Open Letter to the Medical Authorities in the Czech Republic

Dear Minister,

in the past year, the Czech Association of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (hereinafter referred to as “ME/CFS”) was involved in negotiations with the representatives of the Ministry of Health of the Czech Republic and the Czech Medical Associations. These negotiations were initiated after a suggestion from our patients’ association. The goal was to draw attention to the neglected situation of ME/CFS patients in the Czech Republic and to initiate the development of clinical practice guidelines (CPG) or otherwise unify the diagnostic, therapeutic and social care for patients with this illness.

During the talks, we were told repeatedly by the Czech medical authorities, that chronic fatigue syndrome as an illness (diagnosis) “doesn't exist”, or that it is a “provisional” or “escape” diagnosis, meaning that all these patients have in fact some other, not yet diagnosed, illness. As a result of these nearly year-long negotiations, a proposal was submitted to the Ministry of Health to include ME/CFS in the clinical practice guidelines program. Subsequently on December 11th, 2019 the proposal was rejected by the Guarantee Commission with the explanation, that “in this case [of ME/CFS], it is not a defined illness in general, but a clinical syndrome. For that reason, an effort to create clinical practice guidelines could not lead to a meaningful outcome with the current state of evidence-based medicine”. At the same time, it was suggested that a protocol of examinations could be developed, “which would differentiate those patients from this syndrome, who suffer from treatable serious diseases – oncological diseases, myasthenia, myopathies, chronic infections, or possibly with multiple sclerosis, and then proceed with the established therapies for these illnesses”.

As the Czech Association of Patients with ME/CFS, we strongly disagree with this position. We are convinced, that the fundamental problem is still a wrong understanding of the term “chronic fatigue syndrome” as a sum of all the conditions, in which chronic fatigue occurs as a symptom. This is incorrect. Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an illness, which usually has an acute, postinfectious onset and is manifested mainly by a major intolerance of both physical and cognitive exertion and a number of neurological (CNS and ANS), flu-like and gastrointestinal symptoms, not only by fatigue. After all, both the terms ME and CFS were introduced on the basis of the contemporary view of this illness and with the official stance of relevant institutions. The World Health Organization classifies “postviral fatigue syndrome” or “myalgic encephalomyelitis” as a neurological disease (diagnosis G93.3, ICD-10). The Centers for Disease Control and Prevention (CDC) in the USA define ME/CFS as a “serious, long-term illness”1; the National Institutes of Health (NIH) define ME/CFS as a “debilitating disease”2. An extensive report3 by the Institute of Medicine (now called the National Academy of Medicine), which was commissioned by several federal institutions of the USA in 2015, evaluated all the available scientific literature and concluded that ME/CFS is a serious biological illness. The conclusion that ME/CFS is a standalone nosological unit was also made in the report by the Health Council of the Netherlands4 in 2018, or in a similar report in Sweden5 from 2019. Due to these aforementioned facts, the question arises on what basis was the decision on this matter made in the Czech Republic and why has the existence of ME/CFS as a separate illness been continuously ignored.

1 https://www.cdc.gov/me-cfs/ - retrieved 15.4.2020
2 https://www.nih.gov/me-cfs/about-me-cfs - retrieved 15.4.2020
3 Institute of Medicine. 2015. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness
5 Swedish Agency for Health Technology Assessment and Assessment of Social Services; report no. 295e, 2019
There are probably few thousands to tens of thousands ME/CFS patients in the Czech Republic and their health and social situation is often desperate. In many cases, this illness leads to substantial disability and to suffering, which is exacerbated by social stigma, unjust psychiatrization and dismissive approach from a significant part of physicians. ME/CFS means something far more severe than just being tired. There is no causal treatment for ME/CFS and the probability of spontaneous recovery is low. We know from the practice of our patients' association, that patients commonly suffer from strong symptoms for decades, without the appearance of another serious disease. This observation is supported by several scientific studies on the clinical course and prognosis of ME/CFS. For that reason, we consider the view that ME/CFS is a “provisional” diagnosis to be absurd and not reflecting reality.

