

# It's time to break the Taboo

## 'Lyme Borreliosis'

- at the doctor and in our social organizations
- at work and in your family
- in the press, on radio and on TV

### Don't let anyone fool you

There is neither any vaccination against ticks nor any risk map.

Ticks live in the whole northern hemisphere.

You can get vaccinated against the viral tick-borne encephalitis (TBE) which is one of several pathogens transmitted by ticks.

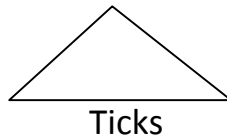
TBE is also well-known as 'Early-Summer Meningo-Encephalitis (FSME)'.

Early-Summer Meningo-Encephalitis (FSME) is a common German synonym for TBE.

This vaccination protects you against FSME but it does not protect you against Lyme borreliosis and other diseases transmitted through ticks.

Ticks are not restricted to special geographical regions.

They are lurking in your garden, in forests, on playgrounds and meadows of open air swimming pools, in your park and even in dunes, everywhere in temperate zones up to 1500 meter.



### Diseases

The currently most important infections transmitted by ticks are Lyme borreliosis and TBE/FSME.

#### - TBE/FSME

TBE respectively Early-Summer Meningo-Encephalitis (FSME) is a virus which partly causes the perilous meningitis. A vaccination prevents this meningitis. An immediate removal of ticks doesn't help because the virus is located in the stinger of the tick and thus directly transmitted when stung. You cannot get any therapy against TBE/FSME but TBE/FSME is restricted to special geographical regions.

#### - Lyme borreliosis

Lyme borreliosis is caused by bacteria. You cannot get any vaccination against this disease because there isn't any. Lyme borreliosis is mostly transmitted by ticks. Wherever ticks are, Lyme borreliosis is transmitted by them. In most cases it can be medically treated with antibiotics if it is realized at an early stage. A prerequisite for a successful medical treatment is that the medication is adjusted to the stage of the infection in terms of its duration and its dose. Depending on the severity of the infection, medication must be given long enough and in high enough dosages. The diagnosis is not easy since the available tests are not always reliable or Lyme borreliosis is out of the scope of the doctor's eyes. For these reasons, this disease remains often undetected. This circumstance leads to misdiagnoses like hypochondria. In late stages you must accept permanent damages and disabilities which restrict the quality of your life in different ways. Patients are often denied getting a therapy because of missing typical symptoms or diffuse test results. Not treating Lyme borreliosis can lead to disability. Patients who are not taken seriously and who don't get a therapy suffer from depressions. Thereby the risk of suicide rises.

### How to protect yourself against Lyme borreliosis?

## 1. **Avoid** tick stings

Remain on walking paths and forest trails. Avoid bushes, coppices, thicket and high grass. Protect yourself with strike-covering clothes and insect protective agents like tick repellent spray. Put your trouser hems into your socks.

## 2. **Head to toe examination of your body and tick removal**

Despite of all imaginable precautions and preventive measures the tick can cleave its way to its blood meal. Check for ticks after every trip in the woods or in the countryside. Examine your body and clothes and the body and clothes of your children for ticks from head to toe. Ticks love to settle in the hollow of the knees, in the genital area, the crotch, in the belly button, in the armpits and at the neck and hairline of your children. Take great care of little nymph-stage ticks. They are as little as a 1 mm big dot. (They are more frequently found on the human body than adult ticks)

The earlier you remove a tick the lower is the risk of getting infected.

Do not remove ticks with your fingers nor with tick tweezers that have thick jaws.

Do not remove ticks with oil, glue or other substances either.

Use precise splinter tweezers or a stamped ticpic (in German: 'Zeckenkarte') instead or put a knife under the tick and cut its stinger off.

Remaining rests are harmless.

## 3. **Perception** of symptoms

The symptoms of a Lyme borreliosis can fade away without a medical treatment but the pathogens are still there. Therefore the perception of symptoms is very important in order to get the right diagnosis.

A red spot around the location of the tick's bite can appear from one day to several weeks after a tick bite. This symptom is called Erythema migrans.

Erythema migrans can also appear at other places on the body where the tick has not bitten (e.g. see figure 1: the so-called erythema migrans on the back, figure 2: the so-called erythema migrans on the leg).

Erythema migrans which centrically grows bigger can appear at several places on the body and it is not always circular. However, about half of the patients do not develop erythema migrans.

