



# INTRODUCTORY REPORT

[HTTPS://FRAME.FOUNDATION](https://frame.foundation)

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# WHO WE ARE

The Foundation for Research and Advocacy for Muscle Pain Education (FRAME) is a 501(c)3 nonprofit organization committed to supporting and informing the medical community and patients on the important role muscles play in acute and chronic pain. Our mission is to conduct groundbreaking research on muscle pain in order to change the way the medical community assesses and treats pain.

FRAME is the first nonprofit organization dedicated to understanding the role of muscles and other soft tissue in acute and chronic pain. Despite muscles accounting for approximately 40% of our body in weight and being the most common reason for low back pain, the mechanisms causing muscle pain are absent in current medical training, causing them to be overlooked by most clinicians.

Ignoring soft tissue and muscles leads physicians to overemphasize the bony spine and nerve tissue as the source of pain, thereby performing often unsuccessful, expensive, and potentially damaging interventions. It is FRAME's goal to be at the forefront of the current standard of care.

FRAME's Board of Directors and Advisors are a diverse group of physicians, researchers, business professionals, and academics. Each member is passionate about the work we do and is committed to improving the lives of those in chronic pain.





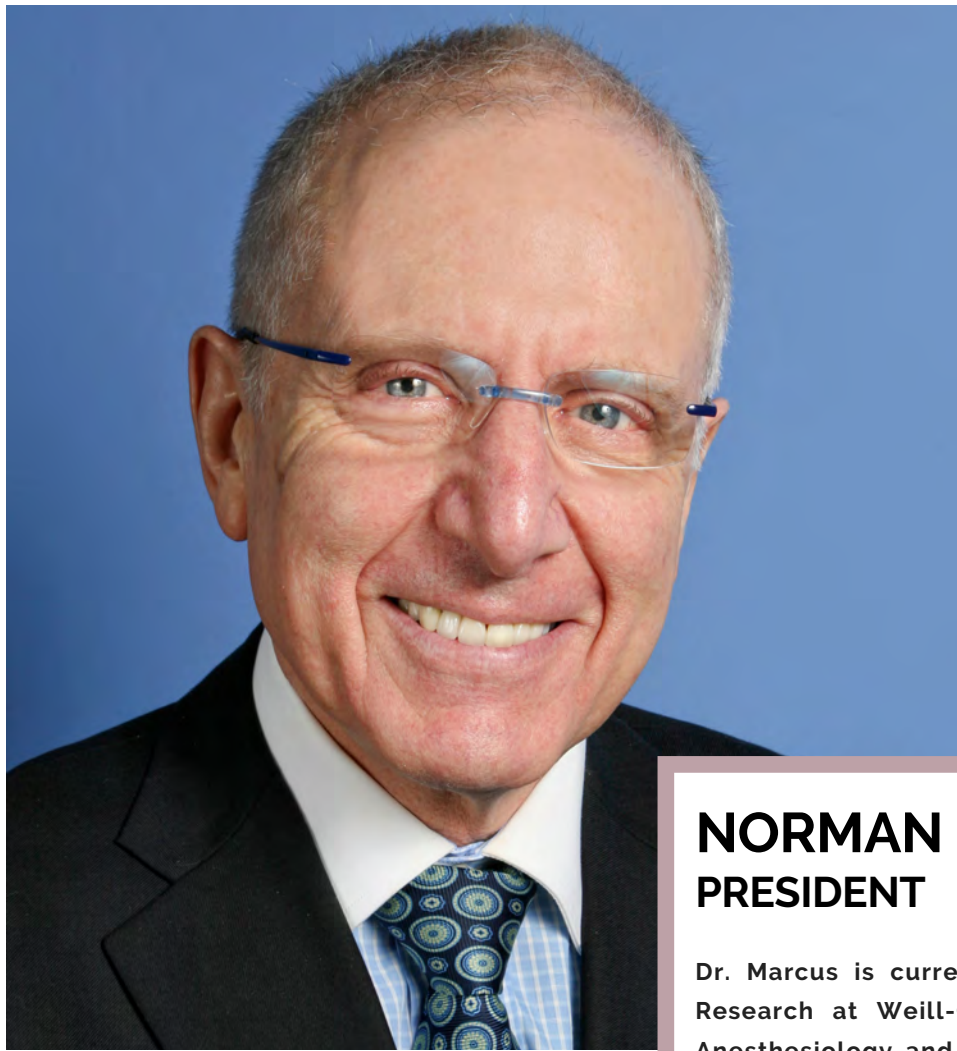
# WHAT WE DO



- We **RESEARCH** how muscles cause pain and the most effective ways to treat them
- We **EDUCATE** the lay public and medical professionals about the role muscles play in acute and chronic pain
- We **ADVOCATE** for the inclusion of muscles in medical school curricula and routine pain assessment and treatment

## OUR OBJECTIVES

- Develop and support medical research to establish accepted evaluation and treatment for muscle pain
- Raise awareness for chronic muscle pain
- Include muscles in routine pain assessment and treatment
- Create a central clearinghouse for muscle pain treatment and education
- Get muscle pain education incorporated in medical school curricula
- Reduce the number of unnecessary procedures by providing more effective and less expensive medical alternatives



## **NORMAN MARCUS, MD**

### **PRESIDENT**

Dr. Marcus is currently the Director of Clinical Muscle Pain Research at Weill-Cornell Medicine in the Departments of Anesthesiology and Neurological Surgery. He has focused on the study of pain throughout his career, with a special interest in muscle pain. He is a past president of the American Academy of Pain Medicine and is currently on the BOD of the American Board of Pain Medicine.

