



a **PATIENT ADVOCACY** International campaign to
research **SYSTEMIC BODY ODOR AND HALITOSIS**

A 501(c)3 Public Charity, USA
A Not For Profit LTD Company, England and Wales

January 11, 2012

Michael Astrue
Social Security Commissioner

Re: Petition to include TMAU in the Social Security Compassionate Allowance list

Dear Mr. Astrue:

I would like to thank you and NORD for inviting Dr. Elizabeth Shephard to file for this benefit on our behalf, who in turn, has asked MEBO Research, Inc. (MEBO) to participate in this application by addressing the quality of life with Trimethylaminuria (TMAU) issues. First, I would like to thank you on behalf of the international community represented by MEBO, for the opportunity you have offered us through NORD to present our case in hopes that persons suffering from this rare disease may be included in the SSA Compassionate Allowance list. TMAU is a rare universal disease, which transcends gender, racial and national boundaries, as noted with sufferers of all races and backgrounds coming together from around the world under MEBO's flagship to proactively pursue research for treatment and a cure.

TMAU is a physical impairment that is socially isolating with adverse implications on quality of life, productivity and psychological health. All sufferers' human interaction is compromised at a most basic level, be it in the workplace, education, general public or indeed romantic and family life, leading to discrimination transcending the home, workplace and in the general public. Offensive odor as a stimulus for the uninitiated creates a strong aversion, an evolutionary response to a potentially infectious stimuli. The evolutionary response to noxious olfactory stimuli is one of disgust. It has been suggested that this serves as a method of guarding against contact with potentially infectious and harmful substances. It is possible that the impact of these conditions on patients' lives is great. Social relationships are one of the pillars of quality of life, and social isolation is known to correlate with psychological comorbidities such as depression and anxiety. TMAU patients frequently tell a sorry tale of constant social rejection, psychosocial assaults, and as a result, usually live lives of isolation with all the associated psychological comorbidity that this entails.

Barriers to obtaining employment at interview

No matter what the qualifications, personality traits, personal appearance and demeanor of a job candidate, human nature being what it is, there is likely to be discriminative and human rights issues if this malodorous medical condition is present. Few employers would be willing to recruit a malodorous person to a workforce, especially for work involving the general public such as sales assistant or waiter/waitress. The repeated rejections are not usually openly discussed, as employers are quite careful not to incite discrimination suits against themselves.

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Workplace discrimination

Those TMAU patients who manage to find employment face further discrimination. As mentioned previously, malodor medical conditions are virtually unknown by members of the general public. The workplace becomes just another platform of compromised social interaction. There are frequent reports of unfair dismissal, sustained bullying campaigns and other inequalities such as being overlooked for promotion, etc.

Such is the stigma and social unacceptability of suffering with malodorous medical condition such as TMAU that many patients attempt to work from home. In these times of global recession however, work of this nature is difficult to come by without specific skill sets.

Social anxiety and depression preventing work

It is unnatural for an individual to exist in a state of constant social rejection. Such maltreatment all too frequently comes at a psychological cost to the TMAU patient. Social anxiety and depression are especially prevalent, and these are well known issues related to decreased productivity and unemployment.

Cost of medical and dietary management

It will by now be readily apparent that even if the symptoms of TMAU can be controlled (not always possible for many patients), its management can become a lifestyle, demanding constant attention and research. If the patient manages to find employment that provides medical insurance benefits, that fact that few medical insurance policies cover conditions like TMAU, would nonetheless result in tremendous financial cost to the patient.

The rareness of the conditions can mean that patients must travel long distance to specialist physicians for consultation and treatment. This is costly not just financially, but in terms of time costs, which could make work difficult for TMAU sufferers.

Dietary supplements, specialist foods, soaps and antibiotics and the other products that aim to control the symptoms do not come cheap.

Barriers to higher education and other qualifications

Since TMAU symptoms present at an early age, education is adversely affected, leading to restricted employment opportunities throughout the person's potentially productive years. As such, TMAU is a condition comprising of anxiety, depression, social maltreatment, bullying in the schools, and general discrimination, which leads the sufferer toward a reclusive life of isolation. This is particularly most damaging during the developmental stage in one's life, puberty, when the odor most typically worsens by hormonal changes, and during which time, the sufferer is consequently bullied in school, compromising his or her normal psychosocial and psychosexual development. In addition, since hormonal changes trigger more severe symptoms just before and during menstruation, females are particularly compromised in their psychosocial and psychosexual development. As a result, many sufferers drop out of school, which later manifest in restricting employment options.



