lyme.no
Norsk Lyme Borreliose Forening

SØRLANDET SYKEHUS

One year with ”FLÅTT DIALOG”: Where are we now?

Gerd Marit Berge

ExtraStiftelsen
Helse og Rehabilitering

Aim:
To create confidence and interaction

”Deliverables” of the project:

1. Arrange dialogue meetings between NLBF and SSHF
2. Write a popular science article explaining laboratory methods for LB diagnostics
3. Arrange a meeting, same topic as the article, where patients have the opportunity to meet some of the professionals

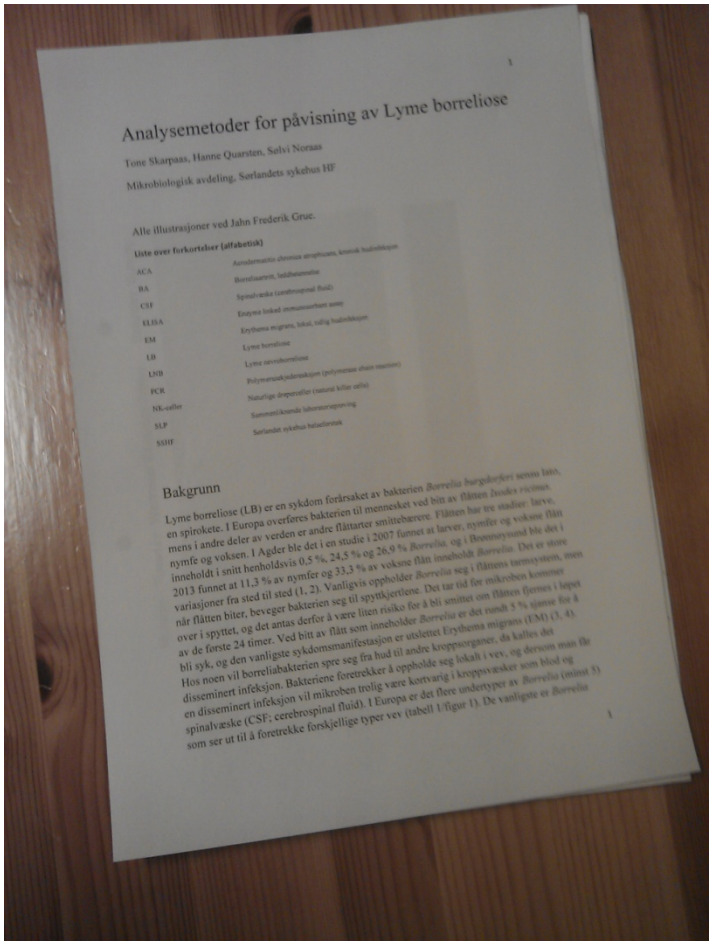
Dialogue meetings

- ✓ Dialogue between NLBF and SSHF
  - ✓ 2 full-day meetings
  - ✓ Main topics: diagnostics and treatment
  - ✓ What do we agree on, what are the controversies?
  - ✓ How can we involve and inspire the medical community and public health authorities in the process of research and dialogue?
  - ✓ Further projects or cooperation?

- ✓ Result?
  - ✓ Better understanding of the disagreements

Popular science article

- ✓ Write a popular science article explaining laboratory methods for LB diagnostics
  - ✓ Has been published at www.lyme.no



Analysemetoder for påvisning av Lyme borreliose

Tone Skarpaas, Hanne Quarsten, Sølvi Noraas

Mikrobiologisk avdeling, Sørlandets sykehus HF

Alle illustrasjoner ved Jahn Frederik Gruc.

Liste over forkortelser (alfabetisk)

ACA	Acrodermatitis chronica atrophicans, kronisk hudinfeksjon
BA	Borrelioartrit, leddbetennelse
CSF	Spinalvæske (cerebrospinal fluid)
ELISA	Enzyme linked immunosorbent assay
EM	Erythema migrans, lokal, tidlig hudinfeksjon
LB	Lyme borreliose
LNB	Lyme nevroborreliose
PCR	Polymerasekjedereaksjon (polymerase chain reaction)
NK-celler	Naturlige drapsceller (natural killer cells)
SLP	Sammenlikninde laboratoriesøkning
SSHF	Sørlandet sykehus helseforetak

