No One Is Coming To Save You

Brave_System771

The only way to get out of this issue is by taking action. We have 4,600 members in this community. The PSSD community in its entirety is likely many times greater than this and yet we are struggling to put anything into the research efforts

If each of the 4,600 gave just $250 we would have over 1 million in research funding. This would likely lead to a detailed understanding of our problem and a viable cure.

Don't you value your sexuality, health, ability to feel pleasure and excitement?

What are we waiting for? No one is coming to save you. We each need to do our part.

https://rxisk.org/pssd-research/ Please step up.

PSSD_Kara

I want to see proof and receipts that RxISK is a trustworthy collector, holder and/or distributor of the money. They already amassed and are holding the RxISK PSSD prize...

They said this in the blog post you linked:

"Donations are made to Centre for Data Based Medicine, a registered charity in England and Wales.

The total is updated manually by our team, so don't worry if your donation doesn't appear immediately. If you have any difficulty donating, please contact us.

There will be a transparent log showing the researchers to whom money has been given and for what projects, as well as indicators of what the preliminary results look like.

None of the money collected will go into anything other than the research."

Brave_System771

I agree that this is an issue. They should release that prize money and dedicate it to research immediately. I messaged them about this and think we should all press this issue. Do you have contact with Dr Healy, Kara?

I think it's important these things get clarified asap so we can progress things.

DangerousFee4

I donated and I want the research to start immediately. Where's the money right now? Who's in control of the fund?

These are all answers this community needs. Someone needs to email them and figure out what's going on.

heavenlydigestion

Here is a link to a charity called "Centre for Data Based Medicine" on England & Wales' official register of charities: https://register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/4005204/

NeitherIndustry2121

What sort of proof is acceptable to you? How can you even prove such a thing

DangerousFee4

Wdym? There's a bunch of money sitting in a fund somewhere. Ive donated and so many others. We all want to know where the money is going.

NeitherIndustry2121

A pledge fund works differently. It does transactions at end

chemifiyed

Life is hard enough. Do you think people with pssd, especisllt young people have any capacity to make loads of money? Everything is fucked.

Brave_System771

Life is hard which is why we need to do our part to support a way out of this hell.

I have had brain zaps, tinnitus, anhedonia, loss of libido and motivation and I am young. I can still donate a couple hundred a month. I am not saying this because I am special or better than anyone. I'm not. I'm saying this because it's within everyone's ability and it is absolutely necessary if we want our lives back.

Brave_System771

Also, I did not say loads of money. I said if each of us gave 250 euros we'd have over a million for research. I am contributing 300 euros every month to research.

mintyfreshknee

You should take that money and start ads about this. Make a non profit co. Interview and lobby people tp listen and research. I don’t see Healy doing anything but collecting depressing stories and making diagnostic criteria. Which is so important but he doesn’t seem like he’s gonna find a cure. I could be wrong.

Brave_System771

I'd love to see PSSD people do that. Be the change you would like to see!

I'm working with the PFS Network and we are doing exactly those things you mentioned.

Naive-Razzmatazz-628

Some, yes. I do really well financially and I have pssd pretty bad. It’s not fun, or as easy as previously.

teacupsndaisies

I’ll be donating. Yeah, it sucks to have to pay for research considering we are all the victims here… but what other choice is there? I’ve had this for a decade now and I’m ready for PSSD to be both acknowledged and studied. $250 pales in comparison to what I and a lot of us have had to endure. My self experimentation has set me back more than once, I’d much rather let someone else figure this out at this point.

Brave_System771

Exactly.

PublicMacaron4082

I would give $50,000 if I though the money would be used productively. But I don't, so I wont.

daftten

What would you consider to be a productive use of the money? Or do you think PSSD is unsolvable?

Difficult-Aside5642

David Healy has done more for people with PSSD than anyone else. I believe it is worth it to trust him with the money. Most published articles on PSSD are either his work or influenced by his work. He was talking about it a decade before anyone else was.

mintyfreshknee

What has he done?

PublicMacaron4082

Nothing groundbreaking if you ask me. No real progress is being made.

Clanless_x

no ones saving me, but sure is coming asking for money bwahaha!

Brave_System771

What an asinine take on what I said. If you don't want to support research into your own medical condition be my guest. Just don't whine years from now when we're in the same position.

hPI3K

Research is not only important for so called "cure" but for recognition. PSSD may make you disabled and unable to work, yet you can't get social security benefits because it is not formally recognized. Researching makes a buzz in medical journals - very important for recognition

Brave_System771

This is a great point. Also, the more research gets done the easier it'll be to see large scale class action suits against drug manufacturers which can then be funnelled into large scale research projects. We as a community have to get the ball rolling though.

viimoons

This community’s adamance in denying the need for research is one of the most bizarre things about this condition. Are you really suggesting that OP is asking for your money? He’s suggesting that the community as a whole donate to research so we can understand and get out of this condition.

Really don’t see much wrong with that, yet for some reason members of this community will go to any length to bash people trying to suggest we take action.

He’s right. No one is going to be able to fix this but us. And as fucked up as it is, we’re gonna have to pay for it to understand it and reliably get out of it. It sucks but that’s the way it is.

throw_awayyy3

I wish I had just 100 to spend on whatever but I'm broke af. Since I dropped out of school because PSSD killed my intelligence it's very hard to earn money.

viimoons

Understandably not everyone is going to be able to donate, however I think it’s a reasonable argument that more of us in iatrogenic illness communities should be more focused on trying to understand the condition from a research perspective in addition to self experimentation.

hairfear

I think very, very few people can legitimately claim they are completely unable to donate. If someone gave $20 per month, they would be giving over $250 per year—that is less than a dollar per day.

viimoons

Sure but some people are bedbound, and not working / stressed about their financial situation due to their condition. This is understandable.

hairfear

Yes, I agree in those cases personal donation may not be possible. Hopefully those critical cases will be able to reach into their support networks for help.

toughluck24

I definitely think some of the people who can’t donate themselves would be able to get a family member to help out. Even people who don’t fully believe in the condition might donate just out of respect. That’s what happened with my father. He’s 50/50 when it comes to believing in the condition but still donates for me.

viimoons

Agreed

Kgriffuggle

I’d rather volunteer to be a part of studies.

Brave_System771

No money no studies

Kgriffuggle

Who are their participants? Instead of throwing money at them, why can’t I volunteer as tribute?

hairfear

If we don’t all contribute as sufferers, we have no hope of any studies taking place. Offering to take part in a study that can’t exist without funding is pointless.

Gixxer250

Donate something even if its $5

Naive-Razzmatazz-628

Healy and RXISK has been around for quite a long time. They are legit. I donated. I hope everyone understands it’s the only way a cure will be found.

PublicMacaron4082

I agree 100%. But I don't trust those researchers. They don't seem to be doing anything with the funds.

mintyfreshknee

What an alarmist post. Donate or die. There’s something off about Healy. And he just works sugg thank you a bunch of urologists who know jack shit. I’d rather lobby brain researchers for real research.

Brave_System771

Feel free to put together an initiative you can take to the community and I'll be happy to consider donating.

Nothing alarmist. If we don't do scientific research we won't be able to treat this condition. It's that simple.