

Written Testimony of
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On behalf of the Chronic Pain Research Alliance

“Pain in America: Exploring Challenges to Relief”

Before the
Committee on Health, Education, Labor and Pensions
U.S. Senate

February 14, 2012

Chairman Harkin, Ranking Member Enzi, members of the committee, thank you for the opportunity to speak with you about how chronic pain affects the lives of millions in our country.

We extend our sincere gratitude to the Committee for passing a bipartisan amendment that called upon the prestigious Institute of Medicine (IOM) to study this public health crisis and develop recommendations on how to improve pain research, medical care and education. I *cannot* overstate its importance. The IOM report and today’s hearing give us renewed hope – hope that our country is listening to us, cares about our plight, and is ready to enact long-overdue change to help us regain our quality of life and ability to contribute to society.

My name is Christin Veasley. I am the executive director of the National Vulvodynia Association (NVA), a non-profit organization dedicated to improving the lives of the 1 in 4 American women, and countless adolescents who, throughout their lifetime, suffer with chronic vulvar (genital) pain. In addition to serving as an organizational representative, I am also a chronic pain sufferer myself. I survived a near-fatal car accident in my teens and found a resolution to the debilitating vulvar pain I experienced in my twenties; however, back and neck pain have been an unwanted companion for 21 years, and since 2008, I’ve developed jaw and facial pain, as well as migraine headaches.

My story echoes the experiences of millions in our country who bravely fight pain every day of their lives. From the moment I open my eyes each morning, the first thing I feel is pain. Just to get out of bed can be an insurmountable challenge. Normal daily living has become more and more difficult and it is a struggle to just get through the day. As the number of hours devoted to medical appointments, managing pain symptoms and coping with unpleasant side effects of medications increase, which for me currently averages 25 hours per week, the most meaningful parts of life can slowly fade away if you’re not diligent. Pain exhausts, depletes and drains you in *every* capacity – physically, emotionally, spiritually and financially. It feels like my life and spirit are being sucked dry, and I have to fight to remain an active participant in my own life. It is only by God’s grace and the support of my family that I function as well as I do.

Because the very purpose of pain is to warn you that something is wrong with your body, it is impossible to ignore it. I am constantly distracted. No matter how hard I try to focus, my mind is cloudy and my attention is scattered, like living with a veil over my face – blurred and unfocused. Work goes undone. Productivity and efficiency are things of the past. I only selectively engage in activities that I once enjoyed with my husband and daughters because of the increased pain and disability that follow. Life doesn't stop – it simply goes on in my absence. In social settings, I do my best to pretend that I'm okay, because no matter how well-intentioned others may be, they simply can't understand. Having previously experienced pain in the vulva for seven years – a part of the body that is not openly discussed in our society – I can testify that the suffering is further compounded by embarrassment, stigma and isolation. While it may be socially acceptable to tell another that you have a headache, women are not comfortable disclosing their inability to sit due to vulvar pain. Chronic pain is an invisible disability. Sadness, isolation, frustration, anger, anxiety, and a host of other unwanted emotions and feelings can dominate you and easily change who you are.

It's logical to ask, "why not see a different doctor or get better treatment?" The answer was recently summarized by a leading pain physician in the journal *Lancet*: "Overall, currently available treatments provide modest improvements in pain and minimum improvements in physical and emotional functioning. The quality of evidence is mediocre and has *not* improved substantially during the last decade." (Turk DC, et al, *Lancet* 2011;377:2226-35.) Because of this, doctors don't have the scientific information they need to make appropriate diagnostic and treatment recommendations. They look at me, shrug their shoulders and really don't have any idea whether a certain medication or treatment is going to work. As patients, we are left completely disillusioned, forced to navigate the health care system on our own and implement a trial-and-error process to find a treatment(s) to lessen the pain. In the last four years alone, I've been to specialists in four different states, have tried fifteen different treatments and still suffer with moderate to severe daily pain. In the last two years, I've easily spent over \$10,000 in out-of-pocket expenses alone. While I am fortunate to have an understanding employer and good health insurance, many in our country are not.

A growing body of scientific evidence backs my experience and that of millions of pain sufferers, i.e., once you suffer from one chronic pain disorder, you are more likely to develop additional pain conditions in other parts of your body. *Additionally, as highlighted in the IOM report, all of what I've just described disparately affects women with chronic pain.*

"After years of misdiagnoses (in my twenties), four miscarriages, four surgeries and, finally, a total abdominal hysterectomy at the age of 25, I am living proof of how poorly women's health needs are addressed. I suffered excruciating pain. This horrible disease ate through my body and eventually devoured my dreams. It is my hope and prayer that no other young woman on the brink of her life endure the pain, humiliation and disappointments that I experienced."

– Shelli, an endometriosis patient

This is the reason why the NVA joined forces with the Endometriosis Association, Chronic Fatigue and

Immune Deficiency Syndrome Association of America and The TMJ Association, to form the Chronic Pain Research Alliance (CPRA) - the first collaborative scientific advocacy effort in our country dedicated to alleviating the significant human suffering caused by prevalent, neglected and poorly understood pain conditions that frequently co-occur and disproportionately affect women. These disorders include vulvodynia, temporomandibular disorders, chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, irritable bowel syndrome and chronic headache.

In 2010, the CPRA launched the Campaign to End Chronic Pain in Women and released the ground-breaking report, *Chronic Pain in Women: Neglect, Dismissal and Discrimination: Analysis and Policy Recommendations*, which for the first time in history documents the human and financial toll that these conditions impose on women, their families and the US economy. (Please see the attached report and additional patient comments.)

The report's key findings include:

- (1) Women report pain that is more frequent, more severe and of longer duration than men, but are nonetheless treated for pain less aggressively. Women's pain reports are often taken less seriously by health care professionals than men's. Medical professionals are more likely to dismiss women's pain reports as "emotional, psychogenic, hysterical or oversensitive" and therefore "not real," leading to more frequent mental health diagnoses.
- (2) Our failure to effectively deal with these pain disorders adds as much as \$80 billion a year in direct and indirect costs to America's annual health care bill, much of which could be saved through an expanded federal research effort and improvements in diagnosis and treatment.
- (3) Despite their impressive personal and economic costs, research funding through the National Institutes of Health (NIH) is severely shortchanged, averaging just \$1.36 per affected woman in 2010. This is less than a tenth of one percent of the annual estimated cost of these conditions. Also, what little research that has been conducted has lacked sufficient coordination, interdisciplinary collaboration and direction. As a result, the disorders' underlying causes are unknown, diagnostic protocols are lacking and there are very few, if any, scientifically proven treatments. Health care professionals are therefore left without adequate knowledge to appropriately diagnose and treat chronic pain sufferers.

"Consider that lost productivity due to diabetes cost \$58 billion in 2007 [and in 2008], NIH spent just over \$1 billion on diabetes research and invested 1.7 cents for every productivity dollar lost. In comparison, last year the NIH spent only \$4 million in CFS research – an investment of less than one one-hundredth of a penny for every productivity dollar lost."

– Jennie Spotila, chronic fatigue syndrome patient

(4) The end result is that Americans suffering with these pain conditions are routinely misdiagnosed, shuffled from office to office, inappropriately treated and left without answers or hope, needlessly suffering. It typically takes several months to years, and multiple consultations, to obtain an accurate diagnosis. When a diagnosis is given, evidence-based treatment options are severely limited. Sufferers are forced to experiment with a myriad of therapies, most with unknown risks and benefits, until they find a treatment(s) to relieve some of their painful symptoms.

"The reason they gave me when they refused to treat me at the emergency room was, 'We can't treat you for pain because we would be treating a symptom rather than the cause of a problem.' My response to them was, 'After 12 years of surgeries and treatment and over \$200,000 in medical expenses, no one has fixed the problem, and in fact, it has gotten worse.'"
- TMJ patient

We applaud Congress, the National Institutes of Health and the Institute of Medicine for their initial steps to address the alarming public health crisis. Going forward, it is essential that:

- (1) HHS-funded research on these conditions is significantly increased, and taxpayer investments be made more efficient and effective by placing greater priority on collaborative interdisciplinary research across the conditions, as well as across HHS agencies and NIH Institutes and Offices.
- (2) HHS agencies aggressively expand, in a multidisciplinary fashion, the cadre of scientists dedicated to studying chronic pain.
- (3) HHS launch an aggressive multi-year awareness campaign, which includes the most current scientific information on the diagnosis, treatment and prevention of these disorders, to educate health care professionals, patients and the American public.

