

The FibroCollaborative Roadmap for Change: *A Call to Action for Fibromyalgia*

The FibroCollaborative and Pfizer Inc are grateful to the Medical Co-Chairs of the Advocacy Working Group for their insight and guidance:

Daniel J. Clauw, MD

Professor of Anesthesiology, Medicine (Rheumatology) and Psychiatry, and Director, Chronic Pain and Fatigue Research Center, University of Michigan

Bill McCarberg, MD

Founder and Attending Physician, Chronic Pain Management Program, Southern California Kaiser Permanente Medical Center



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FOREWORD: A MESSAGE FROM THE CO-CHAIRS



In October 2009, we had the distinct privilege of serving as co-chairs of an unprecedented meeting that brought together a diverse group of medical, professional and consumer advocacy organizations all focused on improving the recognition, diagnosis and management of people with a serious, chronic widespread pain condition called fibromyalgia (FM).

We came together at a critical juncture. While FM has previously been described as “poorly understood,” that is emphatically no longer the case. Over the last 20 years, and especially in the last ten, our understanding of fibromyalgia has increased exponentially. An improvement in our mechanistic understanding of FM helped lead to testing of drugs that should work in FM, and they did, leading to recent approvals by the U.S. Food and Drug Administration (FDA) of treatments specifically for the condition. We now know that the widespread pain and tenderness that are the hallmark symptoms of FM are at least partly the result of neurochemical imbalances in the central nervous system that lead to a “central amplification” of pain perception. In other words, people with FM feel more pain in response to painful stimuli as well as to stimuli that are not normally painful. Our understanding as to why this central amplification of pain perception occurs has helped to explain the varied (and often confounding) symptoms people with FM experience, and has been instrumental in suggesting ways the condition can be better managed. This in turn has had a galvanizing effect on those who for years have struggled to raise awareness, improve diagnosis rates and enhance the lives of people with FM.

In the “real world,” however, timely diagnosis and comprehensive management of FM has remained elusive for many, sometimes tragically so. Many people with FM still go from clinician to clinician over the course of multiple years without receiving an accurate diagnosis, all the while coping with disabling pain, fatigue and sleep disturbances that can have a profound effect on their daily lives. Healthcare practitioners, especially those in the primary care setting where people with FM first present and require ongoing care, can find the challenge of diagnosing and managing FM patients, with their variable symptoms and comprehensive care needs, frustrating and overwhelming. The burden of FM on individuals, the healthcare system, and society overall is substantial. Attention must be paid.

In response, *The FibroCollaborative Roadmap for Change: A Call to Action for Fibromyalgia* represents an unprecedented effort by diverse professional organizations and advocacy groups to identify challenges and set a shared agenda for collaboratively taking action to improve the lives of all those affected by this debilitating disorder. The document which follows is an important beginning, but will be significant only to the extent that we take these recommendations, actively share them and use them to inspire creative new approaches and collective action. Improving the diagnosis and management of FM within our healthcare system presents many challenges. The time is right to combine our skills, perspectives and energies to address them and make a difference in a great many lives.

Daniel J. Clauw, MD

Professor of Anesthesiology, Medicine (Rheumatology) and Psychiatry,
and Director, Chronic Pain and Fatigue Research Center, University of Michigan

Bill McCarberg, MD

Founder and Attending Physician, Chronic Pain Management Program,
Southern California Kaiser Permanente Medical Center



EXECUTIVE SUMMARY

...despite
advances in
knowledge
about FM...
approaches to
FM diagnosis
and management
remain unclear.

Purpose

This document presents a Roadmap for Change in how fibromyalgia (FM) is understood, recognized, diagnosed and managed. It describes current barriers that contribute to delayed diagnosis and optimal care, especially in the primary care setting. This document also recommends priority actions needed to address these barriers to improve outcomes for people with FM.

Rationale

Fibromyalgia is one of the most common musculoskeletal pain conditions in the United States,¹ estimated to affect more than 5 million Americans (or between 2-5% of the adult population).^{1,2} Characterized by chronic widespread pain, FM is usually accompanied by poor sleep and fatigue; people with FM also report experiencing deep tenderness, soreness, stiffness and flu-like aching. Persistent and debilitating, FM can have a devastating impact on a person's life, affecting a person's ability to work and engage in everyday activities, as well as affecting relationships with family, friends and employers.³

While the exact causes of FM are not fully known, a growing body of evidence suggests that neurological changes and a heightened sensitivity to stimuli ("central amplification") may contribute to the pain caused by the condition and other symptoms. However, despite advances in knowledge about FM as a distinct medical condition and the availability of new treatment options, for many healthcare practitioners (HCPs), approaches to FM diagnosis and management remain unclear.

