

The Tick Victims' Self-help Group is promoting an increase in international information and awareness for patients, their relatives and general public

The need for continual information

The Tick Victims' Self-help Group (SHG Zeckenopfer) was founded over 20 years ago to support those suffering from TBE, borreliosis or ehrlichiosis as a result of tick-bite, and also provide support for victims' relatives.

The Tick Victims' Self-help Group organises group meetings and activities such as outings throughout Austria for its members and their relatives, aimed at helping the exchange of experiences. Talks on health matters, questions of social provision and treatment options are held regularly. Christine Freund, the director of the Tick Victims' Self-help Group mentions the assistance in concerns regarding social provision as a particularly important service: "We take on the work of applications for care costs and represent victims or their relatives in their dealings with authorities".

Another focus for the Tick Victims' Self-help Group is their publicity work, which seeks to create greater awareness about the dangers of the TBE virus (and other infections transmitted by tick bite) and the serious implications of the diseases caused. Information days in hospitals, pharmacies and communities and information stands at trade fairs dealing with health and retirement matters aim to improve the public's knowledge about TBE prevention measures. With this aim in mind, the self-help group also hands out its own information material such as leaflets and folders about TBE and borreliosis. The SHG has around 400 members across Austria and is unique of its kind in Europe. Further information can be found on <http://www.zecken.or.at>.

Severe TBE disease in Styria

"The sequelae of TBE can involve particularly severe consequences. That makes us especially concerned to show people what the course of the disease can be following a tick bite. Unfortunately, many people are still too unaware of this", says Christine Freund. "It is often not just a matter of a single stay in hospital. The damage caused

by the disease brings serious changes to victims' lives and is also an enormous burden for their relatives.”

The case of a 74-year-old farmer living in Styria provides an example of the serious effects that TBE can have. Until the tick bite he had been in good physical health. Despite the fact that they lived in an area where TBE was known to be endemic, neither he nor his family were vaccinated.

In early May 2004, Herr B. was bitten by a tick. Three weeks later he was admitted to hospital; not long after that he developed paralysis of all four limbs and also respiratory paralysis. He spent nearly a year in hospital. With no prospect of recovery, on his release from hospital Herr B. needed full-time care. A care home was out of the question for the family. Since the patient needed intensive personal and technical care, the family adapted a room to serve as a hospital room, in a major and expensive alteration to their home. Since his return from hospital, Herr B. has been cared for by the members of his family around the clock.

Christine Freund concludes, “Sadly, it is often not until we hear of serious cases of illness like this that those around sit up and take note. Following this case, everyone in the seven neighbouring houses had themselves vaccinated against TBE, including Herr B’s immediate family.”