Unfortunately, patients are often not diagnosed even in the typical postinfectious cases, which meet all the published diagnostic criteria for ME/CFS. Frequently, patients are forced to give up seeking medical care and they become invisible to the healthcare system. Furthermore, even those who are almost fully disabled, cannot access disability pension because the diagnosis G93.3 is not included in the decree on disability assessment by the Ministry of Labour and Social Affairs. Patients are also sometimes recommended to undergo graded exercise therapy (GET) or other forms of “activation”. These activation therapies might be effective in other illnesses that are manifested with chronic fatigue, however, in ME/CFS these frequently lead to an objective deterioration in health, which can even be irreversible. The fact, that physicians recommend a therapy which is harmful to the patients, is unacceptable. Alarmingly, ME/CFS occurs in children as well, whereas these pediatric cases are to the best of our knowledge ignored in the Czech Republic.

We are convinced that the unification of diagnostic and therapeutic care would be beneficial for all the stakeholders, as it would lead to the reduction of patient visits to physicians and the number of tests performed on them. Importantly, early diagnosis and implementation of resting regime are known to improve the prognosis of ME/CFS. The development of the protocol of examinations for ruling out other diseases that has been suggested will again not help the patients with ME/CFS, but only the patients with other, not yet diagnosed diseases.

As patients with myalgic encephalomyelitis/chronic fatigue syndrome from the Czech Republic, we ask for help. The rejection by the Guarantee Commission and the negative stance of the Czech Medical Associations mean, that we have been left in a desperate situation once again. We ask for nothing else than equal access to medical and social care. The Czech Association of Patients with ME/CFS offers a constructive approach and participation in any steps, that will improve the situation of the patients.

To support our stance, we attach signatures of researchers and physicians, who endorsed the content of this open letter. We also enclose several personal messages from ME/CFS sufferers in the Czech Republic, documenting their situation and the severity of the illness.

We hope you will understand our appeal and take action. Sincerely

Ing. Jan Choutka  Tomáš Tahavský  Ing. Jana Outratová, CSc.  Lenka Králová  Ing. Jarmila Rýdlová, PhD.

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6 Vink M., Vink-Niese F., Diagnostics 2019, 9, 124
7 Evaluation of a survey exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programmes, Oxford Clinical Allied Technology and Trials Services Unit, Oxford Brookes University, 27th February 2019
8 Jason et al, Child Youth Care Forum 2020, 1–17
Support from experts:

We, the undersigned, claim that ME/CFS is a defined biological illness, whose existence has been objectively proven. According to evidence-based medicine, this illness can be diagnosed and differentiated from other illnesses manifested with chronic fatigue. The World Health Organization classifies ME/CFS in ICD-10 as a diagnosis G93.3 (in ICD-11 as 8E49). Based on the current state of knowledge, it is possible to develop guidelines for ME/CFS. Graded exercise therapy (GET) and cognitive behavioral therapy (CBT) are not effective for the treatment of a majority of ME/CFS cases and can lead to a significant deterioration in health of ME/CFS patients.

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This open letter has been sent to the following addressees:

- Mgr. et Mgr. Adam Vojtěch, MHA – Minister of Health of the Czech Republic
- Dipl.-Pol. Jana Maláčová, MSc. – Minister of Labour and Social Affairs of the Czech Republic
- prof. MUDr. Miroslav Ryska, CSc. – President, Guarantee Commission
- prof. MUDr. Josefa Bednařík, CSc., FCMA - Chair, Czech Neurological Society
- prof. MUDr. Petr Panzner, CSc. – Chair, Czech Society of Allergology and Clinical Immunology
- doc. MUDr. Svatopluk Býma, CSc. – Chair, The Society of General Practice
- prof. MUDr. Jiří Zeman, DrSc. – Chair, Czech Pediatric Society
- prof. MUDr. Věra Adámková, CSc. – Chair, Committee on Health Care, Chamber of Deputies, Parliament of the Czech Republic
- MUDr. Lumír Kantor, Ph.D. – Chair, Committee on Health and Social Policy, Senate, Parliament of the Czech Republic
- MUDr. Milan Kubek – President, The Czech Medical Chamber
- MUDr. Pavel Březovský, MBA – Director, The National Institute of Public Health (NIPH)
Enclosure to the open letter to representatives of Czech medical authorities from 22/6/2020

