**Introduction slide**: Hi Hayla, thank you so much for the introduction. Hello everyone, it's great to be speaking with you today and I'm so happy to share this presentation with you all. So I'd like to give just a brief background to this talk; I started my studies in college without knowing really anything about this grouping of illnesses at all, and was really lucky to be exposed to this world through some of the people in my life at the time and through some coursework that really shined a light on the difficulties that patients face and how unique they are in the medical setting. Fast forward a few years from that introduction, and I spent the entirety of my final year in school conducting a literature review and interviewing students to really answer two main questions; to 1) get a sense of where we were today and 2) how we got here.

**Part I slide**: So I'll be moving through three parts in this talk, starting with some specific chronic illnesses and their origins which are likely earlier than you may expect.

**MUS slide**: ME/CFS, fibromyalgia, and chronic Lyme disease share a host of medically unexplained symptoms (MUS). This is not to say that there aren't underlying medical explanations of course, but that physicians and researchers are forced to establish diagnostic criteria usually in the absence of biomarkers or other clinical pathology. These diagnostic criteria are based on subjective symptoms that are often quantified and categorized through qualitative measurements, things like graded scales or the tender point examination as an example. While each of these respective illnesses have a unique path to their emergence in modern medicine, they share a lot of similarities in terms of symptoms, methodologically as diagnoses of exclusion, and their philosophical issues within biomedicine and society.

So obviously the breadth of shared symptoms is wide, and this is only a brief selection here, but ranging from chronic pain and specific tender areas, fatigue, impaired motor function, and visual, hearing, and cognitive disturbances. These types of somatic symptoms are unable to be corroborated by medical technology, no matter how real they are to the patient. And that is the crux of what makes these illnesses so unique. And speaking more historically, illnesses with this shared symptom set has shifted from being objects of religion long ago, to different specialties in medicine like neurology, rheumatology, immunology, repeatedly, psychology, unfortunately.

For these reasons, I chose to trace these illnesses from some of their earliest iterations in the primary literature to their current form. In this process, it was clear that a long legacy of conditions composed of somatic symptoms, fatigue, and pain preceded the seemingly 'new' emergence of these three diseases as they are currently understood. I only briefly delve into this history in order to create context and linearity in their

chronology to better understand the modern patient experience. To start, we'll begin with the earliest biomedical iterations that informed the more recent clinical criteria and case definitions, and refer to the collection of these three specific illnesses as 'contested chronic illnesses.'

So I think this audience is more familiar with these conditions, but I want to highlight the origins of their first appearances and really set them in context to these two other notions of neurasthenia and hysteria.

ME/CFS: The emergence of myalgic encephalomyelitis was first used to describe a pattern of disease outbreak that was documented in the 1940's and 50's in many places, also described as "Iceland Disease," "Akureyri disease," "benign myalgic encephalomyelitis,". The term 'encephalomyelitis' was used to describe inflammation (-myelitis) of the brain (-encephalo), as the disease was perceived as an infectious onset affecting the central nervous system.

One the first case documentations was published in The Lancet journal in 1957. It described a series of outbreaks of an unknown infection that affected the central nervous system. In the 1950's the first 16 cases were at first misunderstood to be forms of polio, meningitis, and pyrexia (fever). The patients' most prominent symptoms included a rapid onset of headache, giddiness (vertigo), pain in the limbs, neck, back, and chest, and extended to symptoms of shivering, paraesthesia (tingling sensation), nausea and vomiting, pain in the ears, visual disturbances, and muscle cramps. Through the physical signs (lack of muscular atrophy and full paralysis) and immunological serology tests the physicians distinguished it from true polio, leaving them perplexed.

By the 1980's, another series of outbreaks with chronic illness symptoms among people who also tested positive for Epstein-Barr virus (EBV), which is the primary cause of mononucleosis. This diagnostic criteria encompassed the symptoms of disabling fatigue and malaise, low-grade fever, and a conglomerate of non-specific symptoms such as myalgia, sore throat, and depression that lasted for at least six months and was accompanied by specific EBV serology. In addition, the criteria required that patients not have malignancy, autoimmunity, or profound immunodeficiency, which could account for these symptoms. This chapter of history is really where most people who are familiar with ME/CFS understand the lineage of the disease to begin.

