



# ME-KONFERANSE STRYN

## A BIOMEDICAL ME-CONFERENCE

### ABOUT THE LECTURERS



#### JØRGEN JELSTAD

**Research journalist and author of the book «De Bortgjemte» («The Hidden Ones»)**

Jelstad has an education as a physiotherapist, but works as a journalist and a writer. The book «De bortgjemte» («The Hidden Ones») is a result of over two years work where he has read thousands of book pages, research articles, doctorates, news paper articles, documentaries, reports and public documents from public records. Jelstad have participated in international conferences, in addition to conferences and seminars in Norway. On the Web,

he has followed research, presentation and committee meetings through streaming.

Jelstad have done well over 100 interviews, some of them several times for several hours, with patients, next-of-kin, researchers, physicians and nurses, physiotherapists, lawyers, activists, politicians and academics. After the book came out in 2011, Jelstad has written updates from the research field on his blogg [www.debortgjemte.com](http://www.debortgjemte.com). Throughout several years he has held lectures about this subject and participated in the public debate about ME. Jelstad has been following this field closely the last decade, and he is really up to date on the latest from the research field, domestically and internationally. He's now working on a new book that will be published in the spring of 2021: "Våre liv, våre stemmer" ("Our lives, our voices"). This is an interview and photo book about ME and is a collaboration with Morten Borgersen, Fin Serck-Hanssen. Two of the initiators tied to the ME polyclinic at Sørlandet Hospital, Kim Fangen and Ole Rysstad, is involved in the project as well. Thousands of Norwegians are living with ME. In this book you get to meet them up close and personal; the patients, their next-of-kin and the researchers that are working to come up with answers.



#### OLA DIDRIK SAUGSTAD

**Professor Emeritus in Pediatrics, Oslo University Hospital, ME researcher at the University of Oslo.**

Some background information about Ola Didrik Saugstad. He worked at the pediatric research institute until 2017. He then retired from that position, but continued working as a researcher at the University of Oslo, where a large research group is going to study ME from a immunological and genetical perspective, through the ImmunoME study. Blood samples from patients will be a focal part of the study. Saustad has received several medical prizes for his work within pediatrics and research on newborns, including the Nordic Medicine Prize, which is the second most important prize in the Nordic countries, only eclipsed

by the Nobel Prize in Medicine.

Saugstad has made several voluntary trips to visit those that have been hit by ME the hardest. He might be the one person in Norway who has seen the largest number of severely ill ME patients. Saugstad has described this experience as shocking. The ME patients are amongst the sickest among the sick. Many of them are bedridden in severe pain, and the sickest in this group is living in a state of semicomatose. Pain might not be the first thing that comes to mind when thinking about ME. What struck Saugstad while visiting the ME patients was the resemblance to patients with encephalitis (inflammation of the brain). - The biggest betrayal done by the Norwegian health care services is the lack of curiosity in finding out the ins and outs regarding this disease, especially considering the severeness of the disease for a lot of the patients in this group. A lot of Norwegian ME patients have been treated poorly, says Saugstad.

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## KRISTIAN SOMMERFELT

**Professor of Child Neurology at the Children's Clinic at Haukeland University Hospital**

Kristian Sommerfelt has a background in working with ME in patients that are children and young persons up until the age of 18, that were diagnosed before they turned 15. He has over 20 years of experience with ME and have solid advice to give patients, next-of-kin and health care workers. Because of the fact school attendance is obligatory, it is easy to get an overview over all below the age of 15 with ME in Hordaland, because the physician refers to the Children's clinic. Sommerfelt is warning against talking about risk factors, and to single out part of the life of a person that can fit into a certain theory. It does not seem that certain personality types are reoccurring as victims of ME. Kristina Sommerfelt has developed a method that he calls The Sorcerer's Hat. This is an efficient method for health care personnel to map out the main problem for their patients. Sommerfelt is saying he pretends to be a sorcerer with a hat. He can then place one symptom after the other in the hat, to metaphorically make them magically disappear. The method is about starting with the most severe symptom first, and then the second-most severe symptom and so on....