Bakgrunn

Lyme borreliose (LB) er en sykdom forårsaket av bakterien *Borrelia burgdorferi* sensu lato, en spirokete. I Europa overføres bakterien til mennesket ved bitt av flåtten *Ixodes ricinus*, mens i andre deler av verden er andre flåttarter smittebærere. Flåtten har tre stadier: larve, nymfe og voksen. I Agder ble det i en studie i 2007 funnet at larver, nymfer og voksne flåtter inneholdt i snitt henholdsvis 0,5 %, 24,5 % og 26,9 % *Borrelia*, og i Brønnøysund ble det i 2013 funnet at 11,3 % av nymfer og 33,3 % av voksne flåtter inneholdt *Borrelia*. Det er store variasjoner fra sted til sted (1, 2). Vanligvis oppholder *Borrelia* seg i flåttens tarmsystem, men når flåtten biter, beveger bakterien seg til spyttkjertlene. Det tar tid for mikroben kommer over i spyttet, og det antas derfor å være liten risiko for å bli smittet om flåtten fjernes i løpet av de første 24 timer. Ved bitt av flåtter som inneholder *Borrelia* er det rundt 5 % sjanse for å bli syk, og den vanligste sykdomsmanifestasjon er utslettet Erythema migrans (EM) (3, 4). Hos noen vil borreliabakterien spre seg fra hud til andre kroppsorganer, da kalles det disseminert infeksjon. Bakteriene foretrekker å oppholde seg lokalt i vev, og dersom man får en disseminert infeksjon vil mikroben trolig være kortvarig i kroppsvæsker som blod eg spinalvæske (CSF; cerebrospinal fluid). I Europa er det flere undertyper av *Borrelia* (minst 5) som ser ut til å foretrekke forskjellige typer vev (tabell 1/figur 1). De vanligste er *Borrelia*

Mini-conference

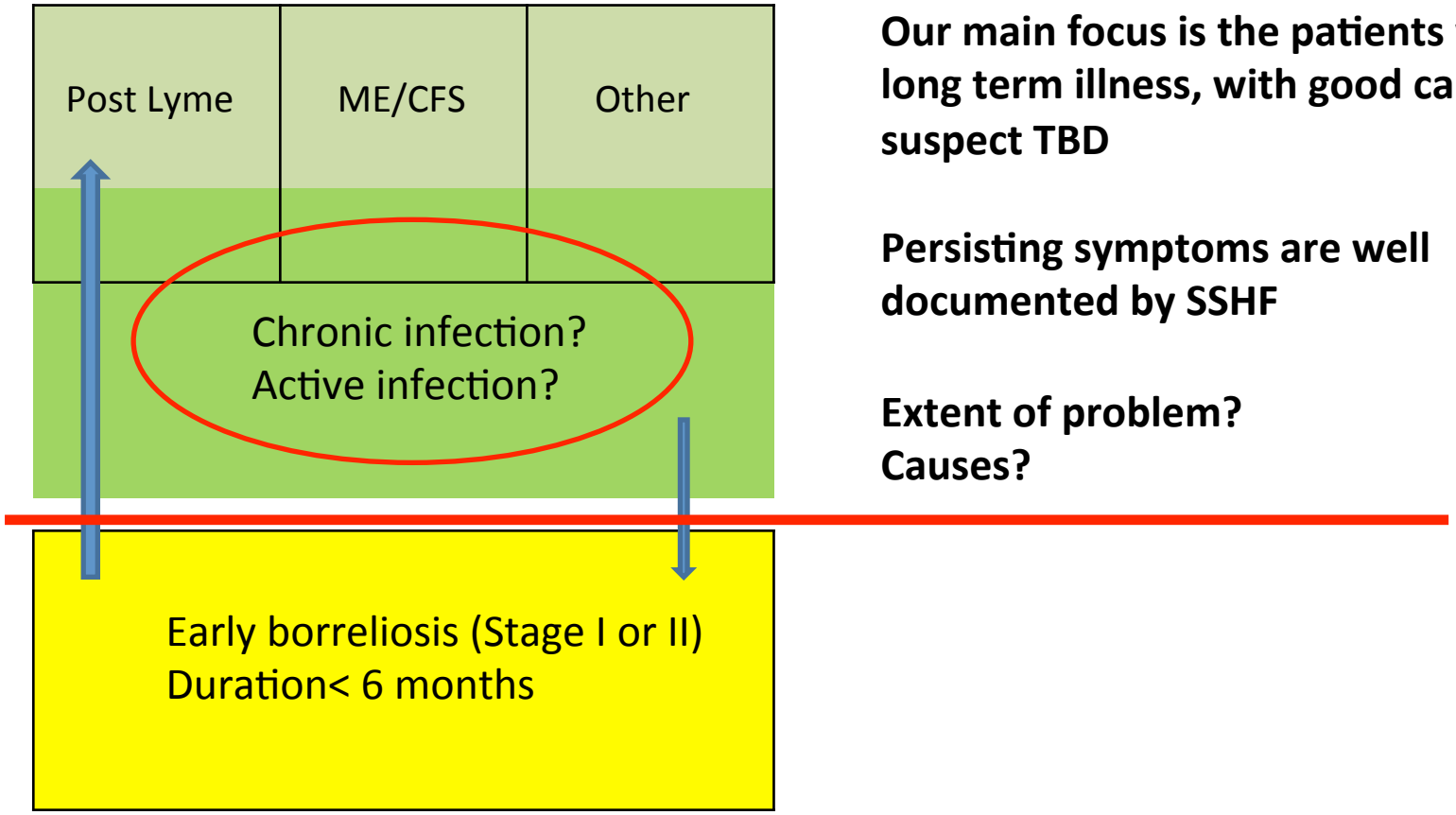
- ✓ Open meeting on LB Diagnostics
- ✓ Guest speakers from abroad:
  - ✓ Dr. Leona Gilbert (Finland)
  - ✓ Prof. Franc Strle (Slovenia)
  - ✓ SSHF speakers
  - ✓ Time for debate
- ✓ Positive response, patients appreciated the opportunity to listen to, and discuss with, the speakers

