

Pentoxifylline: shows amazing results but it's a potent immunosuppressive agent: your opinion?

- Thread starter [serg1942](#)
- Start date [Jan 5, 2021](#)

- [1](#)
- [2](#)
- [3](#)
- [4](#)

Next

[Jump to new](#) [Watch](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Hi guys,

I recently learned about pentoxifylline because it was prescribed to a friend of mine with ME/CFS by an immunologist, who said that 50% of his ME/CFS patients improved on it.

She was reassured that it was mainly an immune-modulator agent, so she had nothing to worry about.

She is doing amazingly well on this drug after about 2 months on it, to the point where she is feeling almost normal.

I have been doing a thorough research on the drug (because I was considering trying it, as I am bedridden, so is my mom and my partner!). And I found that it actually is a powerful immunosuppressive agent. Most available studies are done in vitro, and they show that it strongly decreases NK cells cytotoxicity, inhibits phagocytic activity of the PBMCs, inhibits T and B cell activation, inhibits expression of adhesion molecules on the surface of CD4+ and CD8+ lymphocytes, lowers total count of leukocytes, decreases neutrophil functions, reactivates CMV, and a long etc. (links to the studies below). It's been also shown that pentoxifylline is as immune suppressive as dexamethasone.

I have only found 2 studies in vivo where immune system status was assessed. In this respect, one study in humans confirmed what the studies in vitro had found repeatedly: after 1 year or more on pentoxifylline, patients showed a 38% and a 41% reduction in NK cytotoxicity compared with patients or with healthy controls, respectively.

The second study I found in humans showed an 11% reduction in leukocyte count after just one month on the treatment, when given to diabetic patients.

I can understand how this drug can work amazingly for some patients. It lowers TNF-alpha, which is a key cytokine in the feeling of fatigue. It also inhibits the T and B polyclonal proliferation, and also quenches autoimmune processes that might play a role in the pathogenesis of the disease. Moreover, it inhibits the translation of the inflammatory complex NF-kappa B, which we know is also key in ME/CFS pathophysiology. It even increases reduced glutathione (what is to be expected when lowering inflammation) and improves microcirculation.

Now, all this might come at a price, and it is my intention to figure out what exactly this price may be.

A 40% reduction in vivo of NK cell function is just a lot. The relationship between low NKs and cancer is certain. For example, there was a 23.6% higher survival rate of gastric cancer patients in 5 years follow-up, if NK functionality was more conserved:

<https://pubmed.ncbi.nlm.nih.gov/11232710>

In this regard I've done some research on the cancer-induced rate of immune suppressive drugs when taken as a single treatment for autoimmune conditions. Thus, a review on the subject explains how, for example, for multiple sclerosis patients taking azathioprine, there's a 30% increase of cancer in less than 5 years, a 100% increase in 5-10 years and a 440% increase in more than 10 years. Similarly, a mean of 8 years follow-up of patients with Wegener's granulomatosis taking cyclophosphamide showed a 2.4-fold overall increase in malignancies per year. In the same vein, patients with psoriasis treated with cyclophosphamide had a 2.1-fold increase of cancer in a 5 years follow-up.

A drug that could be compared to some extent to pentoxifylline is the anti TNF-alpha Infliximab, given that pentoxifylline is known for its capacity to lower TNF-alpha levels. In this case there are mixed results. For example, some studies do not show more cancer rates in Crohn's disease patients taking Infliximab, but other trials demonstrated a 2-3 fold increase in the risk of non-Hodgkin lymphomas, in patients with rheumatoid arthritis taking Infliximab (although to be fair, this comparison is not completely adequate given that Infliximab is a single targeted drug, versus pentoxifylline which shows immunosuppressive

properties in numerous branches of the immune system):

<https://pubmed.ncbi.nlm.nih.gov/12581698>

<https://pubmed.ncbi.nlm.nih.gov/1739240/>

In summary, what I'm asking is not whether it would be worth taking the risk to take immune suppressants in ME/CFS, as, of course, the answer is: it depends! .

What I'd like is for you to help me figure out the real risks in terms of future cancer that might entail the chronic use of pentoxifylline. Unfortunately this is a pretty cheap drug which have not been properly studied.

Thank you so much in advance for your insights and opinions,

Best!

Sergio

Bibliography:

- Pentoxifylline given to patients for more than a year showed a 38% and a 41% less cytotoxicity compared to patients and controls, respectively:

<https://link.springer.com/article/10.1007/PL00005346>

- Pentoxifylline strongly suppressed NK cell function in vitro:

<https://pubmed.ncbi.nlm.nih.gov/1593221/>

- Pentoxifylline inhibits granzyme B and perforin expression following T-lymphocyte activation by anti-CD3 antibody, in mice:

<https://www.sciencedirect.com/science/article/abs/pii/S0192056196000690>

- Pentoxifylline reduces pro-inflammatory cytokines and inhibits adhesion between leukocytes and endothelial or epithelial cells. There may also be inhibitory effects on neutrophil, T and B lymphocytes and NK cell activity:

<https://www.sciencedirect.com/science/article/pii/B9780702028588500142>

- Pentoxifylline may inhibit HIV expression indirectly by diminishing TNF production and directly, by decreasing activity of NF-kappa B:

<https://pubmed.ncbi.nlm.nih.gov/8699854/>

- Pentoxifylline decreases neutrophil function, decreases leukocyte response and proliferation, inhibits B and T cells and decreases Th1 cytokines and increases Th2 cytokines:

<https://onlinelibrary.wiley.com/doi/full/10.1002/vms3.204>

- Pentoxifylline, after one month given to type-2 diabetes patients: decreases 11.1% of total leukocyte count, decreases CRP and ESR, and increases reduced glutathione:

<https://pubmed.ncbi.nlm.nih.gov/17613279>

- Pentoxifylline inhibits binder and killer cell generation, cytotoxicity, proliferation, regulation of surface antigen expression, and induction of cell surface receptors:

<https://link.springer.com/article/10.1007/BF01541173>

- Pentoxifylline increases fibroblast collagenases and decreases collagen, fibronectin and glycosaminoglycan production (...) Pentoxifylline is an inhibitor of production of IL-1 and IL-6, an inhibitor of T and B cell activation, and a suppressor of neutrophil degranulation:

<https://escholarship.org/uc/item/6270c6vm>

- Pentoxifylline Promotes Replication of Human Cytomegalovirus In Vivo and In Vitro:

<https://ashpublications.org/blood/a.../Pentoxifylline-Promotes-Replication-of-Human>

- Pentoxifylline inhibits natural cytotoxicity as effectively as dexamethasone:

https://www.researchgate.net/public...forin-dependent_natural_cytotoxicity_in_vitro

- Pentoxifylline strongly reduces total number of monocytes capable of fagocytizing latex particles in vitro:

<https://pubmed.ncbi.nlm.nih.gov/3023514/>

- Pentoxifylline suppressed expression of adhesion molecules LFA-1 and VLA-4, in CD4+

and CD8+ lymphocytes:

[https://www.jni-journal.com/article/S0165-5728\(96\)00198-1/fulltext](https://www.jni-journal.com/article/S0165-5728(96)00198-1/fulltext)

[#1](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Marylib](#), [Aspire2021](#), [Abha](#) and 15 others



[bensmith](#)

Senior Member

Messages

1,482

Likes

3,160

Not sure about the answer but im so sorry you and your family is bed bound. Hugs bro.,

[#2](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Mary](#), [Hufsamor](#), [Mariaba](#) and 7 others



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

It's definitely not considered nearly as immunosuppressive as steroids as it doesn't affect numbers of circulating lymphocytes. Also it doesn't have the horrible side effects of steroids limiting their use for more than a few days at a time.