As a consequence, only a small portion of people with FM – some estimates suggest only one in four⁴ – are actually diagnosed with the condition. In addition, it takes five years on average to be correctly diagnosed,⁵ and this journey is longer for many.

About *The FibroCollaborative Roadmap for Change*

The FibroCollaborative Roadmap for Change: A Call to Action for Fibromyalgia is a product of the Advocacy Working Group, representing 16 medical, nursing, professional and patient advocacy organizations. The group's focus is to identify barriers to FM diagnosis and management, and recommend priority actions to overcome those barriers by promoting greater understanding of FM and encouraging adoption of clinical best practices in diagnosis and management — particularly in the primary care setting where most people with fibromyalgia first present and seek ongoing care. The FibroCollaborative is an educational initiative sponsored by Pfizer Inc.

The FibroCollaborative Roadmap for Change was developed based on comprehensive research, including in-depth discussions and interviews with more than 40 individuals from patient advocacy and medical/professional organizations as well as leading researchers and clinicians. Most of these organizations (see list, page 18) also participated with Pfizer in an Advocacy Working Group meeting in Washington, DC, on October 2, 2009, to help finalize *The FibroCollaborative Roadmap for Change* and begin brainstorming its implementation.

The Call to Action – Key Recommendations

To improve the health and well-being of people with FM and to reduce the impact of FM on the lives of people living with the condition and their family and friends, the FibroCollaborative Advocacy Working Group recommends the following priority actions:

Promote Awareness and Understanding

Improve awareness and understanding of FM as a distinct medical condition with often debilitating symptoms and one that can be more quickly and accurately diagnosed and more effectively managed in the primary care setting.

Improve FM Recognition and Diagnosis

Improve HCP and patient recognition of FM symptoms and streamline the diagnostic process in order to shorten the “diagnostic journey” for people with FM.

Facilitate Dialogue

Improve the quality of dialogue about FM between HCPs and their patients and help people with FM better communicate about the condition and their day-to-day experience with family, friends and others in their support network.

Enable Comprehensive Management

Improve the ability of HCPs, especially those in the primary care setting, to effectively manage FM within their practices and, as part of a multidisciplinary team, to improve patient outcomes.

FIBROMYALGIA: AN OVERVIEW



A Common, Chronic Widespread Pain Condition

The name
fibromyalgia
comes from “fibro”
meaning fibrous
tissues (such
as tendons or
ligaments), “my”
meaning muscles,
and “algia”
meaning pain.

Fibromyalgia (FM), one of the most common musculoskeletal pain conditions in the United States¹ — the third most common after osteoarthritis and back pain² — affects more than 5 million Americans (or between 2-5% of the adult population).^{1,2} Characterized by widespread pain, FM is often accompanied by poor sleep and fatigue. People with FM also report experiencing deep tenderness throughout the body, soreness, stiffness and flu-like aching.

Many people with FM experience trouble sleeping and “non-restorative sleep,” as well as profound fatigue during the day and cognitive difficulties (*e.g.*, problems concentrating or communicating clearly, memory lapses). With FM, pain and poor sleep may have a synergistic effect, each worsening the other.⁶

Both men and women get FM, but the condition is more common in women, who account for 80-90 percent of diagnosed cases (although it is thought that FM may be under-diagnosed among men).⁷ It is most common in people between 35 and 60 years of age, but symptoms often become present earlier in life, and prevalence increases with age. Research shows the condition may have a genetic component and can run in families⁸ and is perhaps triggered in genetically susceptible individuals by biological stressors such as physical trauma, infections, early life trauma and war deployment.⁹

Fibromyalgia symptoms can “wax and wane,” varying in intensity from day to day and by physical location. For some people, symptoms are so severe that even simple tasks of day-to-day life become exceedingly difficult. Others may experience only moderate discomfort. FM can exist on its own or co-exist with other painful conditions such as osteoarthritis, rheumatoid arthritis or low back pain. Furthermore, FM is frequently accompanied by other associated conditions that are thought to exist along a spectrum of central sensitivity syndromes with FM (see ‘Causes and Risk Factors,’ page 8), including irritable bowel syndrome, interstitial cystitis, restless leg syndrome, temporomandibular disorder (TMD), tension-type headache/migraine, chronic pelvic pain and endometriosis, chronic prostatitis, among others.^{9,10}