Fibromyalgia: the term "fibrositis" was first used in 1904 to describe pain and tenderness across areas of muscles and joints in the lower back, arms, and shoulders accompanied by a stiff neck and sore throat. Because the onset of pain was often slow and persisted long after injury, they chose against naming the condition "neuralgia" or

“myalgia”, meaning nerve and muscle pain, respectively, because of their implied a spontaneity of pain. The fibrositis term replaced and encompassed conceptions of “lumbago” (back pain) and “muscular rheumatism” that were distinct from the pathology of rheumatoid arthritis, which was by then well known.

By the 1940’s, fibrositis was thought to be caused by strain, wear and tear, chill, and worry, or some combination of these factors. It was diagnosed in evidence of a patient’s fibrositic nodules, small lumps that were often, but not always, located in the patient’s points of tenderness. The term was often conflated with psychogenic rheumatism, a condition of fibrositis-like pain that was thought to be psychosomatic, or invented by ‘deliberate malingers' to avoid doing work. But diagnostic criteria continued to evolve into the 70s, 80s, and by the 90s where the more current understandings of what we know as ‘fibromyaglia’ really started to develop.

Lyme disease and chronic Lyme: In the 1960’s and 70**’**s a group of people from Lyme, Connecticut began to present a host of unexplained symptoms such as paralysis, headaches, and severe fatigue. Although this population was determined to have ‘Lyme disease’, physicians did not know what caused it until the 1980’s when researchers identified the bacteria responsible, *Borrelia burgdorferi,* that was carried by ticks

Since that discovery, antibiotic treatments have been successfully developed for treating early presentations of Lyme disease. More severe symptoms develop if not treated early, such as Lyme arthritis, late neurologic Lyme disease. Still, these conditions can also be treated with long-term courses of antibiotics. In some cases, patients continue to report symptoms even after antibiotic treatment; this is the subset of patients understood to have CLD or PLDS. It wasn’t until 2004 that the International Lyme and Associated Diseases Society (ILADS) proposed a criterion of symptoms that included fatigue, cognitive, sleep, and neurological impairments, headaches, and musculoskeletal problems to describe this group of patients whose symptoms continued to remain.

Taking a step back, these are relatively recent in their emergence as discrete categories of disease, but people were experiencing similar symptoms even earlier and can be summarized by two preceding conditions. The next most recent condition that preceded this shared set of symptoms is neurasthenia.

**Neurasthenia slide:** First coined 1869, neurasthenia was used to describe a person with a lack of so-called ‘nervous energy’. This was conceptualized before the 19th century acceptance of neuron theory and its role in the central nervous system (CNS) and impacted how neurological diseases were understood and the field of neurology was developing.

At that time, neurological disease was understood under a ‘reflex arc’ model of the nervous system, which claimed a finite amount of nervous energy circulated inside the body through a closed system in a series of channels, akin to the advent of electrical circuits. This energy was thought to be housed in the brain, digestive system, and reproductive organs. It was thought that people’s nervous systems were overloaded by the rise in technology of the Industrial Revolution, like steam engines, electricity, and general modernization. And Further, the changing social roles of women entering the workforce were thought to quite literally overwhelm the nervous capacity of women.

The symptoms of neurasthenia were categorized by motor and sensory symptoms, things like muscle weakness, an incapacity for physical exertion or a “profound” exhaustion, giddiness (loss of balance and dizziness), general pains and aches, headaches, sensitivity to light and sound, cognitive impairment, unrefreshed sleep, poor digestion and circulation. Importantly, Patients were excluded from the neurasthenia diagnosis if they had another organic disease of the stomach, rheumatism, hysteria, hypochondria, melancholia, or other psychoses that accounted for their symptoms. The images included in this slide were featured in medical text books from the late 1800’s, that really act as artifacts and show how these symptoms were thought of at the time.

**Clinic images slide:** Interestingly, not everyone was prone to neurasthenia; it was hypothesized that only affluent populations, especially in North America, were susceptible to the impacts of modernization and rampant capitalism. This was really tied to both race and class. This ‘evidence’ viewed these conditions as a result of racial superiority, reflective of the social Darwinism that emerged after Charles Darwin published his evolutionary theory in 1859 to equate that more ‘civilized’ populations were more evolved, including their nervous systems , and made them more susceptible to this malady.