He started and co-directed the first pain center in New York City at Montefiore Hospital from 1978-1984, then established and directed the Lenox Hill Hospital Inpatient Pain Center from 1984-1998. From 1995-1998, he also directed the Princess Margaret Pain Treatment and Functional Restoration Center in Windsor, UK. He received a \$500,000 grant from Medtronic to study outcomes at pain centers for the American Academy of Pain Medicine in 1990.

He has written two books, *Freedom from Pain* and *End Back Pain Forever* and has published numerous journal articles and academic textbook chapters. He has 3 patents on his approach to evaluate and treat muscle pain and is currently working on producing an instrument that will allow most clinicians to identify and treat specific muscles that are the source of common back, neck and shoulder pains.

Dr. Marcus also serves as a Scientific Advisor to FRAME.



## **CHRISTOPHER HAYES, PHD**

### **DIRECTOR/CO-FOUNDER**

Dr. Hayes is a retired Professor of Psychology and founding Chairman of the Master's Program in Gerontology at Southampton College of Long Island University. As the Director of the Center on Aging at the Catholic University of America in Washington, D.C., he developed a variety of Administration on Aging (A.o.A.) research grants addressing bereavement, ethnicity, and support group models for caregivers. In 1992, Dr. Hayes founded the National Center for Women and Retirement Research (NCWRR), the first academic research body in the U.S. focusing on the pre-retirement planning needs of mid-life women. Over his academic career, Dr. Hayes was the Principal Investigator of 17 national research studies and raised 6.4 million dollars in research funding. Dr. Hayes is an author of a variety of popular and academic books on age-related topics.

In 1996, Dr. Hayes received the Long Island University Scholarly Achievement Award for research and education dedicated to improving the lives of older adults. Currently, Dr. Hayes is an advocate for patients addressing chronic pain and trains volunteer facilitators for bereavement groups for the Diocese of Rockville Center on Long Island.



## **A LETTER FROM NORMAN MARCUS, MD**

I am grateful to everyone who has supported the mission of FRAME in 2020. FRAME relies on the contributions of clinicians, patients, and those who have come to understand the importance of including muscles in our evaluation and treatment of common pain syndromes.

In my 50 years as a physician I have witnessed thousands of patients whose pain could have been relieved sooner if painful muscles had been diagnosed and treated. Many unnecessary and costly surgeries and nerve blocks are administered to patients causing and prolonging pain and suffering.