It is only through an expanded, smarter and more cost-effective federal research effort that: i) we will better understand the causes and mechanisms of chronic pain, as well as delineate which treatments are effective and do not harm; ii) the medical community at large will learn how to recognize and adequately manage pain; and iii) medical professionals will have scientifically proven information they need to make appropriate diagnostic and treatment recommendations. **Then, and only then, will the haphazard treatment of chronic pain, as well as costly and wasteful health care spending come to an end, giving the millions of American pain sufferers like Madalyn the one thing they desperately want returned to them—their lives.**

"My doctors just threw up their hands, not knowing what to do with me. I went to four doctors and each one said something different. I can't believe I have to go through this, and the expense is unbelievable. I am in so much pain and I just want my life back."

- Madalyn (age 19) – suffers from chronic fatigue syndrome, fibromyalgia and TMJ

Attached please find a copy of the CPRA's report and additional patient comments to be considered for inclusion in the record.

Chronic Pain in Women: Neglect, Dismissal and Discrimination

ANALYSIS AND POLICY RECOMMENDATIONS

JUNE 2011



 Produced by
campaign to
end chronic pain in women
www.EndWomensPain.org

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PREFACE

The Chronic Pain Research Alliance (CPRA) was formed to promote awareness and research of neglected poorly understood chronic pain conditions that affect millions of American women. CPRA updated its original white paper (pdf available [here](#)) to summarize progress made in this area since May 2010 and to provide updated policy recommendations to further CPRA goals.¹

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ABOUT THE CAMPAIGN TO END CHRONIC PAIN IN WOMEN



This Campaign aims to improve women's lives by raising awareness of chronic pain conditions that disproportionately impact women, as well as the neglect, dismissal and discrimination faced by women suffering with these disorders. This Campaign informs policy makers, health care professionals and the general public about the lack of scientific research conducted on these conditions, as well as the poor quality of education health care providers receive on chronic pain. It also promotes implementation of The 2010 Affordable Care Act to ensure that its programs include a long-overdue emphasis on women's pain conditions. The recommended policies could provide solutions that would save our nation billions in wasted health care costs each year. Equity demands no less.

Visit us: www.EndWomensPain.org

¹ Produced by M2 Health Care Consulting for the Campaign to End Chronic Pain in Women with financial support from Pfizer and through the extensive volunteer contributions from organizational leaders of the Chronic Pain Research Alliance.



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BACKGROUND AND EXECUTIVE SUMMARY

Chronic pain – defined as pain persisting more than six months – is all too common. It is estimated to affect 25 percent of Americans and account for more than 20 percent of all physician office visits.¹ Unfortunately, women bear the brunt of inadequate care and suffering experienced by chronic pain sufferers. As many as 50 million American women live with one or more neglected chronic pain disorders.* For the majority, our health care system offers frustratingly little help. In fact, most face neglect, dismissal and discrimination.

While chronic pain exacts a heavy personal toll on millions of women, it imposes a staggering financial burden as well. Our country's failure to support an adequate research effort and train medical professionals in the appropriate diagnosis and treatment of just six of these conditions – chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular (TMJ) disorders and vulvodynia - adds as much as \$80 billion a year in direct and indirect costs to American taxpayer's health care bill.*

Much of this spending is unnecessary and wasteful, as women are forced to visit multiple health professionals for months, and sometimes even years, before obtaining an accurate diagnosis and appropriate treatment. This delay can cause a woman's symptoms to worsen and may predispose her to developing chronic pain in other areas of her body, greatly impacting the quality of her life.

Despite their enormous personal and financial burden, the National Institute of Health's (NIH) research investment in the six conditions has been glaringly shortchanged. **In 2010, the NIH's research investment in these six disorders totaled only \$64 million – about two-tenths of one percent of its total budget. This is an average of just \$1.36 for every affected woman and represents less than one-tenth of one percent of the annual estimated cost of these conditions.** Also, what little research that has been conducted to date has lacked sufficient coordination, interdisciplinary collaboration and direction. As a result, the disorders' underlying causes are unknown, diagnostic protocols are lacking and there are very few, if any, scientifically proven treatments. Health care professionals are therefore left without adequate knowledge to appropriately diagnose and treat chronic pain sufferers.

A growing body of literature also documents a pattern of discrimination in the medical care of women with chronic pain. Studies show that:

- Women report pain that is more frequent, more severe and of longer duration than men, but are nonetheless treated for pain less aggressively;
- Compared to men, health care professionals often take women's pain reports less seriously;

*This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

- Medical professionals are more likely to dismiss women’s pain reports as “emotional, psychogenic, hysterical or oversensitive” and therefore “not real,” leading to more frequent mental health diagnoses rather than providing appropriate pain care.^{2, 3}

“After examining me and doing an ultrasound, my doctors said the only problem I had was in my head...”

*Rosemarie
Suffers from endometriosis*

The good news is that solutions are on the horizon; for example, expanded and better-coordinated research efforts could help to identify the causes of, and effective treatments for, these conditions. Likewise, improved medical education would enable health care professionals to better recognize and diagnose

these disorders. Additional recommendations, detailed in this report, would greatly improve women’s quality of life and cut billions in unnecessary wasteful care, thus helping to “bend the curve” of health care spending.

Since the release of our initial report in May 2010, the following encouraging steps have been taken:

- The United States Senate, in its fiscal year 2011 budget, called for an expanded and better-coordinated research effort on these conditions, as well as improved education of health professionals.
- In response to Congressional requests, the NIH commissioned the prestigious Institute of Medicine of the National Academy of Sciences to study the public health impact of chronic pain and develop recommendations to improve pain research, medical care and education. After months of deliberation, the distinguished panel is expected to release a landmark report summarizing its findings and recommendations on June 29, 2011. We hope that this report will redefine how our nation thinks about and confronts our country’s chronic pain epidemic.
- The Agency for Healthcare Quality and Research (AHRQ) has planned an analysis of the economic impact, including health care costs and lost productivity, of these disorders.
- The Army Surgeon General released an impressive new report, identifying the need for significant pain care and management reform in the military and for veterans. In response, the Department of Defense and the Department of Veterans Affairs are beginning to implement these recommendations.

These recent advances lay the groundwork for much-needed reform. Nevertheless, a significant amount of work remains, as is detailed in the policy recommendations of this report. Building upon these initial successes, we *can* improve scientific research and medical care provided to millions of Americans, thereby containing our nation’s rapidly rising health care bill.

CHRONIC PAIN IN WOMEN: AN OVERVIEW OF KEY CONDITIONS

As many as 50 million women suffer from at least one of these chronic pain disorders: chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular disorders

and vulvodynia.* All cause(s) of each are not known at this time and most are diagnosed by a process of exclusion.

Current research indicates that these conditions frequently coexist, or “overlap.”^{4, 5, 6, 7, 8, 9, 10, 11, 12, 13} Some women suffer from two conditions, while others have three or more. In some cases, women suffer from one condition for many years before developing a second or third condition; in other cases, those afflicted experience symptoms of several conditions simultaneously.^{14, 15}

The following chart provides a summary of each condition, including its prevalence and economic impact.