**Globe slide:** As time progressed, the diagnosis of neurasthenia waned in popularity in the United States with the eventual rejection of the reflex arc model of neurology at the turn of the 20th century. Instead, conflicting models of the emerging CNS on one hand, and psychogenic manifestations on the other, developed to account for the neurasthenia symptoms in patients.

Here, it is clear that limits of medical knowledge shaped the etiology of neurasthenia during its heyday and struggled to adjust as new models of the body emerged and scientific advancements changed our understanding of biology. The patients of neurasthenia were in a similar predicament to patients with some contested chronic illness now. Interestingly, while the neurasthenia diagnosis has faded in the United States, it has remained a prominent diagnosis in China. The social scientist Arthur Kleinman has theorized that the diagnosis functions there as an alternative to

psychological diagnoses in the face of the stigma of mental illness in China. While its use has changed over time and over places, it is clear that this set of symptoms is somewhat universal and can be found across different cultures and times.

**Hysteria slide**: the second condition that preceded this set of symptoms even earlier is Hysteria. Literally translated from the Greek word for uterus, *hystera,* hysteria was used to describe the behavioral fits of women whose disease was located in their womb, affecting different areas as moved throughout the body (or so they thought) (Hysteria, 2019). Notions of hysteria persisted for thousands of years to be both highly gendered and connotated with religious excitement during the Middle Ages, and later reemerging during the Salem witch trials. At the turn of the 20th century hysteria was divorced from these connotations and framed as an object of neurology as a “psycho-neurosis”. Although this description might sound psychological in origin, the physical symptoms were described as longer lasting symptoms of visual and hearing impairments, paralysis, rapid pulse, and fever.

By the turn of the 20th century a new wave of hysteria emerged and this began in France, championed as an organic neurological disease by a physician Jean-Martin Charcot. Current connotations of hysteria are almost exclusively psychological and social, and have been extensively explored by feminist theorists as a tool of medicalization, oppression, and the pathologization of women’s bodies. Although many credit Charcot with the fabrication of the hysterical phenomenon, in Charcot’s lifetime, he was seeking to do just the opposite by *validating* the symptoms of hysteria by asserting their cause as neurological. Charcot worked in the famous Salpêtrière, a sanatorium that held thousands of women, from whom they deemed the insane, elderly, and those debilitated from natural disease as essentially an infirmary. He quickly rose to prominence and was credited with distinguishing what we now know as multiple sclerosis (MS) and Parkinson’s disease among his patients at the sanatorium. He was among the same cohort of physicians distinguishing the symptoms of other erratic behavior and debilitation among women between MS, epilepsy, and hypochondria. As these differentiations evolved, the legacy of hysteria still persisted and wasn’t removed from the Diagnostic and Statistical Manual (DSM) until 1980.

So to zoom out, and take a look at this conceptual timeline, each of these diagnoses and diagnostic criteria in their emergence were initially viewed in the same tension between organic disease and psychosomatic presentations, or theologic origin earlier on. And today,  each of the most current diagnostic criteria have all become increasingly biomedicalized with consensus as organic diseases that have not yet been fully understood, and this becomes the main challenge for patients.

**Chronology slide:** So now that the context has been set for how we got here with this really complex history, the next question is to really examine where we are. So in this next portion I'd like to highlight a few models/ concepts that are helpful for characterizing the experience of patients from the social sciences and medical humanities.

**Illness narratives (Arthur Kleinman) slide**: Within the medical model, the objective, measurable change in health is known as 'disease.' The other side of the dichotomy instead pertains to the subjective, social experience of a change in health known as 'illness' to sociologists  in particular. In most circumstances, the patient's subjective experience of illness is confirmed by a physician's objective observation of that change in health. This confirmation serves an important function for the sick. It acts as permission for the patient to access the sick role, the socially accepted behavior of the sick. This process takes place in the clinic, where the physician-patient encounter has been one of the primary tools for assessing disease. So when the boundaries between illness and the experience of the disease are not so solid, this patient narrative brings autonomy and patient-centered understanding. The illness narrative is really the account of the lived experience of illness by the patient, regardless of their disease state.

**Goals of medicine (Eric Cassel) slide**: The second concept is the philosophical underpinnings of the goals of medicine and how  they can negatively impact the patient experience in this case. Primarily, the main theme that emerges in the tension managing uncertainty; patients grapple with the inability to be known and believed and understood by the institution of biomedicine and their clinicians, while clinicians grapple with the inability to effectively help patients and fulfill their role as a healer.

