Consider Chiari Campaign (2012)

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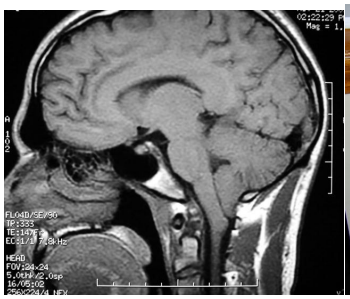
Executive Summary

Chiari malformation (CM), its related "sister" condition syringomyelia (SM), and a handful of related disorders (RD), are estimated to affect over 1 million Americans—up a staggering 300% in the last decade. CM symptoms mimic other more commonly diagnosed clinical conditions and, as a result, CM and SM, despite increasing prevalence, are still not widely considered as a possible diagnosis for patients presenting with textbook symptoms. Furthermore, Chiari is only diagnosable with expensive, underutilized MRI technology. In order for doctors to *Consider Chiari,* we need to educate them about the symptoms and the fact that they often mimic symptoms of other more readily defined clinical diagnoses. Despite the initial cost, we need to encourage physicians to utilize MRI—the only diagnostic tool that can definitively rule in or out the presence of Chiari malformation. When this behavior is adopted early in the relationship with the presenting patient, the emotional, financial and time savings realized by everyone participating in the healthcare system can be substantial. Our "Consider Chiari" campaign should be instrumental in helping make this happen.



Introduction

Chiari Malformation (CM), its "sister" condition syringomyelia (SM), and a handful of related disorders (RD) are crippling conditions that, today, are estimated to affect over 1 million Americans (www.csfinfo.org). Sadly, because its symptoms mimic those of many common aliments such as migraines, the disease is often misdiagnosed. These missed and "mis" diagnoses have a tremendous social, emotional and financial cost on patients and physicians who deal with the disorder. The only way to definitively diagnose CM is with an MRI scan. Prevailing wisdom at insurance companies and hospitals is to discourage the use of this relatively expensive technology as a first line of defense in making diagnoses. However, it must be stressed that while expensive at the outset, the appropriate use of MRI technology as it relates to the diagnosis of CM, will actually lower the overall cost of CM/SM/RD care. Ordering cheaper tests (that ultimately can't answer the CM/SM/RD question anyway) as opposed to an MRI for patients presenting with CM symptoms is current common practice.

1.0 Background, Situation and Focus

In 1986, a young mother, Dorothy Poppe, was in a desperate search to find out what was crippling her middle son. Through four years of grueling tests, numerous specialist visits and expensive procedures, a diagnosis of Chiari malformation and syringomyelia was finally made after a new, scientifically advanced procedure called Magnetic Resonance Imaging (MRI) was conducted in 1991. (MRI technology became available for clinical use in 1982 (http://content.healthaffairs.org/content/17/5/195.full.pdf+html). At the time, 22 families with children who had received a diagnosis of Chiari malformation found each other. In 1991, CM was regarded as a rare, orphan disease.

In 1999, another young mother, Lory Watson, was in a similar desperate search for the elusive diagnosis for her own son. Despite the fact that MRI technology was more readily available (by 1995 there were 3,705 MRI sites in the U.S.), it still took two years of the same grueling tests, countless unnecessary surgeries and expensive procedures for her own son to finally be properly diagnosed. By this time, Ms. Poppe had been working to raise awareness about CM and, through her efforts, a central database housing Chiari information existed. However, Chiari was far from a household name. Ms. Watson was unaware that a website with information that could help her son even existed. Even more disturbing was that none of the doctors and specialists on the Watson case had even considered CM as a possible diagnosis (this, in spite of the fact that Ms. Watson's son presented with classic Chiari symptoms). Interestingly, at about this same time, based on newly available MRI evidence, the estimated prevalence of CM was believed to have reached over 250,000 U.S. cases. What was once considered a rare disease was becoming more prevalent.

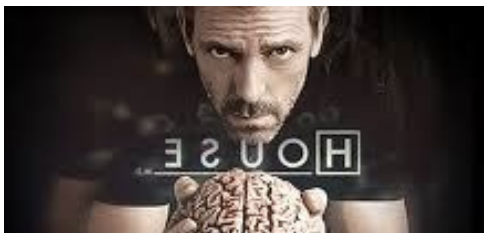
Fast-forward to today, and the number of MRI units continues to grow. Accordingly, the prevalence of CM, SM and RD continues to rise. Despite this, getting an accurate timely diagnosis remains one of the greatest sources of frustration and economic burden for patients. Many have still never heard of Chiari, and, as a result, are unable to advocate for a diagnosis. And, even though the growth in the prevalence of these disorders is staggering, CM is still not widely considered as a possible diagnosis for patients presenting

with textbook Chiari symptoms. This is taking a great toll, emotionally and financially, on every person participating in the health care system.