Although FM can impact mood and cause psychological distress, research has shown that the prevalence of current depression in people with FM is comparable to the incidence in people living with other chronic pain conditions¹¹ and that depression and anxiety do not cause FM. While psychiatric conditions often co-occur with FM, they should not be confused with FM or viewed as being the same condition.¹⁰ When they do co-exist, major depression/anxiety disorder and FM both need to be treated; treatment aimed at mood dysfunction alone may result in suboptimal outcomes.¹⁰

Diagnosis Can Be Challenging

The variability of FM symptoms and the degree to which symptoms can mimic other conditions or be signs of other conditions that also may be present in a person with FM (comorbidities) is one of the reasons that many healthcare practitioners, especially in the primary care setting, find it challenging to diagnose FM.

As a consequence, only a small portion of people with FM, some estimates suggest only one in four,^{4,12} are actually diagnosed with the condition. A person's diagnostic journey – from when he or she first sees a primary care practitioner about symptoms, is referred to various specialists, undergoes various tests and treatments, and is finally correctly diagnosed with FM – takes five years on average⁵ and is longer for many. Along the way, undiagnosed FM can have a devastating impact on a person's life while healthcare costs mount for specialist referrals, procedures and ineffective treatments. In combination with lost work days, lost income and disability payments, FM thus imposes large economic burdens on society as well as on affected individuals.¹³

This is unfortunate on many levels because establishing the diagnosis is an essential component of successful FM management.¹⁴ Studies have shown that an FM diagnosis alone (irrespective of whether the condition is effectively treated) improves patients' health satisfaction and that newly diagnosed FM patients report fewer symptoms and fewer major symptoms over the long term.¹² In addition, following a diagnosis of FM, the cost of medical resources utilized significantly declines.¹⁵

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Formal diagnostic criteria for FM were established by the American College of Rheumatology in 1990 and include a history of widespread pain lasting longer than three months in all four quadrants of the body (*i.e.*, above and below the waist, and on both sides of the body); and pain in 11 of 18 tender point sites on digital palpitation.¹⁶ These criteria were originally designed to standardize classification for participants in clinical trials, and their use in clinical practice has not been widespread. Alternative diagnostic criteria appropriate for use in clinical practice and that do not require a tender point exam are being investigated.¹⁷ However, when knowledgeable and trained on the tender point exam, many HCPs find it useful for confirming the presence of widespread tenderness.¹⁸

A complete medical history and physical exam are crucial for a correct diagnosis. Routine laboratory and x-ray testing is usually normal in people with FM. Special attention must also be paid to differential diagnosis – that is, to identifying conditions that can mimic FM (*e.g.*, hypothyroidism, inflammatory rheumatic diseases such as polymyalgia rheumatica) or that may coexist with FM (*e.g.*, autoimmune

or inflammatory disorders, other peripheral pain states [*e.g.*, osteoarthritis, low back pain, spinal stenosis, neuropathies, and psychiatric disorders]) so that appropriate treatments can be initiated.¹⁹

In general, extensive rule-out testing and specialist referral are not necessary to accurately diagnose FM; a positive diagnosis can be made on the basis of symptoms identified during the history and physical exam. However, clear and practical guidelines for FM diagnosis are needed, especially in the primary care setting where comprehensive assessment and differential diagnosis are important but time with individual patients is limited.

FIBROMYALGIA: AN OVERVIEW

It is as if
the “volume
control setting”
for pain is
abnormally
high in people
with FM...

Causes and Risk Factors

Fibromyalgia originally was known as “fibrositis” because it was initially considered an inflammatory muscle condition, a type of rheumatic disorder. However, over time research failed to demonstrate that inflammation or any actual joint, muscle or nerve damage was involved.

While the exact causes of fibromyalgia are still not fully understood, a growing body of evidence implicates changes in the central nervous system that lead to a central amplification of pain perception¹⁰ – including a heightened sensitivity to stimuli that are not normally painful (allodynia) and an increased response to painful stimuli (hyperalgesia). It is as if the “volume control setting” for pain is abnormally high in people with FM, the result of both increased excitability of central neurons and reduced pain inhibitory mechanisms.