Several messages from ME/CFS patients in the Czech Republic.
“Only my family knows me like this. When I am rarely able to go out, other people see a „healthy“ person. I was completely healthy before, then everything changed one day.”
Alena - ME/CFS 5 years

“The fact that there is no diagnostic biomarker for our disease doesn’t mean we are not ill”

“The fact that I will probably be permanently disabled by an illness without a known treatment was paradoxically not the worst thing to accept. The worst was the disbelief and downplaying by my own family and friends when I was rapidly losing the ability to take care of myself (I was 16 at that time).”

“While I was fighting every day for such a basic things like to get to the bathroom on my own, don’t collapse in a shower or prepare a meal, my family systematically refused to help me and said that I should stop with that nonsense and that according to the bloodtests I am healthy.”
Eva - ME/CFS 11 years
“The disease started right after the highschool. I was loosing my energy quickly, I was constantly exhausted. Over time, I was gradually managing less and less.”

“When I’m better, I manage a 15 minutes walk, most of the day I have to stay in bed. I have constant pain in my joints, muscles and the whole body. I get exhausted even after the slightest exertion. My illness is like a never-ending flu, just without the fever. I went through a lot of examinations, all with just marginal abnormalities. I still don’t have a diagnosis.”
Filip - ME/CFS 7 years

“Fatigue, exhaustion, muscle and joint pain. Neverending flu-like symptoms.”

“I try to live like everything is alright. I manage to work but I struggle with fatigue. I recieved antidepressants and vitamins. I’ve already tried many methods and doctors, it cost me a lot of money. Greetings to everybody.”
Hanka - ME/CFS 22 years
“Chronic fatigue syndrome” is something far worse than just being tired.

“On a better day, I am able to go for a walk for 15 minutes. Often, I must stay in bed for few days after that. On a worse day, I am not able to stand up from bed, I am not able to read, perceive a conversation or look a screen for more than few minutes.”
Honza - ME/CFS 5 years

“17 years ago I went through a major emotional stress and after that a strange flu with high fevers. Afterwards, an unexplainable heavy fatigue appeared. I underwent a lot of examinations, all negative. Since then I am constantly exhausted both physically and mentally. After the slightest exertion I collapse.”

“In the recent years I just struggle and spend my days in bed. I manage to leave my flat once in a few days for the necessary grocery shopping. I still manage the basic hygiene and cooking, but I can’t afford to spend more energy than for survival. This is not life, this is misery!”
Jana - ME/CFS 17 years
„For me, the illness started after high fevers in puberty. Since then, it took away my life, the ability to live normally as other people, it took my friends and family. I had to learn to live bedbound and to fight with pain every day. I lived only for a while, survived for a long time, and now I just struggle.“ Jana - ME/CFS more than 20 years

„I feel like a flower without water.“

„Every day since I wake up I feel fatigue and malaise and I feel overall terrible. It usually lasts until noon, sometimes all day.“
Jirka - ME/CFS more than 20 years
“In December 2017 I fell ill with a strange flu and high fevers. I almost could not walk and I suffered from pain that I have never experienced before.”
“Despite of affirmations that there is nothing wrong with me, after a physical or mental exertion I always developed persistent headaches and malaise. Blurred vision and sensitivity to light and sound also appeared.”

“I still tried to go to work, but instead of a lunch break I always had to go to sleep for an hour. When I tried to work on PC, I developed vertigo and malaise, at home I couldn’t watch TV, because I couldn’t bear watching the screen. I struggled hard to continue to go for trips with my son as I hoped it would be OK, but I always just got worse after that.”