Sommerfelt has been working with a lot of different extreme diseases and severe disabilities. He's pointing to an odd peculiarity when comparing ME to other patient groups. In cases of severe disability, an extensive support system and service apparatus is set in motion. But when it comes to ME, there's no apparatus that's automatically being set in motion. Patients with severe or extremely severe ME are not able to use the specialist health services in an ordinary way, because it is hard to transport these patients when their sickness is that severe. It is of the essence that health care personnel turns a new leaf and starts visiting these patients in their homes. It is also important to take care of the next-of-kin of these patients. Sommerfelt thinks that the ME patients might overreport how much they are able to do. It is important to have clear, objective measuring parameters, or at least ask the patient's next-of-kin about the function level of the patient.



## KARL JOHAN TRONSTAD

**Professor at the Institute for biomedicine, at the University of Bergen**

In collaboration with Øystein Fluge and Olav Mella at the Cancer department at Haukeland University Hospital, Tronstad is leading the project «Defective energy metabolism in ME/CFS». The project, that has received grants from the Norwegian Research Council, aims at developing new knowledge about the disease mechanisms, with a particular emphasis on the energy metabolism amongst patients with ME/CFS. His research group are focusing on how metabolic deviations can contribute to diseases, by, among other things, studying the functions of the mitochondria (the power plant within the cells). By looking for metabolic changes in patient samples, and then compare the findings in laboratory studies on grown cells, the group aim to find out more about mechanisms resulting in ME/CFS. The strategy is to measure the biochemical composition in the blood samples from ME/CFS patients, to then look for a connection that can explain symptoms, the severity degree and the duration of the disease.

They have found changes to the components in amino acids, and the results indicate a malmanagement of central parts of the energy conversion. Now they are moving on to other substances in the body, like lipids (fats) and substances with particular functions, like vitamins. In addition they are looking for genetic changes, and possible connections with deviations in the energy metabolism, in families affected with ME/CFS. This way, through detailed biochemical and genetic studies, they are seeking to identify key factors that can build the foundation for the development of biomarkers and a new treatment.

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### INGRID GURVIN REKELAND

**Acting chief physician at the Department for cancer treatment and medicinal physics, Haukeland University Hospital, PhD scholarship holder at the University of Bergen.**

### ØYSTEIN FLUGE

**Chief physician at the Department for cancer treatment and medicinal physics, Haukeland University Hospital, and professor at the University of Bergen.**



Since 2008, Øystein Fluge and Olav Mella has shown interest for ME patient and ME research. They eventually established a research group at the Department of cancer treatment at Haukeland. The research group has expanded the last years, and is composed of physicians and researchers, nurses, research technicians, molecular biologists and exercise therapists, collaborating with the group lead by Tronstad.

**Øystein Fluge** has lead multiple clinical studies and an extensive laboratory work. The last couple of years his research group has conducted two studies trying out different types of medication; RituxME and CycloME. Rituximab is an antibody that depletes B cells from the circulation, whereas cyclophosphamide is a cell cancer that influence both the B cells and the T cells. The hypothesis is that ME is a type of auto immune disease, and that the immune system is key as far as the mechanisms causing the disease is concerned. After finishing of the clinical studies, the research group has focused on the biobank samples taken during the studies, and the situation regarding potential medications, moving forward.

In 2020 this group conducted a study with continuous registration of activity with the help of the activity wristwatch Fitbit. The participants did not receive any treatment, but the goal was to find out whether this was a good method for assessing patients participating in future studies. They have mapped out the natural cause of symptoms and activity through a 6 month period.

**Ingrid Gurvin Rekland** is working 50 percent as acting chief physician at the Department for cancer treatment, Haukeland University Hospital, with a 50 percent PhD scholarship from Helse Vest (the Health Trust West). She has been working in the ME research group and with laboratory work and analyses tied to the clinical studies. In 2018, she started her doctorate project "Myalgisk encefalopti (ME): Medikamentell behandling, sykdomsmekanismer og biologiske markører" ("Myalgic encephalomyelitis (ME): Medicinal treatment, disease mechanisms and biological markers"). Her main focus now is analyzing biobank samples, with the goal of understanding the mechanisms behind the disease and identify possible biomarkers.