Current research supporting this understanding of FM includes functional magnetic resonance imaging (fMRI) studies of the brain documenting differences in how people with FM and normal controls respond to pain stimuli.²⁰ Researchers have also found abnormal levels of neurochemicals involved in pain processing in the brain and central nervous system of people with FM. For example, levels of substance P, the agent which signals the brain to register pain, are three times higher in the cerebral spinal fluid of people with FM than in normal controls.²¹ On the other hand, metabolite levels of the neurotransmitter noradrenaline, which functions in part to modify the intensity of pain signals entering the brain, are lower in people with FM.²² Recent research has shown that FM patients exhibit an abnormal dopamine response to painful stimulation.²³ Dopamine is a neurotransmitter that plays a role in motor control, pleasure and motivation, and recent evidence suggests it may also be involved in pain modulation.²³

Emerging evidence also suggests that environmental, genetic and other factors may be involved in pain sensitivity and predispose individuals to developing FM.⁸ A number of “stressors,” including physical trauma or injury, infections (Lyme disease, hepatitis C, parvovirus, Epstein-Barr virus), emotional stress, and certain catastrophic events (*e.g.*, war deployment) may trigger the onset of FM, especially in genetically susceptible individuals.²⁴

Table 1. Risk Factors for FM

Genetic Factors ⁸	<ul style="list-style-type: none">• Relatives of people with FM are at higher risk for FM<ul style="list-style-type: none">– First-degree relatives are eight times more likely to have FM
Environmental Factors ²⁴	<ul style="list-style-type: none">• Physical trauma or injury• Infections (Lyme disease, hepatitis C)• Other stressors (<i>e.g.</i>, work, family, life-changing events)
Gender ²⁵	<ul style="list-style-type: none">• Women are diagnosed with FM approximately seven times more often than men

A Disabling and Costly Condition

Fibromyalgia can have a devastating impact on a person’s life, affecting a person’s ability to work and engage in everyday activities, as well as affecting relationships with family, friends and employers.³ Pain relief can be elusive and, just as critically, support from the healthcare system as well as family and friends can be lacking.

This is largely because FM is virtually invisible. No injury or open wound, no obvious physical damage or directly measurable ailment is evident in FM. Unlike many conditions, FM cannot be detected through a blood test or x-ray, and, consequently, many people with FM share the all-too-common and frustrating experience of being told, “It’s all in your head.”

Table 2. Key FM Domains and Impact Identified by People with FM³
Not ranked by order of importance

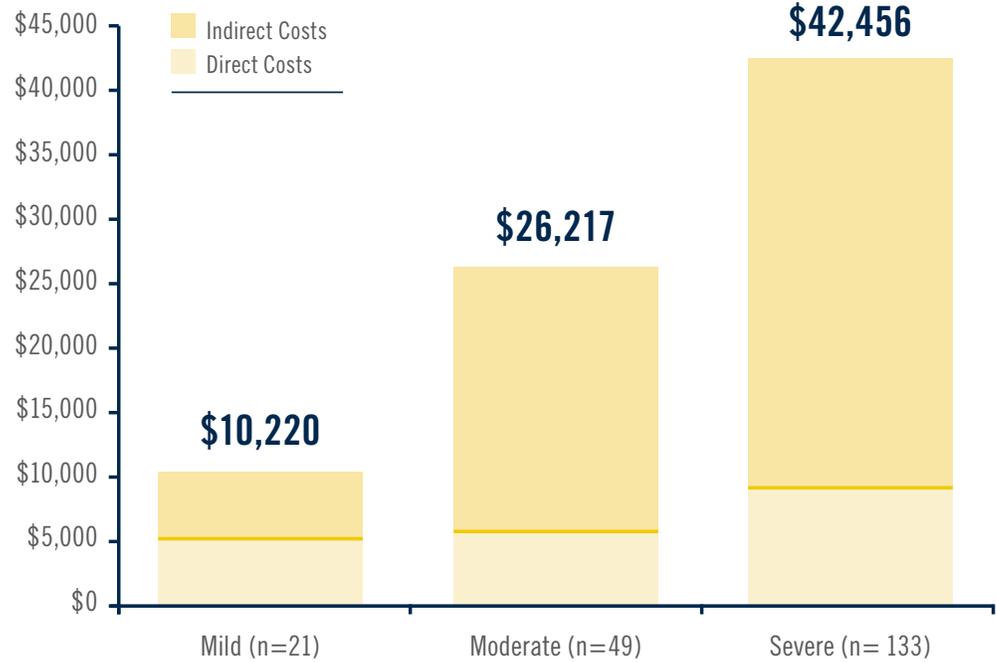
Physical Domain	<ul style="list-style-type: none"> • Pain • Fatigue • Disturbed sleep
Emotional/Cognitive Domains	<ul style="list-style-type: none"> • Depression, anxiety • Cognitive impairment (decreased concentration, disorganization) • Memory problems
Social Domain	<ul style="list-style-type: none"> • Disrupted family relationships • Social isolation • Disrupted relationships with friends
Work/Activity Domains	<ul style="list-style-type: none"> • Reduced activities of daily living • Reduced leisure activities/avoidance of physical activity • Loss of career/inability to advance in career or education

