## Questionnaire survey on post-vaccination symptoms among peer support group of Finnish families

**Introduction:** Since 2009 especially adolescents have experienced multifaceted serious neuropsychiatric symptoms, which have influenced negatively their everyday life and whose causes have remained unknown in thorough medical evaluations. Thus, most of these patients have ended up to a psychiatric consultation and the families have faced the unfortunate fact that there are no evidence-based treatments available for their seriously ill family members. Consequently, in order to find answers to several open questions a few active members of the Finnish peer support group designed an internet-based questionnaire, the results of which we have not been able to get published in any official peer reviewed medical journal.

**Methods:** The survey was meant for anyone, who had experienced severe post-vaccination symptoms (without any identifiable etiology) between 2009-2017 or to the family of affected persons. The questionnaire included detailed questions (incl. 33 items of multiple choice questions) on health before and after vaccination as well as on given diagnoses, time from vaccination to the onset of symptoms, type, severity and development of symptoms, reporting frequency of suspected adverse reaction(s) to health officials, the geographic distribution of the respondents and financial consequences of the diseases to the families.

**Results:** The respondents (n=129) represent whole Finland. Adult patients responded the questionnaire by themselves or together with their assistants and parents responded on behalf of their children. Most of the respondents (69%) had been 7-19 year old at the onset of symptoms and 71.3% of the affected had been females. Most of the respondents considered their health excellent (69%) or good (28.7%) before falling ill. Only three respondents (2.3%) considered their health poor due to recurrent infections, borreliosis and neuropathy.

All 129 study participants informed to have received all nationally recommended vaccinations. Almost all respondents (126 out of 129) had received swine flu (Pandemrix<sup>®</sup>) vaccine between autumn 2009 and winter 2010. In 104 out of 129 respondents the symptoms had started after Pandemrix<sup>®</sup> vaccination; in three participants the symptoms had appeared right after the vaccination. Seventeen respondents had received HPV-vaccine, either Cervarix<sup>®</sup> (n=15) or Gardasil<sup>®</sup> (n=2) in 12 of whom the symptoms had started right after the vaccination. In HPV-vaccinated respondents the symptoms had increased after each booster shot.

The suspected adverse reactions had started in most of the respondents within 2 weeks (37.3%) or 2-3 months (27%) of vaccination. In 107 respondents (82.0%) the symptoms had started within 6 months of vaccination with the vaccine (PANDEMRIX<sup>®</sup>, CERVARIX<sup>®</sup>, GARDASIL<sup>®</sup>, IXIARD<sup>®</sup>) that the respondent suspects as a cause for her/his symptoms.

The most common first symptoms were fatigue or abnormal sleep needs (73.6%), chronic fever (28.7%), muscle and/or joint pain (42.6%) as well as flu like feeling (30.2%). The most common chronic somatic symptoms, still persistent at the time of filling the questionnaire were fatigue (86.8%), low resilience (74.4%), difficulties in memory and cognition (67.4%) and recurrent nightmares (64.1%). In addition  $\geq$  30% of participants reported sensory hypersensitivity, tachycardia and muscle weakness. Over 50% of the respondents needed assistance in their daily activities and six of them were fully dependent on the others' help. Only 23 respondents (18%) were able to live without assistance or aids. Some had been ill already for 8.5 years during which the severity of their symptoms had varied.

The affected had received numerous symptomatic and disease diagnoses the most common of which were narcolepsy (40.6%), chronic fatigue syndrome (36.7%) and postural tachycardia syndrome (POTS, 24.2%). Typically each respondent had many different diagnoses.

The suspected adverse reaction had been reported to health officials only from 71 respondents (55%). The suspected adverse reaction had been reported to the health official (either by an affected person her-/himself or her/his relative 67.6%), clinician (37.8%) or nurse (16.2%).

These "mysterious" syndromes have driven many families (67.5% of respondents) into significant financial difficulties when they have sought help from private clinics and/or when the other parent has been forced to leave his/her job in order to be able to take care of his/her sick child.

**Conclusions:** Based on this questionnaire survey the temporal association between vaccinations and the onset of multifaceted neuropsychiatric symptoms is evident. It is unlikely that this finding would be only a coincidence, since similar cases as observed in this study (around all parts of Finland) have been reported also elsewhere in the world (1-6). The true causality is supported also by the emerging number of research papers published the medical literature (e.g. 7, 8) according to which aluminum and other vaccine ingredients may cause multi-path autoimmune diseases.

In addition, the well-known low reporting frequency of suspected adverse reactions (< 1-10%) by health professionals (as evidenced also in this survey) may explain (at least partly) why health officials have not recognized the potential safety hazards caused by multiple vaccinations with vaccines that contain neurotoxic ingredients such as e.g. aluminum. Unreported and, thus, unlisted adverse reactions will remain unidentified if the collaboration between patients, clinicians and basic researches is not strengthened.

There is clearly an urgent need for further studies on vaccine safety.