

CENTERS AND INSTITUTES SELF-STUDY/PROGRAM REVIEW

Center/Institute: Fibromyalgia & Chronic Pain Center

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Name of Primary Author(s) if different from the director(s) of the Center/Institute: N/A

Mission and Goals

The mission of the Fibromyalgia and Chronic Pain (FMPC) Center is to advance research and education related to fibromyalgia and other chronic pain disorders.

The goals of the FMCP Center are to:

- Conduct interdisciplinary research
- Provide training for undergraduate and graduate students
- Facilitate support and education for persons with FM and other chronic pain conditions, as well as their significant others
- Raise public awareness about FM and other chronic pain conditions, and its effects on individuals, their families, and significant others

The FMCP contributes to the Goal 1, Objective 1.2 of the Fullerton Forward 2024-2029 Strategic Plan, which is to: "Provide equitable, engaging, and innovative learning experiences to foster students' ability to apply the knowledge, skills, and cultural awareness gained through their academic programs."

The FMPC is committed to creating high-impact experiential learning opportunities (e.g., applied and basic research, internships, service learning) that enhance student learning experiences and outcomes, and prepare them beyond degree completion (e.g., graduate and professional school, career and employment). It also aims to increase faculty-student engagement opportunities and to encourage discovery and scholarly inquiry.

Activities

Research: Over the past five years, the FMCPCC has been engaged in a variety of research activities. One major activity was the completion of Wave 6 (fall 2018) of the longitudinal study: “Physical and Cognitive Status of People Aged 50+ with and without Fibromyalgia: A Longitudinal Study, 2008 to Present.” This study involved researchers and students from several schools and departments on campus, including public health, kinesiology, nursing, biology, aging studies, and psychology. Undergraduate and graduate students assisted faculty in writing the IRB application, recruiting participants, training fellow peer research assistants, collecting data and organizing data collection, entering data into statistical packages, and developing workshops, community and professional presentations, as well as peer-reviewed publications.

Beginning in 2022, a major project has been the reorganization of the separate data files collected during each wave of the longitudinal study into a single cohesive file that will allow for the examination of longitudinal data. Multiple students have been engaged in this process and it has been an excellent opportunity to involve them in the discussion of concepts such as statistical reliability and validity, data entry methods and best-practices, data coding and analysis, and data management and safety.

Center faculty have continued to mentor and advise graduate student theses and projects, some of which were secondary data analyses from the existing longitudinal study or novel research questions that required students to develop their own instrumentation, recruit participants, and collect and manage their own data.

Since 2022, we have been working on a new study exploring the effects of the COVID-19 pandemic on participants from the original longitudinal research. Because COVID-19 poses a greater risk to people with FM, our data collection has been done through mail-in questionnaires and over the phone. Questionnaires include several from the original study and some new ones that investigate the effect of COVID-19 on these individuals.

These myriad research activities serve the FMCPCC mission and goals by engaging members of the FM community and raising awareness about FM through participant engagement and subsequent professional and community presentations/publications.

Community Engagement: The FMCPCC has traditionally supported the local community by hosting monthly support group meetings on campus for people living with fibromyalgia, chronic pain, and fatigue. These meetings consist of professional speakers, and roundtable discussions, and provide a place for people to build a sense of community and validation of their illnesses. We have also hosted a feedback conference for participants from our longitudinal study after each wave of data collection. We were able to do this in spring 2019. This conference involved presentation of measures, some reporting of study outcomes, and workshops which participants could attend (e.g., brain health, nutrition, meditation, etc.) The COVID-19 pandemic, however, upended many of these activities. The population we serve is older and has medical comorbidities. Given the risk COVID-19 poses (and still poses) to this population, we have had to halt our outreach activities and focus instead on research. In addition, monthly support group meetings have moved to zoom.

Organizational Structure and Governance

The FMCP has a Director of Operations, Director(s) of Research, and a Director of Education. The Director of Operations oversees all daily operational tasks including, but not limited to, phone/email/postal correspondence, website maintenance, and community and university relations. The Director(s) of Research oversees ongoing research projects and database management. The Director of Education oversees community outreach programs and dissemination of research findings. An Advisory Committee consists of faculty and their graduate students who work with the data generated by the Center. The Advisory Committee meets once every semester to discuss the progress of ongoing projects, to develop new projects, and to evaluate opportunities for funding (both intra- and extra-mural).

Students are included in the organizational structure as well, and are assigned management positions such as Lab Manager, Data Lead, Communications Lead, and other leadership positions as the need arises. Students in management positions meet regularly with faculty directors to determine ways in which to best meet the short- and long-term goals of the FMCP.