FRAME's Board of Directors and committees have labored for the past year to address the factors that perpetuate the absence of muscles as a source of pain in the medical curriculum and in the awareness of patients suffering in pain. The studies that FRAME is undertaking are crucial to help well-meaning physicians realize that they will be more effective when muscle treatment becomes part of the standard of care.

FRAME is the culmination of my good fortune to have worked with Hans Kraus and Siegfried Mense, pioneers in the clinical and pathophysiological aspects of muscle pain, and all my patients who are living proof that pain can often be eliminated by recognizing all the reasons it exists. We look forward to another year of clinical studies and sharing our collective experience with both clinicians and patients.

A handwritten signature in black ink that reads "Norman Marcus M.D." The signature is written in a cursive, flowing style.



## A LETTER FROM MANDY GARTEN, EXECUTIVE DIRECTOR

2020 was a difficult year for everyone but despite the challenges, it was a successful year for FRAME. As I celebrate my 2nd year as Executive Director of FRAME, I look back on how far we have come as a foundation and look to the future of all the exciting projects to come.

I know first-hand the impact pain can have on a person's life. My pain started at the age of 10 and was relentless and all encompassing, but over the years I have found doctors who are willing to listen, look outside the box, and treat my muscles as the source of the pain. It took many years, but at 34 I am a different person who can do things I never imagined, like walk miles a day, work, and enjoy life, and I know that is possible for others if we continue to push forward with our research and education initiatives.

FRAME is unique in that we are run by both medical providers and patients; we understand every side of the chronic pain experience. We are not only run by patients and clinicians, but we also target both in our research. We explore both the physical and psychological aspects of pain.

The continued success of our foundation would not be possible without our amazing volunteers, board members, supporters, and partners. Our volunteers have put in countless hours and worked tirelessly over the past year to begin research projects to further understand the chronic pain journey. I want to personally thank each and every one of you for your time, dedication, support, and commitment over the past year. I am so proud to be part of this organization led by volunteers and could not imagine working with a better team.

*Mandy Garten*



# DID YOU KNOW...

**40%**

OF BODY WEIGHT IS  
MUSCLES.

CHRONIC PAIN IS THE

**#1**

CAUSE OF DISABILITY IN  
THE UNITED STATES.<sup>1</sup>

**\$560 BILLION**

THE ESTIMATED ECONOMIC IMPACT  
FROM MISSED WORKDAYS AND  
MEDICAL EXPENSES DUE TO CHRONIC  
PAIN PER YEAR.<sup>1</sup>

- GLOBALLY, 1 IN 5 ADULTS SUFFER FROM PAIN.<sup>2</sup>
- CHRONIC PAIN IMPACTS MORE AMERICANS THAN HEART DISEASE, CANCER AND DIABETES... COMBINED.<sup>3</sup>
- 1 IN 10 ADULTS ARE NEWLY DIAGNOSED WITH CHRONIC PAIN EVERY YEAR.<sup>2</sup>
- THE VALUE OF LOST PRODUCTIVITY DUE TO PAIN RANGED FROM \$299 - \$335 BILLION PER YEAR.<sup>1</sup>
- CURRENT CHRONIC PAIN TREATMENT PROTOCOLS PROVIDE ONLY MINIMAL IMPROVEMENTS IN FUNCTION.<sup>4</sup>

1. Gaskin DJ, Richard P. The economic costs of pain in the United States. J Pain. 2012; 13(8): 715-724.

2. Goldberg DS, McGee, SJ. Pain as a global public health priority. BMC Public Health. 2011; 11:770. Published 2011 Oct 6.

3. Reuben DB, Alvanzo AA, et al. National Institutes of Health Pathways to Prevention Workshop: the role of opioids in the treatment of chronic pain. Ann Intern Med. 2015; 162(4): 295-300.

4. Turk DC, Wilson HD, Cahana A. Treatment of chronic non-cancer pain. Lancet 2011; 377(9784): 2226-2235.

# COMPLEXITIES AND TRANSFORMATION OF THE PAIN EXPERIENCE

The physical aspect of chronic pain is well documented, but the psychological aspect is far less studied and understood. An unexplored issue is how the chronic pain journey may offer patients an opportunity to cultivate a more proactive, positive viewpoint of their suffering and life situation.