Borreliolymphocytoma is another symptom which can appear during an early stage of Lyme disease.

It is a mostly half-round to nodular lump, often a bluish to reddish swelling which appears in large numbers with children (see figure 3).

Blood tests are often erroneously wrong during early stages of Lyme disease because it takes several weeks until antibodies are produced by the immune system. Therefore do not rely on the results of blood tests!

The early stages of Lyme disease can correspond with a general feeling of illness similar to a flu without further symptoms. In this case it is difficult to give a diagnosis as you cannot evaluate if it is Lyme borreliosis or another disease transmitted by ticks (e. g. ehrlichiosis, babesiosis) or a completely different infection.

All of these symptoms can disappear or reappear at random.

Facial paralysis, swollen joints on one side (see figure 4), heart inflammation (carditis), inflammation of the brain (encephalitis), nerve inflammation (neuritis) and skin inflammation (dermatitis) are typical of the late stages of Lyme disease (Acrodermatitis chronica atrophicans, figure 5).

## **Versatile Pathology**

Lyme borreliosis becomes noticeable through diffuse and unspecific symptoms such as

- Weariness, lassitude, prostration,  
low stamina
- Headache
- Malaise, a general feeling of discomfort / being unwell
- Arthralgia, joint pain
- Ankylosis, joint stiffness
- Muscle pain, Myalgia
- Muscle cramps
- Myasthenia, muscle weakness
- Subsultus, twitching muscles
- Pain in the back
- Heart palpitation, allodromy (gallop rhythm, extra-systole),  
Tachycardia (racing heart)
- Sleep disturbances (sleep disorders, insomnia)
- Night sweat
- Mood swings
- Irritability
- Lymphoma
- Pain in the limbs, restless legs
- Stomach trouble and gastro-intestinal discomfort
- Bottom of foot pain or heel pain
- Visual disorders, visual impairment
- Earache, hearing disorders
- Dizziness, disturbances of balance(equilibrium)
- Sensory disturbances such as pins and needles,  
burning pains, numbness, twinges and stabbing pains
- Shooting pain
- Stiffness in the neck, neck pain and cracking in the neck
- Weight gain, weight loss
- Bladder dysfunction
- Aching ribs
- Alcohol intolerance

The symptoms change in their severity, side of the body and location. Fever occurs rarely. Little children may attract attention because of their relieving posture, apathy, character change and learning difficulties. Lyme borreliosis is often confused and misdiagnosed as:

- Fibromyalgia, rheumatism, overstress of the knee joints
- Cervical-shoulder-arm-syndrome
- Carpal tunnel syndrome
- Disc herniation
- Neurological diseases like ALS (Amyotrophic lateral sclerosis),  
Motoneuron disease, stroke
- Depressions and different other mental disturbances
- Somatoform disorders
- Multiple sclerosis
- Dementia
- Arthrosis

## Your membership in the BFBD will help

Our organization is a non-profit association which pursues only charitable objectives. Membership fees and donations are tax-deductible.

The membership fee is debited from your bank account per automatic debit transfer system once per year in order to save superfluous administrative costs. The first direct debit for the current year can occur at any time.

The membership can be cancelled with a period of 4 weeks' notice at any time. The direct debiting mandate can be revoked at any time.

- I apply for an individual membership in BFBD.  
Annual subscription  (minimum amount 48 €)
- I apply for a reduced\* membership in BFBD.  
Annual subscription  (minimum amount 24 €) \* Please enclose an official notification about Hartz4 or about your pension
- We apply for a couple membership in BFBD.  
(Adults with the same address)  
Annual subscription per person  (minimum amount each 30 €)

First name                      family name

Profession (voluntary information)

Street

Postal code (zip code)/city or town

Telephone number              fax

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Account number              bank code

Bank

Date                              signature

I agree that this information will only be used for the statutory management of our association.

My membership was acquired by

## Literature ordering

Hereby I order the literature given below (plus 2 € delivery cost per order – delivery and invoice will be sent per post)

Surname

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Zip code/city or town

Date                      signature

Piece(s)

Piece(s)

Piece(s)

Piece(s)

Piece(s)

Piece(s)

Piece(s)

All prices include VAT.