These structures by consequence force people socially to view these illnesses as less threatening or serious in comparison and this lends itself to the social stigma and Inability to access the sick role, which includes the permittance to be exempt from certain activities and for patients to view themselves as someone who is 'sick'. In both the organic disease and mental health narratives, patients are often not helped or respected in either direction. It is not just that the mental health narrative is used by clinicians as a scapegoat and patients receive treatments that are helpful, like cognitive behavioral therapy, but these patients don't respond to that treatment and then are also rejected by and not succeeding in that treatment either by returning to health. In both camps they are left without much effective treatment and return to health.

**Typography of Illness and Disease (Sarah Nettleton):** Next, I'd like to introduce, this typology of illness and disease that sarah Nettleon developed is a really wonderful graphic to tie both of those concepts together, so to orient us on the left axis,

Medical knowledge was dichotomized into 'certain' or 'uncertain' and consent into 'agreed' or 'contested.' She demonstrates that traditional disease is confirmed by medical knowledge and consent (permission) is accepted, and therefore falls into category A. Patients with MUS fall into category D, in which medical knowledge is uncertain about their symptoms (in the absence of disease) and consent of their illness is contested. She concludes that the boundaries of each category are continuously solidified and adjusted as our understanding of the etiology and pathology grows. This greater understanding is largely fueled by more advanced methods in technology and imaging. However, as more boundaries and categories are created between the spectrum of 'healthy' and 'ill,' ambivalence grows as well. As it relates to that larger theme of uncertainty, the need to become more precise intensifies and those left in the gray area of ambivalence demand more categorization to be understood in this medical system and accepted socially as 'ill'. This really gets to the heart of how a diagnosis is not just so important for the actual treatment of one's disease, but how it validates and functions in their sense of sense and navigation through the world

**Healthy/unhealthy disabled (Susan Wendell) slide:** Susan Wendell's, who's work began in the discourse of disability studies distinguishing those with disabilities who are also ill from those who are disabled, but healthy. This was an attempt to counter the devaluation of disabled people by society and the medicalization of disabled people under the assumption that all disabilities should be prevented, treated, and cured by medicine. She describes how other chronic conditions are being welcomed into disability groups, including fibromyalgia and ME/CFS. In addition, she points to the entanglement of this issue with feminist theory and women, as they are more likely to have disabling chronic illnesses and have unique illness experiences from men.

Wendell describes 'healthy disabled' as those whose physical condition and capabilities are relatively stable and predictable, and may consider themselves otherwise as 'healthy'. In contrast, those who are disabled and experience illness are described as 'unhealthy disabled.' To aid in the distinction, she also defines 'chronic illnesses' as those which are long lasting, are usually not cured, and not immediately life threatening. In relation to the function of diagnosis, she has championed thinking of chronic illness from a patient-entered perspective as opposed to this disease or diagnosis-centered understanding because of the fluctuations that are often present in one's ability, the severity, and the duration of illness. And that this way of thinking provides a much richer view into the world of chronic illness.

She breaks down these chronic conditions and their symptoms temporally, including those that are typically acutely chronic, or fluctuating between periods of acute episodes and periods of dormancy. Her point is that people with chronic conditions (arising from illness) are often socially treated as those with disabilities.

So these frameworks really help to give voice and clarity to some of the deeper causes of stigma and barriers to care that patients with ME/CFS, fibromyalgia, and chronic Lyme can face. That their symptoms on their own can be so debilitating, but why they have such a distinct illness experience from those with other types of disease

**Part III slide**: The third part that I'd like to describe is the qualitative interviews. For my senior thesis I conducted ethnographic interviews with college students to get a grasp of their lived experience and investigate these themes found in the social sciences in their own words. Shown here is the cover of my thesis, where I chose a series of questions to get at these topics: the doctor patient relationship, lived experience, how mental health has been situated in their illness, and how their illness may have been shaped by other aspects of their identity.

**Summary slide**: In summary, these chronic, contested illnesses of hysteria and neurasthenia preceded the current conditions of ME/CFS, fibromyalgia, and chronic Lyme and were the subset of chronic illnesses I chose to focus on.