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Science AMA Series: We are a team of scientists and therapists from the University of Marburg in Germany researching chronic pain. We are developing a new treatment for Fibromyalgia and other types of chronic pain. AUA!

CHRONIC_PAIN_AMA [R/SCIENCE](#)

Hi Reddit,

We're a team of scientists at the University of Marburg: Department of Medical Psychology which specializes in Chronic Pain. Our research is focused on making people pain free again. We have developed SET, a treatment that combines a medical device with behavioral therapy. Our research shows that patients are different - heterogeneous - and that chronic pain (pain lasting over three months without a clear medical reason) patients typically have a depreciated autonomic nervous system (ANS). More importantly, the ANS can be trained using a combination of individualized cardiac-gated electro stimulation administered through the finger and operant therapy focused on rewarding good behaviors and eliminating pain behaviors. With the SET training, a large percentage of our patients become pain free. Although most of our research has been focused on Fibromyalgia, it is also applicable to other chronic pain conditions. See [more information](#)

I'm [Prof. Dr. Kati Thieme](#), a full professor at the [University of Marburg](#) in the Medical School, Department of Medicinal Psychology. If you suffer from chronic pain, or would somehow like to get involved and would like to help us out, please fill out this short [survey](#). It only takes a few minutes, and would be a great help! Thanks!

Answering your questions today will be:

Prof. Dr. Kati Thieme, PhD - Department Head, founding Scientist, Psychotherapist

Johanna Berwanger, MA - Psychologist

Ulrika Evermann, MA - Psychologist

Robert Malinowski, MA - Physicist

Dr. jur. Marc Mathys - Scientist

Tina Meller, MA - Psychologist

We'll be back at 1 pm EST (10 am PST, 6 pm UTC) to answer your questions, ask us anything!

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CORRESPONDENCE:

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Do your treatments also address the chronic fatigue or sleep disorders often associated with fibromyalgia? Have your patients seen improvement in other areas beyond chronic pain?

[StringOfLights](#)

Yes, we see even that the improvement of sleep is the very first effect. Not seldom, the patients feel asleep while they are getting the electrical stimuli on the finger and report in the first 3-4 session that they feel so tired and deeply relaxed after the therapy. We ask them to go with that, not to fight against that and even to lay down and sleep whenever they want. Pretty quick they sleep much better during the night. The fatigue is going away with the time. A further effect is the reduction or remission of

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cognitive impairment.

Our treatment reactivates the baroreflex sensitivity, means the baroreceptors in your neck (carotis) are going more active and rely the signals to the brain stem, to the NTS (nucleus tractus solitarius) that activates other areas (thalamus, primary and secondary somatosensory cortex - SS-I and SS-II, insula) known as pain network that can exaggerate or inhibit pain. The psychological pain therapy activates the inhibition in the prefrontal cortex and insula that communicate with SS-I and SS-II. The reflex is down, the circle is closed. Inhibition works. The NTS is responsible for the regulation of pain, blood pressure, blood sugar, anxiety, and sleep. In communication with the other brain areas, different diseases can be influenced by SET (our therapy) such as: Hypertension and various heart diseases, sleep apnoe, restless legs, immune function and activity in rheumatoid arthritis, diabetes mellitus Typ I and II, low back pain, migraine (shows the fastes effects) and partially osteoarthritis.

The effects are either related to the primary symptom as high blood pressure or pain, or it is related to secondary symptoms such as enhanced immune activity and is synergistic with pharmacotherapy in reducing inflammation.

Do your treatments also address the chronic fatigue or sleep disorders often associated with fibromyalgia? Have your patients seen improvement in other areas beyond chronic pain?

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Our University of Marburg RCT study with 65 patients showed a significant decrease of pain severity (MPI) after SET in comparison to Sham ($p > 0.001$), an increase of BRS, an increase of heart rate variability (HRV), and changes in the high frequency component of the R-wave corresponding to parasympathetic tone (HF; Thieme, 2014). Furthermore, the sympathetic outflow measured by micro-neurography was significantly reduced (Lautenschlaeger, 2014) after SET.

Do your treatments also address the chronic fatigue or sleep disorders often associated with fibromyalgia? Have your patients seen improvement in other areas beyond chronic pain?