SUMMARY OF COMMON PAIN CONDITIONS DISPROPORTIONATELY AFFECTING WOMEN

Disorder	Description / Symptoms	Prevalence (US Pop)	Prevalence in Women	Symptom Onset	Misdiagnosed-Undiagnosed	Economic Cost (US, Annual)
Chronic Fatigue Syndrome	Chronic, debilitating fatigue and other characteristic symptoms. Symptoms: Chronic fatigue. Sleep difficulties. Problems with concentration and short-term memory. Flu-like symptoms. Pain in joints and muscles. Tender lymph nodes. Sore throat. Headache. Postexertional relapse.	Up to 4 million ¹⁶	Four times more common in women ¹⁷	Highest between 40-59 ¹⁸	More than 80% have not been diagnosed ¹⁹	\$17-24 billion (direct & indirect) ²⁰
Endometriosis	Chronic pelvic pain due to growth of endometrial tissue outside of the uterus. Symptoms: Pelvic pain before and/or during menstruation. Pain during/after sexual activity. Fatigue. Infertility. Heavy bleeding. Intestinal upset, painful bowel movements and/or low back pain with periods.	6.3 million ²¹	Affects women (extremely rare in men)	66% before the age 20 ²²	50% of women with endometriosis see at least five providers before receiving a diagnosis and/or referral ^{23, 24}	\$22 billion (direct & indirect) ²⁵
Fibromyalgia	Fibromyalgia is a chronic condition characterized by widespread soft tissue pain, as well as accompanying comorbidities such as disturbed sleep, fatigue and cognitive difficulties.	6 million ²⁶	Nine times more common in women ²⁷	Between 20-50 ²⁸	Has not been studied	\$20 billion (direct & indirect) ²⁹

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

SUMMARY OF COMMON PAIN CONDITIONS DISPROPORTIONATELY AFFECTING WOMEN

Interstitial Cystitis	Pelvic pain, pressure, or discomfort related to the bladder typically associated with urinary frequency and urgency, in the absence of infection or other pathology. Symptoms: Pressure, pain or tenderness in the bladder and/or pelvis. Chronic pelvic pain. Urinary frequency and urgency. Pain during/after sex. Increased pain as bladder fills.	8 million ^{30, 31, 32}	70% women ^{33, 34, 35}	Between 28-67 ³⁶	38% misdiagnoses rate ³⁷	\$66 million (direct & indirect) ³⁸
TMJ & Muscle Disorders	Group of conditions that cause chronic pain and dysfunction in the jaw joint and muscles that control jaw movement. Symptoms: Dull aching pain in the face, jaw, neck, or shoulders. Jaw muscle stiffness. Limited movement or jaw “locking.” Painful clicking, popping or grating in the jaw joint when opening or closing the mouth. A change in the way the upper and lower teeth fit together or bite that feels “off.”	35 million ³⁹	90% of the most severe cases are women in childbearing years ⁴⁰	Between teens and 50 ⁴¹	4 years from symptom onset to diagnosis ⁴²	\$32 billion (direct & indirect for orofacial pain) ⁴³
Vulvodynia	Chronic vulvar pain without an identifiable cause. Symptoms: Pain or discomfort with sexual intercourse, tampon insertion or sitting. Burning or other painful sensations in the vulva (area surrounding the vaginal opening). Redness/swelling of the vulvar tissue.	6 million ⁴⁴	Only affects women	Highest between 18-25/teens ^{45, 46}	40% remain undiagnosed after 3 medical consults ⁴⁷	Is currently being studied.

CHRONIC PAIN IN WOMEN: EVIDENCE AND IMPACT OF NEGLECT, DISMISSAL AND DISCRIMINATION

This section highlights both the evidence and impact of the neglect, dismissal and discrimination faced by women with chronic pain. As shown in Figure 1, a growing body of evidence demonstrates:

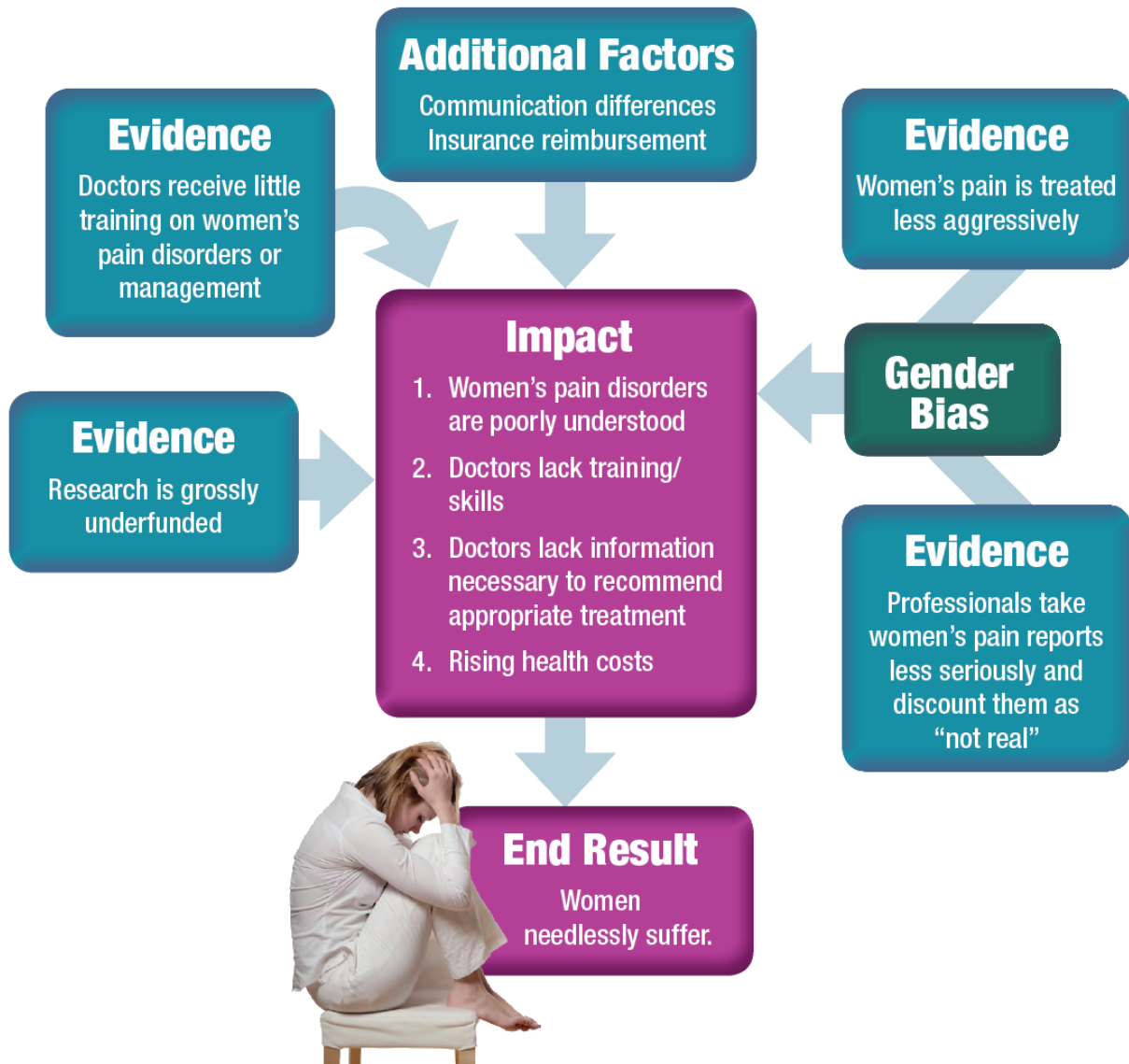
- One’s gender affects pain assessment and treatment. In other words, compared to men, women’s pain is treated less aggressively, and health care professionals are more likely to take women’s pain reports less seriously and discounted as “emotional, psychogenic, hysterical or oversensitive” and therefore “not real”⁴⁸;

- Chronic pain research, particularly that focused on conditions that solely or predominantly affect women, is grossly underfunded and inefficiently coordinated by the federal government; and
- Doctors and other health care providers receive little or no training on pain management or pain conditions that solely or predominantly affect women.

In addition to contributing to our nation’s rising health care bill, this “perfect storm” ultimately results in the unnecessary suffering of millions of American women because:

- The basic mechanisms and efficacy of treatments prescribed for these chronic pain conditions are poorly understood;
- Medical professionals lack the knowledge and proper training necessary to appropriately diagnose and treat these pain disorders; and
- Clinicians lack evidence-based data on which to base treatment recommendations.