Since Chiari can only be properly diagnosed with MRI, it's essential that doctors 1) Recognize the symptoms of Chiari and 2) Order an early MRI to ascertain a definitive diagnosis. By thinking about Chiari as a possible diagnosis, everyone who participates in the healthcare system will enjoy the benefits of reduced costs overall, both emotional and physical.

2.0 Situation Analysis

- Internal strengths going into the campaign are numerous. First, we have already established a 501(c) 3 called the Chiari & Syringomyelia Foundation (CSF). Inside this, we have cultivated relationships with the world's top physicians in the field of Chiari malformation. Many of these doctors can provide an inroad for us into their University or medical facility. Additionally, CSF houses the world's most up to date research on CM/SM/RD. Doctors with little knowledge on these conditions can find peer-reviewed info on the site. This adds legitimacy to our message. CSF is also willing to underwrite the launch of the campaign. The board of directors and the board of trustees have approved the plan concept and creative that we have developed to date. The issue is of the highest priority to the organization. There is a dedicated paid staff that is available to help execute the plan. CSF staff is familiar with the procedures involved with accessing physicians at their annual meetings. Making relationships at these meetings is essential for developing future relationships within the universities and hospitals we may wish to access as part of the campaign. Additionally, we are reaching out to potential underwriters that may also benefit from the campaign. For example, MRI companies will enjoy the benefits of increased MRI usage. They may be willing to spread our message for us.
- Internal weaknesses to minimize would include disagreement on how and where to speak to the target audience with a limited budget. Additionally, doctors currently on the board who must approve the campaign have differing opinions about how best to convey the message, as each comes from a different discipline and background. It will be a challenge to appease each of them. Also, staff is limited and the campaign may prove to be labor-intensive. Volunteers may be needed to help implement the plan across the country. CSF does not have a large, reliable, volunteer base. As far as launching new campaigns, CSF has been relatively successful. However, because this campaign may rely heavily on doctor participation to get it off the ground, we will be competing for their limited and valuable time. Communications with physicians has been untimely in the past as they are pulled in many directions at once.



- External opportunities of the campaign are many. Today's culture and economy are focused on decreasing medical costs and increased patient involvement and responsibility in their own health care. MRI, while expensive at the outset, will actually lower the overall cost of CM/SM/RD care. Additionally, cheaper and easier refined MRI technology is already under development and clinical testing at several universities around the country. We have existing relationships with neurosurgeons who practice at hospitals affiliated with universities. Their influence might be able to open access to med school students who would benefit from exposure to CM even before they begin their residency and even prior to their ability to effectively advocate for the use of MRI. These students would offer an additional target audience for us should the campaign evolve into being able to support an expanded target.
- External threats to the campaign exist as well. There may well be a threshold where doctors "burn out" on learning about the next, up and coming "rare" disease. Until the prevalence of the disorder shows up within physician practices, it may be difficult for them to develop an affinity for the disorder. Additionally, more established conditions might consume the already limited time they would have available to think about Chiari as a possibility. Culturally, currently there are no well-known, contemporary celebrities that suffer from CM, so doctors in general might not identify the disease as increasing in prevalence or as part of the main stream. There is also an economic threat from insurance companies and HMO's who currently discourage the use of expensive MRI technology as a first line of defense in diagnosing patients. Until hard to quantify data is available to change their minds, they will continue to discourage MRI's even as we advocate for them. This may cause some retaliation on their parts. Finally, the state of Obama-Care may influence what insurance companies will be allowed or willing to pay for as we go forward. Until the Supreme Court rules on his plan, we are at a loss to know how impactful our campaign even CAN be.

3.0 Target Market Profile

The target audience is members of the medical community who could 1) potentially recognize the symptoms of CM/SM/RD and 2) make a recommendation that an MRI be ordered to determine a definitive diagnosis. This group would include, but is not limited to neurosurgeons, neurologists, radiologists, general practitioners, internists, interventionists, pediatricians, orthopedists, nurses and residents. These are members of the medical community who share a passion for medicine and expansion of their medical knowledge. They view continued education as an essential element determining their success as a physician. This is a large group of people. However, a representative sampling

of this group can be found at nearly every teaching hospital in urban cities across America. For the purposes of this project, we have selected Lutheran General Hospital in Park Ridge, Illinois as the location for our campaign trial launch.