The Center directors and staff meet with the community support group leaders approximately once every semester to discuss scheduling of the room, technical assistance, speaking engagements, and any instrumental or programming needs and wants from the community.

Resources and Sustainability

The FMCP functions through intramural funding, unpaid student practicums, internships, and volunteers. The Center's Directors and affiliated faculty volunteer their time to accomplish the mission and goals of the Center. The following are sources of funding received since the last review period, which has helped to support over 40 undergraduate and graduate students.

2022-2023: Piazza, J. R. Junior/Senior Faculty Research Award, *Aging with Fibromyalgia: Understanding the impact of COVID-19*. Total Costs: \$6,693

2022-2023: Piazza, J. R., HHD Research Support Program; Total Costs: \$3000

2021-2022: Piazza, J. R., HHD Research Support Program; Total Costs: \$1500

The FMCP has two offices located within the Public Health Research Labs. KHS 106F is primarily used for scheduling and interviewing participants, collating and mailing out packets of questionnaires, and conducting cognitive assessments. We recently purchased new computers for student use. KHS 106A is used to clean, enter, and code data, which is stored in locked cabinets in the room. We recently purchased a new computer for this room, as well. The FMCP Center also uses KHS 106G, which is a shared storage space with other faculty from the Department of Public Health. The Department of Public Health assigns the space, while the Department Chair regularly solicits needed research space among Public Health faculty to determine accommodations for new research projects. Operational costs to maintain electricity, telephone email services, and other campus facilities are absorbed through the Department of Public Health, while costs related to materials are from the various funding sources from faculty.

Despite no assigned time for faculty efforts, the Center has continued to maintain high-quality scholarly research and creative activities, provide high-impact practices for students, and engage and collaborate with the community. With the existing funds in the FMCP Philanthropic Foundation account, along with the continued volunteer time of the Center faculty and

community partners, as well as student interns and volunteers, the FMCPCC plans to maintain the same level of research, scholarly, and community activities as it has during the past six years.

Highlights and Accomplishments

One of the major accomplishments of the FMCPCC during the last seven-year period has been the completion of Wave 6 (fall 2018) of the longitudinal study, as briefly described above. Though Wave 6 initially marked the end of our longitudinal study (i.e., ten years since we had started in 2008), the COVID-19 pandemic led us to reconsider concluding the study. Specifically, with the advent of chronic or “Long-haul” COVID, health providers quickly began comparing post-infection symptoms with those experienced with Fibromyalgia. This naturally led our team to wonder how those actually diagnosed with Fibromyalgia might be faring. Though the pandemic upended our ability to conduct in-person research for our very sensitive population (i.e., aging adults with compromised immune systems), we decided to conduct a post-COVID data collection wave via mailed survey and telephone assessments. We are in the midst of this wave now.

Between Wave 6 and the current post-COVID wave, we have been able to involve nearly 50 additional undergraduate and graduate students in our research, including Honors, McNair, and MSTEM STAR Scholars. These students have had first-hand experiences in the research process, including participant recruitment, neurocognitive and physical performance assessment, data entry, and data analysis. Additionally, many students have used the data to present research at regional and national conferences and to complete their theses and projects (see Appendix A for a list of student-led publications and manuscripts).

These accomplishments and activities have contributed to the mission and goals of both the Center and the College, and they align with several goals of the CSUF Strategic Plan. Students engaged in multidisciplinary research are trained to offer physical, health, and mobility assessments; they have live interactions with people living with FM; they raise public awareness and education by presenting at professional conferences; they are exposed to and explore different career paths and opportunities; they persist at the university by engaging with Center activities for at least one year; and many have been successfully admitted to graduate school programs.

Planning and Strategic Outlook

The core FMPC faculty meet to discuss the upcoming goals and activities every semester, including grant seeking, research studies, and community engagement. The goals of the Center for the coming 3-year period are as follows:

- 1) Finish the ongoing post-COVID-19 study
- 2) Create a complete, aggregated file containing all data collected since 2008;
- 3) Continue to analyze the current dataset, with particular attention paid to longitudinal analyses;
- 4) Continue to train graduate and undergraduate students in literature searches, data entry, data cleaning, statistical analyses, and data presentation and publications;

- 5) Provide education to research participants and their caregivers, using findings generated by the data;
- 6) Provide technical assistance and ongoing support to the local support group;
- 7) Collaborate with support group and other community and national partners on educational and awareness events;
- 8) Seek additional funding to support the above activities.

These goals are aligned with the Center's and CHHD's mission statements and goals.