Figure 1: “The Perfect Storm of Women’s Pain Policy” – How discrimination impacts women with chronic pain.



RESEARCH DISPARITIES

In 2011, the National Institutes of Health (NIH), the nation’s medical research agency, received \$30.7 billion in taxpayer funds to fulfill its mission to improve the health of the nation. The NIH supports research that extends “healthy life,” reduces the “burden of illness and disability,” and studies the causes, diagnosis, prevention and cure of human diseases.^{49, 50} However, considering that up to 50 million American women are affected by the six conditions examined in this report and the associated costs to our nation approach \$80 billion per year*, funding for research on these conditions has been severely shortchanged.⁵¹

Despite over a decade of repeated Congressional requests to significantly increase research dollars allocated to these disorders, in 2010, NIH spent just \$64 million on all of them combined— about two-tenths of one percent of its total budget. **This is an average of just \$1.36 for every affected woman and represents less than one-tenth of one percent of the annual estimated costs of these conditions.** In fact, as shown in Table 2, no pain condition ranks in the top 50 research/disease areas funded by the NIH. Funding for all chronic pain conditions combined barely makes the top 70, ranking 68th in research areas funded over the past several years. In addition, chronic pain is as prevalent as cancer, heart disease and diabetes combined, yet the NIH spends 96% less on chronic pain research.

Table 2: Estimates of Funding for Various Research, Condition and Disease Categories⁵²

Rank	Research/Disease Areas (Dollars in millions and rounded)	FY 2010 Actual (Includes ARRA)	FY 2011 Estimated
1	Clinical Research	\$12,260	\$10,707
2	Genetics	\$8,913	\$7,470
3	Prevention	\$6,832	\$5,981
4	Cancer	\$6,626	\$5,823
5	Biotechnology	\$6,885	\$5,675
6	Neurosciences	\$6,309	\$5,513
7	Infectious Diseases	\$4,458	\$3,888
8	Brain Disorders	\$4,466	\$3,845
9	Women's Health	\$4,140	\$3,689
10	Behavioral and Social Science	\$4,129	\$3,525
11	Clinical Trials	\$3,642	\$3,282
12	Pediatric	\$3,765	\$3,282
13	Bioengineering	\$3,926	\$3,162
14	HIV/AIDS	\$3,407	\$3,086
15	Health Disparities	\$3,079	\$2,726
16	Minority Health	\$2,838	\$2,525
29	Heart Disease	\$1,564	\$1,328
36	Diabetes	\$1,199	\$1,044
68	Pain Conditions – Chronic	\$404	\$360

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

An examination of the NIH research support (per affected person) allocated to these six pain conditions compared to other chronic conditions also brings to light the dramatic underfunding of research on women’s pain conditions. Table 3 provides several examples.

Table 3: Comparison of NIH Grant Funding to Prevalence for Selected Chronic Conditions, 2010

Chronic Condition	US Patient Population	NIH Research \$ 2010 ⁵³	NIH Research \$ Per Patient
Parkinson’s Disease	1 million ⁵⁴	\$172million	\$172.00
Diabetes	23.6 million ⁵⁵	\$1.2 billion	\$51.00
Depression	20 million ⁵⁶	\$470 million	\$23.50
Endometriosis	6.3 million	\$16 million	\$2.54
Interstitial Cystitis	8 million	\$13 million	\$1.63
Fibromyalgia	6 million	\$9 million	\$1.50
Chronic Fatigue Syndrome	4 million	\$6 million	\$1.50
Vulvodynia	6 million	\$3 million	\$0.50
TMJ Disorders	35 million	\$17 million	\$0.49

An expanded research effort for these six chronic pain disorders is essential — not only to help sufferers obtain relief, but to alleviate the associated economic, social and personal burdens. The government’s current research investment is woefully inadequate for this task.

EFFECTIVE EVIDENCE-BASED TREATMENTS ARE LACKING

Due to a lack of basic research on the underlying mechanisms that both trigger and maintain chronic pain, as well as specific pain syndromes and their treatment, the causes of these conditions remain a mystery, and evidence-based treatment options are severely limited. Sufferers are forced to experiment with a myriad of therapies, most with unknown benefits and risks, until they find a treatment or combination of treatments that helps to relieve some of their painful symptoms.

“The overall quality of treatment for pain in the United States remains unacceptable for millions of patients with persistent pain” ⁵⁷

Pain medicine position paper. Pain Me, 2009

Consider:

- **Chronic Fatigue Syndrome:** “Since no cause or cure for CFS has been identified, treatment programs are directed at relieving symptoms. There is no single treatment that fixes the illness at its core, but management aimed at reducing symptoms can improve function and allow people with CFS to engage in some of the activities of daily living.”⁵⁸
- **Endometriosis:** “No permanent cure for endometriosis has been found. Symptom relief is the primary goal of existing treatment options, which may be pharmacological or surgical.”⁵⁹
- **Fibromyalgia:** “There is considerable uncertainty surrounding the precise etiology, diagnosis criteria, and clinical management of [fibromyalgia] FM. Moreover, the extensive comorbidity associated with FM may increase potential for misdiagnosis by attributing painful symptoms to other causes. Given the ambiguity surrounding etiology and relatively recent development of treatment guidelines, management of FM likely has involved multiple visits to many different medical specialists...as well as multiple trials of different prescription drugs.”⁶⁰
- **Temporomandibular (TMJ) Disorders:** According to the NIH, “There is no widely accepted, standard test now available to correctly diagnose TMJ disorders.”⁶¹ “Because more studies are needed on the safety and effectiveness of most treatments for TMD, experts strongly recommend using the most conservative, reversible treatments possible.”⁶² Furthermore, “generally accepted, scientifically based guidelines for diagnosis and management of TMD are still unavailable. For the majority of TMD patients, the absence of universally accepted guidelines for evaluation and diagnosis compromises the goals of consistent and conservative therapy. The lack of standard treatment protocols accepted across professional specialties means that many patients and practitioners may attempt therapy with inadequately tested approaches.”⁶³
- **Vulvodynia:** “The treatment of vulvodynia is confounded by the fact that the cause is unknown in a majority of cases... It is important to recognize that rapid resolution of vulvodynia is unusual even with appropriate therapy. Whereas a 100 percent improvement rate is desired in all patients, most women with vulvodynia do not reach that level.”⁶⁴

THE HEALTH CARE SYSTEM AND ITS PROFESSIONALS ARE ILL-EQUIPPED TO SERVE WOMEN IN PAIN

Physicians' lack of understanding of chronic pain starts right from the beginning – in medical school. “Despite the clear need for competency in pain assessment and management skills, there is ample evidence that this competency is lacking at all levels of medical training.”⁶⁵ Few graduating physicians in the US have been exposed to comprehensive multidisciplinary pain education. In a recent letter to the editor of the journal *Academic Medicine*, professors and students from the Yale University School of Medicine wrote that an “Association of American Medical Colleges (AAMC) survey in 2000–2001...found that only three percent of medical schools had a separate course in pain management in their curricula; the situation is not much better today [2009].”⁶⁶ This is despite multiple studies highlighting “the lack of training in chronic pain management for resident physicians and the need to develop programs that address the challenges of providing care to chronic pain patients.”⁶⁷

The lack of education for temporomandibular disorders is a prime example. “In dental school, most universities give 10 to 15 lectures on TMD and orofacial pain conditions with no clinical supervision or training at all, and physicians probably get one lecture at the most.”⁶⁸ It is thus no surprise that the evaluation, diagnosis and management of TMJ disorders are not well understood by professionals in the dental and medical communities.

