	9	5
Create or work on your own blog	11	12	11
Participate in an online discussion	7	8	8

* indicates a significant difference between those without chronic conditions and those with chronic conditions.

~Twitter and social network site use have grown since this survey was fielded.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=1650. Interviews conducted in English or Spanish. Margin of error is $\pm 8\%$.



Analysis:

According to the research, there are two activities which stand out among people living with chronic disease: blogging and online health discussions. While uptake for these activities is low overall, but those who have participated often praise the information they

find! For example, one person wrote, “[An] online support group helped me learn about the disease and provided comfort in knowing that my symptoms were not ‘just in my head,’ and helped me take steps to adjust to living with a chronic condition.” Which sounds strikingly similar to the testimony of many in the SEID/CFS/ME! Furthermore, research shows that using a social networking site, reading someone else’s blog, using Twitter or another service, creating or working on one’s own blog, and participating in an online discussion, all made the list of internet activities for the chronically ill!

The internet is like a secret weapon – if someone has access to it.

Those who are online have a trump card. *They have each other.* This survey finds that having a chronic disease increases the probability that an internet user will share what they know and learn from their peers. They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going (Fox & Purcell, Chronic Disease and the Internet, 2010).

Maintaining a forum on my website would be very difficult, especially considering that there are many free alternatives such as Facebook and others. This is why I propose having a sister Facebook page supplementing my actual website. The Facebook page will be the same name, and therefore, attract people to my website. I can share articles videos and other forms of digital media to my Facebook page, enabling people to leave comments, and facilitate discussions amongst one another. Because Facebook is a social networking site, people can befriend others, and create their own community of support. By having this forum and social community, I will receive feedback from the SEID/CFS/ME community on ways to improve my website, and what features and

information is desired. In essence, this feedback would be my own form of data collection.

Online support groups

Eight percent of internet users living with chronic disease say they participate in an online discussion, a listserv, or other online group forum that helps people with personal issues or health problems. Holding all other variables constant in the current survey, living with chronic disease increases the probability that an internet user will participate in online discussions.

The few people who have used such groups often praise the information they find. As one person wrote, “[An] online support group helped me learn about the disease and provided comfort in knowing that my symptoms were not ‘just in my head,’ and helped me take steps to adjust to living with a chronic condition.”

Another e-patient wrote, “I live in a small town and it is helpful to be able to use the internet to find others that have the same condition as I do” (Fox & Purcell, Chronic Disease and the Internet, 2010).

Implementation:

Launch website partnered with a sister Facebook page (by the same name to enhance recognition and search engine optimization) that provides an online social forum to facilitate the community that plays such a vital role in improving the lives of those living

with chronic health issues. Like my website, my Facebook page will create a platform for me to share a wide variety of multimedia including, but not limited to: photos, videos, articles, up-to-date news on the latest advancements and treatments. Unlike my website, the Facebook page will enable me to receive feedback from my users in the form of “likes” and comments. This feedback will come directly from my target audience, helping me adapt the content of my knowledge base platform to cater to their needs and preferences. But most importantly, as demonstrated by the research, the Facebook page will enable the SEID/CFS/ME community to communicate with themselves: “liking” each other comments, and starting threads of conversations in reply to each other’s comments. It will enable people to send “friend requests” to each other, creating a vast online network of information and support.

DISCUSSION:

Based on careful consideration and review of previous published literature related to the topic, the most effective way for me to reach my objective is through an online presence combining a traditional website, paired with a mobile version of that website accessible on smartphones and tablets, partnered with a sister Facebook page (by the same name) that provides an online social forum to facilitate the community that plays such a vital role in improving the lives of those living with chronic health issues.

As the name controversy was addressed in the “Introduction” section, special consideration will be given to how the disease is identified and how those names are positioned on the site. I will use the most recognized names for the disease to ensure that, regardless of the name used in a

search by my target audience, they will find my site. Special attention will be given to the arrangement, placement, and coloration of how the names will be displayed based on further research. Consideration of my target audience, those afflicted by SEID/CFS/ME, will be top priority.

