ME-KONFERANSE STRYN
A BIOMEDICAL ME-CONFERENCE

INVITATION

We are inviting to a digital ME conference from April 13th to April 14th, 2021. All the latest information can be found at www.mekonferansestryn.no. As earlier, the ME Conference Stryn will be a biomedical conference, by the initiative of the undersigned. This will be the third conference of this kind, and it's been two years since the last ME conference took place in Stryn in 2019. In both 2016 and 2019, the ME Conference Stryn was a private initiative by the Skrede family, but it was registered as a non-profit organization in the official Norwegian registry of organzations in spring 2020.

This years the conference will be a two day long professional conference, that will provide insight into up to date research and research experiences within biomedicinal research on ME, nationally and internationally. In addition to this, there will be an evening lecture, where it's intended to present the subject matter in a more easily understable way. Check the program and enclosed information for more information about the evening lecture. We are hoping that as many people as possible will attend this conference. We are hoping that you will inform your colleagues, members of your organization excetera to display this poster. We will highly appreciate if the county phsyicians will inform their counties, if the health trusts add this information to their calendars and if the municipalities add this information to their home page and inform their employees about this conference.

N.B.! Binding registration on March 15th, 2021, at the latest. It's important that everyone that wants to participate in this conference register the necessary information at deltager.no, that we will be using this year. The link can be found on www.mekonferansestryn.no . The registration fee has to be paid at registration, using Vipps or card. Unfortunately, payment through invoice will not be possible this year, due to the fact that we have experience with having problems with getting payment that way. We need at least 100 participants on the subject days for the conference to happen.

Deltager.no is integrated with the Webinar solution ClickMeeting, that we will be utilizing. We will choose a solution where one kan register for the conference, and if one does not have the opportunity to see all the lectures streamed Live, those that have paid kan log on again at deltager.no and watch the lectures at the time of their convenience. Participants will automatically get forwarded from the registration platform to the platform where the Webinar/Digital conference will take place. A link will then appear, that will lead to the conference. It is not necessary to download any software or App to participate. We are hoping that this solution will make it possible for as many people as possible to participate.

We are hoping to make a video of the evening lecture, that will include short interviews with the researchers. We are thinking of putting this video out for sale on our homepage.

All the information is on our home page, including printable PDF files. Anders Hamre Sveen has helped us out with the English translation.

We are trying to keep our Web page as up-to-date as possible.

Agnete Skrede Ester Anny Skrede Arne Skrede

2021: PROGRAM

Tuesday, April 13th. 1st day of conference

Time

11.45: **Welcome**

12:00: ***Journalist and academic at the School of Public Health at the University of California, Berkeley*: David Tuller:** «A critical look at the methods in the PACE study, Norwegian cognitive behavioral therapy combined with music therapy for chronic fatigue after Epstein-Barr virus infection among youth and the portrayal of ME/CFS in Norwegian media. **Video – Language: English**

12:30: ***ME researcher, immunologist and professor of Epidemiology at Columbia University, New York*: Mady Hornig**: «Robust evidence for ME/CFS as a biological disease - distinct immune signatures in the cerebrospinal fluid in ME suggesting immune dysregulation in the central nervous system as a function of sub-group and disease course». **Video – Language: English**

13:10: **Break**

13:30: ***Specialist in Anesthesiology / Intensive care and pain relief, Bragée clinics, Stockholm: Björn Bragée***: «Research and a published study that indicates there's a coexistence of hypermobility and constriction of the neck column. Examination of the brain and the cervical spine by magnetic resonance imaging (MR). Constriction of the cervical spine. Changes in the optic nerve that can indicate an increased pressure in the fluid surrounding the brain». **Language: Swedish**

14:10: **Break**

14:20: ***Professor of Analytical chemistry and Neurochemistry at the Institute of chemistry - Biomedical Center at Uppsala University in Sweden*: Jonas Bergquist** «Molecular diagnosis and treatment of ME/CFS – analysis of cerebrospinal fluid as a unique source for Neurochemical biomarkers for ME/CFS». Research on COVID-19 might produce important information on the research on ME. **Language: Swedish**

15:00 **Break**

15:10: ***Professor at the Institute for Biomedicine. the University of Bergen*: Karl Johan Tronstad:** «Does ME/CFS stem from energy failure in the body's cells?» - research on Energy metabolism. **Language: Norwegian**

15:50: **Break**

16:00: ***Doctor at the Department for cancer treatment and medicinal physics at Haukeland University Hospital, Phd- at the University of Bergen*: Ingrid Gurvin Rekeland**
***Doctor at the Department for cancer treatment and medicinal physics at Haukeland University Hospital, Professor at the University of Bergen*: Øystein Fluge:** «Medicinal treatment and bio-markers in regards to ME/CFS» **Language: Norwegian**

17:00: **Break**

17:10: ***Professor of Child neurology, at the Children's clinic at Haukeland University Hospital: Kristian Sommerfelt*:** «Pitfalls and useful strategies during diagnosis and follow-up treatment». ME research and prognosis among children and the young. **Language: Norwegian**

17:50: **Break until 6:00 pm**

Evening lecture.