I read too that pentoxifylline also improves red blood cell deformability and blood viscosity. Ron Davis's lab wrote a paper showing reduced deformability in ME/CFS

[Red blood cell deformability is diminished in patients with Chronic Fatigue Syndrome](#)

Last edited: Jan 5, 2021

[#3](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [J.G.](#), [stefanosstef](#), [Pyrrhus](#) and 2 others



[Nat kea](#)

Messages

21

Likes

54

In our country, pentoxifylline is often prescribed to people with osteochondrosis. But I drank without a prescription, we have it without a prescription. It had a very good effect on performance, on eyesight, on hair loss, the skin on my face became pink, healthy. But it caused some nervous excitement and intensification of my neuralgia. So sorry. The effect was excellent, I did a lot of things. But to endure severe pain is beyond my strength ..

[#4](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Mary](#), [pattismith](#), [stefanosstef](#) and 2 others



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Thank you [@bensmith](#)! I really appreciate your comment!

Hi [@leokitten](#), yes, pentoxifylline does improve RBCs deformability, and this is one of the reasons why it might be helpful in ME/CFS.

When I say that it is considered as powerful as corticosteroids, it is because an in vitro study shows a similar degree of immunosuppression as does dexamethasone, but this is just an in vitro assay:

"(...) pentoxifylline inhibits natural cytotoxicity as effectively as dexamethasone. However, the result of PTX inhibitory influence is observed much earlier than that of dexamethason

(...)"

https://www.researchgate.net/public...forin-dependent_natural_cytotoxicity_in_vitro

And as far as not lowering circulating leukocytes, well it does lower in vivo an 11.1% the total count of lymphocytes in just 1 month (as shown in a study I posted above). However, what is more concerning to me is that this drug seems to halter the functionality of white blood cells much more than their numbers. Thus, It reduced a 40% the cytotoxicity of NKs in vivo. And also over a 40% the Phagocytic capacity of monocytes in vitro...

But this is exactly the reason of my post: why doctors say that it is not immunesupresive despite of what the literature says?

Thank you for your opinion!

Best

Sergio

[#5](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Marylib](#), [Learner1](#), [ChrisD](#) and 2 others



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Hi [@Nat kea](#),

Thank you for you answer. I am so sorry that you had to stop it when you were seeing so good results! It must have been frustrating! Thank you for letting me know your experience!

Sergio

[#6](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Aspire2021](#) and [sb4](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[serg1942 said:](#)

But this is exactly the reason of my post: why doctors say that it is not immunosuppressive despite of what the literature says?

Probably because they do not see increased risk of infections from patients taking it long-term, whereas with steroids this is not the case. People take pentoxifylline every day long-term for peripheral artery disease.

[#7](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Marylib](#), [serg1942](#), [sb4](#) and 1 other person



[crypt0cu1t](#)

IG: @crypt0cu1t

Messages

583

Likes

1,540

Location

[California](#)

It's not surprising that it works. I personally know of a few people with ME/CFS that has nearly recovered on similar drugs such as Cellcept and Azathioprine.

[#8](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Marylib](#), [MartinK](#), [stefanosstef](#) and 2 others



[pattismith](#)

Senior Member

Messages

3,416

Likes

6,641

This drug may be useful to people with high NK cells, high TNF alpha and high neutrophil count.

[@serg1942](#) , Do you know if your friend was in this subset?

[#9](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [Marylib](#), [serg1942](#) and [sb4](#)



[JES](#)

Senior Member

Messages

1,168

Likes

2,722

Lots of medication inhibit TNF-alpha indirectly, the antidepressant bupropion is one example, but millions of people take bupropion without any correlation drawn to cancer as far as I know. Fish oil is another one, I have read studies that high-dose especially lowers it quite a bit.

So yeah, this is more of an opinion, but based on the above two examples I wouldn't be super concerned.

[#10](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 5, 2021](#)

[Report](#)

Likes: [stefanosstef](#), [sebaaa](#), [serg1942](#) and 2 others



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Thank you guys for your inputs!

[@leokitten](#), you might be right (I hope you are for the sake of my fiend and of those who choose to take it!). However, in ME/CFS, we have usually low NKs and we barely show infections. Still, it's been shown that we have more chances of getting cancer than general population. This is relatively easy to explain, given that we lack a powerful Th1 and Th17 response (mainly CD8+) to mount a proper response to infections. So, not showing infections doesn't necessarily mean that pentoxifylline cannot entail greater chances of developing cancer. Also, we don't know if pentoxifylline is actually immune suppressing patients taking it, because there haven't been proper studies conducted (and patients taking it are usually elderly people with chronic diseases, so it would be hard to discern a greater occurrence of cancer) . However the in vitro and limited in vivo evidence still seems concerning to me.

Hi [@pattismith](#), actually she usually has very low NKs, I think normal neutrophils and I don't think she's measured TNF-alpha. But it is my gues that she must have had high TNF-alpha because she did show high perforin levels, meaning that macrophages are trying to stimulate NKs!

[@crypt0cu1t](#), I agree with you. There are many immune-suppressive drugs on the market yet to be explored for ME/CFS, which will show great benefits.

Hi [@JES](#), thank you for yor reply! Well, one thing is lowering excessive inflammation (this is known as immune modulation, and as you say it can be achieved by many molecules, including fish oil, turmeric, vit C, quercitine, LDN, etc.), and a very different one is immune-supression. Normally, immune modulation lowers inflammation when high while increasing the immune system when low.

So, those of you who think that there's nothing to worry about with pentoxifylline, how do you explain the literature I have listed above? I mean, if reproduced by other studies, a 40% decrease in in vivo NK function wouldn't be acceptable for any medication on the market...

Thank you all again for sharing your opinions!

Sergio

[#11](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 6, 2021](#)

[Report](#)

Likes:[Marylib](#), [Learner1](#), [leokitten](#) and [1 other person](#)



[Reading Steiner](#)

Senior Member

Messages

224

Likes

554

well perhaps it could be used as a research tool to explore the mechanics of me/cfs if it is not suitable for long term consumption. Its interesting to reconsider about rituximab responders.... being in the UK I have not had any tests done via the NHS that would rule out being in the subgroup which respond to rituximab. Does nobody find it remarkable that there are drugs now which have been confirmed to be effective in some way ?