[StringOfLights](#)

To add to the sleep issue: We've had the chance to send a group of our patients to the sleep lab and on top of them subjectively reporting better sleep quality, this is what we found in the lab as well: More deep sleep phases in the first half of the night (which are insufficient before therapy) and a significantly better sleep efficacy.

Thank you for doing this AMA. I am the head mod of [/r/ChronicPain](#) and suffer from Trigeminal Neuralgia, among other issues. What are your thoughts on current treatments available to folks with chronic pain? How about the current push to make opioids unavailable to legitimate pain patients?

I'm excited for your work and hope it provides many with the relief they so desperately need.

[djspacebunny](#)

Studies show that long term opiate use actually increases pain. The brain in response to the receptor blocking that opiates cause, increases the number of receptors. Although very helpful for acute pain, over time they have a very negative result on chronic pain. Furthermore opiates have huge societal downside, that include dependency, addiction, increasing dosage level, personality effects, and all too common a transition to heroin, when they are not made available. Interesting the most commonly prescribed American opiate is not legal in Germany. Opiates have clearly been over scribed in the US.

What else can a doctor do in the 15 minutes that they have to hear your symptoms? The impact of pulling them back however is very disruptive for physical and psychological reasons. We strongly believe that most pain patients can become pain free with behavioral therapy, however it takes both time and a good therapist. Unfortunately this is not available to most chronic pain patients.

Thank you for doing a fascinating AMA! I have run into this infrequently, as most people (in the USA) don't utilize mental health providers to manage chronic pain. A couple of small questions:

What do you classify as pain behaviors?

Is there any room for treatment using Acceptance and Commitment Therapy or mindfulness, or have you looked at those as potentially testable models?

[scumbag_therapist](#)

Hi, thank you for your interest in our work and your question!

As pain behaviors we classify broadly any behavior that facilitates the pain taking up more power and space in the patient's life. Therefore pain behaviors can be individually different but typical ones would be verbal or mimic expression of pain, avoidance behaviors, being active until the pain gets too high thus negatively reinforcing resting behavior, often leading into the vicious circle of activity causes pain -> being less active -> muscle reduction, stiffness -> activity causes more pain, and so on.

We work out together with the patient what their personal pain behaviors are and encourage them to replace those with healthy behaviors, eg using training algorithms for several kinds of activity (household, work, free time...).

Our treatment is mainly focussing on operant techniques but there are elements of mindfulness in it, like enjoying a cup of coffee as doing something good for yourself (and using that as positive reinforcement for eg trying to do the house cleaning in a healthier way, with breaks scheduled independently of the pain and in a time span early enough so that the pain does not increase).

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There are studies that show that ACT is effective, however you have to take all of these studies with a grain of salt. What is needed in a behavioral change in the patient and this is hard to achieve. In some patients the techniques that you mention will work and in others, the majority unfortunately they fail. We have that patient heterogeneity is essential. The difference in patients can clearly be seen in physiopsychological parameters such as stress response, muscle tension, skin conductance, biochemical levels and many others. One key seems to be the patient's attitude toward their pain. If patients can move from "What I cannot do because of pain" to "what I can do". From "This always hurts" to "Sun is beautiful today and I have great friends". The focus on pain increases the pain and if you can forget about the pain, it is no longer there. Mental health is a very large component.

For those of us with chronic pain, but no concrete diagnosis, it can be exceedingly difficult to get proper attention from doctors. For example, my pain went untreated for nearly 5 years before I finally paid for a CT scan out of pocket. All because my doctor and insurance didn't think it was medically necessary. Now, 10 years and multiple surgeries later, I still have difficulty getting the medication and treatment I need.

How would you council those with chronic pain on how to discuss medication requirements with your doctor?

I think you folks are absolutely on the right track treating both mental and physical aspects of pain. When it goes on for so long, that pain can become mind numbing. It can be so hard to seek treatment when you just need a breath of fresh air. So often physical pain is treated while ignoring the mental strain. I remember telling my parents that i was tired and couldn't follow this cycle much longer without faltering. It took them 6 years to understand that i was mentally and emotionally tired and that i needed more help than a pill could afford.

There are so many people out there that need this compassion to take that next step towards recovery. That internal struggle to cope so often mirrors the external pain.

Thank you for doing this ama. I wish you the very best in your work.

[tastytoast](#)

Thank you so much! We hope we can help more people in the future as soon we have the miniaturized device that can go to physicians an therapists. We wish you our very best!

