English version of

The Norwegian Public Health Institute's controversial ME-science

The Norwegian Public Health Institute's assignment is to share quality-assured information, advise on public health and prevent illness and health damage. When it comes to the illness ME, however, NPHI refers to controversial science that aggravates the situation for patients.

Written by Nina E. Steinkopf, 30.09.2019, author of www.melivet.com

You may have read the blog post about how the Lightning Process got established in Norway; see a Google-translation here.

I sent the blog post to a number of health-institutions and asked for their points of view. Yesterday I got a response from the Norwegian Institute of Public Health. My translation:

«Hi and thank you for your email.

If I understand you correct, you're asking about the Public Health Institute's view on Lightning Process (LP).

I have conferred with experts here who know of, and have worked with research summaries related to ME, diagnosis and treatments.

At the Norwegian Institute of Public Health, we have no opinions regarding individual treatment methods. We find, assemble and communicate knowledge-based information. We have some basic criteria for this, and when we do have a view, it's linked to what we consider as good and solid research. It's possible to read what criteria we use in several of the examples of knowledge summaries / overviews on ME/CFS below.

During the previously called Knowledge Center for Health Services, the following were published:

2006: https://www.fhi.no/publ/eldre/diagnostisering-og-behandling-av-kronisk-utmattelsessyndrom-myalgisk-encefa/

English: https://www.fhi.no/en/publ/2009-and-older/diagnosis-and-treatment-of-chronic-fatigue-syndromemyalgic-encephalopathy-c/
https://www.ncbi.nlm.nih.gov/books/NBK464796/

2011: https://www.fhi.no/publ/2011/behandling-av-kronisk-utmattelsessyndrom-cfsme/

English: https://www.fhi.no/en/publ/2011/treatment-of-chronic-fatigue-syndrome-cfsme/

And, after transitioning to the Norwegian Public Health Institute, the following research summaries / research articles have been published:

2016: https://www.fhi.no/publ/2016/forskning-pa-arsak-til-og-behandlingseffekt-av-kronisk-utmattelsessyndrom-c/

English: https://www.fhi.no/en/publ/2016/research-on-etiology-and-treatment-for-chronic-fatigue-syndrome-cfs-me/

2016: https://www.fhi.no/publ/2016/tilpasset-trening-kan-redusere-utmattelsessymptomer-hos-personer-med-kronis/

English: Cochrane Database Syst Rev. 2016: Exercise therapy for chronic fatigue syndrome

Sincerely,
Christina Rolfheim-Bye
Director of communications
Folkehelseinstituttet/Norwegian Public Health Institute“

I responded:

“Hi, and thank you for your quick reply.

You write that “At the Norwegian Institute of Public Health we have no opinions regarding individual treatment methods. We find, compile and communicate knowledge-based information. ”

As mentioned in the story about how LP got a foothold in Norway, the Norwegian Institute of Public Health (NIPH) has also contributed:

In 2012, NIPH applied for NOK 9 million to study LP, and journalist and LP-practitioner Live Landmark was appointed to the research group.

A director at NIPH, Per Magnus, wrote an article about Lightning Process together with Landmark which was published in the Journal of the Norwegian Medical Association in 2016. The article was strongly criticized by a number of experts, read more here.

In 2018, Live Landmark gave a lecture at a CFS/ME research conference. The conference was organised by, among others, NIPH. Landmark gave lectures even though she’s not a scientist. She presented the study protocol for a planned study on LP. The study will be conducted by LP's franchise founder, healer and osteopath Phil Parker, who will investigate whether the “powerful and magical program“ he has developed has positive effect. According to the study protocol, Landmark is affiliated with BI Norwegian Business School.
BI has rebutted this.

In January this year, senior consultant Preben Aavitsland at NIPH wrote an article in the newspaper Bergens Tidende, stating that “In the real world, ME patients improve, recover, and return back to work. Patients who recover have followed the advice of the health authorities, even sought holistic rehabilitation or more psychological approaches” and links directly to Recovery Norway’s web page, a “patient association” which is lobbying and marketing LP. This was a comment on a petition, in which 7265 patients, caretakers and health professionals demand treatment which is based on solid scientific evidence; a cry for help to stop the harmful treatment ME-patients are subject to.

LP is classified as Complementary and Alternative Medicine by the Norwegian Directorate of Health, the Consumer Authority and Norway’s National Research Center in Complementary and Alternative Medicine, NAFKAM. LP is based on hypnotherapy and neurolinguistic programming. Replace the word LP with "homeopathy" or "intercession"; How does this correspond with "finding, assembling and communicating knowledge-based information"?

And furthermore; Why does NIPH believe that much-needed public research funds should be used to finance studies on alternative medicine, owned by a foreign franchise company? I would like an answer to this.

"Good and solid science "

You refer to four studies that NIPH considers to be "good and solid science".