Where are we now;
from the patients point of view?

- Disagreements or uncleared questions?
- Do we speak of the same patients?
- What to do now?

lyme.no
Norsk Lyme Borreliose Forening

”The world” - as the patients see it



Our main focus is the patients with long term illness, with good cause to suspect TBD

Persisting symptoms are well documented by SSHF

Extent of problem?
Causes?

?

The specialists in the health care system tend to define their focus – and thus their responsibility – mainly to be cases of early LB. Allthough they also see cases of Stage III LB

lyme.no
Norsk Lyme Borreliose Forening

?

The limit is set, based on **two hypotheses:**

1. Long term ill patients with active LB infection will always have a positive antibody test

2. The recommended treatment will always kill the bacteria

NLBF questions both

lyme.no
Norsk Lyme Borreliose Forening

Focus on long term illness because:

- These are the angry and despairing patients, **seriously ill and abandoned by the health care system**, who go to the private clinics abroad
- These are the patients that step forward, in the media, and ask for attention and help
- These are the patients that try to report good effect of «un-authorised» treatment
- These are the patients where we have **least knowledge**

lyme.no
Norsk Lyme Borreliose Forening

What will it take to create trust?

- Mutual respect, a greater responsibility by the ”strong” party
- Take the patients seriously, listen to patients’ experiences
- Information needs to flow both ways, every patient must be allowed to tell about their experiences and to be believed
- The ”complicated” patients can not be ”defined away” from help
- Create new knowledge!
  - Relevant knowledge that answers the patients’ questions

lyme.no
Norsk Lyme Borreliose Forening

What next?

- Document treatment effects
- Improve diagnostics, especially direct detection of bacteria
- Interdiciplinary effort focusing on the long term ill, and the ”complicated” cases
  - Take responsibility also for ”Post Lyme”, ME/CFS, other…
- Both patients and clinicians have to be open to different explanations, more than one possible cause, to illness.

It’s not important to be right, but to get help… (NLBF)

lyme.no
Norsk Lyme Borreliose Forening

”Flått dialog”: What did we achieve?

- Better communication in the project group between NLBF and SSHF,
- Better understanding of the problems of ”complicated cases” and long term illness
- Inspiration to do relevant research, also on co-infections
- Inspiration for HOD and HD to include patients in the work on how to deal with LB and TBD

ExtraStiftelsen
Helse og Rehabilitering

Thank you for your attention

lyme.no
Norsk Lyme Borreliose Forening

SØRLANDET SYKEHUS