Adapted from Arnold LM, et al. *Patient Educ Couns.* 2008; 73(1):114-120.

FIBROMYALGIA: AN OVERVIEW

With recent research and treatment advances, the prognosis for people with FM has continued to improve.

Figure 1. Annual Costs by FM Severity



Kruskal-Wallis Test performed on the median total costs – Mild: \$7,034, Moderate: \$14,454, Severe: \$39,740 ($p < .0001$)
Adapted from Goldenberg D, et al. Presented at American College of Rheumatology, 2009

Considering that FM often develops at the peak of a person's wage earning years, the cost of FM in terms of lost work days, lost income and disability payments clearly imposes large economic burdens on society as well as on affected individuals. A study recently presented at the American College of Rheumatology 2009 Annual Meeting found that total estimated direct costs (*e.g.*, diagnostic tests, physician office visits, prescription medications, patient out-of-pocket costs, and assistance with activities of daily living) and indirect costs (*e.g.*, lost productivity due to FM) averaged approximately \$35,000 per patient per year.¹³ Costs increased with the severity of FM, with indirect costs accounting for the largest share of the burden.

Managing Fibromyalgia

A multidisciplinary approach to managing FM, coordinated by the primary care practitioner with full involvement of the patient and utilizing both pharmacologic and nonpharmacologic therapies (*e.g.*, education, cognitive therapy, exercise), has been shown to be effective.¹⁴ With recent research and treatment advances, the prognosis for people with FM has continued to improve.

However, despite advances in knowledge about FM and the availability of new treatment options (including pharmacologic treatments that address some of the neurological changes seen in FM), for many HCPs, FM remains a poorly understood medical condition, and approaches to diagnosis and management are unclear.

A CALL TO ACTION FOR FIBROMYALGIA: WHY NOW?



In the last decade and especially within the past five years, significant progress has been made by researchers to understand fibromyalgia, and also by clinicians to improve the diagnosis and management of the condition. People with fibromyalgia and their advocates are energized by new research and the availability of new treatment options and are working hard to increase awareness and understanding of FM. Yet significant challenges remain.

Interviews with the broad spectrum of organizations and individuals participating in *The FibroCollaborative Roadmap for Change: A Call to Action for Fibromyalgia* identified a number of persistent barriers to helping the millions of Americans with fibromyalgia. These include the following:

Inadequate Awareness and Understanding

- Despite advances in scientific knowledge about FM, for many HCPs approaches to diagnosis and management remain unclear.
- There is lingering doubt among some HCPs that FM is a distinct clinical condition.
- People with FM can be regarded as overwhelming, sometimes requiring more time than is typically allotted for a routine visit – or worse, they are unfairly stigmatized as hypochondriacs, attention-seekers or drug-seekers.
- Many people with undiagnosed FM lack awareness/ understanding about the condition and actions they can take to support diagnosis and management.
- Lack of FM knowledge among family members, friends and the general public can lead to (or result in) a lack of support for many people with FM, which leaves many feeling isolated and misunderstood.

Delayed Recognition/Diagnosis

- The variability and complexity of symptom presentation makes it difficult to recognize the cardinal symptoms of FM, especially in the primary care setting where time is limited.
- A lack of confidence among many HCPs about their ability to effectively manage FM and help their patients leads to a reluctance to diagnose.
- The absence of current best practice diagnostic guidance and HCPs' fear of missing another important diagnosis results in excessive rule-out testing, specialist referrals, and delayed diagnosis, which compounds the patient's distress and increases utilization of healthcare services.