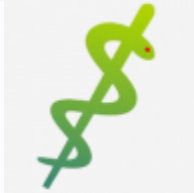
[#12](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 6, 2021](#)

[Report](#)

Likes: [Marylib](#), [Pearshaped](#) and [serq1942](#)



[Hip](#)

Senior Member

Messages

16,515

Likes

35,820

Some years ago I tried a related compound called **propentofylline**, and there is some discussion about both propentofylline and pentoxifylline in [this short thread](#).

(I experimented with propentofylline because it increases expression of brain glutamate transporters, which remove glutamate from the brain; there's some speculation that the "wired" feeling of ME/CFS may involve high brain glutamate; propentofylline may have sharpened my mind and reduced my brain fog, but I did not take it for long enough to fully evaluate the drug).

[This is a report](#) of an ME/CFS patient who tried pentoxifylline for one month, but noticed no benefits.

New Patient? ► [ME/CFS — A Roadmap for Testing and Treatment](#)

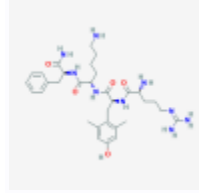
[#13](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 6, 2021](#)

[Report](#)

Likes: [Marylib](#), [Aspire2021](#), [stefanosstef](#) and 4 others



[mitoMAN](#)

Senior Member

Messages

503

Likes

889

Location

[Germany/Austria](#)

[serg1942](#) said:

I recently learned about pentoxifylline because it was prescribed to a friend of mine with ME/CFS by an immunologist, who said that 50% of his ME/CFS patients improved on it.

I doubt about these statements, similiar to another CFS doctor quoted recently that claimed 90% Success Rate.

Rituximab trial ended up having less successrate then the Placebo group.

[#14](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 6, 2021](#)

[Report](#)

Likes: [Marylib](#), [Badpack](#) and [stefanosstef](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[mitoMAN](#) said:

I doubt about these statements, similiar to another CFS doctor quoted recently that claimed 90% Success Rate.

Rituximab trial ended up having less successrate then the Placebo group.

Well, yes, who knows... I only know a friend of mine to whom it is working really well. But, judging by its profile I wouldn't be surprised if it worked for many fellows...

[#15](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes:[Marylib](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Hi [@Hip](#), thank you for your message. I didn't know about propentofylline. Is it also an antiinflammatory as pentoxifilline?. Yes, I think there is some evidence on the high glutamatergic synapses in ME/CFS, and I think this is the reason why clonazepam works for some of us, when no benzo works.

Thank you for sharing the link. I'm going to read it. (It is interesting though that pentoxifillie took 2 months to work for my friend).

Take care,

Sergio

[#16](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes:[Marylib](#), [Hufsamor](#), [Pyrrhus](#) and 1 other person



[Learner1](#)

Senior Member

Messages

5,956

Likes

10,859

Location

[Pacific Northwest](#)

[@serg1942](#) I am a stage 3 cancer survivor and have spent quite a bit of time in the cancer world in the past 6 years. I have met a number of people who hit various cancers, typically lymphoma or leukemia, from being in immunosuppressive drugs.

I think you are very wise to be concerned about the effects of pentoxifylline. Many cancer treatments rely on NK cells functioning to work, so anything that diminishes their function could be scary - in fact, my low NK cell function has been a worry in case I experience a recurrence.

It might be prudent to dig through the various effects it has on the immune system, and maybe get tested for the problems that pentoxifylline seems to solve, and then figure out what's driving those - hidden infections, some sort of toxicity (mycotoxins?) or more likely, some sort of autoimmunity and then treat those.

I know I've gotten a long way with antivirals, antibiotics, LDN, IVIG and Rituximab to unwind the several serious problems we identified and ME/CFS that I developed as a result of my cancer treatment.

If you use pentoxifylline without any more in depth investigation, I'm not sure you'd know what caused the problems in the first place and there may be unexpected side effects or unwanted other problems that develop, like cancer or sepsis, another common problem with immunosuppressants.

Best wishes....

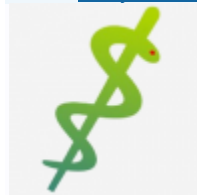
[#17](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Marylib](#), [stefanosstef](#), [serg1942](#) and 1 other person



Hip

Senior Member

Messages

16,515

Likes

35,820

I would think that unless you have an active cancer, the concern over reduced NK function from pentoxifylline should not be an issue in a short term test, to see whether this drug might improve your ME/CFS.

If pentoxifylline did substantially improve ME/CFS, and you thus wanted to take it indefinitely as an ME/CFS treatment, that's when further investigation into the consequences of reduced NK function might be warranted.

ME/CFS patients have reduced NK functioning anyway, and there's no evidence to suggest this leads to a greater incidence of cancers in the ME/CFS patient population.

In any case, [there are a number of drugs and supplement which can boost NK function](#), so these might be taken alongside pentoxifylline to counter the NK suppression. For example, the supplement MGN3 Biobran increases NK activity by 300%.

Interestingly enough, "pentoxifylline has been found to sensitize some cancer cell lines to chemo- and radiotherapy". Ref: [here](#).

And [this study](#) gave pentoxifylline 400 mg three times daily for 12 months to breast cancer patients after radiotherapy treatment, and the study concluded " the combination of pentoxifylline and vitamin E was safe and may be used for the prevention of some radiation-induced side-effects".

New Patient? ► [ME/CFS — A Roadmap for Testing and Treatment](#)

[#18](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Marylib](#), [Hufsamor](#), [stefanosstef](#) and 4 others



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

There are many papers that show the potential anticancer sensitizing effects of pentoxifylline when combined with other cancer therapies.

[#19](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Marylib](#) and [serg1942](#)



[Learner1](#)

Senior Member

Messages

5,956

Likes

10,859

Location

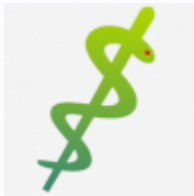
[Pacific Northwest](#)

[Hip](#) said:

In any case, [there are a number of drugs and supplement which can boost NK function](#), so these might be taken alongside pentoxifylline to counter the NK suppression. For example, the supplement MGN3 Biobran increases NK activity by 300%.

I've been on several of the substances in that list for quite awhile and can't say they've done anything helpful for my NK function. It's one thing to read studies but another to experience something in realtime.

[#20](#)



[Hip](#)

Senior Member

Messages

16,515

Likes

35,820

[Learner1](#) said:

I've been on several of the substances in that list for quite awhile and can't say they've done anything helpful for my NK function. It's one thing to read studies but another to experience something in realtime.

There are always people who do not respond to a treatment, so an N=1 case showing a negative result does not invalidate the studies. Here are three studies which indicate Biobran (MGN-3) boosts NK function:

[Enhancement of human natural killer cell activity by modified arabinoxylan from rice bran \(MGN-3\)](#)

[Biobran/MGN-3, an arabinoxylan rice bran, enhances NK cell activity in geriatric subjects: A randomized, double-blind, placebo-controlled clinical trial](#)

[Arabinoxylan rice bran \(MGN-3/Biobran\) enhances natural killer cell-mediated cytotoxicity against neuroblastoma in vitro and in vivo](#)

The other thing is, were your NK tests from a reliable lab?