18:00: ***Professor Emeritus in Pediatrics, researched at the University of Oslo*: Ola Didrik Saugstad**
«A new light on ME» - summary of the latest biomedicinal research findings. **Language: Norwegian**

19:00: **Break**

19:15: ***Research journalist and author*: Jørgen Jelstad: «**ME – The development in regards to research, the general view on ME and funding for bio-medicinal research through decades». **Language: Norwegian**

20:15: **Closing statements for the first day.**

Wednesday April 14th: 2nd day of conference

09:00 **Opening, *Welcome. Day 2.***

09:10 ***Professor in Pediatrics at Oslo University Hospital:* Ola Didrik Saugstad**
«The ImmunoME study at Oslo University Hospital» about immunology and genetics in regards to ME - published research findings and the findings of possible subgroups. **Language: Norwegian**

09:50: Break

10:00: ***Doctor in specialized education and scholarship holder at the University Hospital in Northern Norway (UNN) Harstad:* Linn Christin Skevling**
«The research project Fecal microbiota transplantation - a blind placebo study, which is an update from The Comeback Study”. Is there a possibility that ME can be caused by a disturbance in the natural intestinal flora, that has been shown to have a different composition, compared to the composition among healthy people? Findings of increased markers in the immune system that might be a sign of bacterial products leaking from the intestines. **Language: Norwegian**

10:40: Break

10:50: ***Senior researcher at Sintef, the Department of Health, Project Manager for «The Services and ME»: Line Melby***
Services and the service needs: An analysis of the mismatch between the existing services for ME-pasients, and what they acually need. **Language: Norwegian**

11.20: ***Researcher at Fafo: Anne Kielland***
The research project «Tjenesten og Meg; trendar i brukaropplevingar» «The Services and ME; trends in the experiences of pasients» **Language: Norwegian**

11.50: Closing statements

The conference will have to adapt to the COVID-19 situation and the national guidelines and rules in regards to this. Therefore, this conference will be a digital conference, streamed on the Web, without the possibility of physical attendance.

Price:
Webinar conference: Both conference days, including both day and evening lectures: 2000,- NOK
Webinar: Evening lecture: 400,- NOK

REGISTRATION – Registering for the conference is binding, and has to be done by March 15th in regards to the digital conference. Conference information can be obtained at www.mekonferansestryn.no . We will be using the registration system deltager.no, where you can pay by card or using Vipps. Regrettably, you will not be able to pay by invoice. The link to the registration form can be located under the heading 'Program' on our Website, and under its own «Registration» button. Registration will be available, starting in January, 2021.

Deltager.no is corresponding to the Webinar solution ClickMeeting, and we will be utilizing that. We will find a way for people to register even though they can't watch all the lectures when they are streamed. Those who pay the registration fee can re-enter at deltager.no and watch the lectures at the time of their own convenience.

VELCOME

We'd like to wish you all welcome to the ME Confernce Stryn, who, due to COVID-19, is a digital confernce. This is the 3rd biomedicinal conference of this kind. The point of the conference is to provide improved knowledge about ME to physicians, health care professionals and other professions that interact with ME pasients as a part of their job, so that they can provide the best possible help, support and care to these pasients. There are some changes compared to earlier conferences: the subject days will spand over two days and will give insight into the latest biomedicinal resarch on ME, nationally and internationally. In addition we are putting on an evening lecture, lasting for a couple of hours, and we are hoping that as many people as possible will attend this lecture. There will be a summary of the lates biomedicinal resarch findings and the current direction of the resarch on ME. There's more information about this in the program.

2020 was the year when the COVID-19 pandemic broke out across the world. In spite of this tragic pandemic, there are a couple of researchers internationally regard COVID-19 as a possibiliy to find out what leads to a human developing ME. ME/CFS, that usually appears when a virus-, bacteria- or fungus infection causing a lasting damage to the immune system, the nervous system and the metabolical system, are often diagnosed years after the original infection, which limits the ability of researchers to study how the disease has developed. In May 2020 the Open Medicine Foundation at Stanford in the USA were early in pointing out that the COVID-19 pandemic is a unique opportunity to study the biological factors that can determine or predict the development of ME/CFS.