Target Market Barriers, Benefits, and the Competition

CSF research amongst physicians has indicated that they are 1) either wholly unaware of CM/SM/RD or their symptoms or, 2) they are aware of the condition but have a misunderstanding of the prevalence of the disease and it remains low on their differential even when symptoms would otherwise place it high. Because of this, they rule out ordering an expensive test, the MRI, and opt instead to pursue a condition that is cheaper to diagnose. These clinical diagnoses of migraine, chronic fatigue, fibromyalgia and the like are cheaper to make, but often are wrong--yet they can't be proven wrong per se without additional data, like a film or a blood test indicating another condition. Another barrier is that many physicians are often reluctant to make a diagnosis on a condition about which they know very little and many are unaware of CSF so they do not realize how easily they can brush-up on peer-reviewed medical information on the disorders. Despite the limited amount of time physicians have to invest in additional learning, we need to communicate the potential benefits to physicians for adopting new behaviors as 1) ultimately providing patients with diagnosis far more quickly than what was previously experienced for Chiari patients—saving on the emotional and overall financial costs as well as the time invested by the patient, hospital and physician and 2) establishing oneself as a medical expert in the field of Chiari thereby being sought out by the already substantial and increasingly large group of Americans each year looking to hire physician to help treat their condition. Misdiagnosing the symptoms or downplaying the severity of CM/SM/RD symptoms are some of the competing behaviors that this campaign will combat. The perceived cost of ordering an MRI verses the actual cost to society is something that must be communicated clearly. Ordering cheaper tests (that ultimately can't answer the CM/SM/RD question anyway) as opposed to an MRI is one of our main competing behaviors to address.

4.0 Marketing Objectives and Goals:

The objective is to spark awareness of the disease putting Chiari on selected members of the medical community's radar in hopes that they think about Chiari as a possible diagnosis. Providing information on the prevalence of Chiari will hopefully help to change the behavior of overlooking the disease as a possible diagnosis. Providing the audience with a pre-presentation and post presentation survey inquiring about their knowledge of Chiari and its symptoms will provide insight into the effectiveness of the campaign. Our goal is to have a 100% of the participants in the grand rounds leave with a clear picture of the common symptoms of Chiari and the fact that they mimic other clinical diagnoses. We also need to convey that the only way to properly diagnose the disease is to order an MRI. Right now physicians are discouraged to order MRI's for many suspected reasons and are often reluctant to do so even as symptoms call for one. Our goal will be to determine exactly why and to address that particular finding in phase II of our campaign. The creative we have developed will stress that MRI is *the* definitive and appropriate study for patients presenting with CM symptoms.

Positioning Statement

We want our target, qualified members of the medical community, to investigate Chiari as a possible diagnosis for patients that are experiencing symptoms that suggest this disorder as a possibility high on the differential. These symptoms mimic other clinical diagnoses of what are thought to be more common disorders. However, an MRI may reveal that CM/SM/RD is really the culprit. Ultimately, when symptoms present, we want doctors to order an MRI to either properly diagnose or rule out the possibility of Chiari.

Marketing Mix and Strategy

Because of HIPA laws, very little data has been amassed about the current CM/SM/RD patient population. Furthermore, no quantitative data exists on physician interaction with CM/SM/RD patients in their practices. We intend to address this problem by accumulating the missing data via the use of grand rounds survey. What we learn will impact how the campaign evolves for phase II. However, for the purposes of the current campaign message, five years of key informant interviews and focus group data from the Chiari & Syringomyelia foundation has provided the foundation for the marketing strategy presented here. Over time, research has revealed that lack of consideration for Chiari as a possible diagnosis among all stakeholders is very likely the main reason that CM/SM/RD cases are under-diagnosed in a timely manner. Our blueprint for program design and implementation to address this key finding is summarized below:

Product

Core: By examining Chiari as a possible diagnosis high on the differential when appropriate symptoms present, everyone will benefit from the overall cost savings to the healthcare system. Doctors will have the added benefit of helping to ease patient frustration as well as ease their own workload when only the necessary and proper tests and procedures are performed on their patients.

Actual: When an MRI is ordered to confirm or rule out CM/SM/RD as a diagnosis, everyone can have peace of mind about the next steps in the patient's care. For those with CM/SM/RD, a trip to a qualified neurologist or neurosurgeon is in order. For those without CM/SM/RD, a valuable data point has been added to the mix in determining their eventual diagnosis. When the MRI is performed early, substantial emotional, financial and time, savings are realized. Our "Consider Chiari" campaign message specifically addresses the behavior we are hoping to promote amongst our target. Implied within the overall campaign is the essential message that an MRI is warranted in the cases where Chiari is considered as a possible diagnosis.