Note that NK function test is not the same as the NK numbers test.

By the way, a study of Biobran (MGN-3) for ME/CFS patients found no benefit for ME/CFS.

Last edited: Jan 8, 2021

New Patient? ► [ME/CFS — A Roadmap for Testing and Treatment](#)
[#21](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Sancar](#), [Marylib](#), [leokitten](#) and 1 other person



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[@Hip](#), [@leokitten](#),

Thank you for letting me know about the studies on pentoxifylline as an anticancerous agent. I have done a further reading of the available literature on the subject, and indeed, there are many papers showing an antineoplastic effects of pentoxifylline in different cancers in mice.

While this is encouraging, I must add that the opposite seems to be also true: pentoxifylline can promote cancer growth in mice. For example, pentoxifylline promotes colon adenocarcinoma-derived metastatic tumor growth in lungs and also in liver of mice:

<https://www.spandidos-publications.com/10.3892/or.11.5.1121/abstract>

<https://pubmed.ncbi.nlm.nih.gov/14534700>

Similarly, it strongly promoted rhabdomyosarcoma-derived tumor growth in mice:

<https://pubmed.ncbi.nlm.nih.gov/7974171/>

A possible explanation, beyond the suppression of cytotoxicity, can be that this drug increases blood flow in cancerous cells. Thus, a human study inserted a catheter in cancerous lymph nodes of 11 oncologic patients with different types of cancer (adenocarcinoma, squamous cell carcinoma, lymphoma, melanoma, and transitional cell carcinoma), and found that pentoxifylline actually increased the blood flux into the tumors, accounting for one of the reasons why it helps chemotherapy to work. However, enhancing blood circulation through the tumors is a way of "feeding" them:

<https://www.sciencedirect.com/science/article/abs/pii/S0167814001004935>

So, how is it possible to show one thing and the opposite at the same time? Well, it seems that pentoxifylline has anticancerous properties, including antineoplastic, antifibrotic, and antiinflammatory properties. It also works at a molecular level inducing cell apoptosis, and inhibiting adhesion molecules on cancerous cells.

But, as I reviewed above, it seems to lower NK (and probably CD8+) cytotoxicity as well as other key aspects of a necessary cellular response against cancer. So, I guess that depending on the type of cancer, its location, and host's immunity status, it will go one way or another (in this regard, the increased blood flow of pentoxifylline to tumors was shown to be dependent on the location of the tumor, in mice:

<https://europepmc.org/article/pmc/pmc1968634>).

However I'd like to make an important point: I am concerned about people with ME/CFS taking this drug. And, ME/CFS patients are already immune-suppressed, with a reduced Th1 and cellular innate (NK dependant) response. Obviously this could tip the balance towards unwanted side effects.

Also, many ME/CFS patients have tested positive for infections, including Lyme disease (I have, by CDC criteria, and meet ME/CFS diagnostic criteria as well).

So, do we know what might happen if we take pentoxifylline with a chronic infection? Well, here's a study showing that pentoxifylline worsens lung damage in mice with chronic tuberculosis:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1783172/>

In summary, I think I have reached a dead end regarding whether the use of pentoxifylline may be dangerous or not. We just do not have enough data, and prospective longitudinal trials in humans are needed.

I think I will err on the safe side though, and won't take this drug for now.

I'm sorry for the "assay"! I really appreciate your inputs and the debate!

Best,

Sergio

[#22](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Marylib](#), [Hufsamor](#), [Pyrrhus](#) and 4 others



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

Hi [@Learner1](#)

Thank you for your advice. I am so sorry that you had to face an advanced state cancer, and that after beating it you developed ME/CFS... (but hey, you beat it!).

I totally agree with you in that it is a wiser approach to "treat the terrain" first (as RichvanK used to put it!). In this regard, I am trying to effectively get rid of *Borrelia Miyamotoi* (the one I tested positive for) with the new drugs for persisters. I will be sending the samples next week to do the mycotoxins test as well. So yes, I am trying to get rid of the stressors and potential triggers of the "Dauer" state, and see how this works out.. However I must recognize that it is tempting to take a drug that might just "do the trick", so this exercise I'm doing of trying to "poke holes" in the possibility of taking this drug safely, is not an easy one!

Take care and thank you again!

Sergio

[#23](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 7, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Learner1](#)



[stefanosstef](#)

Senior Member

Messages

528

Likes

1,300

I might try this, it's OTC here and dirt chip. How soon do you get benefits if you respond to it?

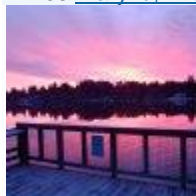
[#24](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 8, 2021](#)

[Report](#)

Likes: [Marylib](#), [mitoMAN](#) and [leokitten](#)



[Learner1](#)

Senior Member

Messages

5,956

Likes

10,859

Location

[Pacific Northwest](#)

[Hip said:](#)

The other thing is, were you NK tests from a reliable lab?

Note that NK function test is not the same as the NK numbers test.

Yes. It was an NK function test ordered by a reputable lab.

[Hip said:](#)

By the way, a study of Biobran (MGN-3) for ME/CFS patients found no benefit for ME/CFS.

Well, then probably not worth taking.

[serg1942 said:](#)

I totally agree with you in that it is a wiser approach to "treat the terrain" first (as Richvank used to put it!). In this regard, I am trying to effectively get rid of *Borrelia Miyamotoi* (the one I tested positive for) with the new drugs for persisters. I will be sending the samples next week to do the mycotoxins test as well. So yes, I am trying to get rid of the stressors and potential triggers of the "Dauer" state, and see how this works out.. However I must recognize that it is tempting to take a drug that might just "do the trick", so this exercise I'm doing of trying to "poke holes" in the possibility of taking this drug safely, is not an easy one!

That sounds like a wise approach.

Unfortunately, though we'd all like a magic bullet, it's unlikely one exists. The situation you just described has the original indilt yo the body, along with a cascade of other effects, so putting the genie back in the bottle is not so simple and why taking a substance affecting one piece of one's illness is unlikely to work if nig gone as a comprehensive approach attacking the other aspects.

[serg1942 said:](#)

In summary, I think I have reached a dead end regarding whether the use of pentoxifylline may be dangerous or not. We just do not have enough data, and prospective longitudinal trials in humans are needed.

I think I will err on the safe side though, and won't take this drug for now.

Sounds wise.

[#25](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 8, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Hip](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[stefanosstef said:](#)

I might try this, it's OTC here and dirt chip. How soon do you get benefits if you respond to it?

I read you have to take it for a couple months to see full benefits or not.

[#26](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 8, 2021](#)

[Report](#)

Likes: [Marylib](#) and [stefanosstef](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

I'm giving it a try because it's so cheap so I ordered it. Will take it for 3 months hope it helps with ME synonyms.