They are proud of being able to initiate a study of pasients with COVID-19 to study the course of the disease and the comorbidities (chronical conditions steming from another disease), to find out if it develops to ME/chronic fatigue syndrome, to study the molecular transformation, if such a transformation occurs. This study will include frequent sampling of bodily fluids, continuously following up with health examinations using apparatus attached to the pasient's body and data on symptoms that will be registered at several different times within a two-year period. It is expected that some of the COVID-19 pasients will get ME/CFS, because we know that several other viruses function as a trigger for this disease.

In the research group led by Jonas Berquist from Uppsala, who will be part of the ME Conference Stryn 2021, they have had a longtime interest to study pasients that might have neuroinflammatory diseases, especially Myalgic encephalomyelitis (ME). In this pasient group the recovery system is drained of energy at the same time as the nervous system and the immune system is compromised. – What we want to study is whether pasients that have gotten a severe COVID-19 infection, have a similar post-viral exhaustion, and if so, to what extent this occurs. We do know about such a connection from other great pandemics, inkluding the Spanish flu, the Asian flu and SARS.

The research group is already looking for neuroinflammatory markers and nerve celle markers with ME pasients, so they are also trying to find these markers in the spinal fluid of COVID-19 pasients. This might show a connection and provide data on what kind of pasients risk suffering longterm , or even chronical, health problems If this is the case, what is the composition of these biomarkers and what other organs are simultaneously affected? Now they intend to follow up and study the state of pasients that are under intensive care that have neurological symptoms.

In late summer 2020, the American researcher Mady Hornig told the Columbia Magazine that we will probably see a new wave of people contracting ME after having the corona virus. «Even though it is premature to conclude whether pasients with COVID-19 can develop ME/CFS or not, earlier studies indicate that 10 percent or more of people that have been severly ill because of a virus infection will be diagnosed with this condition later on. It these numbers apply to COVID-19, Hornig says, then millions of people all over the world can be at risk». With this crisis an opportunity arises: Hornig and other experts on ME/CFS regard this pandemics as their best opportunity so far to examine the physiological root causes to this disase and develop treatments. Hornig is now performing several studies aiming at identifying the risk factors related to ME/CFS among COVID-19 pasients and to lay the foundation for new strategies for prevention and treatment.

Jørgen Jelstad have been following the ME research closely the last decade. In the fall of 2020 he wrote the following: «- An increasing number of media articles are describing how a significant percentafe of people with COVID-19 are struggling with severe symptoms several months after becoming ill. Symptoms that in many cases are resembling ME. Even the editor in the foremost scientific publication, Nature, writes the following about “long COVID” in his editorial: t is of the essence to listen to what those with this condition are saying, in a way that, tragically, people with ME were not listened to».

There's no doubt that ME is a disabling disease. It is a disease with major consequences; for the one contracting it, the pasient's nex-of-kin and society as a whole. SF-36 is a certified form mappinf out the quality of life, that several of the lecturers have touched upon earlier. SF-36 has been a focal tool in the research on ME/CFS. SF-36 is a form meant to map out the health related qualiry of life, and it's a standardised and certified measuring tool that is often used in health research. The pasients themselves fill out the form where they rate their own experience of their own health thorugh several questions that are divided into eight sub-categories. These eight categories are physical ability, physical role, bodily pain, generalth health, vitality, social function ability, emotional role and mental health. Compared to other pasient groups, such as those with cancer, arthritis and depression, ME pasients score lower on the health index (according to a study from 2011).

ME pasients are diagnosed based on diagnose criteria. Strict diagnose criteria have been established (the Canada criteria and ICC), and they have been determined by the leading physicians and researchers in the international ME field. Following these criteria, it's estimated that between 0,2 and 0,4 percent of the population is afflicted with this disease. That is 2 to 4 people per 1000. In Norway this means about 10 000 to 15 000 pasients. On numerous occasions, Jørgen Jelstad has shown graphs with the numbers showing how small an amount of funding that have been allocated to resarch on ME, compared to other severe diseases, such as MS, Lupus and arthritis, based on numbers from the National Institute of Health (NIH) in the USA. The situation in Norway has not been any better. In 2015, two important reports came out of the USA. One of them came from the Institute of Medicine (IOM), the other once came from the National Institute of Health (NIH). Both these American reports concluded that ME pasients have been let down for years by both the health care services and the authorities.