Augmented: In order to help in supporting the desired behavior of "Considering Chiari" as a possible diagnosis, we will endeavor to make certain that the target is constantly reminded of this message. During grand rounds, while the physicians are busy for several hours, the CSF team intends to "transform" their working environment such that when they

exit the seminar, there is a noticeable difference in their surroundings. Posters, table tent cards, Kleenex boxes, prescription pads and most importantly, coffee cups (as they are featured in the actual creative) with the "Consider Chiari" message will be scattered around the hospital when they return to their work environment. Our hope is that these reminders will serve to reinforce the message, "Consider Chiari", long after we have left the building and they have moved on to other things. Additionally, pre-lecture surveys that we will administer during the grand round lecture are intended to lead to additional augmented services by CSF—their data providing valuable insights into the type of education–related seminars we might need to add to phase II of the campaign.

Price

The cost to the medical community to simply recognize Chiari on the differential is free. However, to confirm the diagnosis with an MRI, someone will ultimately pay. For some physicians, to ordering an MRI will not affect their bottom line. These will be these easiest amongst our target to call to action. For others, ordering an MRI will indirectly affect their HMO reimbursements if they go over some stated annual maximum in their practice. Since every doctor negotiates his own contract with the insurance companies, it will be impossible for us to identify and segment this portion of our target. It will be important that the overall message addresses this concern in some way. We must convey the message that emotional, financial and time savings will be worth what price they may pay indirectly as insurance companies enforce their quotas. To not confirm or deny the presence of CM/SM/RD when the symptoms present can have a ripple effect on overall healthcare costs, as unnecessary tests and procedures are undertaken in the search for a diagnosis. Additionally, the emotional cost to physician and patient for missing a diagnosis that has been under their noses for years is substantial.

Place

The sooner the medical community regards Chiari as a possible diagnosis to correlating symptoms, the better off we all will be. In order for this to happen, we need Chiari and its' presenting symptoms to be introduced to medical professionals as early as possible in their medical education. While medical students might be a good place to start this process, our initial target for phase I will focus more on those already inside the medical system—people who not only can start "considering Chiari", but who can also effectively advocate for an MRI *now*. Med students will be reserved as a potential target for phase II of the campaign. There are many places to reach our target if we require that they meet only the first objective of the campaign, to simply ponder Chiari when symptoms present. However, if the second component of the campaign (order or advocate for an MRI to confirm) is included in the criterion, the places in which our target is likely to act drops substantially. As we see it, there are two key times where our target market will have the opportunity to perform both of our desired behaviors. Firstly, when our target is in a self-selected learning environment, such as when they attend grand rounds at their hospital, when they

read medical journals and publications, or when they attend their annual medical conferences, they are in the frame of mind to accept new medical information and perhaps apply it to existing cases in their practice. Another place in which they might act would be at their offices as they interact with patients or quietly consider their cases when writing reports at the end of their day. Perhaps the coffee cup from which they drink while writing such reports or a logoed scrip pad could be a way to keep our campaign message front and center with the medical professional pondering a complex case. Depending on our budget, we would need to prioritize the importance of our available distribution channels.

Promotion

Communication channels selected for our "Consider Chiari" campaign will include grand rounds venues at teaching hospitals, print publications widely read by medical professionals (both print and web based and both read in their work mode and leisure mode) and a Consider Chiari CSF presence (including print materials and give-aways) at the annual meetings of selected medical professional groups including but not limited to the RSNA, AAP, AAN, AAGP, AANS, and the CNS. Chicago will be our test market for a national campaign launch and as such, our first grand rounds meeting will be held at Lutheran General Hospital in Park Ridge, Illinois. This meeting will be the first of the bi-annual lecture series that will be offered in the Chicago market. In October, the Congress of Neurological Surgeons will meet in Chicago and there we will experiment with a "Consider Chiari" presence at the convention as well as introduce the "Consider Chiari" creative that we designed and developed has been approved by the board at CSF

