



Woerden/Zuurdijk/Groningen, 19 March 2018

Press Release

MEASURES URGENTLY NEEDED FOR ME-PATIENTS

The reaction of the combined patients' organizations of the Netherlands to the Advice of the Gezondheidsraad (Dutch Health Council)

The organizations of ME- and CFS-patients support the recommendations of the Health Council regarding ME (1).Improvement of the situation of ME-patients is urgently needed. Concrete measures are now required.

Today, the Health Council concludes that ME is a serious, chronic illness which substantially affects patients' functioning and quality of life. Care for ME must improve, and The Netherlands is way behind on scientific research, the Advice notes. An estimated 30.000 to 40.000 ME-patients live in the Netherlands. The patients' organizations advocate the energetic execution of the measures listed below.

Review the Guideline

The Health Council does not pronounce on the Guideline CFS from 2013. The patients' organizations conclude that this Guideline is outdated and must urgently be reviewed. It recommends behavioural and exercise therapy as the (only) preferred treatment. This must be revoked immediately.

Treatment and care, expert centres

Here and now, care for ME-patients can and must improve, the Advice states. According to the patients' organizations, this requires training of health workers based on present-day scientific knowledge and patients' knowledge. Treatment for ME must be made available in specialized centres across the country. The necessary funds must amply be made available by the government.

Stimulating biomedical research

ME is caused by biomedical processes. Scientific research into this is urgently required. According to ZonMw, the organization that finances health research on behalf of the government, this requires at least 2 million euro's annually during a ten-year programme. The patients' organizations ask the minister to make this amount available.

Social-medical assessment

As a result of their illness, many ME-patients are dependent on benefits or social services and adaptations regarding work, education, mobility or home.

At social-medical assessments, too often the degree of disability resulting from the illness is not sufficiently taken into account. This must be redressed.

Time for action

ME is a serious illness. In the 'minor' cases, patients can no longer fully participate at school, at work or in social life. They are partly dependent on care given by others. Those worst affected are completely bedridden, shielded from light and sound, practically without social contact and sometimes even artificially fed.

The patients' organizations urgently appeal to the minister, doctors and all those responsible to take action on behalf of ME-patients.

The patients' organizations in the field of ME and CFS:

ME/ CVS Stichting Nederland, Theo Kuiphof, chairman

ME/cvs Vereniging, Yvonne van der Ploeg

Steungroep ME en Arbeidsongeschiktheid, Catrinus Egas, chairman

- (1) ME (Myalgic Encephalomyelitis) is sometimes referred to as Chronic Fatigue Syndrome (CFS). Many ME-patients are diagnosed with CFS. The patients' organizations and eminent physicians want the name CFS abolished, as it leads to wrongful views and