- ◆ **Goals:** To understand the chronic pain journey and psychological dimensions of suffering
- ◆ **Methods:** Conduct 75 phone interviews with chronic pain patients and identify common themes to create and disseminate 10,000 written surveys
- ◆ **Outcome:** Using the survey responses, we will create a 25 question Pain Awareness Index that group patients along a continuum of pain awareness and potential action steps to modify self-imposed barriers that diminish quality of life


# SURVEY OF CLINICIANS AND SOFT TISSUE


We know that the pathophysiology and treatment of muscle pain is not included in current medical school curricula and there is no medical specialty designated to muscles. In order to determine how to move forward with education, we need an analysis of the current standard of care and understanding of soft tissue related pain.


- ◆ **Goals:** To understand if and how physicians incorporate muscles into the evaluation and treatment of chronic pain and how it differs among institutions
- ◆ **Methods:** Disseminate surveys to physicians who work with chronic pain patients from specific medical institutions and associations to be analyzed by our corporate sponsor, Accenture
- ◆ **Outcome:** An observational study analysis about how physicians incorporate muscles into the evaluation and treatment of chronic pain

# HYPERMOBILE EHLERS DANLOS STUDY

Hypermobile Ehlers Danlos Syndrome (hEDS) is a genetic disorder that is believed to be underdiagnosed; it takes an average of 10-20 years to receive an accurate diagnosis. There is only a clinical diagnosis at this point with no genetic marker found to date.

 **Goals:** Find a genetic marker for hEDS and reduce the 79 symptoms to a core 8 diagnostic criteria

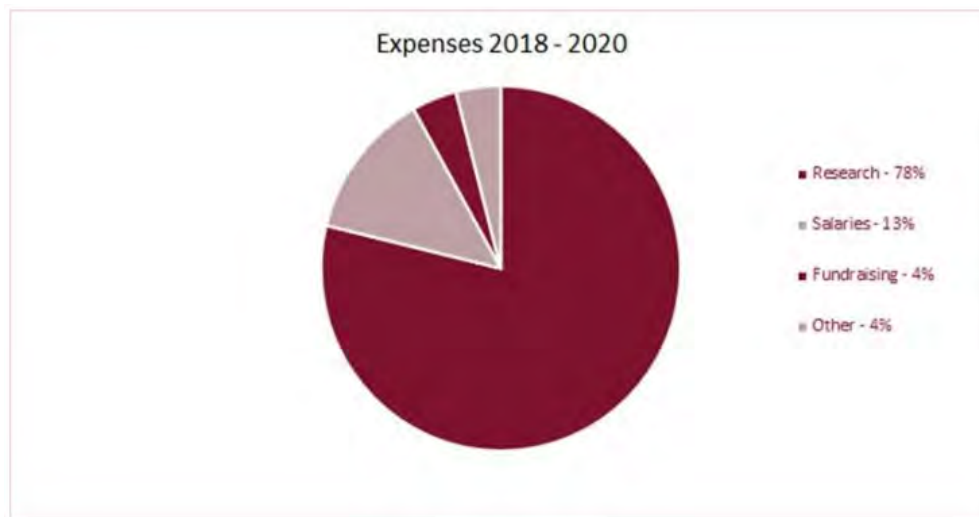
 **Methods:** Our corporate sponsor, Accenture, will use Artificial Intelligence to analyze tens of thousands of Ehlers Danlos medical records obtained from various medical clinics and datasets in a novel and innovative way

 **Outcome:** Streamline and simplify diagnostic criteria for hEDS in order to cut down on the amount of time it takes to diagnose