Jirka - ME/CFS 2 years and 2 months

“This photo was taken on the day of my name-day celebration. They celebrated without me, I was too sick. With this illness you never know how you’re going to feel in an hour. A day of celebration means, that you are wearing a nice T-shirt in bed and you make a selfie to enjoy it. When you feel the worst, nobody knows about it because nobody can see you.”

Lenka - ME/CFS
“My physician tells me, that “chronic fatigue syndrome” doesn’t exist and that it’s just a provisional diagnosis for cases when the physician can’t find the cause of your problems.”

“The situation of ME/CFS patients in the Czech Republic is very bad and the attitude of the majority of physicians is dismissive. The psychiatrization of ME/CFS is wrong and can cause a lot of harm.”
Leona - ME/CFS 4 years

“Dear husband, thank you for your love and understanding, when our whole family must accommodate to the exhaustion that destroys both my and your life.”
Lia - ME/CFS 15 years
I fell ill after a viral infection in September 2001. I lost a lot because of the disease, but above all I couldn’t fully and actively live through the childhood and adolescence of my daughter. I lost a relationship, I lost a beautiful job (singer in an opera choir) and I can no longer teach either. I get exhausted with everything - reading, conversation and everything that normally makes people happy.

“...I feel like I’m in debt to my daughter, as I was prepared to give her much more than the disease allowed me to give. But it is not for the lack of will. Everytime you try, you pay for it badly. That’s what is so terrible and cruel about this disease.”
Lucie - ME/CFS 19 years

“I fell ill at the university. I had to give up my studies and then I was not even able to cope with a short job. For a few years I am now at home without any support. Unfortunately, the physicians don’t know the disease or don’t take it seriously. I still have no diagnosis.”

“...I can’t stand. On better days I manage to walk a little bit. The whole day I have muscle pain and I’m exhausted. I would love to have a normal life, but the maximum exertion I can usually tolerate is one trip to the bathroom.”
Marika - ME/CFS 6 years
“We have to speak up, because no one else will do it for us.”

“From a happy and active person I became a prisoner of my exhausted and aching body.”
Milena - CFS and fibromyalgia 16 years

“ME/CFS is a serious physical illness. I was diagnosed only after 5 years and found medical care after 10 years of suffering, when I was already in severe state.”

“Some doctors ignore this disease, whereas abroad the seriousness of ME/CFS is compared to the terminal stage of cancer...”
Nina L. T. – ME/CFS 25 years
„What did the disease steal away from me? Family, I can’t have a job, social and cultural life, freedom. The diseases progresses and brings new diagnoses and problems,... I don’t even now what to say, I constantly need the help of other person, there is less and less things that I manage to do on my own ……”

Pavla - ME/CFS

„I missed out on enjoying the best part of my life. The constant fatigue and exhaustion limit me in every day life. I spend most of the time in shadow and quiet to avoid headaches. I must rely on the help from others.“

Pavlina - ME/CFS 30 years
My problems started after an infection when I was only 13 years old. Today I am 40. A lot of the times I was on the brink of complete exhaustion.

All my blood tests and immunological tests are completely negative, except of some minor abnormalities.

Petra - ME/CFS 27 years

I got this disease after a viral infection in July 2018. Over time, I am losing my ability to walk. I can now walk only a short distance and only with sticks. I can no longer manage the household, shopping or get to a doctor. The doctors didn’t help me at all, they don’t know ME/CFS.

Renata - ME/CFS 1,5 years
„I live without any support from the social system. I can leave my flat once or twice a week for two or three hours. Had it not been for a longtime financial support from my family and friends, I wouldn’t be alive today."

"I always loved to go for a walk to a forest... Now, I can only sit by an open window for 10 minutes, that's all I can manage. I am afraid I will never see forest again."

"All my professional life I was helping people. Who will help me now?"
Zuzana, ME/CFS 25+ years