After the launch of the initial knowledge base described above, additional research opens major possibilities into the expansion of my knowledge base in the future in the following areas:

1. Fox's study is American. Since I want a global impact, I would welcome research from other countries.
2. Fox's study was exactly what I needed to pinpoint the needs of my target audience. In my research, I was delighted to learn of her sister study, titled, "Family Caregivers are Wired for Health," that provides updated statistical and demographic data on the caregivers, that is, the people caring for those living with the chronic illness or disease. It includes information about Internet technology access and use, communications preferences, and how those caring for those with chronic disease track and monitor the conditions of loved ones.

Two-thirds of U.S. adults live with chronic disease – their own or a loved one's.

Fox (2013):

Even search itself turns out to be a social activity. Half of all health searches online are performed on behalf of someone else, including among people living with chronic conditions who probably have quite a few of their own concerns. This is another bedrock finding of the Pew Research Center, dating to the year 2000, when we first began measuring Americans' use of the internet to gather health information. Fifty-three percent of online health information seekers living

with one or more chronic conditions report that the last time they went online for health information it was related, at least in part, to someone else's medical situation. Forty-three percent of health information seekers living with chronic conditions say their last inquiry was about their own concerns, compared with 36% of those who report no conditions (Fox & Duggan, The Diagnosis Difference, 2013).

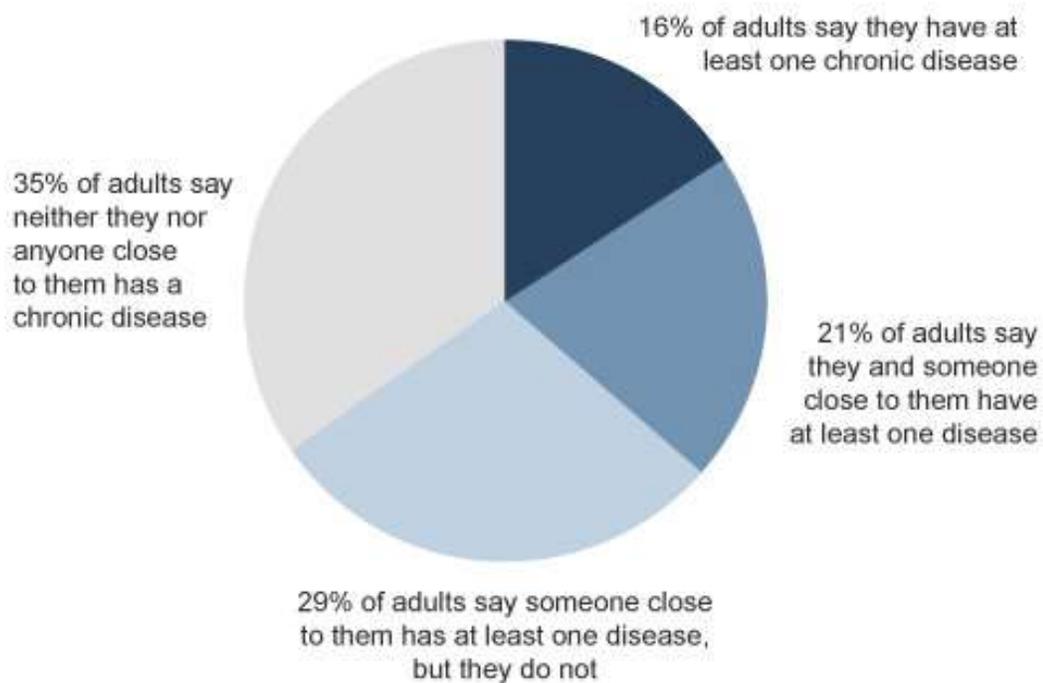
Fox (2010):

The broader footprint of chronic disease emerges when loved ones are taken into account.

This survey finds that 29% of adults say that although they do not have a chronic disease, someone close to them has a chronic medical condition such as asthma, diabetes, heart disease, high blood pressure, or cancer. Since half of health searches are conducted on behalf of someone else, the social life of chronic disease information may be more wide-ranging than might be suspected by looking only at the population of adults who live with these conditions. A forthcoming report from the Pew Internet Project will focus on family caregivers (Fox & Purcell, Chronic Disease and the Internet, 2010).

Chronic disease footprint

Most Americans are living with chronic disease – their own or a loved one's.



Source: Pew Internet & American Life Project Survey, November-December 2008. N=2253. Interviews conducted in English or Spanish. Margin of error is $\pm 2\%$. Totals can add to more than 100% due to rounding.