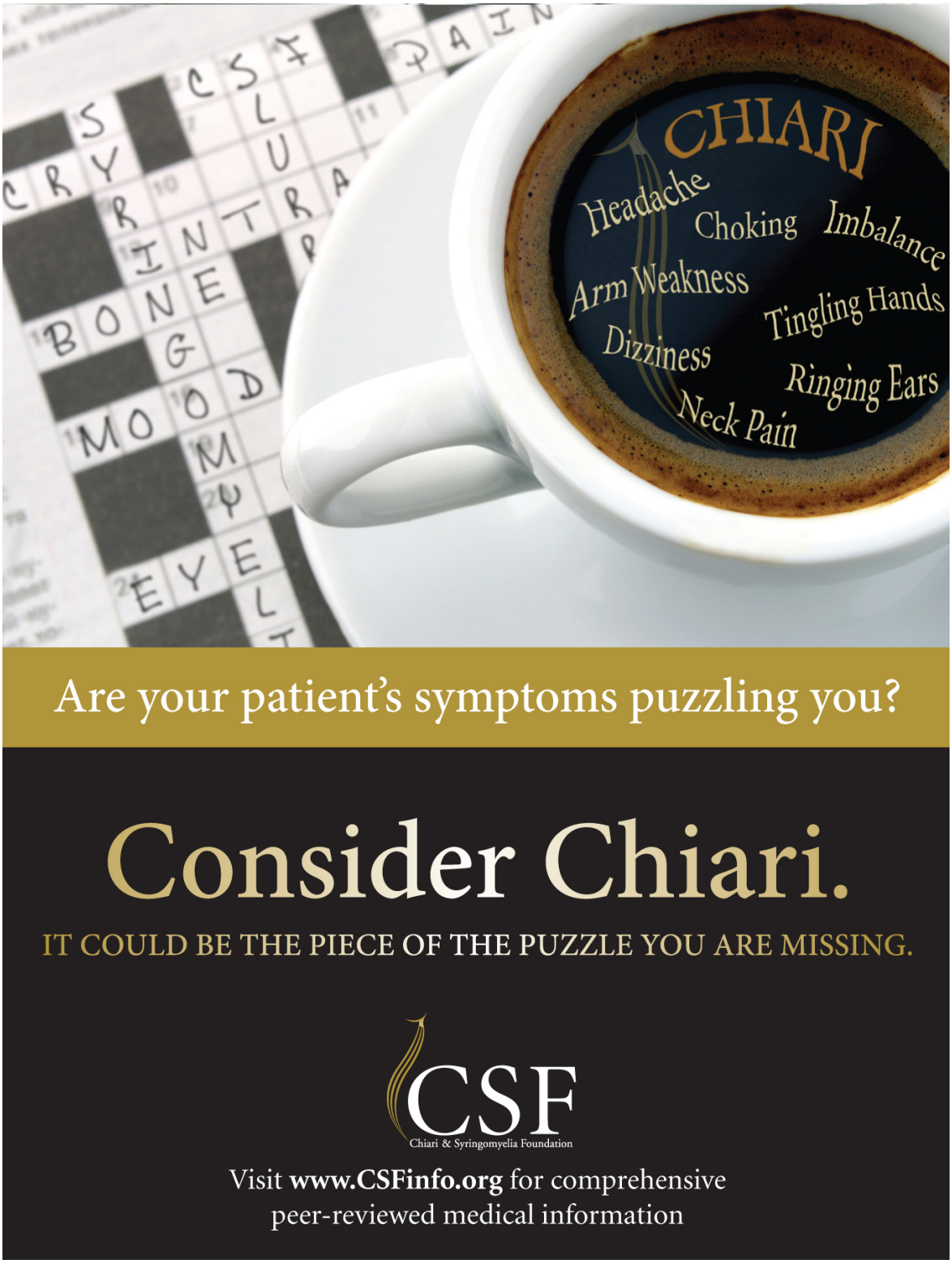
Where our project stands:

Having met with a neurosurgeon who offered to be the face of our campaign in Chicago we were able to lock in a cancellation date for grand rounds held at Lutheran General Hospital. All of our creative, aside from the mug, has been approved by the board and is ready to be utilized however we see fit. The relationship we have with the neurosurgeon in Chicago has allowed us to connect and market the grand round to other neurosurgeons and doctors in the area. The executive director for CSF is on board with our campaign and ready to assist us with the execution of the grand round as soon as our number is called. Being that we are in a cancellation spot we are not sure when we will be called in to host the grand round at Lutheran General Hospital and therefore need to be prepared to act quickly. A group of volunteers still needs to be assembled to help support the campaign the day of the grand round and the creative needs to be printed.

Are your patient's symptoms puzzling you?

Consider Chiari.

riate and often definitive study.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Arm Weakness
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