[#27](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 15, 2021](#)

[Report](#)

Likes: [Marylib](#) and [mitoMAN](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[leokitten](#) said:

I'm giving it a try because it's so cheap so I ordered it. Will take it for 3 months hope it helps with ME synonyms.

I hope it works for you as well as it is still working for my friend!! Keep up posted, and if possible, try to check your perforin levels after a few months on it! Take care! Sergio

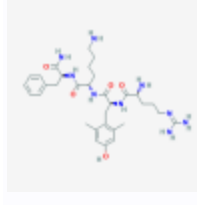
[#28](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 15, 2021](#)

[Report](#)

Likes: [Marylib](#), [Pyrrhus](#) and [leokitten](#)



mitoMAN

Senior Member

Messages

503

Likes

889

Location

[Germany/Austria](#)

[leokitten](#) said:

I'm giving it a try because it's so cheap so I ordered it. Will take it for 3 months hope it helps with ME synonyms.

Please keep us updated If you want we can make a **#Pentoxifylline** channel on the CFS Treatment discord

[#29](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 15, 2021](#)

[Report](#)

Likes: [Marylib](#) and [leokitten](#)



leokitten

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[@serg1942](#) what's the dosage regimen this immunologist is prescribing to patients?

[#30](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 21, 2021](#)

[Report](#)

Likes: [Marylib](#)



serg1942

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[leokitten](#) said:

[@serg1942](#) what's the dosage regimen this immunologist is prescribing to patients?

Sorry I couldn't reply earlier. He is prescribing 400 mg BID. My friend who is doing so amazingly well on it is on this dose.

However you'd still have room to raise the dose in the future up to 1200 mg daily.

I hope it helps! Please keep us posted!

Best wishes!

Sergio

[#31](#)

[Like](#) [Quote](#) [Reply](#)

[Jan 23, 2021](#)

[Report](#)

Likes:[J.G.](#), [Marylib](#), [mitoMAN](#) and 2 others



[MartinK](#)

Senior Member

Messages

310

Likes

470

Hi [@serg1942](#) sorry for this little off-topic post.

How it looks your b. miyamotoi treatment? And what test detect it? Phage from REDlabs? ;-)

Thanks!

[#32](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 15, 2021](#)

[Report](#)

Likes:[Learner1](#)



[Hufsamor](#)

Senior Member

Messages

Likes 2,476

Likes

9,442

Location

[Norway](#)

[serg1942](#) said:

She is doing amazingly well on this drug after about 2 months on it, to the point where she is feeling almost normal.

This is more than a month ago...is she still feeling good?

[#33](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 15, 2021](#)

[Report](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[MartinK](#) said:

Hi [@serg1942](#) sorry for this little off-topic post.

How it looks your b. miyamotoi treatment? And what test detect it? Phage from REDlabs? ;-)

Thanks!

Hi Martin,

I tested positive for B. Miyamotoi by the qPCR borrelia phage test from Redlabs. However, I had years ago a positive LTT and also an "almost" positive IgM Western Blot (one band was borderline, but considering that I usually had low total IgMs, this could be considered as a positive). My CD3-CD57+ cells are also always very low, with a normal CD38+, what I think makes a convincing case for a true active Lyme infection.

Unfortunately I have so many GI sensitivities, that I can't tolerate neither disulfiram nor dapsone, which are the cutting-edge and newest antibiotics that treat the persistent form of the borrelia... However, my partner, who also suffers from severe ME/CFS and is also positive for Lyme disease, took disulfiram for over 4 months, and her inflammatory markers normalized. However she is still with the same symptoms and she is still positive for Borrelia Miyamotoi. Now she is following the so called "double dapsone protocol" as published by Dr. Horowitz, including Dapsone, rifampicin, doxycycline, hydroxychloroquine, nystatin,

methylene blue and very high doses of activated folates (plus probiotics, antioxidants and biofilm breakers). She is herxing like hell,so she is definitely killing bugs. Let's hope Dapsone does the work!

I hope this is helpful!

Sergio

[#34](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 17, 2021](#)

[Report](#)

Likes:[Sancar](#), [Marylib](#), [MartinK](#) and 2 others



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[Hufsamor said:](#)

This is more than a month ago...is she still feeling good?

She is feeling incredibly well, doing a pretty normal life, although last time she told me how she waa doing, she said that she would still have to push herself further in order to ascertain the whole degree of her improvement...

Interestingly, her MQS seems to be pretty much gone too (again, she'd like to test herself getting exposed to more toxins). And, her Hashimoto's is also receding. She still hasn't measured her thyroid auto-antibodies yet, but she has had to lower the dose of thyroid hormones, because she was showing signs of hyperthyroidism at her usual dose.

Finally, and I am sorry for being such a spoilsport, her NKs, CD8 and total T lymphocytes have all gone down. And this is in agreement with the studies I quoted here showing that this drug is an immunesupresive agent.

Best!

Sergio

[#35](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 17, 2021](#)

[Report](#)

Likes: [sb4](#), [Sancar](#), [Marylib](#) and 2 others



[Hufsamor](#)

Senior Member

Messages

2,476

Likes

9,442

Location

[Norway](#)

[serg1942](#) said:

her Hashimoto's is also receding. She still hasn't measured her thyroid auto-antibodies yet, but she has had to lower the dose of thyroid hormones, because she was showing signs of hyperthyroidism at her usual dose.

I'm wondering...is it possible the medication works mainly for thyroid issues?

[@leokitten](#) please let us know how it goes, if you decide to try

And the same goes for [@stefanosstef](#) of course.

#36

[Like](#) [Quote](#) [Reply](#)

Feb 17, 2021

[Report](#)

Likes: [Marylib](#) and [leokitten](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[Hufsamor](#) said:

I'm wondering...is it possible the medication works mainly for thyroid issues?

[@leokitten](#) please let us know how it goes, if you decide to try

And the same goes for [@stefanosstef](#) of course.

I don't think it works at the thyroid level specifically.

When I reviewed the literature on this drug, I found a paper hypothesizing that it could

reduce Hashimoto's, because autoimmunity is linked to chronic inflammation. So, you calm down your autoimmune T effector cells, and the attack to the thyroid is also reduced.

Here in Spain there are a few ME/CFS fellows that are trying it too, so we'll soon know if it works for many, or if my friend has just been lucky!

Best,

Sergio

[#37](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 17, 2021](#)

[Report](#)

Likes: [Sancar](#), [Nat kea](#), [Marylib](#) and 2 others



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[Hufsamor](#) said:

I'm wondering...is it possible the medication works mainly for thyroid issues?

[@leokitten](#) please let us know how it goes, if you decide to try

And the same goes for [@stefanosstef](#) of course.

I have pentoxifylline but trialing low dose abilify now so can't mix. Might be a long while until I trial it. Also because this drug seems to take a couple months to notice any benefit or not complicates things

[#38](#)

[Like](#) [Quote](#) [Reply](#)

[Feb 17, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Hufsamor](#)



[Badpack](#)

Senior Member

Messages

382

Likes

967

[@serq1942](#) any updates on your friend and the few ME/CFS fellows ?