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## LINN CHRISTIN SKJEVLING

**Physician in specialization at UNN Harstad**

In a collaborative project between the medical department and the psychiatry department at UNN Harstad, a study on people with the CFS/ME illness will be conducted. This study has been titled "The Comeback Study". Linn Christian Kjenvling is the initiator of this project that have received fundings from the Research Council in the spring of 2017. Dr. Skjevling is a scholarship holder for the study on irritable bowel syndrome at the medical department UNN Harstad. They have recently conducted a study treating irritable bowel syndrome with fecal transplants. Through this work, they got on

the trail of the theory of applying the same treatment principle on CSF/ME patients. - When looking at studies concerning other diseases, we now know that an unbalanced intestinal flora can be normalized through transplanting bacteria from a healthy donor to the intestines of the patient. Findings have shown increased markers in the immune system that can be a sign of bacteria leaking from the intestines. - It will be a blind placebo study, meaning that neither the donor nor the patient will know who will receive the specific kind of treatment. Dr. Skevling will present the up-to-date information from "The Comeback Study". They are still in the clinical phase, so he will not present any conclusive results, just the background for this study and the development in the study, so far.



## LINE MELBY

**Senior researcher at Sintef, the Health department**

The researchers from Sintef and Fafo have started up a new social studies research project titled «Tjenesten og Meg» («The services and ME»). In the research project «Tjenesten og Meg» the researchers are studying the needs of ME patients and the study is to develop new knowledge with the goal of creating good, public services that corresponds with the needs of ME patients and their next-of-kin. The researchers are going to study the demographic and socioeconomic

background of the ME patients and their families, their encounters with public services such as education, the health services, the social services, including the occurrence of ME in Norway. The project is divided up into 3 work packages, all with their own subgoals and methods. Work package 1 is a registration study, work package 2 consists of in-depth interviews and work package 3 is a survey

## ANNE KIELLAND

**Researcher at Fafo: «The Services and ME»**

Kielland presents some selected findings from the survey in this project. The subject matter will be the experience that patients have had with services within rehabilitation, work try-out programs and the Norwegian Children Protection Services; how the employees in the services have assessed and tried to understand the patients and hope and optimism in an everyday life riddled with challenges. She will touch on prevalence across diagnosis boundaries, based on her project in collaboration with Leonard Jason and DePaul University.



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### MADY HORNIG

**Professor og forskar ved Columbia University Mailman School of Public Health**

Mady Hornig, MA, MD is a doctor, researcher and scientist at Columbia University Mailman School of Public Health where she is also an associate professor of epidemiology. She is a physician-scientist known for her animal model and clinical research into the role of microbial, immune and toxic factors in the development of different brain conditions, including autism, ADHD, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection (PANDAS), mood disorders, schizophrenia, myalgic encephalomyelitis and age-related cognitive changes. Dr. Hornig has written a number of publications on ME/CFS.

In 2015, she said: «We now have firm evidence to support the idea that ME is not about psychology. Our results indicate that when it comes to ME, there's a distinct immune signature in the cerebrospinal fluid. This correlates with an immune activation of the central nervous system». Her research team's findings concluded that ME/CFS patients had, in the part of the peripheral blood known as plasma, a severely high level of the inflammatory markers known as cytokines, but only in the early stages of the disease. In the later stages, patients mostly had lower levels of these inflammatory markers than healthy control subjects. Dr. Hornig is participating in the [The Center for Solutions for ME/CFS](#), the new research centers financed by the National Institutes of Health (NIH). Research in these centers is focusing on the microbiome and its interaction with the intestinal system, and how this can influence the immune system and thereafter affect the brain. Mady Hornig and her team are also doing research into how COVID might be leading to ME/CFS in some individuals, with several ongoing studies on the subject and more being planned.



### BJÖRN BRAGÉE

**Specialist in anesthesiology / intensive care and pain relief, Bragée clinics – Stockholm:**

Some back ground information about Björn Bragée: He's been working in the field of pain for about 30 years. He is now a semi-retired physician at Bragée clinics, a large rehabilitation clinic focusing on pain, fatigue syndrome and ME/CFS, located in the region of larger Stockholm. He's involved in research on pain and ME/CFS. As a pain physician, Björn Bragée, he has always fought for the right for pasients in pain and their right to a diagnosis and receiving a good treatment. - When I started out as a physician nobody cared about those that have prolonged pain, he says. They were regarded as winy, and people where at a loss about what to do with them. The situation is better now, but not good enough. People within the health care professions still have a lot to learn about this subject.