A CALL TO ACTION FOR FIBROMYALGIA: WHY NOW?



According to a survey conducted by the American Pain Foundation, nearly half of all people with FM (48%) have experienced difficulty with coverage for FM pain treatment.²⁶

Ineffective Dialogue

- A lack of common language to understand and describe the condition, its symptom presentation and impact on daily life contributes to ineffective dialogue between people with FM, their HCPs and often their support network, including family members.
- This problem is compounded by FM itself, as it is often accompanied by cognitive difficulties, making it difficult for people with the condition to clearly communicate their symptoms and experiences.

Complexity of Management and Limited Capacity/Access

- Although primary care practitioners see the majority of FM patients and, even after specialist referral, are the ones most likely to manage them on an ongoing basis, they have limited time available for each patient and are not always connected to supportive networks of specialists and allied health professionals to facilitate the multidisciplinary team approach to management that FM requires.
- No single specialty owns FM, and many HCPs lack the clinical experience to comprehensively manage patients with FM. This is compounded by the limited capacity of specialists such as rheumatologists, who have historically played a major role in FM diagnosis and management.
- In the current healthcare system, FM care is fragmented, and there is insufficient insurance coverage/reimbursement available for screening, diagnosing and educating people with FM or coordinating their care.
- Many people with FM, even if they have supportive/knowledgeable HCPs guiding their care, confront barriers with regard to insurance coverage/reimbursement that denies them access to approved medical treatments and non-medical therapies.

THE FIBROCOLLABORATIVE ROADMAP FOR CHANGE: KEY RECOMMENDATIONS



Promote Awareness and Understanding

Objective: Improve awareness and understanding of FM among key stakeholders (e.g., HCPs, people with FM, families/friends, general public, employers, payers, policymakers) as a distinct medical condition with often debilitating symptoms and one that can be more quickly and accurately diagnosed and more effectively managed.

Priority Actions:

- Increase recognition of FM as a chronic pain condition that deserves timely diagnosis and comprehensive management.
 - Create forums for addressing the stigma of FM and overlapping and comorbid conditions (e.g., irritable bowel syndrome, depression).
 - Clarify association between FM and depression (i.e., it's not “all in your head”), emphasizing that the incidence of depression in people with FM is comparable to that of people living with other chronic pain conditions¹¹ and that depression and anxiety do not cause FM.
- Direct education and training efforts to HCPs in the primary care setting.
 - Educate primary care HCPs regarding the biological basis of FM pathophysiology in ways that help “make sense” of symptoms, diagnosis and management, and that can help HCPs explain these things to their patients.
 - Promote HCP education about FM specifically and chronic pain generally in graduate/medical school, through residency and post-graduate education, and in required continuing medical education for all HCPs.
- Focus attention on FM as an important public health concern by employing a top-down/bottom-up strategy to educate about the condition, prevalence, and burden of illness and its far-reaching impact.
 - Increase recognition among local, state and national policymakers of FM as an important public health concern and of the need for timely, accurate diagnosis, comprehensive management and access to care.
- Explore collaborations with state-based organizations such as pain, primary care, and rheumatology organizations; with other advocacy groups such as those focused on conditions that often coexist with FM (e.g., rheumatoid arthritis, depression); and with healthcare leaders to identify opportunities for joint efforts and for providing FM-specific information in their educational/outreach programs to colleagues/HCPs, consumers and state policy makers.
- Monitor relevant state and federal legislation (e.g., National Pain Care Policy Act of 2009) and advocate for passage; identify opportunities to ensure that FM/chronic pain is included.
- Encourage the creation of Fibromyalgia Task Forces in state legislatures and/or health departments to generate awareness and educate consumers, HCPs, employers and payers.
- Engage employers and payers by better defining the economic burden of FM and the impact of FM on employers in the United States in terms of employee (both patient and caregiver) absenteeism, forced disability, reduced productivity and overall health insurance costs.
- Highlight chronic pain/FM issues relevant to healthcare reform.
- Further identify the educational needs of different stakeholders (including people with FM – both men and women – and family/friends, HCPs, policymakers, employers, payers/case managers, medical/HCP/allied health students, social workers, etc.) and tailor information accordingly.
 - Develop comprehensive, tailored patient education tools and support group networks to help set treatment expectations and goals, encourage compliance and facilitate patient self-management:

THE FIBROCOLLABORATIVE ROADMAP FOR CHANGE: KEY RECOMMENDATIONS

- » Profile patient demographics and breadth of patient types.
- » Evaluate the way different stakeholders prefer to receive information (*e.g.*, print, media, social media, one-on-one or groups, etc.) and ensure all channels are utilized and account for different searching/learning/networking styles.
- » Ensure all materials are understandable and accessible (apply health literacy principles), culturally and ethnically sensitive and age/gender appropriate.
- Help people with FM and friends/families/others navigate the Internet to access relevant, credible information.
 - » Create Web-based “FM Clearinghouse” or similar portal to easily link visitors to existing FM resources among advocacy and professional organizations, and local, state and federal agencies.
- Leverage traditional as well as social media (*e.g.*, blogs, YouTube) in creative and engaging ways (*e.g.*, videos of FM patients/family; video/art contests) in order to:
 - » Raise awareness of FM and put a face on the FM patient and family, and
 - » Facilitate networking and direct communications (information and experience sharing) between individuals.
- Support research to advance understanding of FM pathophysiology, risk factors, symptoms (*e.g.*, relationship between pain and sleep disorders), and FM co-morbidities.

Improve FM Recognition and Diagnosis

Objective: Improve HCP and patient recognition of FM symptoms and streamline the diagnostic process in order to shorten the diagnostic journey for people with FM.

Priority Actions:

- Enhance HCP ability and confidence in identifying and diagnosing FM via educational initiatives and dissemination of best practices and tools, especially in the primary care setting.
 - Help HCPs recognize FM symptoms more quickly and prompt earlier consideration of an FM diagnosis.
 - » Educate HCPs to “see the forest through the trees” and recognize cardinal FM symptoms, including associations between chronic widespread pain and fatigue/sleep disturbances.
 - » Develop new educational approaches (*i.e.*, creative case studies) to help HCPs more readily recognize the person with FM in clinical practice – *i.e.*, to “paint the picture” of the FM patient.
 - Provide clear direction on FM recognition and diagnosis to streamline the process for HCPs and reinforce HCP confidence in their ability to diagnose.
 - Adapt existing diagnostic criteria and/or algorithms to be more practical in the primary care setting, emphasizing that FM is a clinical, symptom-based diagnosis (on the basis of history/physical exam) and not a diagnosis of exclusion requiring extensive rule-out testing and specialist referral.
 - » Develop tools/best practices to enhance history taking/intake, including utilization of regional pain score, pain diagrams, consumer/patient completed questionnaires/screeners, etc.
 - » Consider creation of a simple tool similar to the PH-Q 9 (nine-symptom checklist for depression) to facilitate healthcare team recognition of patients, diagnosis, tracking treatment plans/progress and sharing of information between primary care practitioners and specialists.

- » Train HCPs to accurately perform an appropriate history and a physical exam (with or without tender points).
 - » Clarify the essentials of differential diagnosis (i.e., diagnosing FM vs. mimics and comorbidities) and provide guidance regarding rule-out testing and specialist referral.
 - » Emphasize that the presence of other conditions does not preclude an FM diagnosis but is important to aid in overall management.
- Educate payers, policymakers and disability policymakers utilizing evidence-based medicine regarding evolution in diagnosis (*e.g.*, FM is a clinical symptom-based diagnosis and can be accurately made using existing ACR criteria (with tender points)¹⁶ or the new criteria (without tender points) proposed by Wolfe et al.¹⁷
 - Reinforce the overall value of diagnosis – answer the question, “Why diagnose?”
 - Provide deeper analysis of patient costs before and after diagnosis, including impact on payers (overall plan costs) and on employers before and after diagnosis.
 - Show impact of early intervention.
 - Demonstrate value in terms of QoL, patient and HCP satisfaction.
 - Advance the FM research agenda with regard to diagnosis:
 - Explore feasibility of advancing development of a diagnostic test and/or biomarker for FM.
 - Explore whether gender bias is a factor in the identification, diagnosis and management of people with FM, and its potential impact.
 - Investigate pediatric FM to help better understand FM progression, early recognition.

Facilitate Dialogue

Objective: Improve the quality of dialogue about FM between HCPs and their patients and help people with FM better communicate with family, friends and others in their support network about FM in general and their day-to-day experience.