[#39](#)

[Like](#) [Quote](#) [Reply](#)

[Mar 14, 2021](#)

[Report](#)

Likes: [Nat kea](#)



[Badpack](#)

Senior Member

Messages

382

Likes

967

strange how often ppl post "i cured cfs with breathing and butter" and then vanish forever
[#40](#)



[Badpack](#)

Senior Member

Messages

382

Likes

967

Trailing it for about 2 weeks now. Does nothing besides making me sleepy. Not sure if something is still to come and the 2 months mark means something at all.

[#41](#)

[Like](#) [Quote](#) [Reply](#)

[Mar 26, 2021](#)

[Report](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[Badpack said:](#)

strange how often ppl post "i cured cfs with breathing and butter" and then vanish forever

I'm so sorry for the late reply. It is difficult to keep up with all the social media plus making headway in research, plus taking care of myself, being so severely affected...:

My friend was doing still pretty well, doing kind of a normal life until 1 month ago, when she got a kidney infection and antibiotics knocked her down.. Now, I guess this will pass and will regain her baseline again.

I am however worried that this infection that seems to not go away easily might be a sign of her immune system being even more compromised by pentoxifylline. Only time will tell.

Will let you know how she does!!

Take care!

Sergio

[#42](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 8, 2021](#)

[Report](#)

Likes:[sb4](#), [Marylib](#) and [Hufsamor](#)



[serg1942](#)

Senior Member

Messages

494

Likes

979

Location

[Spain](#)

[Badpack](#) said:

Trailing it for about 2 weeks now. Does nothing besides making me sleepy. Not sure if something is still to come and the 2 months mark means something at all.

Yes it does!! Give it at least 3 months. Feeling worse at the beginning seems normal!!!

[#43](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 8, 2021](#)

[Report](#)

Likes:[Sancar](#), [Marylib](#) and [Aspire2021](#)



[Badpack](#)

Senior Member

Messages

382

Likes

967

<https://pubmed.ncbi.nlm.nih.gov/33231568/>

here could be a clue why it could work. It elevates dopamine in the brain. Just like Abilify. I stopped taking it after i got heavy fever attacks. Never got them before, even with Cfs. Was a bit scary. But i used 400mg x3. Maybe i restart someday with 400mgx2 and see where it leads.

[#44](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 15, 2021](#)

[Report](#)

Likes: [Sancar](#), [Marylib](#), [mitoMAN](#) and 4 others



[Martink](#)

Senior Member

Messages

310

Likes

470

<https://ammes.org/treatment/pentoxifylline/>

When I read this...I wonder - it also works similarly to nimodipine? Nimodipine is not immunosuppressive agent I think - maybe better choice.

"Some clinicians have recommended pentoxifylline in ME/CFS to increase blood flow to the brain"

[#45](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 16, 2021](#)

[Report](#)

Likes: [Sancar](#) and [Marylib](#)



[Aspire2021](#)

Messages

3

Likes

3

[serg1942](#) said:

Yes it does!! Give it at least 3 months. Feeling worse at the beginning seems normal!!!

Are you seeing any side effects in people with CFS who are starting this? Are you seeing any herx reactions

[#46](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 21, 2021](#)

[Report](#)



[Aspire2021](#)

Messages

3

Likes

3

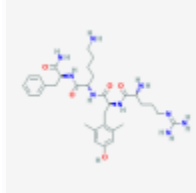
[@Badpack](#) Can you elaborate on the fatigue you were feeling prior to the fever. Was it a wired and tired? More groggy? Also is it possible that you were Herxing? What was your dosing schedule and did you start off with 400 3x's a day?

[#47](#)

[Like](#) [Quote](#) [Reply](#)

[Apr 23, 2021](#)

[Report](#)



[mitoMAN](#)

Senior Member

Messages

503

Likes

889

Location

[Germany/Austria](#)

[MartinK said:](#)

<https://ammes.org/treatment/pentoxifylline/>

When I read this...I wonder - it also works similarly to nimodipine? Nimodipine is not immunosuppressive agent I think - maybe better choice.

"Some clinicians have recommended pentoxifylline in ME/CFS to increase blood flow to the brain"

Interesting. Here is probably the real reason why Pentoxifylline COULD work. Contrary to Nimodipine, this would allow a better blood flow in the entire body?

Pentoxifylline may also address another blood problem common to ME/CFS. The late Dr. L.O. Simpson, a pathologist from the University of Otago Medical School in Dunedin, New Zealand, discovered that **patients with ME/CFS had irregularly shaped red blood cells, making it more difficult for blood cells to pass through capillaries.** Dr. Simpson believed the decreased cerebral blood flow in ME/CFS was the consequence of abnormally shaped blood cells. **Many of the symptoms of inadequate blood supply such as light-headedness, vertigo, and cognitive problems might be alleviated if blood flow were increased.**

Apart from pentoxifylline's well-known effects on blood flow, it also has broad antiviral activity. A study conducted in 1993 by a team of Russian scientists found that Trental [pentoxifylline] was an "effective broad spectrum virus inhibitor." Pentoxifylline also has the ability to inhibit proinflammatory cytokines, which researchers have found to be upregulated in ME/CFS patients.

[#48](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 27, 2021](#)

[Report](#)

Likes: [Sancar](#), [Nat kea](#), [Marylib](#) and 3 others



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

I think nimopidine is a very different drug from pentoxifylline, it's used to treat vasospasm and hypertension.

[#49](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 27, 2021](#)

[Report](#)

Likes: [Sancar](#) and [Marylib](#)



[Learner1](#)

Senior Member

Messages

5,956

Likes

10,859

Location

[Pacific Northwest](#)

[mitoMAN](#) said:

The late Dr. L.O. Simpson, a pathologist from the University of Otago Medical School in Dunedin, New Zealand, discovered that **patients with ME/CFS had irregularly shaped red blood cells, making it more difficult for blood cells to pass through capillaries.** Dr. Simpson believed the decreased cerebral blood flow in ME/CFS was the consequence of abnormally shaped blood cells. **Many of the symptoms of inadequate blood supply such as light-headedness, vertigo, and cognitive problems might be alleviated if blood flow were increased.**

<https://my.clevelandclinic.org/health/diseases/17732-vitamin-deficiency-anemia>

[#50](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Martin aka paused](#)||M.E.



[Martin aka paused](#)||M.E.

Senior Member

Messages

2,199

Likes

7,045

It did nothing for me except diarrhoea. But I tried it just for one month. Was that too short to be sure? How long does it normally take to see an effect?

IG: [paused_me](#)

[#51](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)



[pattismith](#)

Senior Member

Messages

3,416

Likes

6,641

[mitoMAN said:](#)

Pentoxifylline also has the ability to inhibit proinflammatory cytokines, which researchers have found to be upregulated in ME/CFS patients.

A 2021 research article may mitigate this anti-inflammatory effect, especially concerning IL-1 β , not every dosing may be effective in this respect:

Furthermore, it has been shown that PTX can modulate IL-1 β synthesis in response to LPS, the most effective proinflammatory stimuli [19], although the exact influence can be different in various tissues [11, 20, 21].