Notably, what medical students do learn about pain assessment and management is focused primarily on the mechanics of pain and not the patient's experience of it. Medical students are taught to determine the presence, location, character and intensity of acute and chronic pain. Upon entering clinical training, students confront suffering patients. This lack of any discussion about patient suffering in their curriculum makes a potent, yet hidden, statement about its apparent insignificance.^{69, 70}

Insufficient research efforts, coupled with the lack of education and training on chronic pain mechanisms and syndromes, leaves health care professionals ill-equipped to appropriately serve pain sufferers. Further, our health care system is “compartmentalized” by specialties, which is not conducive to comprehensive chronic pain assessment; for example, a woman might consult

When Pain Becomes Too Burdensome For the Disease-Treating Specialist

“I am a 26-year old female with fibromyalgia and a mixed connective tissue disorder (MCTD) closely related to systemic lupus erythematosus, and I experience widespread muscle and neuropathic pain that oftentimes becomes so debilitating that it impairs basic functioning such as standing and walking.

After several attempts at managing my pain through different narcotic pain relievers that had failed, my rheumatologist referred me to the medical center's pain clinic to have a pain medicine specialist take over the pain management aspect of my case. Among his reasons for referring me to a pain medicine specialist, the rheumatologist claimed, was that he was already overwhelmed with managing my disease to keep the MCTD from chronically flaring up and keeping track of the prescription medications relating to those goals. He explained that adding and monitoring narcotics further complicated his workload and required additional time to monitor interactions as well as his vulnerable Drug Enforcement Administration number.”

a clinician with expertise in the area of the body where she experiences pain, but that specialist likely lacks an appropriate understanding of chronic idiopathic pain.

Women with symptoms indicative of interstitial cystitis (painful bladder syndrome) will typically consult a urologist; those with TMJ pain will be sent to a dentist; and those with vulvodynia will seek help at the gynecologist's office. This is an important "first stop" for women, because known causes for their pain such as infections or viruses need to be ruled out. Once all of the potential instigators are eliminated, and it is determined that a woman has "idiopathic" pain, are these "organ-specific" providers the most appropriate professionals to manage chronic pain, which is likely a dysfunction of the central nervous system, and not a dysfunction of the "end-organ" where the pain manifests? If women shouldn't be managed by these specialists, who should manage them? Today, no appropriate "medical home" for women with these conditions exists, and this is particularly true if they suffer from more than one of these disorders. The problem is easy to illustrate: Can you imagine a woman talking to her dentist about her jaw and her vulvovaginal pain, or to her gynecologist about her TMJ problems?

Lack of health professional education and clear diagnostic/treatment guidelines due to inadequate research results in delayed diagnoses, misdiagnoses and delayed initiation of appropriate treatment, which can cause the woman's symptoms to worsen and may predispose her to developing chronic pain in other areas of her body.

CONTRIBUTING TO THE RISE IN HEALTH CARE COSTS

As previously stated, these chronic pain conditions cost our nation up to \$80 billion a year.* Substantial health care savings could be achieved through improved diagnostic tests and utilization of evidence-based treatments. Those afflicted are routinely shuffled from doctor to doctor before a diagnosis is made, each time incurring substantial costs. Women are often inappropriately treated and left to experiment with a multitude of therapies, most with unknown benefits. As a result, it often takes months/years and multiple expensive consultations for a woman suffering from one or more of these disorders to obtain an accurate diagnosis and initiate treatment that helps to relieve some of her painful symptoms.

For example:

- Forty percent of women with chronic vulvar pain remain undiagnosed after three medical consultations.⁷¹ Rapid resolution of vulvodynia is unusual even with appropriate therapy, and remission occurs in less than 25 percent.⁷²
- Fewer than 20 percent of chronic fatigue syndrome (CFS) patients in the United States have been properly diagnosed.^{73, 74} Because there is no diagnostic test or biomarker that clearly identifies CFS, diagnosing the disorder is particularly difficult.

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

- The fact that those with fibromyalgia (FM) frequently suffer from one or more other conditions may increase potential for misdiagnosis by attributing the condition's painful symptoms to other causes. Given the ambiguity around FM's etiology and relatively recent development of treatment guidelines, the management of FM frequently requires multiple visits to medical practitioners and several trials of different prescription drugs.⁷⁵
- For those with TMJ disorders, it takes an average of four years from symptom onset to diagnosis.⁷⁶ Over 50 treatment modalities, a remarkable array of medications, and a number of various surgical procedures are in the TMJ treatment armamentarium. A recent survey by the TMJ Association found the most helpful therapy was thermal – hot and cold packs. The most jaw surgeries performed on one person (from the TMJ Association database) were 62 and the patient died at the age of 41. A most cited 1992 study estimated the annual cost of TMJ treatments to be \$32 billion.⁷⁷
- Fifty percent of women with endometriosis see at least five health care professionals before receiving a diagnosis and/or referral.^{78, 79} No permanent cure for endometriosis has been found.

This delay in diagnosis and initiation of appropriate treatment can cause a woman's symptoms to worsen and may predispose her to developing chronic pain in other areas of her body, adding additional billions in unnecessary health care costs. **The lack of knowledge concerning the effectiveness of various treatments is not only expensive and inefficient, it imposes a huge burden on patients, payers and society as a whole.**

GENDER BIAS AFFECTS WOMEN'S MEDICAL CARE

Even though women experience pain that is more frequent, are more sensitive to pain and are more likely to report pain when compared to men, they are often met with “disbelief or other obstacles at their initial encounters with health-care providers.”⁸⁰ Therefore, it is not surprising that women with chronic pain frequently experience difficulty in seeking an explanation for their suffering. As previously stated, it often times takes several years for a woman with chronic pain to obtain an accurate diagnosis and initiate appropriate treatment.

“It’s a relief to finally have names for my conditions after suffering most of my life with a myriad of symptoms.”

*Susan, 53
Suffers from vulvodynia, IC,
and fibromyalgia*

Studies indicate that physicians demonstrate the least confidence in diagnosing *women's* medical conditions, and that women suffering with chronic pain are frequently told they have psychiatric conditions.⁸¹ If a physician is unsure of a diagnosis, he or she is likely to try one of three strategies with a patient: (i) normalize the symptoms; (ii) tell patients there is no disease; or (iii) use metaphors to explain the symptoms.⁸² However, “normalization of symptoms and telling

patients that they don't have a disease is not effective and may even result in more health-care seeking.”⁸³ It certainly creates stigma, and this problem is worse for women because most patients “with unexplained clinical conditions” are women.⁸⁴

“My doctors just threw up their hands, not knowing what to do with me. I went to four doctors and each one said something different. I can’t believe I have to go through this, and the expense is unbelievable. I am in so much pain and want my life back.”

*Madalyn (19)
Suffers from TMJD, CFS & FM*

A study of women with CFS and fibromyalgia showed that a lack of visible symptoms or changes in symptoms was also a cause for physician “disbelief.” “Absence of visible external signs of the illness contributed to [the patients’ reports] being called into question, and many believed that evident external symptoms would have enhanced their credibility.”⁸⁵

It is well-documented that women “report more severe levels of pain, more frequent incidences of pain, and pain of longer duration than men, but are nonetheless treated for pain less aggressively.”⁸⁶ In 2007, Canadian researchers reported: “Among 50,000 patients presenting to an emergency department with a main ambulatory care diagnosis of acute myocardial infarction, unstable angina, stable angina or chest pain, we found that women were more likely than men to be discharged home and less likely than men to undergo cardiac catheterization or revascularization.”⁸⁷ A recent study of emergency patients with similar presenting symptoms found paramedics gave morphine to men reporting pain, but did not provide morphine to treat pain in women.⁸⁸

If women suffering from conditions with well-established diagnostic and treatment guidelines such as cardiovascular disease experience such neglect and discrimination, consider what women who suffer from chronic pain syndromes, for which diagnostic and treatments guidelines have not been widely established, experience in their quest for appropriate diagnosis and treatment. Their reality is shockingly dismal.

WOMEN IN PAIN CONFRONT STIGMA

Women suffering from these pain conditions experience profound stigma as a result of the government’s inadequate research efforts, medical professionals’ lack of knowledge, society’s lack of awareness and gender communication differences. As one social scientist noted, “these illnesses are shrouded in great uncertainty, which can enhance their stigmatization potential.”⁸⁹

The following study results demonstrate the suffering and stigma experienced by women with these conditions, as well as the grave impact on their quality of life.