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Intervention possibilities:

However, if these problems were to be addressed with proper treatment and the necessary accommodations become available in a timely manner of the adolescent's development, the sufferer would stand a better chance of developing psychosocially and psychosexually in a healthy manner in order to achieve social and academic success to his or her potential, and thus become productive citizens. It is imperative to clearly state that the proper treatment and accommodations will most probably never become available to the student unless TMAU is classified as a disability by SSA and listed in the Compassionate Allowance list to receive necessary help in a timely manner. To have to wait a year or two to qualify for SSA benefits, could mean that the student will get too far behind in his or her studies, thus creating a significant barrier toward ever achieving the educational foundation to face the academic challenges of future university studies.

Barriers to accessing welfare benefits

For some patients, leaving the house and exposing themselves to strangers who invariably respond in the predictable abusive manner is a very traumatic experience. Some patients are virtual prisoners in their own homes because of the anxiety that has developed. As such, a protracted bureaucratic battle to receive social security is far from ideal.

Potential alternative opportunities to these problems

Even though it is important to portray in this application the social ostracization and consequent psychological trauma this rare disease produces, I would also like to present to you the alternative and life-altering opportunities, which could become available by being in the SSA Compassionate Allowances list. Being on this list could potentially prevent and even reverse the above-mentioned psychosocial damage with simple cost-effective measures. Simply being on this list would "bring back to life and out of solitary confinement," ostracized patients by expediting the process of receiving the necessary assistance.

By being in the SSA Compassionate Allowance list, patients with uncontrollable body odor conditions would thus qualify to enroll in the Vocational Rehabilitation Program (VR) as persons with disabilities, which would empower sufferers to receive the necessary career preparation and qualification to become productive citizens and consequently, to proudly provide for their families. The psychosocial consequences of these body odor conditions are potentially manageable with the proper support system.

As sufferers have to bear years of waiting, and most probably a lifetime in isolation for the necessary research to develop an effective treatment and a cure, the programs offered by the SSA Compassionate Allowances list would assist sufferers in expeditiously receiving the very much needed support and accommodations. These accommodations could entail something as simple as allowing for a more private office space in which the sufferer's odor is not offensive to others,

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and where the patient feels safer. Another potentially beneficial accommodation could be the opportunity to work from home on a full-time or part-time basis as needed, especially during women's menstrual cycle, when the symptoms are exacerbated by hormonal changes. In addition, benefits including diagnostic tests, such as TMAU testing, nutritional and genetic counseling, and mental health treatment aimed at helping the patient cope with his or her disability would have a tremendously positive impact in a sufferer's life.

In addition to including TMAU on the SSA Compassionate Allowance list, I would also request that a clause be added to the TMAU listing allowing for possible future induction of additional yet-to-be diagnosed systemic body odor conditions not related to commonly known physical illnesses. Not all those who test positive for TMAU are able to control their odor with the recommended TMAU Management Protocol, thus possibly implying that there may also be additional genetic and metabolic causes of odor that still need to be researched and identified. Additionally, it is most unfortunate that not all body odor sufferers can financially afford to pay for their own TMAU Test in the United States, due to the employment difficulties the condition innately produces, and therefore, sufferers go undiagnosed. It is for this reason that I request that a clause be added to the TMAU classification of disabilities that may allow the future induction of yet-to-be identified similar conditions in this classification.

Conclusion

TMAU should not just be considered biologically as a simple enzyme deficiency. We believe that a more accurate model would take into account the inevitable psychosocial factors that result. TMAU patients face great adversity, the condition transcends all aspects of life, to the extent that living a normal life is simply impossible for a great many patients. It is a testament to human determination that suicide rate does not seem to be greatly raised. We draw parallels with other oppressed groups from history, for example homosexuals, racial minorities, certain religions, etc. The hypocrisy of common public opinion in selectively offering sympathy and support towards certain conditions such as cancer and yet showing total disregard for the human rights of patients with a different medical problem is astounding. Until such time as either there is a cure or public awareness has been raised to the point where discrimination is no longer present, TMAU patients most definitely are a deserving group to qualify for the compassionate allowances for rare medical conditions.

Fundamentally, each TMAU sufferer dreams of leading a normal life in which one could be an active member of some, and preferably all aspects of society. Like most persons who suffer from rare diseases, a typical body odor sufferer aspires to obtain educational or vocational training that would provide him or her with the opportunity to have a productive career conducive to a sense of self-worth and empowerment to provide for oneself and one's family.

We urge you to consider providing people in the United States with this opportunity to come out from their systematic socially imposed "solitary confinement." Consequently, if you provide us with this benefit, MEBO Research will then use this listing to present to other governments as an example of how cost-effective special programs such as these could open doors to such a



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restrictive disability and thus allow patients to be productive citizens while we wait for research to find a cure.

I look forward to discussing this further as the application process advances. Please do not hesitate to contact me at any time.

Sincerely,

María P. de la Torre
Founder and Executive Director