The results of the current study revealed that in all LPS-stimulated cell lines, **PTX increased IL-1 β release in a dosedependent manner.**

However, **this induction was diminished by the highest concentrations of PTX** (100 μ M and 1 mM) in endothelial cells

[Effect-of-pentoxifylline-on-expression-of-proinflammatory-cytokines.pdf \(researchgate.net\)](#)
#52

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)

Likes:kewia, Marylib and Martin aka paused||M.E.



[Aidan Walsh](#)

Senior Member

Messages

227

Likes

147

[serg1942 said:](#)

She is feeling incredibly well, doing a pretty normal life, although last time she told me how she waa doing, she said that she would still have to push herself further in order to ascertain the whole degree of her improvement...

Interestingly, her MQS seems to be pretty much gone too (again, she'd like to test herself getting exposed to more toxins). And, her Hashimoto's is also receding. She still hasn't measured her thyroid auto-antibodies yet, but she has had to lower the dose of thyroid hormones, because she was showing signs of hyperthyroidism at her usual dose.

Finally, and I am sorry for being such a spoilsport, her NKs, CD8 and total T lymphocytes have all gone down. And this is in agreement with the studies I quoted here showing that

this drug is an immunesupresive agent.

Best!
Sergio

Can the test for B. Myamotoi not be run on the United Kingdom NHS labs or even privately in the UK? What cost is involved to do where you mentioned?

Last edited: Jun 28, 2021

[#53](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)

Likes: [Marylib](#)



[Learner1](#)

Senior Member

Messages

5,956

Likes

10,859

Location

[Pacific Northwest](#)

[Aidan Walsh](#) said:

Can the test for B. Myamotoi not be run on the United Kingdom NHS labs or even privately? What cost is involved to do where you mentioned?

<https://www.mayocliniclabs.com/test-catalog/Clinical+and+Interpretive/64970>

[#54](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)

Likes: [Sancar](#), [Marylib](#) and [Aidan Walsh](#)



[Aidan Walsh](#)

Senior Member

Messages

227

Likes

147

[Badpack](#) said:

strange how often ppl post "i cured cfs with breathing and butter" and then vanish forever

I have never seen the post on butter with breathing as well, I wonder about the fat content of butter I have heard it before someone was eating a full butter daily on a keto diet. Do you have the link on the butter mentioned? I think I may have seen this in a Keto diet before the Woman on a Facebook link 'The Business Person'

[#55](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)



[Aidan Walsh](#)

Senior Member

Messages

227

Likes

147

[Learner1 said:](#)

<https://www.mayocliniclabs.com/test-catalog/Clinical+and+Interpretive/64970>

thanks, Lerner, I am so sorry to learn of your Cancer3 diagnosis as well. Mayo won't be good to me in the UK

[#56](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[Martin aka paused||M.E. said:](#)

It did nothing for me except diarrhoea. But I tried it just for one month. Was that too short to be sure? How long does it normally take to see an effect?

I believe I read it takes up to 2 months taking 800-1200 (2-3 times a day after food) to see full effects

Last edited: Jun 28, 2021

[#57](#)

[Like](#) [Quote](#) [Reply](#)

[Jun 28, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Martin aka paused||M.E.](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[Pentoxifylline for vascular health: a brief review of the literature. McCarty et al. Open Heart \(2016\)](#)

[#58](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 1, 2021](#)

[Report](#)

Likes: [Marylib](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

I've started taking it now since a few weeks. Taking 400 mg bid (not tid). First two things I noticed is made me much more "regular" bathroom-wise and for me it's a positive as ME unfortunately has given me periods of constipation which never had pre-ME, that's gone now. I also already feel better circulation to my lower legs and feet which due to ME have felt like there's really poor circulation to lower extremities causing them to hurt and to lose most of my subcutaneous tissue there.

I don't think this is a drug that's going to have a sudden or marked positive influence on ME symptoms that you will clearly notice even after a couple months. But it's going to globally reduce inflammation, improve RBC deformability and viscosity issues, and all of its other potentially positive vascular and anti-inflammatory effects on ME pathology that over a longer span of time could promote improvement.

I think even if it doesn't have a direct effect on ME symptoms it mostly likely will have a positive effect on ME compounded problems as we age... we cannot move very much, we cannot exercise, because of energy issues and PEM many times many of us haven't had a good diet because you cannot cook, you know all the issues that come from having this

illness long term. If it can help significantly improve general cardiovascular health parameters then that's a good thing.

EDIT: and so far no side effects that I can report

Last edited: Aug 1, 2021

[#59](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 1, 2021](#)

[Report](#)

Likes: [Marylib](#), [Hufsamor](#), [mitoMAN](#) and 3 others



[Marylib](#)

Senior Member

Messages

846

Likes

868

[stefanosstef](#) said:

I might try this, it's OTC here and dirt cheap. How soon do you get benefits if you respond to it?

[@stefanosstef](#) What country has it OTC - over the counter? Thanks.

[#60](#)



[Marylib](#)

Senior Member

Messages

846

Likes

868

[leokitten](#) said:

I've started taking it now since a few weeks. Taking 400 mg bid (not tid).

EDIT: and so far no side effects that I can report

[@leokitten](#) I am wondering how you got it? Did you not need a prescription? Seems you are in the US. Glad you are not having undesirable side effects so far. It seems like an interesting one to try. I do take into account the negatives that others have expressed, so thanks to everyone for your comments.

[#61](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 2, 2021](#)

[Report](#)

Likes: [leokitten](#) and [mitoMAN](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[Marylib](#) said:

[@leokitten](#) I am wondering how you got it? Did you not need a prescription? Seems you are in the US. Glad you are not having undesirable side effects so far. It seems like an interesting one to try. I do take into account the negatives that others have expressed, so thanks to everyone for your comments.

goldpharma.com shipped from a pharmacy in Germany, though not sure now with supposed new EU-wide import law changes if they can import to your country. I know there is no problem shipping to US and UK from goldpharma.

EDIT: regarding potential negatives, if you take 400 mg bid instead of tid then reduces risk of side effects while I believe still maximizing benefit if you make sure to buy the slow release tablets (I think most if not all versions are slow release now) and take it after a meal. And just bears repeating no one ever knows how it will affect without trialing, though if you are very ME sensitive to meds then sure you can likely predict, but if you are like me and don't have sensitivity to many meds I try things because could be I have little to no side effects.

Last edited: Aug 2, 2021

[#62](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 2, 2021](#)

[Report](#)



[leokitten](#)

Senior Member

Messages

1,397

Likes

3,487

Location

[U.S.](#)

[Hip said:](#)

In any case, [there are a number of drugs and supplement which can boost NK function](#), so these might be taken alongside pentoxifylline to counter the NK suppression. For example, the supplement MGN3 Biobran increases NK activity by 300%.

MGN3 Biobran is so super expensive! Unaffordable unless you have a lot of extra money to burn.

