

# The frustration and fascination of fibromyalgia

30 years of dedicated scientific work in the field of fibromyalgia has made American professor Daniel Clauw one of the world's leading experts on fibromyalgia. Therefore, it is a great honor to present an interview with Daniel Clauw who provides his thoughts on the past, present and future of fibromyalgia.

## Frustration & Fascination

Frustration and fascination. Those feelings struck a young physician named Daniel Clauw more than 30 years ago when he first became acquainted with the patients who lived with the complex pain condition that was later recognized as fibromyalgia. "I was originally trained as a rheumatologist and when I first met patients with fibromyalgia back in the 1980s, it was frustrating to work with a disease where we had such limited knowledge. But on the other hand, it was also fascinating to me as a scientist to stand face-to-face with a pain condition with so much to discover and explore scientifically."



*Daniel Clauw, M.D., is a Professor at the Medical School at the University of Michigan. Professor Clauw is one of the world's leading experts on fibromyalgia and serves as the Director of the Chronic Pain and Fatigue Research Center.*

## Dedicated scientific research

Thus, the scientific curiosity of Daniel Clauw was awoken, and that curiosity is still intact to this day where Clauw is a Professor at the University of Michigan. He continues to unfold his dedicated scientific research in the many dimensions of fibromyalgia and is keen to reach as many as possible with his knowledge.

"For me as a researcher, it is important to talk and write as much as possible about fibromyalgia, not least to change the attitudes among those who still do not recognize fibromyalgia as a genuine physical pain condition. Fortunately, great progress has been made for patients with fibromyalgia compared to 10 or 20 years ago."

"But having said that, there are still many doctors and other healthcare professionals around the world who do not recognize fibromyalgia. Therefore, there are still major challenges for each of the many fibromyalgia patients who are struggling with the lack of recognition and are fighting against allegations of being untrustworthy in their pain condition."

## Not a psychiatric diagnosis

A common challenge for many fibromyalgia patients all over the world is the psychological and psychiatric approach to treating chronic pain. Daniel Clauw dealt with this matter during a recent fibromyalgia research convention in Vienna where leading fibromyalgia experts from all over the world were gathered. Clauw acknowledges that fibromyalgia patients can suffer from psychological side effects, for example as a consequence of many years of uncertainty without proper diagnosing and treatment in the health system. However, Clauw stresses unequivocally that fibromyalgia must never be treated as a psychiatric diagnosis as fibromyalgia is a genuine physical pain condition which originates from highly complex mechanisms in the pain system of the humane body.

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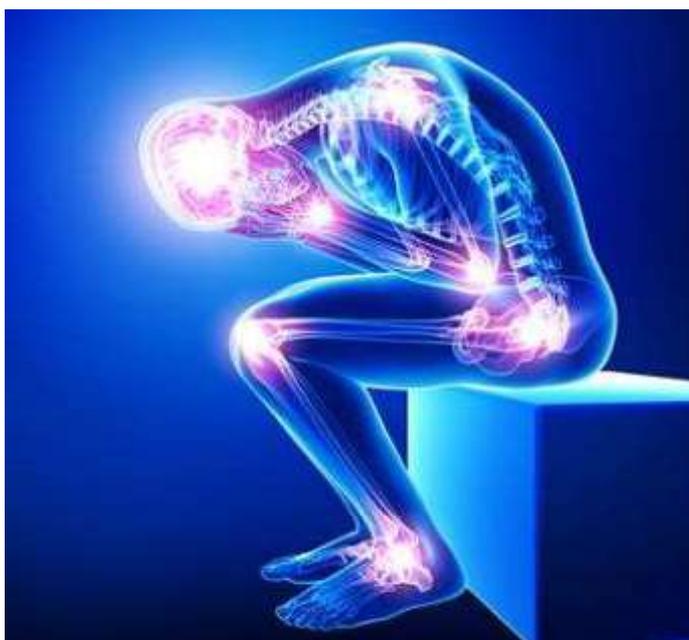
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### **Targeted treatment**

Daniel Clauw believes that the continued widespread failure to recognize fibromyalgia is a symptom of a general problem in the medical world. "The medical world has a problem diagnosing and treating chronic pain. If a doctor encounters a patient with pain in the knee, the doctor is trained to look isolated at the knee. However, that approach is not adequate in the case of fibromyalgia which cannot be detected in an X-ray image. Unfortunately, we do not yet have brain scans that can detect the processes in the brain's central nervous system that cause fibromyalgia. However, I foresee that within 5-10 years, we have developed MRI brain scans that will enable us to initiate targeted and individualized treatment of fibromyalgia patients, for example with the right balance between medical treatment and physical training."

### **Fibromyalgia and genetics**

A widespread concern among parents with fibromyalgia is the potential risk of their children being genetically disposed to fibromyalgia. Daniel Clauw explains about this hereditary concern: "There may be a limited risk of heredity but the vast majority of children who come from families with fibromyalgia do NOT end up with the disease themselves. If we look at the population as a whole, we estimate that between 4-6% have fibromyalgia, and for children with fibromyalgia, my estimate is that the risk of developing fibromyalgia is 15-20%. Therefore, it is important to emphasize that there is an 80% chance that one's children will never have fibromyalgia. Let me use the following analogy: If you head out into a thunderstorm, there may be a risk of being struck by lightning, but fortunately, only a few are actually hit by lightning!"



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### **Lady Gaga and John F. Kennedy**

Thanks to world-famous pop singer Lady Gaga, fibromyalgia has enjoyed global attention on a scale like never before during recent years. What does Daniel Clauw think of Lady Gaga's candid tales of life with fibromyalgia? "I find it positive when a celebrity like Lady Gaga helps raise awareness about fibromyalgia and scientific papers have actually been written about celebrities who would probably be diagnosed with fibromyalgia today. One of them is former US President John F. Kennedy, where scholars have studied his medical records and concluded that his pain symptoms might well be fibromyalgia."

### **New chapters to be written**

However, all is not good when celebrities go public with their illnesses, Daniel Clauw says, citing a media encounter he has had in the case of Lady Gaga. "A journalist contacted me and asked me to comment on a picture of Lady Gaga smoking a cigarette in London. The journalist wanted me to say in no uncertain terms that Lady Gaga smoking a cigarette was absolutely appalling because she was a fibromyalgia patient. However, I told the journalist that it was completely ridiculous to adopt that approach to the story. I have no knowledge at all about Lady Gaga's smoking habits! Nor would I ever criticize a diabetes patient for eating an unhealthy meal and Lady Gaga definitely does a lot of good for fibromyalgia patients, so I completely refused to participate in that article!" Let that be the final words for now but the future holds new chapters to be written in the daily quest to achieve new milestones in the important fields of fibromyalgia research and treatment!

*Interview & article by  
Jens Arenbach Nielsen  
The Danish Fibromyalgia Association*

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