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[tastytoast](#)

Yes, you are right. All that I can say is that the doctors have it difficult too. They really have no solutions that consistently help and yet want to help their patients. All too many people, especially back patients, go through surgeries where the data show that they have no long term efficacy. In many cases, they make things worse. You are also right with the huge impact that chronic pain has on ones life. It impacts everything in both mind and body. The pills don't work, mostly, but is the only fast bandaid. Behavioral change does help and often makes patients pain free, but is a long and hard

process.

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[tastytoast](#)

Thank you. One key to medication is to take the prescribed amount at the same time each day or when your doctor says. If you take pain meds when you have pain, as a chronic pain patient (opposite result for scute pain), it becomes a pain behavior and the pain medication become a pain reward, just making things worse.

With respect to the doctor, in most cases he is not the answer. You have effect a behavioral change. The pain network and reward structures need to be disrupted and health behaviors need to be put in place.

How is Fibromyalgia currently defined medically? My understanding was that it was a diagnosis that often results from the exclusion of other causes of chronic pain.

[nate](#)

According to the criteria of the American College of Rheumatology (ACR, Wolfe et al., 2010), Fibromyalgia (FM) is either defined as chronic widespread pain and tenderness in at least eleven of 18 defined tender points (Wolfe et al., 1990) or, based on the current ACR-criteria, the case definition and diagnostic criteria for fibromyalgia asses a widespread pain index (WPI) and the symptom severity (SS) of cognitive symptoms, unrefreshed sleep, fatigue, and number of somatic symptoms ((WPI \geq 7 AND SS \geq 5) or (WPI = 3– 6 AND SS \geq 9)) with a similar level of symptoms for at least 3 months, and is not caused by a disorder that would explain the pain (Wolfe, 2010).

What is your response to the doctors and other 'professionals' that refuse to accept fibro as a legitimate disease?

My mother has it and many people tell her it's a made up condition and it's not real pain.

What do you refute this with? I know it's real. I live with her.

[MyTenderCarrion](#)

MRI studies shows that the the perceived pain is real. There is a strong relationship to what people perceive as the pain level and what is seen in the images.

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[MyTenderCarrion](#)

Although this was not always the case, it is a real disease. It can be seen in the mind (brain imaging) and in the body (depreciated autonomic nervous system). These are called tender points and are common in FM patients. It can or cannot be combined with mental disorders such as depression, anxiety, and many others.

Would your approach work for patients who have chronic pain for a clear medical reason? I ask because my family has Ehlers Danlos Syndrome and my mother was in severe chronic pain. I have mostly lower level pain so far but I have moderate to severe dysautonomia. Another question: would your approach help someone with a dysautonomia condition such as Postural Tachycardia Syndrome? I was thinking maybe the autonomic nervous system could be trained away from tachycardia?

Edit for chronic pain sufferers who may be reading this comment: My mother and I were diagnosed with Fibromyalgia before we were diagnosed with Ehlers-Danlos syndrome. Unfortunately, depending on your country, many doctors are not familiar with EDS and may mistakenly diagnose Fibro instead. You may want to look into EDS if you are having Fibro symptoms, especially if you have joint flexibility, instability, or dislocations.

[IceLizard3](#)

Unfortunately, we don't have any experiences with EDS. We see that each chronic pain disease can change behavior, mood and anxiety that reinforces the pain symptoms by activating sympathetic endocrine responses such as norepinephrine that influences brain and immune system. Our method that extended the behavioral pain therapy to a training of baroreceptors and brain stem activity can be helpful to reduce the overwhelming activity of our nervous system. What the consequences might be is not yet clear. However, when we have treated patients with inflammatory disease, we saw effects on the immune and hormone system that were synergistic with pharmacotherapy in reducing inflammation. The support of effects of other treatment methods with reduction of medication, or the reduction of tiredness and fatigue can be worthwhile.

Have you guys found evidence for, or do you believe that there is a strong mental component associated with chronic pain/RSI? I have recently just come out of 2 years of chronic hand (no pathology identified) pain, and long story short, the biggest change was me fundamentally and completely changing my thought patterns in relation to my hand.

[Its_all_fucked](#)

Yes, we found some evidence. I remember a guitarist and painter who has trouble with that. Our treatment could help them to increase their parasympathetic responses and reduced the level of muscle tension. They started with swim training that increased the strength in the shoulder muscles in order to relieve the pattern in the hand.