The first study, from 2006: "Diagnosing and Treating Chronic Fatigue Syndrome / ME" by Wyller et al., is as you may be aware, associated with controversy. The reason is, as mentioned in the report - about “Patient participation”; “An adult representative, who also has extensive clinical and scientific expertise, participated in the first part of the project period, but withdrew due to disagreement on the inclusion criteria. A youth representative also resigned. In the final phase, the Norwegian Myalgic Encephalopathy Association has chosen to resign as they disagree with parts of the report's content… .. ».

The ME association, which had participated in the project, withdrew as a protest against its contents and refused to sign the report. The reasons for their withdrawal were that:

- The report conflates ME with other diagnoses
- The illness is perceived in a way the patients don’t recognize
- The illness is placed somewhere between psyche and soma without scientific basis
- Patients regard the recommended treatments as either not helpful or downright harmful
- The recommendations are based on highly criticized studies with poor results where several patient groups are conflated
- The consequences of the malpractice are not mentioned
- There is too little focus on science providing pathological findings - despite the fact that there are numerous studies showing immunological, neurological and endocrine abnormalities in ME patients.
- "The report could make the situation for ME patients even worse than it is today."

A report published by the Directorate for Health and Social Affairs the following year summarized i.a. that there was

- Lack of knowledge about the condition in the social-, welfare- and healthcare services, and
- Lack of agreement on implementation of clinical diagnostic criteria.

As stated in a letter to the editor of the Journal of the Norwegian Medical Association with the title "A setback for the patients", the report from 2006 led to more concern - rather than to better quality of health services: "Those who conducted the report knowingly and willingly chose to omit information on large patient surveys revealing that graded exercise therapy and cognitive behavioral therapy either largely don’t work or are harmful."

How can NIPH regard this study as "good and solid science" when it aggravated the situation for patients?

In the second study, the 2011 "Treatment of Chronic Fatigue Syndrome, CFS / ME" it’s stated:

"The primary studies included in the overviews we refer to in this report have used various sets of diagnostic criteria, including the Centers for Disease Control and Prevention (CDC) 1994 criteria, Oxford 1991 criteria and Australian 1990 criteria."

The Oxford criteria only require one symptom (fatigue), and in addition there may be 3 other symptoms. These criteria do not require the exclusion of depression. The prevalence is 0.9% which means that 47,000 people in Norway may fulfil these criteria. By using the Oxford criteria, ME is mixed with mental disorders; which means that patients who are depressed and fatigued may mistakenly end up with an ME diagnosis, and ME-patients who are diagnosed according to these criteria are placed in the same group of patients as those with mental disorders.

The CDC criteria from 1994 have a prevalence of 0.23 - 0, 42% (23,000 people in Norway) and the Australian criteria have a prevalence of 0.37% - 20,350 people in Norway. This is almost four times the Canada criteria, which are recommended by the Norwegian Directorate of Health.

The Canadian criteria require at least 8 symptoms to be present, as well as mental illness having been ruled out as cause of symptoms. It’s estimated that approx. 0.11% of the population, or 5,750 people in Norway meet these criteria.

As you can see, there is a big difference between the sets of criteria used. Therefore, it is highly uncertain whether the study concerns ME patients or patients with depression, or whether it is a mixture of several different patient groups. Such a mix-up means that the results of the study cannot be transmitted to one type of patients. Therefore, the study cannot be regarded as "solid".

Might it be an idea for NIPH to rely on recent research where the Canadian criteria are applied in future?

The 2016 study "Research on aetiology and treatment effect for chronic fatigue syndrome CFS/ME" is essentially a list of selected publications:

https://www.fhi.no/en/publ/2016/research-on-etiology-and-treatment-for-chronic-fatigue-syndrome-cfs-me/