## About us

### What is the

**‘Borreliose und FSME Bund Deutschland e. V.’ (BFBD)**

The current patient organization was borne from the ‘Lyme-Borreliose Bund e.V.’ which was founded in Hamburg in 1994. The BFBD was registered in the register of associations in 1999. The main part of the self-help-groups, self-help-associations, self-help-advisors and more than 1300 members and sponsors belong to the BFBD.

All big health insurances acknowledge, appreciate and sponsor our work which primarily focuses on prevention through information for endangered persons and emphasizes the advisory services for affected persons and their relatives.

## **Borreliosis self-help-groups**

There are more than 100 borreliosis-self-help-groups and counsellors for borreliosis each German Federal State give regional help and information. They are supported with advice, education and information material by the BFBD, the 'Borreliose und FSME Bund Deutschland e.V.'.

You can find each self-help-group online at <http://www.borreliose-bund.de> and in our newsletters.

## **We will help you along your way**

**Phone: 0180 500 6935** (0.14 €/min from the German landlines, maximal 0.42 €/min from a mobile phone)

From Monday to Thursday from 10 a.m. - 12:30 p.m.

Evening counselling service: every Monday and Friday from 6 p.m. - 8 p.m.

Every Saturday from 4 p.m. - 6 p.m.

On the phone you will speak to other affected borreliosis patients who have a wide spectrum of knowledge. These volunteers will give you advice on how to proceed further.

You need patience if you call the hotline at times when our hotline is almost always busy.

As a member you can ask one of our offices for advice and then you will be called back as soon as possible.

### **Please note that**

**self-help counselling does not replace the advice of a doctor.**

## **Tasks – Objectives – Projects**

### **It's time to break the **taboo 'Lyme - disease'****

- at the doctor and in our social organizations
- for politicians at federal and regional level and for EU officials
- for research projects
- at the doctor and in our social organizations
- at work, in your family and our society
- in the press, on radio and on TV

**Borreliosis should neither be defined down nor hushed up any longer. It must not be dismissed any longer as a negligibly infrequent disease either.**

### **We are fighting for you in terms of:**

- information to patients and doctors
- Strengthening the patient's rights
- dissemination of information material
- support of self-help-groups
- interactive health care policies
- public relations

## Benefit to the public and charity

The BFBD (Borreliose und FSME Bund Deutschland) is acknowledged as a non-profit association.  
The BFBD is a member of:

B.A.G. = DER PARITÄTISCHE Deutsche Arbeitsgemeinschaft Selbstgruppen e.V.

### Membership subscriptions and donations are tax-deductible.

Bank account for membership subscription and donations: Hamburger Sparkasse

Bank code 200 505 50, bank account no. 1275 123345

BIC: HASPDEHHXXX

IBAN: DE53 2005 0550 1275 1233 45

Register of associations Darmstadt VR 82436

Tax Identification number 08 250 54337 – KO1

## Your membership will help you

Become a member and support us – if you want- even through your disease.

BFBD represents the interests of hundreds of thousands of patients who fell ill by tick bites. The more we are, the more effectively we can achieve the urgently necessary amendments for the diagnosis, therapy and prevention of tick-borne diseases.

Members receive the newsletter 'Borreliose Wissen' for free, furthermore a free-of-charge initial 'VdK'-counselling, a counselling outside the office hours and even a counselling about experts and lawyers.

## Information – Counselling – Help

**Neither positive nor negative blood tests are suitable for a decision on a diagnosis and therapy. Discomforts and a possible tick experience are decisive for the diagnosis.** In case of uncertainties do not hesitate to contact the BFBD (Borreliose und FSME Bund Deutschland e.V.) or to get in touch with a self-help-group in your region. There you will get advice from people who are personally affected by Lyme-disease.

B O R R E L I O S E

F S M E B U N D

D E U T S C H L A N D

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[www.borreliose-bund.de](http://www.borreliose-bund.de)

This flyer is also available in Arab, French, Italian, Polish (only translation), Russian, Turkish and German by download from the homepage or on paper in the headquarters.

Come and join the biggest virtual self-help-group for victims of tick bites in Europe at

[www.borrelioseforum.de](http://www.borrelioseforum.de)

More than sixteen thousand registered users exchange information, support and help each other with useful tips at

[www.zecken.de](http://www.zecken.de)

[www.zecken.info](http://www.zecken.info)

Translated by Roger Hellmuth