One internet user may collect information to send to multiple friends and relatives, hoping to jump-start an interest in that person's health. As an e-patient wrote, "Both my brother and sister are diabetics. Neither is very concerned or tries hard to avoid foods that are bad for them. I send them reprints and copy anything I find. I am a pest but they need it. I also have a 58-year-old friend who

is afraid to know his [A1C] numbers. I also bombard him. Not knowing is no longer an excuse” (Fox & Purcell, *Chronic Disease and the Internet*, 2010).

By using this data, I could create a dual site: that is, when a user visits my URL, (s)he would be prompted by a welcome screen with two buttons. The left button would say: “Click here if you have SEID/CFS/ME.” The right button would say: “Click here if you CARE for someone with SEID/CFS/ME.” Same website, but each individual side designed to cater to each target audience’s specific needs based on Fox’s research.

To take the concept of a “dual site” to a third level, I was inspired when my research led me to the website of Jessie Riley. Riley is the author of the *Invisible Cosmic Zebra Collection* of 18 how-to workbooks for 18 invisible illnesses. Riley penned the 100-page books to bring hope and humor to recently diagnosed patients and give an inside look at the complex reality of living with chronic, invisible illnesses. From her site I learned that, according to *Disabled World*, 96% of people with chronic medical conditions live with an illness that is invisible. Celiac disease, Crohn's disease, diabetes, fibromyalgia, lupus, Lyme disease, migraines and many others are considered "invisible illnesses" because there are no outward signs that anything is wrong with the body (ACCESSWIRE, 2016). Seeing how she cleverly uses humor, to not only educate people on their illness, but to help them cope, made me realize the need for such resources for **pediatric** SEID/CFS/ME. As a result, I foresee the addition of a third button on my welcome page, saying “Click here for KIDS with SEID/CFS/ME.”

3. Fox’s study also collected data on the ability and preferences of the chronically ill to track and monitor health by tracking indicators such as weight, diet, exercise routine,

blood pressure, sleep patterns, and headaches. 4% of those chronically ill use an app or other tool on their mobile device or phone, another 4% of this group used a computer (such as spreadsheet), and 1% of this group used a website (Fox & Duggan, The Diagnosis Difference, 2013). This research opens the possibility of the development of a SEID/CFS/ME mobile app available for download from the Apple App Store or Google Play Store. As mentioned in Figure 3, Fox's research reveals that few pay for online content: For this reason, my app would be absolutely free. While there are a few CFS apps available, with the causes and treatments of SEID/CFS/ME not being fully known, I think it would be wise for me to wait for these medical advancements before moving forward with the creation of an app. I am hoping the development of a SEID/CFS/ME app will become a possibility as my dissertation for a PhD, as I would need to conduct my own research with SEID/CFS/ME patients to determine what they need in an app.

SUMMARY & CONCLUSION

In conclusion, my review of Fox's research, in addition to the contributions of other respected researchers, defends my strategy to meet my objective of producing a web-based knowledge base platform built with a person suffering from SEID/CFS/ME in mind.

What began as "medical odyssey" six years ago-- traveling the country, meeting with specialists and other health care providers, and hearing the personal stories of others—gave me a great wealth of knowledge. As a person with SEID/CFS/ME, my goal was to make information and resources available to those with SEID/CFS/ME, as well as raise awareness for the disease. I was not sure how to effectively do this, in terms of whether it should be a website, a promotional

DVD, a commercial, etc. As a digital storyteller, in the Digital Storytelling program, I am aware of the multitude of mediums available, but to maintain the integrity of my project, it was critical that I let the research navigate my design.

By understanding offline, online, and mobile technology use of those living with chronic disease, as illustrated by Fox's research, I was able to develop my online presence around these needs.

As Fox so eloquently stated in 2010:

The internet is like a secret weapon – if someone has access to it.

The deck is stacked against people living with chronic disease. They are disproportionately offline. They often have complicated health issues, not easily solved by the addition of even the best, most reliable, medical advice.

And yet, those who are online have a trump card. They have each other. This survey finds that having a chronic disease increases the probability that an internet user will share what they know and learn from their peers. They unearth nuggets of information. They blog. They participate in online discussions. And they just keep going (Fox & Purcell, Chronic Disease and the Internet, 2010).

While in the initial stages I envisioned a website may be the solution, further analysis indicated that a website is not enough. While a website is a phenomenal venue to archive, collect, display and assemble information and resources-- it has its limitations. Both mobility and sociability are required, as indicated by the research. For that reason, my website cannot stand alone.