Today, Björn Bragée is also fighting for pasients with ME/CFS. This is a group that currently often is being questioned, and many pasients find themselves being offered going to therapy, even though they themselves feels this doesn't help them. - Time and time again, the pasients are proven right, Bragée says. They were right about amalgam disease. They were right about fibromyalgia. Now, everything is indicating that the pasients are right about ME/CFS. In 2014 Björn Bragée and his wife Britt Bragée created the «Bragée clinics». Earlier, they were both running the pain clinic Kronan in Stockholm. They were both approaching the age of retirement, but decided to invest everything in a new clinic.

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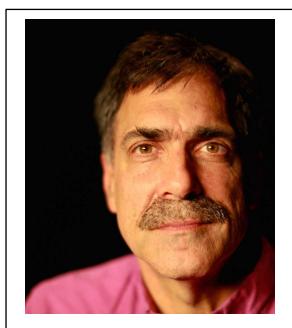


## JONAS BERGQUIST

**Professor of Analytical chemistry and Neuro chemistry at the Institute of chemistry at Uppsala University in Sweden**

Open Medicine Foundation (OMF) are financially backing the creation of a third ME/CFS related research center, at Uppsala university in Sweden. This new research center in Uppsala is lead by Jonas Bergquist (MD, Phd), member of the scientific board at OMF. He is going to collaborate with Massachusetts General Hospital and Harvard Affiliated Hospitals, led by Ronald G. Tomkins (MD, ScD) and Wenzhong Xiao (PhD) from Harvary university. Including Montreal, OMF now have four CRC centers for ME/CFS research (five if one counts the soon to be finished center in Melbourne).

This newly added research center will focus and targeted molecular diagnosing of ME/CFS. The goal is to produce falsifiable strategies for treatment. There has been a considerable effort in Uppsala to produce an analysis of cerebrospinal fluid as a unique source of neurochemical biomarkers of ME/CFS. Doctor Bergquist is studying a lot of conditions, including neurodegenerative diseases. His research on ME/CFS is focused on characterizing the neuro immunologic aspects concerning the disease, using proteomics and metabolomics, particularly focusing on studies of cerebrospinal fluid and autoantibodies. Several studies are currently being conducted that might shine a light on the mechanism that results in long-term virus induced cognitive complications, often referred to as "brain fog". Jonas Bergquist and his resarch team at Upssala are also using the Covid-19 pandemic as an opportunity to understand late injuries from Covid and the link between Covid-19 and ME/CFS.



## DAVID TULLER

**Journalist and academic coordinator of Health policy and Journalism at the University of California, Berkeley.**

David Tuller, DrPH, was a reporter and an editor for ten years at The San Francisco Chronicle, and functioning health editor at Salon.com. He's regularly been writing about public health and medical issues for The New York times, the policy journal Health Affairs and several other publications. Since 2015, he has been studying scientific, methodical and ethical problems on the research on the disease, or the cluster of diseases, known by different names such as Myalgic encefalomyelitis, Chronic fatigue syndrome, ME/CFS or CFS/ME. His ongoing series on this problem, Trial By Error, is published on Virology Blog, a science page hosted by Vincent Racaniello, who's a Microbiology professor at Columbia University.

Jørgen Jelstad wrote the following at [detbortjemte.com](http://detbortjemte.com): «In his extensive article, which includes over 16.000 words, Tuller deals with a controversial study from the ME/CFS field, know as the PACE study. The PACE study is the largest treatment study in the ME/CFS field. It deals with two controversial forms of treatment; Cognitive behavioral therapy and Graded exercise therapy. These two models of treatment have been mentioned a lot in the debate regarding ME/CFS. David Tuller's article is shining a critical light on the methods that are the subject of the PACE study. Critique and debate are both essential for science to progress. The PACE study has carried, and still carry, a lot of weight in the field of ME. The more defining power a study has, the more transparency is needed, for that is the very foundation of a critical and enlightening discussion. Tuller's article is a valuable contribution to transparency and debate».