

***Chronic pain in persons with myotonic dystrophy and FSHD.*** Authors: Jensen MP, Hoffman AJ, Stoelb BL, Abresch RT, Carter GT, McDonald CM.

Paper published by colleagues at the University of Washington and University of California, Davis

These authors reported a high prevalence of pain in DM and FSHD patients. The paper highlights that 91% of the participants in this study were members of the Registry (235 of 257 total enrollees). The paper also highlights the eagerness of our population to participate in research, as 296 individuals contacted our colleagues at UC-Davis to participate, of which, 235 (79.4%) subjects completed and returned their questionnaires.

Their results indicated that 60% of DM and 82% of FSHD patients reported pain, with 23% of these respondents reporting that their pain was severe. Most patients reported having pain symptoms for over 10 years. The most common sites of pain were located in the lower back (74% of FSHD patients and 66% of DM patients) and legs (72% of FSHD patients and 64% DM patients). Average pain was greatest for those patients with assistive devices. Overall, pain was reported to have a moderate degree of interference with enjoyment of life (mobility, work, recreational activities).

Part of the author's conclusions indicated that there remains, *"too few options for pain relief of patients with DM and FSHD and chronic pain. There is a substantial need for the development to effective and long-lasting pain treatments that can be made easily available that have a few negative side effects."*

More results and conclusions can be found at:

[http://www.ncbi.nlm.nih.gov/pubmed/18226657?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed\\_ResultsPanel.Pubmed\\_RVDocSum](http://www.ncbi.nlm.nih.gov/pubmed/18226657?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum)

These results and other information presented by Dr. Jensen and colleagues indicate that pain is a very significant symptom of DM and FSHD. More research and clinical guidelines are needed to identify treatments for pain.