Front-page article in Swiss daily 20 Minutes on 26 August 2022, mentioning OPIS and featuring a patient suffering from SUNCT whom we provided support to, who has used ayahuasca successfully to relieve his pain. OPIS publicized this case to call attention to the promise of certain controlled substances for the treatment of agonizing conditions like cluster headaches and SUNCT, and how current drug laws restrict medical access.



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«Faute de solution médicale, l'ayahuasca m'a sauvé la vie»

SANTÉ Atteint d'une maladie rare et incurable, un Vaudois se soigne avec cette plante hallucinogène.

«Il y a deux ans, j'ai ressenti une douleur intense d'un côté du visage, raconte Juan Pablo. Je suis allé chez le dentiste, pensant à une rage de dents. J'ai fini chez un neurologue: j'ai un SUNCT, une maladie rare et sans traitement connu.» Atteint de crises de douleur brèves mais récurrentes, jusqu'à 250 par jour, il a vécu l'enfer. «J'ai fait une tentative de suicide pour y échapper. Nous étions cinq à avoir été diagnostiqués en même temps en



Suisse: les quatre autres se sont tués», raconte le trentenaire. Un phénomène connu pour d'autres maladies cousines, ex-

Des psychédéliques pour soigner

La molécule DMT, présente dans cette plante venue d'Amérique du Sud et classée en Suisse comme un stupériant psychotrope, a très peu fait l'objet de recherches médicales. Mais son effet contre certaines douleurs a déjà été observé, tout comme celui du LSD et de la

psilocybine. Les psychédéliques sont aussi de plus en plus utilisés au stade expérimental pour lutter contre la dépression, et l'ayahuasca est étudiée en ce sens à la clinique psychiatrique universitaire de Zurich. Elle est aussi utilisée de façon récréative par certains fétards. plique Philippe Ryvlin, chef du département des neurosciences cliniques du CHUV: «On les appelle «suicidal headaches», car elles sont liées à un fort taux de suicides. C'est moins connu pour le SUNCT.»

Désespéré mais soutenu par l'association OPIS, qui lutte pour une plus grande attention aux souffrances intenses, Juan Pablo a exploré des voies moins conventionnelles. «J'ai essayé beaucoup de choses pas ou peu efficaces. Puis i'ai testé

Pas d'explication

Le SUNCT concerne moins d'une personne sur 15'000, et quelque 80 nouveaux cas par an en Suisse, C'est toutefois une maladie rare et méconnue, qui cause d'intenses douleurs. Le coupable: un nerf facial qui dysfonctionne brièvement des dizaines de fois par jour. Elle se déclare généralement entre 35 et 65 ans, sans que la médecine comprenne pourquoi. Aucun traitement efficace n'a été trouvé, confirme Philippe Ryvlin.

l'ayahuasca. C'est dégueulasse, mais ça m'offre trois semaines de répit après chaque prise. Ça m'a sauvé la vie!» Cette automédication est en place depuis huit mois. Seul hic: c'est illégal en Suisse. «En tant que médecin, on ne peut évidemment pas la prescrire, rappelle Philippe Ryvlin. Mais on peut jouer un rôle d'information du patient.» La recherche pourrait ouvrir des portes, mais rien n'a été lancé en Suisse pour le moment. - PAULINE RUMPE



English translation of the on-line version of this article (https://www.20min.ch/fr/story/faute-de-solution-medicale-layahuasca-ma-sauve-la-vie-812067966485)

PSYCHEDELICS

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"Ayahuasca saved my life when there was no medical solution"

A man from the canton of Vaud suffering from a rare disease that causes terrible pain finally found relief in this drug from South America. Its medical use is still poorly documented.

by Pauline Rumpf



Listen to Juan Pablo's testimony about the ordeal he endured and how he made it through: https://www.20min.ch/fr/video/le-traitement-a-layahuasca-ma-sauve-la-vie-138409046565

"Two years ago, I had intense pain on one side of my face. I went to the dentist, thinking I had a toothache. I ended up going to a neurologist; he diagnosed me with SUNCT syndrome, a rare disease with no known cure."

That day, Juan Pablo's life turned upside down. Then suffering from short but extremely frequent attacks of pain, up to 250 a day, he had to stop working and lived through hell for almost two years. "It was so bad and so omnipresent that I attempted suicide. Five of us in Switzerland were diagnosed around the same time: the other four took their own lives," says the thirty-something. This is a phenomenon known for other related diseases, explains Philippe Ryvlin, head of the department of clinical neurosciences at the CHUV (Lausanne University Hospital): "They are called *suicide headaches* because they are linked to a high suicide rate. This effect is less known for SUNCT."

Desperate but supported by the OPIS association, which fights to bring greater attention to intense suffering, Juan Pablo did some research and explored less conventional paths. "I read that LSD was used for some migraines, so I tried it. It gave me relief, but only as long as the substance was present. Then I tried ayahuasca. It's disgusting, but it gives me three weeks of relief after each dose. It saved my life." He has been self-medicating for eight months, with no signs of dependence or addiction.

Psychedelics enter medicine

The DMT molecule, present in this plant from South America and classified in Switzerland as a psychotropic drug, has been the subject of very little medical research, and even none concerning its effect on SUNCT. But its impact on certain pains has already been observed. "This is also the case for LSD, or psilocybin, contained in hallucinogenic mushrooms, which has been able to provide relief to patients suffering from certain violent neurological disorders such as cluster headaches," says the founder of the OPIS association, Jonathan Leighton, with studies to back up his claims. The family of psychedelic drugs is also increasingly used at the experimental stage to treat depression, and ayahuasca is being studied notably at the Zurich University Psychiatric Clinic. It is also used recreationally by some partygoers.

"I can only be pleased that this patient has found something that helps him," says Philippe Ryvlin. The only problem: ayahuasca is illegal in Switzerland. Juan Pablo has found a way to exploit a grey area of the law, but prefers to remain discreet. "As a doctor, we obviously can't prescribe it," says the neurologist. "But we can play a role in informing the patient." A research framework, which is more open, could allow

for experimentation, with much effort and dedication on the part of a doctor or researcher. Nothing has yet been launched in Switzerland in this area.

A rare disease... but not that rare

SUNCT affects less than one in 15,000 people, and is therefore classified as a rare disease. In Switzerland, it nonetheless represents some 80 new cases each year, according to a theoretical calculation. "There are presently only a few dozen cases mentioned globally in the literature," says Philippe Ryvlin. The syndrome generally occurs between the ages of 35 and 65, but "we don't know why," he concedes. The culprit, as in another related disease called cluster headaches, is a facial nerve that malfunctions and affects the sympathetic and parasympathetic systems of the face for a few seconds or even minutes. Dozens of such attacks occur every day.