



LEBENSNERV

Foundation for the Facilitation of Research on psychosomatic effects associated with Multiple Sclerosis (MS)

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Why LEBENSNERV ?

Two women with MS, Dr. Sigrid Arnade and Susanne Same (née Wolf), established the foundation LEBENSNERV in the fall of 1991 because up to now insufficient attention has been paid to psychosomatic aspects of multiple sclerosis (MS). There is a huge amount of research on somatic aspects of the illness, but psychological and psychosomatic issues are less well investigated. LEBENSNERV regards itself as a coordination point and a forum for initiatives who consider MS (and also other chronic illnesses) from a holistic point of view. This approach is unique for an MS organization in the German-speaking region.

Who or what is LEBENSNERV ?

The LEBENSNERV foundation combines this holistic point of view of MS and of people with MS with the philosophy of the worldwide "Independent Living Movement". This is a special and unique quality of the foundation's work in Germany, too. To this end, LEBENSNERV wants to encourage people living with MS to live their lives independently and actively **with** the disease and not **against** the disease. In addition, LEBENSNERV encourages people with MS to rediscover their own powerful inner resources.

PEER

LEBENSNERV is committed to the "peer concept" ("concept of similarly affected persons"). This means that all decisions about the orientation and content of the work of the foundation are taken by persons with MS or other chronic illnesses themselves. This includes intensive and trustfull cooperation with non-affected persons. However, the work of the foundation is dominated by the perspective of the experts in their illness and their role model for others. For LEBENSNERV the term "PEER" stands for the same or similar concern of all actors, but also for the following:

- P** - Psychosomatic medicine (**P**sychosomatik)
- E** - Empowerment (**E**mpowerment)
- E** – Self-responsibility (**E**igenverantwortung)
- R** - Resources orientation (**R**essourcenorientierung)

What does LEBENSNERV do?

Encouragement of research activities:

Research prizes, working groups and symposia

Networking and information:

Periodical FORUM PSYCHOSOMATIK (2 x per year, free of charge, print, audio tape and online)

Training, continuing education:

Curriculum development, training and education of people with MS and chronically ill people as counselors based on the peer counseling concept; empowerment training to discover personal resources, with special consideration of gender and immigrant backgrounds

Counseling:

Counseling services by trained counselors who themselves are living with MS or a chronic illness or disability

Psychosomatic medicine - what do we mean by that?

If you focus on the linguistic composition of the term you will find the components "psyche" (Greek for "soul") and "soma" (Greek for "body"). In a very simplified way, this means that that psychosomatic medicine looks at the relationships and the interaction between somatic and psychological factors in the human being.

In modern psychosomatic medicine, as represented by the foundation LEBENSNERV, it is assumed that the human organism is an interactive networked system. This system is not static but in constant interaction and relationship with environmental and social impacts. The system tries constantly to produce a stable form of "matching" - one might even say to produce a dynamic "balance".

In case of illness this optimal "matching" is lacking. Symptoms of the illness are not considered as a result of defects, but as an indication of compensation or experiments in compensation within in a living system .

A loss of "matching" can be triggered by a variety of factors that can occur in the different environmental and social interactions. How these processes work exactly for instance in a person with an autoimmune illness such as multiple sclerosis (MS) is still largely unknown and the subject of much current research. In addition it is still open how the results of such research can be used concretely for people with MS in their everyday lives.

In order to support a holistic (also called "integrated" or "bio-psycho-social") point of view of MS, the foundation LEBENSNERV is working together with many individuals and organizations from politics, science, research and practice .

Multiple Sclerosis - what does it mean?

Multiple sclerosis (MS) is one of the most common neurological diseases, and despite intensive research to date neither the cause of MS is known nor can the disease be cured. In Germany more than 120,000 people are living with MS, two thirds of them women.

Multiple sclerosis occurs when the central nervous system becomes inflamed in many places (Latin for "multi" = many) and these inflammations then produce scarring (Greek "skleros" = hard). This can lead to a variety of symptoms: movement disorders, in places loss of sensitivity, loss of balance, rapid fatigability, rectum or bladder problems, etc. In addition, there are often visual impairments and language disorders.

The process of MS is unpredictable. The illness is usually intermittent and the symptoms initially often regress temporarily; sometimes the symptoms are progredient (progress evenly). For 30 - 40 percent of those who are living with MS, the illness develops in a benign way, so that they can live a largely "normal" life and there is no problem in being employed. MS usually begins in young adulthood and leads to profound uncertainty and a feeling of a lack of integrity of the entire identity of the person concerned. Experiences of the foundation LEBENSNERV and results of research suggest that there iare positive psychological effects if people themselves take responsibility for the conditions of living with their illness. Those who are active themselves feel less vulnerable, less helpless and hopeless. For example, they discover that apparently firmly set limits may be moved and that life is more than just MS. Simultaneously then, under certain circumstances MS can be perceived as an enrichment and resource despite all the limitations and associated problems.

*The foundation will appreciate your donations.
The foundation is accredited as a charitable organization and will issue contribution receipts.*

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(20-02-2014)