I have several questions.

Have you studied the impact of strong, positive social connections on symptoms of fibromyalgia patients, or the lack of them?

How influential are food allergies - or allergies in general - on the development and presentation of fibromyalgia symptoms?

Do you believe or have evidence that it is a potentially reversible condition?

How connected is psychological wellbeing to fibromyalgia onset and/or presentation?

Is there any evidence that the sufferer can "reset" themselves physically and/or psychologically to a non-fibromyalgia state?

I also tried to click on the surveys to participate and the links didn't work for me. Do you have an alternate link or email that I can participate via? Thank you!

[LuckyDucky](#)

Here is a link with the survey in German: <http://setmarburg.com/> Does it help you?

A note about me being biased

I was leading a very active life, in my late 20s, when I became ill. My renal professor has diagnosed me with Loin Pain Haematuria Syndrome. The main symptoms are blood in your urine and the same type of kidney pain/renal colic that people have when they get kidney stones. I experience these symptoms everyday. It's rare, incurable and as such my professors (One in renal,one in pain etc), have put me on opiates.I wasn't able to continue working. Lo an behold I haven't become a drug addict.

I found examples what other people with my condition had said, finally gave them relief. It's stronger stuff than I'm on. To give you an idea, if I manage to fall asleep, I often wake myself up screaming from the pain, contorting around from the spasms. This is while I'm on morphine. I took that list of examples to my pain consultant and he gave a flat out "No"... because #opiates.

I sat in his office crying and asked how it could be ethical to leave me in this amount of pain, with no end. I told him that if I presented at the emergency department, they would prescribe those painkillers on that list,because that's what they give to people with kidney spasms/renal colic. And he replied: "Yes,they would". And I said to him "But, because I have to experience this pain every day for the rest of my life,unlike those people with kidney stones,who only temporarily, I'm not allowed to be prescribed the medication that has been shown to provide relief,when nothing else does?" And he said "Yes"...because # opiates.

I suppose that it doesn't matter what I say because, based on the logic of this AMA, I'm just *using my pain to get societal rewards and attention*. So, I guess all this *attention*, is totally worth the loss of a decade long career in the health service, giving up sports, giving up the gym, becoming my partner's financial dependant, being able to complete perhaps one chore a day and leave the house once a week.

Yay for me! I'm off to bask in the glow of my *societal rewards*.

End of note about bias

(EDIT) I did have a question typed out here but I've deleted it because I've read some disturbing things in the rest of your comments for this AMA. It seems that you believe people are faking in order to get attention:

[pain can be reinforced by social responses as "rewards"...](#)

[as soon the patient gets the attention on her/his pain, the network is activated and the patients perceives the pain more intense than before](#)

In society most illnesses are met with a sympathetic response to symptoms. Yet , somehow it's only people who have pain as a symptom, are singled out as using it as some kind of tool to get a reward? Why are you not telling people with say asthma/diabetes/ulcerative colitis that their symptoms are a way of getting "rewards" from society ?

Once key seems to be the patients attitude toward their pain. If patients can move from "What I cannot do because of pain" to "what I can do". From "This always hurts" to the "Sun is beautiful today and I have great friends". The focus on pain increases the pain and if you can forget about the pain, it is no longer there. Mental health is a very large component.

Again, why aren't other groups of patients told to just forget about their symptoms and that their symptoms will dissappear as a result? No one telling people with Diabetes that their foot will magically reappear if they just "forget" about it. No one telling people with Bipolar Disorder that they don't actually need medication for their symptoms - All they need to do is forget about them symptoms and adopt a can do attitude!

When I am asleep I am not conscious, so how is it that my excruciating pain wakes me up ? By your logic, I've forgotten about it, so I should be symptom free.

I've always been wary of things that require you to believe in them to work. And I'm getting hints of that here. Surely, it shouldn't matter what attitude a patient has if something actually works.

[We have trouble getting out ideas accepted in spite of University based RCT studies.](#)

So are you saying that your work hasn't been peer reviewed?

Can you please cite the research that supports the following :

[However, the new generation of physicians observe for example that a surgery is going often worst when the whole family is there before the surgery and gives a high amount of solicitous behavior.](#)

Your survey Focuses on two main points ,which I find very telling:

- How desperate people are in their willingness to try something else.
- The most amount of money they would be willing to part with.