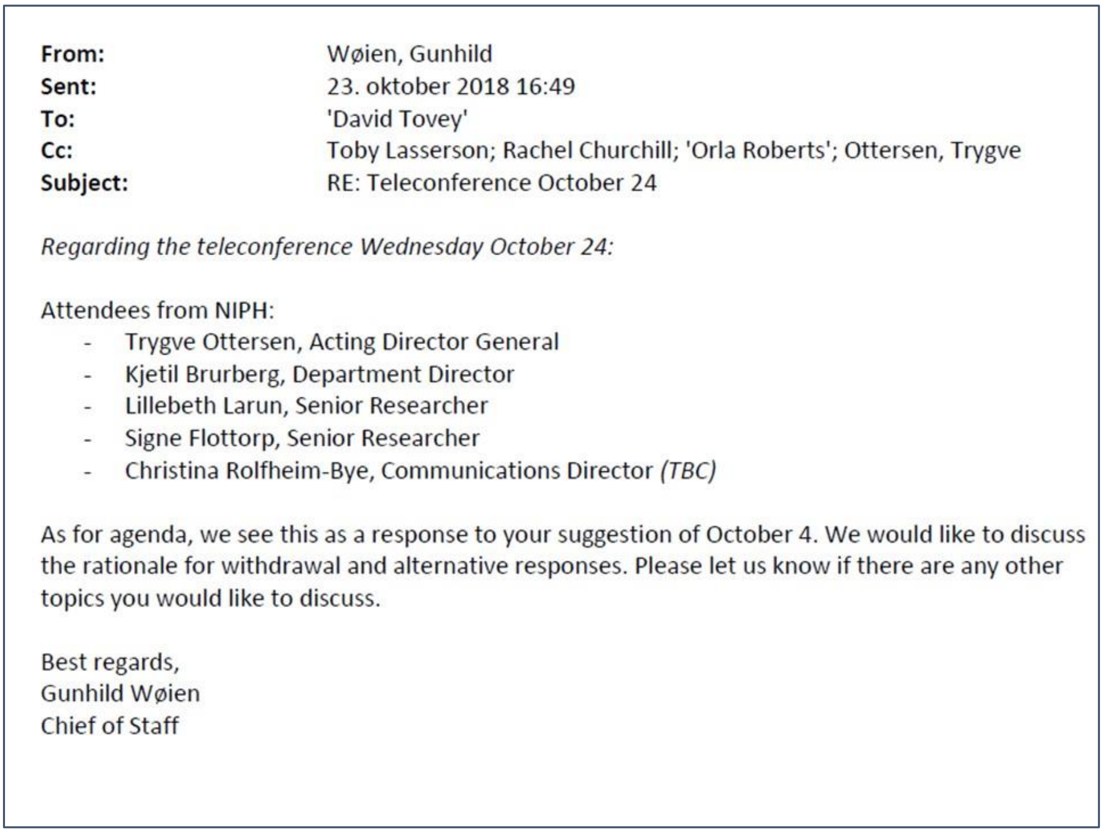
Download Norwegian report here:
https://www.fhi.no/globalassets/dokumenterfiler/notater/2016/rapport_2016_arsak-og-behandlingseffekt_cfsme.pdf

«The selection of relevant references was made only on the basis of title and summary. We did not read the articles in full text and did not evaluate the methodological quality of the overviews or obtained results from the overviews ».

Could you tell me in what way this report has contributed to the benefit of patients?

As for the last study you're referring to, "Customized exercise can reduce fatigue symptoms in people with chronic fatigue syndrome, CFS/ME", Cochrane Database Syst Rev.: “Exercise therapy for chronic fatigue syndrome”, it is interesting that you, in October last year, together with lead author of the study Lillebeth Larun, was invited to a teleconference with Dr. David

Tovey, director of Cochrane at the time, to discuss Cochrane's rationale for withdrawal of the study.



From: Wøien, Gunhild
Sent: 23. oktober 2018 16:49
To: 'David Tovey'
Cc: Toby Lasserson; Rachel Churchill; 'Orla Roberts'; Ottersen, Trygve
Subject: RE: Teleconference October 24

Regarding the teleconference Wednesday October 24:

Attendees from NIPH:

- Trygve Ottersen, Acting Director General
- Kjetil Brurberg, Department Director
- Lillebeth Larun, Senior Researcher
- Signe Flottorp, Senior Researcher
- Christina Rolfheim-Bye, Communications Director *(TBC)*

As for agenda, we see this as a response to your suggestion of October 4. We would like to discuss the rationale for withdrawal and alternative responses. Please let us know if there are any other topics you would like to discuss.

Best regards,
Gunhild Wøien
Chief of Staff

Which means you are probably aware that this study is also very much controversial and can hardly be considered as "solid and good science".

In May, NIPH director of research and innovation Atle Fretheim sent a revision of Larun's exercise review to dr. Tovey - to which Dr. Tovey replied that Cochrane did not plan to publish it.

(The quotes are from Virology blog, Trial by Error; What’s up with Cochrane’s exercise review.)

““With great regret and disappointment, I am afraid that I am not able to publish this version,” Dr Tovey wrote. “As we have discussed, the scrutiny that this review and this decision will be subject to means that we cannot publish a new version unless it is clear that the review is as watertight as humanly possible…In particular, I remain concerned that the presentation in general, but in particular of the short term results on fatigue, remains too optimistic.”
In discussing exercise therapy elsewhere in the e-mail exchange, Dr Tovey referred to it as “an intervention that really probably has very little to contribute”—a view at serious odds with the review’s claims of benefits.
Experts in study design recognize that unblinded trials relying on self-reported outcomes, like those included in this review, generate unknown amounts of bias and cannot provide reliable evidence.”

Today, in 2019, ME-patients are still being treated with graded exercise therapy and cognitive behavioral therapy – despite the lack of evidence that these methods have positive effect or are safe - and despite a large number of reports showing that patients deteriorate as a result of this type of intervention. The information communicated by the NIPH does not, as you may see, contribute to improving the situation for the patients. Therefore, I suggest that NIPH in the future also find, compile and communicate biomedical ME research.

I look forward to an answer to the above.

Sincerely,
Nina E. Steinkopf

To which NIPH responded on 30. September 2019:

“In NIPH, many experts have been working on this topic for several years, and many at the institute wish to contribute with their knowledge, to patients with ME diagnoses.

I uphold my initial answer, that as an institute we do not have any defined view on this but seek and compile knowledge whilst requiring quality to the knowledge we obtain. It’s founded in a desire to understand and thereby contribute. I hope there is understanding and respect for this.”

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