Consider:

- **CFS and Fibromyalgia:** One study of women with both disorders showed that they experienced stigma from both health care professionals and those in their social network. “Fibromyalgia in particular can be classified by other people as a women’s complaint,

which may be deprecatory. CFS is perceived as more dubious by the women themselves, their social surroundings, and their caregivers,” adding to the feelings of stigmatization.⁹⁰

- **Interstitial Cystitis/Painful Bladder Syndrome:** “Patients with IC/PBS report significant sleep dysfunction, depression, anxiety and stress compared to asymptomatic controls.” Further, patients perceive lower levels of social support compared to patients without IC.⁹¹
- **Temporomandibular (TMJ) Disorders:** In the case of TMJ, “failed treatments and recurrent pain episodes contribute to life stresses with a pattern of frustration, hopelessness, and even depression,” according to a technology assessment conducted by NIH.⁹² The terminology itself can be stigmatizing. The general public and patients usually recognize these conditions under the abbreviation “TMJ.” Patients prefer such an abbreviation due to their fear that by the use of the term “disorder,” health care providers, insurance companies, as well as family members and friends, may be more inclined to believe that these conditions are psychological in nature—a perception rejected by the overwhelming majority of TMD patients.⁹³
- **Vulvodynia:** The presence of pain in patients with vulvodynia is correlated with psychosocial impairment and decreased quality of life.^{94, 95} “Women with vulvodynia report a substantial negative impact on quality of life, with 42 percent feeling out of control of their lives and 60 percent feeling out of control of their bodies.”⁹⁶ Sufferers experience additional isolation and stigma because genital conditions are still not openly discussed in our society. Fewer than 25 percent of women reported feeling comfortable disclosing vulvodynia to their closest female friends.⁹⁷

RECOMMENDATIONS

COMBATING CHRONIC PAIN IN WOMEN: IDEAS FOR CHANGE

As documented in this report, chronic pain conditions that solely or disproportionately affect women exact a significant human and financial toll; however, they are poorly understood and neglected. An aggressive comprehensive set of reforms is imperative to addressing this major health care problem. Implementation of these reforms will result in substantial short- and long-term improvements in patient care and quality of life, as well as substantial health care cost savings and major improvements in the productivity of our workforce.

More effective and efficient research on women’s chronic pain conditions would provide our nation with a tremendous opportunity to make a significant difference in the lives of millions of American women and achieve substantial long-term health care cost savings. The following policy recommendations would greatly improve sufferers’ medical care and quality of life, while also playing a crucial role in “bending the curve” of future health care spending.

National Institutes of Health (NIH)

In 2010, we recommended that NIH-funded research on pain conditions that solely or disproportionately affect women, including chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular disorders and vulvodynia, should be substantially increased to be more commensurate with the collective toll these conditions take on individuals and the nation. Additionally, we noted that increased funding should be directed toward expanding basic and clinical research on the causes, diagnoses, treatment and prevention of these chronic pain conditions. We are pleased to share that NIH has responded by funding the Institute of Medicine Pain Study. The NIH Pain Consortium focused its 2011 annual research meeting on overlapping pain conditions. Additionally, NIH is supporting research conferences on TMJ, vulvodynia, chronic fatigue syndrome, and the overlapping nature of these conditions. Research funding levels for these conditions, however, did not significantly change. While these steps are encouraging, there is still a significant amount of work that needs to be done.

NIH-funded investments can be made more efficient and effective by placing an even greater priority on interdisciplinary research across disciplines pertinent to these conditions. NIH should support the creation of four or more regional Women's Chronic Pain Conditions' Centers of Excellence, to be established at leading academic health centers across the nation. In addition to conducting research, they should provide women with access to teams of health professionals with training in state-of-the art diagnostics, therapies and, where appropriate, prevention protocols for chronic pain.

Specifically, the NIH Director should coordinate, with all relevant Institutes and Centers, a trans-Institute research initiative that will support studies aimed at identifying common etiological pathways, with the goal of identifying potential therapeutic targets. Additionally, the NIH should organize/convene a conference that will bring together a wide range of basic and clinical scientists from multiple specialties, as well as professional and patient advocacy organizations, to present and discuss the latest scientific discoveries and develop future research recommendations in this area.

“After 12 years of surgeries and treatment and over \$200,000 in medical expenses, no one has fixed the problem, and in fact, it has gotten worse.”

A TMJ patient

NIH must move aggressively to expand, in a multidisciplinary fashion, the scientific field dedicated to studying chronic pain conditions that solely or disproportionately affect women. Accordingly, the NIH Director should support initiatives to foster the careers of graduate students and postdoctoral fellows in all areas of biomedical research related to chronic pain conditions. This effort should include loan repayment programs for those agreeing to work three or more years in this research field.

There is clearly a need for NIH to substantially increase the amount of funding provided for research on pain mechanisms/disorders. NIH's investment in this area, relative to the public health and economic impact of chronic pain, is inadequate. Significantly increasing research funding would profoundly advance our understanding of chronic pain's basic underlying mechanisms and help to develop improved treatments. Many examples demonstrate this

potential; the state of HIV/AIDS understanding and treatment was literally revolutionized by a dramatic increase in NIH investment in HIV/AIDS research.

For additional funding to be effectively utilized, some inherent weaknesses in the NIH's structure must be addressed. One potential model for improving the development and coordination of pain research is to build on the existing structure; additional authority should be given to the Pain Consortium to better coordinate and fund pain research across the many Institutes and Centers (ICs) currently supporting this scientific area. The Consortium should be given an annual budget of no less than \$200 million and increase over time. In addition, the Consortium should be led by no more than two ICs, including other IC representatives on an advisory committee. The Consortium should work with consumer, professional and patient advocacy groups and regularly report directly to the NIH Director and to Congress.

Another possible approach to improving pain research coordination and accountability would be for the NIH Director to appoint one Institute to lead the NIH's pain research effort/portfolio. This change would have the benefit of greater accountability and improved decision making, however, such a change would have to be accompanied by commitment and support of pain research from other ICs. It would be a great loss if such a change were to lead to an overall reduction in pain research effort/focus and the loss of crucial multidisciplinary research.

Centers for Disease Control and Prevention (CDC)

The CDC should launch a program to study the prevalence and incidence of, and risk factors shared by, the following chronic pain conditions: endometriosis, interstitial cystitis, fibromyalgia, temporomandibular disorders, vulvodynia and chronic fatigue syndrome.

In addition, the CDC, with support from and in collaboration with other federal agencies, should launch a multi-year awareness campaign that will: i) educate the public about the seriousness and societal costs of these conditions, ii) make available and promote sources of reliable information on the symptoms, diagnoses, treatment and overlapping nature of the disorders, and iii) provide information to women with chronic pain about how to effectively communicate with their health professionals about these conditions.

Using the latest scientific information on the diagnosis, treatment and prevention of these disorders, CDC should support an aggressive multi-year campaign to better educate health care professionals, particularly those working in primary care settings. This campaign should include the development of continuing medical education courses for professionals in practice and curricula for medical schools and other health care training programs. Overcoming bias should be a core part of medical, nursing and allied health curricula, as well as a component of health professionals' continuing medical education.

Agency for Healthcare Research and Quality (AHRQ)

AHRQ should complete, in a timely manner, its planned analysis of the economic impact, including health care costs and lost productivity, associated with these disorders. In addition, government, health care payers and medical professionals should develop and utilize coordinated

health information technology systems to better track pain conditions to determine their changing prevalence and treatment outcomes.

Department of Defense and Department of Veterans Affairs

The Department of Defense, particularly the Office of the Army Surgeon General, is to be commended by the seriousness with which it is confronting the chronic pain epidemic. The recommendations made in the [May 2010 Office of the Army Surgeon General Pain Management Task Force Final Report](#) should be promptly executed by the DOD and DVA, and where appropriate, should be extended to other federal agencies, including NIH. Specifically, the reports call for an expanded and better-focused chronic pain research effort, as well as the development of comprehensive Centers of Excellence. These Centers would expand research and develop/disseminate the latest research findings to health care professionals during their initial and continuing medical education, and should serve as a model throughout the federal government. In addition, the report calls for a concentrated education effort for patients, their family members and health care professionals, which is extremely important and should be developed in coordination with other federal agencies.