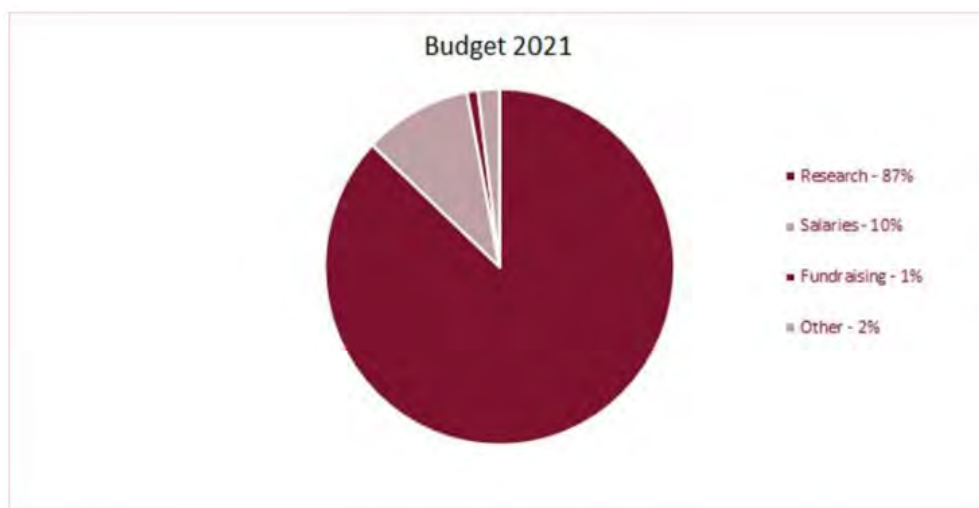


# OUR CURRENT STATE

Our goal as a non-profit is to dedicate as much of our resources as fiscally possible to current and future research. Historically, research has represented over three-quarters of our budget.



It is estimated that research will represent approximately 90% of total 2021 expenditures.



# PARTNERS/COLLABORATORS



One of the leaders in embracing innovation to drive value in organizations, has donated, and continues to donate significant resources in the form of services and technology to FRAME. Accenture utilizes their expertise in the artificial intelligence (AI) in analyzing data sets with the goal of establishing correlations among pain sufferers' records and discovering potential genetic markers. Their collaboration from 2019 to present day helps FRAME to fulfill the research initiatives.



FRAME has been working with many physicians at the Weill-Cornell Center for Comprehensive Spine Care in understanding current standards of care, where difficulties lie in changing the standard, and how various treatments have helped patients with chronic pain. We have collaborated with WCM in collecting patient data to better understand patient outcomes. Since FRAME's inception, our research has been a collaboration with Weill Cornell physicians, and we continue to work with them to further our research and education goals.

## SPONSORS



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# FRAME WORKSHOP AND RETREAT



Team building and relationships are important in any organization. Our inaugural retreat was an opportunity for Board and committee members to learn about each other and align on our collective vision for FRAME. One of the pillars of FRAME is the research that needs to be conducted in order to fully comprehend muscle pain and how it can be treated properly.

During our retreat, our members engaged in several discussions regarding our mission and the future, debating top-down versus bottom-up research for pain treatments. Treatment outcomes have been found to be difficult to collect, so discussions included obtaining real-time data from pain centers in New York City. Artificial intelligence will be used to analyze this information to drive our clinical research projects. Additional research projects were also discussed, with priority given to those that matched FRAME's mission.



# FRAME GALA



Thank you to all those who supported FRAME's inaugural fundraising dinner at Bryant Park Grill in New York, NY.

Among the attendees were a number of influencers in the medical community including Dr. Thomas Blanck, past Chairman of Anesthesiology at NYU Langone, Dr. Robert Cancro, past Chairman of Psychiatry at NYU Langone, Dr. Arthur Jenkins, co-director of the Neurosurgical Spine Program at Mt. Sinai, and Dr. Neel Mehta, co-director of the Comprehensive Center for Spine Care at Weill-Cornell Medicine.

Also in attendance were corporate sponsors, including LiteCure, Cisco, Lenovo, Brooadcom, NetApp, and VasoMedical.

FRAME held a silent auction with numerous distinct items to encompass multiple tastes, including four week-long badges to the PGA championship, a goalie stick by Lundqvist of the NY Rangers, a weeklong all-inclusive trip to a prestigious lodge and resort, restaurant gift certificates, artwork, as well as personalized and autographed celebrity memorabilia.

The event raised over a third of our fundraising revenue, and, after costs of the event, were used solely for research purposes.