After careful consideration and review of published literature related to the topic, I feel the “most” effective way for me to reach my objective is through an online presence combining

a traditional website, paired with a mobile version of that website that is accessible on smartphones and tablets, partnered with a sister Facebook page (by the same name) that provides an online social forum to facilitate the sense of community that plays such a vital role in improving the lives of those living with chronic health issues.

By implementing this “triad” approach, I believe I will close the “gap” and increase availability, accessibility, usability, and mobility in what the Pew Research Center identified as the “diagnosis difference”--or “gap” in online behaviors between someone who is chronically ill and someone who is not.

By understanding this “gap,” I was better able understand my target audience, and consequently, develop a *more* effective project. And by effective, I mean developing my online presence around *their* needs.

To achieve the “*most*” effective reach, I would need to conduct my own research, exclusive to the SEID/CFS/ME community.

After the launch of my triad-approach knowledge base, I see major potential in exploring new potentials and expanding this project on my own with the possibilities mentioned above in the discussion. For the future, I have full intentions of maintaining this website, as it already fits into my weekly routine. I continuously check the Google newsfeed for recent updates on the disease. Only a few stories are worthy of reposting and I save these stories to my Bookmarks-- I must have hundreds. Now, instead of saving these article to my bookmarks, I can post them both to my Facebook page. In doing so, I can expect to receive feedback in the form of “likes” and comments, and if it appears it is a well-liked article, I can then archive it on my website. So the content of my website will be a reflection of my Facebook page, and vice versa. In essence, it is

like I'm conducting my own online research within and of it itself.

And finally, another plus to having this triad approach to an online presence, is a quote from the movie, *Field of Dreams*, “Build it and they will come.” By having this platform built, I will expect a loyal following and social network to grow. Once established, this platform has the potential of reaching thousands, if not millions worldwide. Each story, each post, each resource... impacting a multitude of people. My dream is that each resource I post, whether it be an article, a news story, a video—will be shared, and re-shared, potentially going viral, having maximum impact, all while being very cost effective at the same time.

PREVIEW OF PROJECT

Method of delivery: videos, photos, personal stories, charts, diagrams, and printable features.

Please see Figure 8 for mock-up prototype of website. Prototype of paired mobile version of site and partnered Facebook Page coming soon, pending approval to move forward by committee.

Figure 5:

Understanding
SEID / CFS / ME
Hope for all who suffer

0001260

Home Symptoms Causes Treatments Personal Stories Find a Doctor Latest News About Me Media

Systemic Exertion Intolerance Disease (SEID)
Chronic Fatigue Syndrome (CFS)
Myalgic Encephalomyelitis (ME)

Chronic fatigue syndrome, or CFS, [also referred to as Myalgic Encephalomyelitis (ME) and recently renamed Systemic Exertion Intolerance Disease (SEID)] is a debilitating and complex disorder characterized by profound fatigue that is not improved by bed rest and that may be worsened by physical or mental activity. Symptoms affect several body systems and may include weakness, muscle pain, impaired memory and/or mental concentration, and insomnia, which can result in reduced participation in daily activities.

Center for Disease Control and Prevention

DISCLAIMER: This website is for information purposes only and should not replace information from a medical professional

Tell us your story:
email: seidcfsme@gmail.com

Connect with others:
Find us on: **facebook.**
Coming soon!

Latest News:

- 10.05.15: With his son terribly ill, top scientist takes on chronic fatigue syndrome

[More News...](#)

How to educate others about your disease

LAUNCH OF PROJECT

On November 13th, 2015, the initial website was launched under the URL:

www.seidcfsme.com

Fox's research reveals that 8 in 10 U.S. adults who sought health information online began their last inquiry at one of the major search engines like Google, Bing, or Yahoo. For this reason, I have chosen domain name URLs containing the words and acronyms of the disease in hopes of search engine optimization so that my website and Facebook are top hits for people inquiring about the disease.

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APPENDICES

Appendix 1: Lerner, A. M., Beqaj, S., Fitzgerald, J., Gill, K., Gill, C., & Edington, J. (2010). Subset-Directed Antiviral Treatment of 142 Herpesvirus Patients with Chronic Fatigue Syndrome. *Virus Adaptation and Treatment* , 2010 (2), 47-57.