Federal Inter-Agency Coordination

Overall, there is a great need for improved coordination and shared resources among the many federal agencies involved in pain care, treatment, education and research to ensure sharing of information, replication of best practices and elimination of overlap and duplication. Particularly the DOD, DVA and HHS must immediately execute better coordination in planning and conduct of their many activities in this important area.

Public-Private Partnerships

The NIH should promote and provide necessary financial backing for the Biomarkers Consortium to undertake a Pain Biomarkers project similar to the Consortium's initiative on Alzheimer's disease. The Consortium is a public-private biomedical research partnership that includes representatives from NIH, FDA, academia and the biopharmaceutical industry (managed by the Foundation for the National Institutes of Health) that endeavors to develop, validate, and/or qualify biological markers (biomarkers) to speed the development of medicines and therapies for detection, prevention, diagnosis and treatment of disease and improve patient care.

In addition, the Analgesic Clinical Trial Innovations, Opportunities and Networks (ACTION), a public-private partnership between the FDA, biopharmaceutical industry and academia network should be strongly supported by all partners and viewed as an important model for the development and pursuit of other similar partnerships to speed the development of improved therapies for chronic pain conditions.

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Chronic Pain Research Alliance
Quotes/Stories from Patients and Family Members

“After examining me and doing an ultrasound, my doctors said the only problem I had was in my head...”

– Rosemarie, endometriosis patient

“Is it too much to ask that we, the patients, no longer be bound to a system where no one professional takes responsibility for the patient - a system of unbelievable referrals with unscientific, unproven treatments (and hope) sold to the patient by each referring physician? In many cases, patients end up worse and more and more destitute, yet they grasp for hope with each referral. Is it too much to ask that we get the protection we deserve under the Hippocratic Oath to do no harm and the laws of the United States?”

- Terrie Cowley, TMJ patient and President of The TMJ Association

“I am a 26-year-old female with fibromyalgia and a mixed connective tissue disorder (MCTD) closely related to systemic lupus erythematosus, and I experience widespread muscle and neuropathic pain that oftentimes becomes so debilitating that it impairs basic functioning such as standing and walking. After several attempts at managing my pain through different narcotic pain relievers that had failed, my rheumatologist referred me to the medical center’s pain clinic to have a pain medicine specialist take over the pain management aspect of my case. Among his reasons for referring me to a pain medicine specialist, the rheumatologist claimed, was that he was already overwhelmed with managing my disease to keep the MCTD from chronically flaring up and keeping track of the prescription medications relating to those goals. He explained that adding and monitoring narcotics further complicated his workload and required additional time to monitor interactions as well as his vulnerable Drug Enforcement Administration number.”

- Fibromyalgia patient

“It’s a relief to finally have names for my conditions after suffering most of my life with a myriad of symptoms.”

- Susan, vulvodynia, interstitial cystitis, and fibromyalgia patient

“My doctors just threw up their hands, not knowing what to do with me. I went to four doctors and each one said something different. I can’t believe I have to go through this, and the expense is unbelievable. I am in so much pain and want my life back.”

– Madalyn, TMJ, chronic fatigue syndrome and fibromyalgia patient

A compilation of emails received by the TMJ Association:

“I have a 46 year old son that is suffering from severe TMJ. He has been under treatment for 15 years for it and everything they have tried, including several TMJ surgeries, have failed. He has now lost his job, (Fire Investigator), has no benefits, is filing bankruptcy and was so desperate with the pain. He lives in Austin, TX. I am willing to sell my home and apply the money to help

him. My husband and I are 73 & 74 so our lives are not as important as his is. He has 2 children still living at home. Since my husband spent 28 years in the army, I think we can get help with housing with them, for us. Please, please, is there any help for him?"

- David's mother (April 2008)

"Our son died as a result of all the suffering he had. David became addicted to his prescription drugs and had gone to a short term re-hab but needed more help. He stayed with us for 2 years and finally went to the hospital to detox, stayed 3 days and then agreed to go into Teen Challenge. His heart had become weakened over the years of prescription medications and he put a Fentanyl patch on and then to get more relief, he put the other patch in his mouth. It was too much for his heart. He was a brilliant man, adored his 3 children and wanted so much to get well. He died September 29, 2010 at the age of 48 sitting in a chair in our backyard and my husband found him very shortly after he died. David left behind a wife, 26 and 19 year old daughter, and a 21 year old son. It is so hard to see what the family can suffer through all this...but these young ones of ours have paid the price for the pain and addiction. Our hearts go out to anyone suffering this dreadful disease. You are doing such a great work and we will keep you in our prayers for February 14th Senate Hearing."

- David's mother (January 2012)

"The hardest thing was to approach my condition rationally, because I needed doctors to take me seriously. What I really wanted to do was to scream or cry out of frustration and utter desperation."

- Vulvodynia patient

"My periods were getting worse, but I was used to having debilitating pain so I did not think that it was necessarily unusual. Eventually, out of sheer desperation, I went to a local clinic ...and [the doctor there] found a pelvic mass of approximately 6-7 cm.... that needed surgical removal. I was in a state of shock. How did it get that way? I had seen doctors on a regular basis for the last year. While I awaited surgery, I had another period where I started hemorrhaging and drifted in and out of consciousness on the floor of a washroom at work. Finally the surgery took place and the doctor told me I had endometriosis."

- Endometriosis patient

"I did get my insurance to pay for most of this by not calling it TMJ (they don't like those letters). My doctor called it jaw joint surgery and a bone spur. The surgery cost over \$30,000 and I paid \$100 co-pay."

- TMJ patient

"The reason they gave me when they refused to treat me at the emergency room was, 'We can't treat you for pain because we would be treating a symptom rather than the cause of a problem.' My response to them was, 'After 12 years of surgeries and treatment and over \$200,000 in medical expenses, no one has fixed the problem, and in fact, it has gotten worse.' The hospital then refused any treatment, even though my blood pressure/temperature was

high, and then labeled me a 'drug-seeker' on my hospital records. Now, I am petrified every time I have to ask for pain medications."

- TMJ patient

"Consider that lost productivity due to diabetes cost \$58 billion in 2007. Last year [2008], NIH spent just over \$1 billion on diabetes research. In other words, NIH invested 1.7 cents for every productivity dollar lost. If NIH allocated research funds to CFS as it has to diabetes, then a 1.7 cent investment per dollar lost would translate into \$1.3 billion dollars in annual research. Apparently, NIH believes that CFS does not merit such investment. Last year the NIH spent only \$4 million in CFS research – an investment of less than one one-hundredth of a penny for every productivity dollar lost."

– Jennie M. Spotila, chronic fatigue syndrome patient

"My daughter has had endo for over four years. Our insurance dropped us because the RN at the company said my daughter (a teen) could have a hysterectomy and not run up all these bills!"

– Jeannie

"I have constant headaches, neck pain, ear and jaw pain. I can't get rid of it. Comes and goes like a roller coaster. Not a happy way to live."

- Michael, TMJ patient

"Endometriosis runs in my family. I suffered years of infertility and had three surgeries. Now my daughter who is 22 has all the symptoms. She's talking to a doctor that wants to burn the lesions off - that's what was done to mine. Have we made no progress at all in reducing scar tissue?"

– Susan

"I am a post-hysterectomy survivor of endometriosis. We found out about my daughter's endo when she was 11. She had painful symptoms before her first period and we went to numerous doctors who told us everything from "Amanda or a family member is making up these symptoms to get attention and/or drugs" to "Amanda just needs to understand that cramps are a way of life for women." Her first surgery was at age 12 and even the doctor who performed the surgery was shocked at the extensiveness of her endo. Now two-and-a-half years later, Lupron, drugs, and more surgery, we are making a last effort to save her reproductive ability."