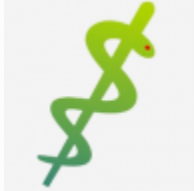
[#63](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 2, 2021](#)

[Report](#)

Likes: [Marylib](#) and [Hip](#)



Hip

Senior Member

Messages

16,515

Likes

35,820

[leokitten said:](#)

MGN3 Biobran is so super expensive! Unaffordable unless you have a lot of extra money to burn.

And not only that, but a [study](#) showed MGN3 is not helpful for ME/CFS.

New Patient? ► [ME/CFS — A Roadmap for Testing and Treatment](#)

[#64](#)

[Like](#) [Quote](#) [Reply](#)

[Aug 2, 2021](#)

[Report](#)

Likes: [Marylib](#), [kewia](#) and [leokitten](#)



Kulandai

Messages

8

Likes

12

[Marylib said:](#)

[@leokitten](#) I am wondering how you got it? Did you not need a prescription? Seems you are in the US. Glad you are not having undesirable side effects so far. It seems like an

interesting one to try. I do take into account the negatives that others have expressed, so thanks to everyone for your comments.

Is this working for you?

[#65](#)

[Like](#) [Quote](#) [Reply](#)

[Oct 6, 2021](#)

[Report](#)



[Kulandai](#)

Messages

8

Likes

12

[leokitten said:](#)

I've started taking it now since a few weeks. Taking 400 mg bid (not tid). First two things I noticed is made me much more "regular" bathroom-wise and for me it's a positive as ME unfortunately has given me periods of constipation which never had pre-ME, that's gone now. I also already feel better circulation to my lower legs and feet which due to ME have felt like there's really poor circulation to lower extremities causing them to hurt and to lose most of my subcutaneous tissue there.

I don't think this is a drug that's going to have a sudden or marked positive influence on ME symptoms that you will clearly notice even after a couple months. But it's going to globally reduce inflammation, improve RBC deformability and viscosity issues, and all of its other potentially positive vascular and anti-inflammatory effects on ME pathology that over a longer span of time could promote improvement.

I think even if it doesn't have a direct effect on ME symptoms it mostly likely will have a positive effect on ME compounded problems as we age... we cannot move very much, we cannot exercise, because of energy issues and PEM many times many of us haven't had a good diet because you cannot cook, you know all the issues that come from having this illness long term. If it can help significantly improve general cardiovascular health parameters then that's a good thing.

EDIT: and so far no side effects that I can report

1. What gains have you had with this? For example from being housebound to going out to shop etc? To drive?

2. Would a lower dose be even safer - wonder?
3. Are there any natural compounds that might be similar?

#66

[Like](#) [Quote](#) [Reply](#)

[Oct 6, 2021](#)

[Report](#)

Likes: [Marylib](#)



[iiketoread](#)

Messages

41

Likes

141

I've been interested to try pentoxifylline. I heard about it when I got a book called "Ramsay's Disease Myalgic Encephalomyelitis and the unfortunate creation of CFS" by Leslie O. Simpson and Nancy Blake. The book was supposed to tell you a treatment plan for me/cfs, so I had to buy the book and it said the treatment is rest and 400mgs X3 daily of pentoxifylline (also 4 grams evening primrose oil and 6 grams fish oils) bc there is an issue with the red blood cells - poor deformability of red blood cells (meaning they're less flexible than they should be) and can't circulate properly into areas such as capillaries.

So I bought some pentoxifylline (Trental) from [Meds.com.mx](#) a year ago, I don't recommend them they didn't send everything I ordered. I started taking the Trental they sent and also amantadine which was stupid bc about a week later I developed a giant rash on the lower half of my face so I'm still not sure if that was from the Trental, or the amantadine or wasn't from either bc it was freezing cold out and my face felt like stinging from the cold air and just blew up into this rash.

I don't know, but I'm still interested in trying pentoxifylline if anyone knows a good place to order this.

I strongly think that there is something going on with my veins or my blood before I ever read about theories of the veins or blood could be underlying me/cfs. I have a serious case of freezing cold hands, nose, ears, feet, and my upper back and I also think my face, head and neck pain are caused by malfunction in the veins causing squeezing pain in my upper body. It's like I have a giant vasospasm in all of the tiniest veins of my upper body.

#67

[Like](#) [Quote](#) [Reply](#)

[Oct 8, 2021](#)

[Report](#)

Likes: [J.G.](#), [Marylib](#) and [Hufsamor](#)



J.G

Senior Member
Messages

160

Likes

547

[iliketoread said:](#)

I've been interested to try pentoxifylline. I heard about it when I got a book called "Ramsay's Disease Myalgic Encephalomyelitis and the unfortunate creation of CFS" by Leslie O. Simpson and Nancy Blake. The book was supposed to tell you a treatment plan for me/cfs, so I had to buy the book and it said the treatment is rest and 400mgs X3 daily of pentoxifylline.

Brilliant. This is the information I was looking for. I don't have access to the book; does Simpson by chance further elaborate on the pentoxifylline dosing regimen, such as starting low(er) and gradually working up to 400mg 3x day? I'm also curious whether Simpson identified subsets in MECFS and, for example, prescribed pentoxifylline primarily to subset X. What symptoms did he look for to assess whether pentoxifylline might be beneficial?

Last edited: Dec 5, 2021

ME/CFS blog @ www.brainfoggedphd.blogspot.co.uk

#68

[Like](#) [Quote](#) [Reply](#)

[Dec 5, 2021](#)

[Report](#)



Shanti1

Senior Member
Messages

413

Likes

1,507

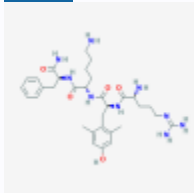
[@dylemmaz](#) I'm I remembering right that you were going to try pentoxifylline? Do you mind if I ask how it went? I have ordered it and should have it in a few weeks.

New #69

[Like](#) [Quote](#) [Reply](#)

[Dec 6, 2021](#)

[Report](#)



mitoMAN

Senior Member

Messages

503

Likes

889

Location

[Germany/Austria](#)

[@leokitten](#) how did your trial go?

I asked two other members that trialed the medication for 1-2 months with zero success

New #70

[Like](#) [Quote](#) [Reply](#)

[Dec 6, 2021](#)

[Report](#)

Likes:[junkcrap50](#)



[Aidan Walsh](#)

Senior Member

Messages

227

Likes

147

I have seen some patients diagnosed now with Eagle Syndrome their styloid on each side of the neck, they also have Jugular compression between C1 & their skulls. Some C1 is picked up on CT Scans, others it is found on color doppler ultrasounds checking blood flow in the Jugular veins in the neck so maybe this medicine above is

increasing the blood flows or doing something to the veins so keep this in mind. I know one Woman on Facebook Eagle Syndrome Group she had 2 Neuro Surgeons present in her Surgeries one an ENT the other a Vascular Surgeon she had styloid removed & Jugular C1 released she climbs mountains now & lifts weights.

One Doctor also said she had also Altitude Sickness & suggested she go live in Miami which she did as well. I have Eagle Syndrome now confirmed on both sides of my neck by CT Contrast

New #71