And then of course people have to sign up for a certain amount of sessions. They also have to go in for top ups when you their "reversible" illness suddenly appears again.

Some Perspective on Opiates

Alcohol: [88000 Deaths per year in USA](#)

Opiates: [20 000 deaths per year in USA\(2nd chart on page\)](#)

Also, I'm not really sure that it's a forgone conclusion that patients on opiates go on to use heroin. Perhaps you are talking about methadone which is medically prescribed for pain.

TLDR

I don't agree with this. I find it disgusting that people with pain are being told to forget about their symptoms and they will go away. If you applied this rationale to any other group of patients, there would be serious repercussions.

It's funny how when something is poorly understood and/or difficult to treat, patients are always then told to change their attitude/mood/behaviour in order to be more positive and can do etc. And then 20 years later, doctors prove it's a real thing ,to themselves.(The patients knew all along.) And then they start treating it differently.

Also PS to doctors - Prescribing opiates is surely better than your patient killing themselves because they couldn't live with the pain.

[Tangelyno](#)

I am not going answer this in detail, but the concept of a reward is not something conscious. Like pavlov's dog that salivates the he hears the bell. The learning is completely automatic and unconscious. So you are not trying to get any rewards, they nevertheless happen. We are talking about chronic and not acute pain > 3 months. The brain is very plastic and, unless the response is conditioned or learned, will automatically ignore and "rewire" itself around an external condition. This can be seen with the loss of a limb, massive weight gain, or any number of other situations. We strongly feel, and others may disagree, that the pain network that perpetuates the pain is in the brain, after a certain time, not in the body. With respect to opiates in the US, the FDA and others have over the last couple of years limited access to opiates due to addiction problems. The NYT is full of articles that describe how this has turned into significantly rising heroin use as pain and other patients seek substitutes. The problem is very real.

Hi all, many thanks for doing this AMA. My wife suffered a horrific accident that has left her in chronic pain. Specifically she suffered a caustick burn to the eye that has triggered her trigeminal nerve. She's been left in constant, daily agony. She's been through 4 surgeries all, unsuccessful and is now active suicidal with the pain to the extent that was she committed to a full time residential pyshiatric care. Her quality of life is non existent. She can't even go outside as the slightest breeze trigger an increase in trigeminal nerve pain. Her life exists around knocking herself put with pain killers and sleeping tablets - which don't actually take the edge off the pain but do knock her out - and lying on a couch wis hung she was dead. It is taking every last ounce of will power for her not to drink herself to oblivion or look to illegal nacoritcs to give her some peace.

I am desperate not to lose my wife to her own hand or drugs. She's been suffering now for 4 years and it's becoming increasingly hopeless. Today she broke down during her CBT therapy and they called her pyshiatric team over concerns she may try to end her life again.

When I saw this I thought it was incredible timing as I was unaware of this treatment possibility.

Have you worked with trigeminal neuropathy patients using this protocol and how long does treatment take. We are based in Europe but I would be more than willing to relocate to your location to have her treated if this is a viable possibility.

Many thanks for your time.

[KoumoriOtoko](#)

From the insufficient information that we see and without wanting to disagree with your medical professionals and with many reservations, we will try and respond. With all due respect, we think that both you and drug addiction are part of the problem. Your trying to help and increasing concern and

helped in conditioning and maintaining the pain. At this this stage, nothing short of an in patient treatment will work that breaks the addiction as a first step. The 2nd step is therapy that results in the realization that there is life beyond the pain. Unfortunately after so many failures this is hard to achieve. Furthermore you as the partner cannot do it and trying has already and will make things worse. It is hard for me to write this and it likely come over as being harsh and callus, but if I understand the situation properly this is the only path forward.

Are you familiar with Dan Neuffer, patient/researcher, and his [ANS Rewire](#) program for ME/CFS and Fibro? Many of us have various dysautonomia dignosis, and the more I learn about it the more I understand how a faulty or damaged autonomic nervous system may be the cause of many of the most debilitating symptoms.

His approach is about becoming aware of autonomic triggers of various kinds, and reducing them so that more normal function can be recovered. Does your device help identify these triggers? Would you agree with his analysis?

[JustMeRC](#)

No, we will look into this. Thanks