– Kari

"I suffer from TMJ have horrible pain in my jaw from constantly clenching it. I've had all new caps put on my bottom teeth and have had 4 teeth pulled due to them breaking as a result of the strain. At times my jaw will lock and it hurts to open my mouth. I wear a night guard that provides some relief at night. This whole process has become extremely expensive and my insurance isn't picking up most of it."

- Jacqueline, TMJ patient

“I suspect there is a lot of suicide in women and girls with endo. I attempted suicide several times as a teen because the pain was that intense. I was planning on trying again in my mid-20s when I discovered the Association. I suspect I may have been successful that time. The Endometriosis Association literally saved my life.”

– Terri

“My 18 year old is suffering terribly with endo, so much so that she has been unable to attend school for the past 1½ years and it has cost her participating in graduation this week. She thankfully is a strong willed young woman and my husband and I are her supporters 100% of the way. We are at a loss on treatment however. She has had two laser treatments with minimal lasting results. My husband is a family physician and he particularly feels helpless.”

– J.

“I have suffered with intermittent headaches, jaw pain, loss of sleep, poor quality sleep for almost 10 years due to jaw clenching/TMJ. I have had two different bite guards, my teeth adjusted for proper bite, seen two different general dentists and two subspecialist dentists. It is obvious to me that there is little consensus between different practitioners and that more research into the treatment of this disorder is needed.”

- Tara, TMJ patient

“After years of misdiagnoses (in my twenties), four miscarriages, four surgeries and, finally, a total abdominal hysterectomy at the age of 25, I am living proof of how poorly women’s health needs are addressed. I suffered excruciating pain and continual bleeding for months. Handed a Rx for Valium or some other medication to “calm” me because doctors felt my symptoms were emotionally induced. This horrible disease ate through my body and eventually devoured my dreams. Years later I find myself with rheumatoid pains, diagnosis of fibromyalgia, Hodgkin’s lymphoma and breast cancer. It is my hope and prayer that no other young woman on the brink of her life endure the pain, humiliation and disappointments that I experienced.”

– Shelli

“I feel as if I am at the end of my rope. I have lost my job and may end up losing my home. I have been able to work since December 2010 & ended up getting fired in January 2011 because my FMLA didn't get approved. I also suffer from allergies and my ENT & I originally thought that was the cause of my ear pain. However, once the redness in my ear tubes went away we discovered I also had TMJ Disorders.”

- Laura, TMJ patient

“Endometriosis bites to the very soul of our lives – everyday! I have grieved the loss of friends, the loss of employment and purposefulness. It’s unbelievable to realize how the basic concept of many is that endo is only a pain thing! Oh, goodness, how can I ever explain that endo is so very much more? It’s fatigue, it’s allergies to all kinds of chemicals/cleansers/perfumes (any kind of public place is a menagerie of smells to be allergic to!), it’s erosion of the can-do attitude, it’s a hounding, cureless “poison” in my body that affects every facet of one’s life!”

– Janeen

"I am 19 years old. I had to graduate from a homeschool program because I was just not physically able to go to school every day. I have not been able to work and every day I hear about that from my parents. I am not able to live up to who they want me to be. It's hard for me because I had always made them proud (i.e., sports, school, community service) but now I can't. They think that I am lazy, when really I want to work. I would do anything to feel well enough to be able to go to a job every day. I don't know what I can do to make them understand what I am going through. I have become severely depressed, developed an eating disorder and feel that every day to get up is a challenge."

– Zoe

"I am 24 and I was diagnosed with vulvodynia when I was 18. I experienced symptoms when I first had intercourse at the age of 17 and was in excruciating pain. All I could do was curl up on the couch the next day. At first, I thought that the pain was normal, that it was supposed to hurt the first time. But the pain wasn't getting better so I went to the doctor, actually four [doctors], and they all told me different versions of the same thing: I was just "tight" or "small" inside; that I just need to relax, that I should just have more sex, etc. One even suggested that I have a glass of wine (remember I was 17 at the time).

I finally found a knowledgeable provider who told me that I had vulvodynia. For the past five years I have been on different treatments including physical therapy, biofeedback and several drug regimens. I've also had a vestibulectomy surgery and then a follow up surgery and I am [still] in chronic pain.

It has been very difficult growing up with this. It has affected so much in my life. Now, after years of living with this, and going through incredibly painful, ultimately unsuccessful, surgeries I sometimes feel as if I have come to terms with this condition. For the most part, I just accept that this part of my life is not going to change and that accepting it and moving on is what I am working on. But I have to say; sometimes it seems that it will be an impossible feat to find a partner who will happily be with me for the rest of his life, especially if I'm not able to have sexual intercourse because of my vulvodynia."

– Tamara

"I am the concerned and exhausted mother of a beautiful teenage daughter who has been suffering for about 5 years with excruciating and sometimes unexplainable pain. I am tired, frustrated and feel like a failure because I cannot help my daughter. I am watching her change, struggling through pain, trying desperately to stay in school and beginning to feel as if there is no end to her misery. Plus, the fact that we have already put in enough money into this we could've bought her a new car and it still isn't over."

- Dawn, Mother of a TMJ patient

"At age 19, I married the man who was and still is my best friend. I was a virgin until our wedding night and when my husband and I first tried to have sex, I cried from the pain. We thought that was just the way things were when sex was new, but in my gut, I had known for

years that something was wrong. Confusion and depression followed. I never wanted to attempt sexual or even mildly intimate contact, and our relationship suffered because of it. At age 20, I was told my symptoms were psychological and that I simply needed to stretch my vagina.

After so many painful and misunderstood exams, and so many shed tears, at age 21, I was diagnosed with vulvodynia. My gynecologist could only offer me anti-depressants in an attempt to numb the physical pain, but the side effects were too much for me and I soon stopped. It took three more years before I was finally able to see a doctor who could help and provide me with treatment options. I am now 24 and am on a treatment plan. Though there is still discomfort, the condition, for me, is largely in my control. Two weeks of treatment was all it took for me to improve, and I had waited in the dark for more than 10 years.”

- Angela

“I am a 16 year old with endo. I was diagnosed this May along with my mother. For years doctors have never taken the pain that my mother and I feel seriously. Sometimes family members even thought that it was hard to believe we were in as much pain as we said we were. One day my boyfriend was reading the newspaper and found an article about endo. He suggested that I might have it, so I brought it to the attention of my mother. My mother and I read it and it hit too close to home. A month later we saw a gynecologist who understood what we were going through. Just the fact that someone understood and didn't think we were crazy made us feel so much better. I was put on the pill, and most of the symptoms have been suppressed. As for my mother, she's still waiting for more options.”

- Emily

“Why do our girls have to suffer so?”

- Mother of an endometriosis patient

“The other women, and men, that I have spoken to have gone through a series of doctor appointments and tests, and felt like they were walking through a maze without any light in sight.”

- Kathleen Matarazzo Specca

“You're almost relieved when your blood work or tests show something because you're like finally this doctor with their fancy degrees is going to believe me, that there is something wrong with me.”

- Therese McAllister

“There is a belief there that when a woman has temporomandibular joint disorder, that it is all because of their stress and their age.”

- Therese McAllister

“I had a surgeon that looked at me and said, ‘Well all women have endometriosis, and you just need to shake yourself off and get back to work.’”

– Therese McAllister

“We know from a lot of research that providers are less likely to make an accurate and speedy diagnosis of female patients, based on what we call feminine style. The way that females, in this culture and this country especially, are trained to communicate at a very early age, are trained to be nicer, to use more qualifiers, to be more indirect, to be more relational – which means we spend more time getting to know someone.”

- Melinda Villagran, Ph.D., Associate Professor of
Health Communication George Mason University

“I’m in too much pain to spend an hour and a half on hold with an insurance company, and the insurance companies know that, and they take advantage of it.”

– Jennifer Feldman

“Twelve surgeries later, I now have bilateral joints. Instead of a house, I have a jaw.”

– Beth Bigge

“I think if this was something that men were suffering from, there would be a lot more money going into the research, and would be a lot more solutions out there for them to choose from.”

– Karen, Vulvodynia patient