Priority Actions:

- Develop a common vocabulary for HCPs and patients to use in talking about FM.
 - Empower people with FM to engage in dialogue with HCPs by providing education and tools to help prioritize and describe symptoms concisely (including symptom severity and impact) and report progress over time to their HCPs.
 - Educate HCPs to listen for clues that should prompt them to ask about chronic widespread pain (*e.g.*, “I hurt all over,” “It feels as if I always have the flu,” “I feel like I have been hit by a truck”) and other common FM symptoms.
- Provide people with FM with information and appropriate language to help them better communicate with family/friends/supportive others about FM in general and their day-to-day experience.

THE FIBROCOLLABORATIVE ROADMAP FOR CHANGE: KEY RECOMMENDATIONS

Enable Comprehensive Management

Objectives: Improve the ability of primary care practitioners to effectively manage FM within their practices and, as part of a multidisciplinary team, to improve patient outcomes.

Empower the person with FM to take responsibility for becoming an active part of the healthcare team and for learning pain management strategies to enhance wellness and reduce suffering.

Priority Actions:

- Define best practices and provide HCPs with education, tools and support to enable comprehensive, efficient management in the primary care setting.
 - Reinforce the value of a multidisciplinary (“integrative”) team approach that looks at the person with FM holistically and utilizes both pharmacologic and nonpharmacologic treatments, as appropriate, including complementary and alternative medicine (*e.g.*, changes in diet and exercise), pain management and self-help.
 - Promote models of excellence and innovative programs and research/assess cost-effectiveness.
 - » Explore the Patient-Centered Medical Home concept as a model for comprehensive and coordinated care in FM.
 - Emphasize the resources available at all levels (community, patient support, referral networks) to help alleviate the burden.
 - Target nurse practitioners (NPs), physician assistants (PAs), registered nurses (RNs), and allied health professionals (*e.g.*, medical assistants, physical therapists) for additional education to strengthen FM expertise to help reach more patients at point of service.
 - Explore role of pharmacists in patient/family/caregiver education and provide pharmacists with appropriate FM education and tools.
- Improve communication among HCPs to promote a multidisciplinary approach to care and ensure consistent quality across professional and medical specialties.
 - Facilitate information sharing and collaboration among HCPs (both traditional and non-traditional) through multiple channels, including:
 - » Comprehensive and dynamic community-based and regional networks and development of collaborative protocols to facilitate continuity of care.
 - » On-line learning communities.
 - » Professional and advocacy organizations.
- Help HCPs and their patients set realistic expectations for management (*i.e.*, there is no “magic bullet”) and promote individualized treatment and goal setting.
 - Advocate for programs to certify or otherwise identify “FM educators” similar to diabetes educators.
 - Explore the utilization of auxillary staff/support personnel (*e.g.*, tele-coaching, peer teachers) to facilitate education and monitor progress of treatment.
 - Encourage the utilization of tools to help people with FM monitor response to treatment and report their progress to their HCPs, to improve compliance and enhance productivity of in-office conversation.

- Increase reimbursement for comprehensive FM management.
 - Demonstrate to payers the value of a team-based approach, including regular consultation among treatment team members, and the cost savings that are achieved when FM is accurately diagnosed and comprehensively managed, similar to other chronic diseases (*e.g.*, diabetes).
 - Assess need to develop quality measures that promote comprehensive management and patient education.
- Emphasize the role the individual with FM must play as part of a multidisciplinary approach to FM management.
 - Educate people with FM about strategies for becoming an active part of the healthcare team.
 - Broaden reach of chronic disease self-management programs (including pain management strategies) to reach people with FM.
 - Ensure adequate availability of patient support networks (in-person/community-based, internet-based, social media).
- Advocate for greater access to comprehensive healthcare and treatment options for FM at both state and federal levels.
 - Improve access to FDA-approved medications.
 - Expand coverage for non-drug therapies.
 - Reduce denials of covered benefits.
- Advance the research agenda with regard to FM management.
 - Pursue research exploring efficacy of new treatments, both pharmacological and non-pharmacological.
 - Identify patient subgroups (on basis of genetics, symptoms, etc.) to aid in tailoring treatment to individuals.
 - Encourage further development of quality and cost-effectiveness measures regarding effective management approaches.
 - Demonstrate positive impact of insurance coverage /reimbursement for patient education on patient outcomes and costs.
 - Investigate FM triggers/risk factors and potential preventive strategies.



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- National Association of Nurse Practitioners in Women's Health
- National Business Coalition on Health
- National Fibromyalgia Association
- National Fibromyalgia Research Association
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