

ME has been recognised by the World Health Organisation since 1969 at which time they emphasized the seriousness of the illness and its profound socio-economic implications. In recent years the number of patients has exploded, as has the socio-economic impact. This disorder is especially worrisome for the economy because it affects an increasing number of children and young adults - the cornerstone of the social welfare system. The drastic increase in long-term economic costs - due to loss of productivity and payment of disability

## SOCIAL COSTS

Less than 4% of patients are reported to recover spontaneously, and a number of these are believed to have originally been misdiagnosed with ME/CFS. **Without effective treatment, any degree of recovery is almost non-existent.** This illustrates the need to fund research that will lead to the development of effective treatment protocols.

The illness has a very negative impact on the patient and quality of life is alarmingly low. Approximately one quarter of ME/CFS patients are entirely house-, bed- or wheelchair bound. One in ten dies prematurely due to major organ failure, cancer, heart disease or suicide.

**The disorder is not rare; the number of patients in Europe is estimated to be two million.** This figure is assumed to be merely the tip of the iceberg, as the illness often goes unrecognized and is therefore not diagnosed. There are - in any case - more patients with ME/CFS than with AIDS, multiple sclerosis, lupus or lung cancer. ME/CFS occurs in all races and age groups and in all levels of society. **At least 10% of the ME/CFS population is younger than 15,** including children under the age of 4. British research has shown that half of all children with a long-term illness have ME/CFS, thus accounting for the largest **school absenteeism of all existing illnesses.**

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - ME/CFS - is an extremely disabling chronic, multi-system, multi-symptom, multi-organ illness. The disorder has existed for generations, but recently its prevalence has increased dramatically. Those affected see their lives disintegrate into an existence filled with chronic pain and exhaustion, as well as numerous other symptoms. Without treatment, these symptoms can last years or become permanent.

## INTRODUCTION

# **Socio-Economic Impact of ME/CFS on Patients and Society**

The extensive social and financial problems faced by the patients and the enormous cost of this illness to society are largely due to lack of understanding and interest from the medical, scientific and political worlds. In Europe there is a lack of government funding for basic scientific research, training of medical specialists, and for the establishment of information-flow between researchers and medical professionals. **Funding for scientific biomedical research and education of healthcare professionals would reduce the socio-economic costs. ESME was established to facilitate the achievement of these goals and thus ease the impact of ME/CFS on patients and society.**

## CONCLUSION

More than 5000 scientific studies have shown clear biomedical abnormalities in patients with ME/CFS. However many doctors wrongly believe that ME/CFS is a mental illness and their patients must deal with disbelief and mistrust on a daily basis. Patients are also treated with scepticism by insurance companies and social agencies. This environment of disbelief causes numerous social, medical and financial problems for patients. The European labor circuit, the Sickness Benefits Act and the education system are simply not designed to accommodate the type of chronic patient that ME/CFS presents and many patients fall between the cracks of social and medical programs. The costs of the illness incur rapidly - the average monthly expense for a mostly bedridden patient is about €700 per month - and without adequate support many patients end up in dire social and financial situations.

## CONSEQUENCES FOR THE PATIENT

Internal Medicine considers ME/CFS to be a serious social health problem. **The estimated direct and indirect socio-economic costs for Europe are approximately €20 billion annually.** These figures are based on an American study from 2008 which also stated that only 10-17% of Americans with ME/CFS are correctly diagnosed. This number is believed to hold true in Europe as well, which implies that **over 80% of European patients are not - or not properly - diagnosed or treated.** Vast numbers of patients are undergoing expensive, unfocused testing in search of a diagnosis and many have endured a variety of potentially harmful treatments. This places a substantial economic burden on society. Discovery and implementation of a diagnostic test and early treatment would save the public health system billions of Euros annually.