The major breakthrough came with the report from IOM, that was published in February, 2015. This report is the result of 15 researchers going through 9000 articles/research reports. Their conclusion is that ME/CFS is a servere, phsyiological, chronic, complex multi disease that is severly disabling. The misunderstanding that the disease is psychogenic or somatic has to be done away with. ME/CFS is a physiological disease that attacks several of the core systems within the body. The research shows that ME pasients have deviations in their immune system, circulatory system and central nervous system.

Because of this, there's been a shift in the perception of ME in the USA the last 5 years. They have moved away from the earlier of advice of cognitive behavioral therapy and graded exercise therapy as a form of treatment. In the fall of 2020 British health service autoritires moved in the same direction, issuing a draft for new guidelines after a thorough review of all available documentation of the right treatment of pasients with ME/CFS. Based on this, ME pasients will no longer be adviced to take part in graded exercise therapy, neither therapy developed from osteopathy, life mastery nor neuro linguistic programing (for example the Lightning Process).

In February of 2015, a press release from Columbia University in New York, where researchers claim to have found solid evidence that points to ME/CFS being a biological disease. Researcher and professor Mady Hornig said «We now have evidence that confirms what millions of people suffering from this disease already knows, ME is not about psychology». Our results implies that pasients with ME have a significant disturbance in the immune signature in the cerebrospinal fluid. This concurs with a immune activation of the central nervous system. We have been so lucky as to have the resarcher Mady Hornig sent us a recorded lecture as part of the biomedicinal ME Conference Stryn 2021.

Several aspects of ME indicates that the immune system gets activated in the brain, which leads to a releasing of inflammation substance. This neuro inflammation vil lead to several symptoms, including fatigue, pain, cognitive impairment and sleep disorder. One hypothesis is that immune cells that are activated and located in other pars of the body infiltrates the brain, which leads to symptoms of ME. Japan is particularly known for research on neuro inflammation in the field of ME. New technology makes it easier to study neuroinflammation.

Luckily, the USA are now putting more of an effort into the research on ME. Recently, three research centers foucing on ME was funded, receiving about 300 million NOK for a period of five year, in addition to the ordinary research allocations (which have increased as well). An increasing number of elite researchers have worked in the ME field, which would not be the case just a couple of years ago. Findings from this research investing will provide more insight into the disease, what's causing it and, hopefully, better methods for treating it.

Norway could become a leading country within ME resarch in the world, but unfortunately, Norwegian health authorities have not entered the scene with funding for biomedicinal research on ME. Now fair is fair, the Norwegian Research Council granted 30 million NOK to four projects through BEHOV-ME (NEEDS-ME) in 2016/2017. Representatives from these projects wil participate in the third ME Conference Stryn and talk about their project. Three out of the four projected that got grants from the Research Council through BEHOV-ME are medicinal research projects. The last one is a social studies project, and a collaboration between Sintef and FAFO, titled «Tjenesten og Meg» («the Services and ME»). The researchers are studying the needs of ME pasients and their families, including the use of and experience with health- and welfare services. The main goal of the study is to find new knowledge in order to create good public services that corresponds to the actual needs of ME pasients and their next-of-kin.

There is ground-breaking biomedicinal research going on at Haukeland University Hpostal and the University in Bergen. The research group, led by the oncologists Olav Mella and Øysten Fluge, who have worked with ME for over a decade now, is no small group. This group has been expanding through the years. The researchers are saying that it is interesting how the ME field has been developing, particularly in regards to the major universities in the USA. Thanks to the Kavli Foundation, this group has, since 2011, been a decisive co-contributor to producing interesting research findings, as well as writing several professional articles that have been published in the last couple of years. Through the clinical studies RituxME and CycloME, a robust biobank has been built up, with blood samples and other sample material from the participants in these studies.

The goal of this research is to map out the disease mechanisms connected to ME, and to identify bio markers for the disease. In collaboration with the University of Bergen they are trying to find out whether energy metabolism can explain parts of the over-all picture clinically regarding ME, and whter ME is caused by an energy failure in the cells in the body or not. They have published an article that shows findings indicating that an important energy enzyme, Pyruvate Dehydrogenase (PDH), are being hampered in ME pasients, which may explain the lack of energy and increased lactic acid production among ME pasients.

In the spring of 2019, Katarina Lien published a research article, where she laid out findings from research into what happens to ME pasients during pysical activity, relating to Protein-energy malnutrition (PEM), recovery time, the lactate level in the musculature, using ergospirometry (CPET). When using ergospirometry, both the oxygen consumption and the lung function. This examination makes for a realistic assessment of the function level of the pasient, which lays the foundation for evaluating which physical achievements he or she will be able to accomplish.

Healthy people and people with ME were both tested on a exercise bike, two days in a row. On the second day, they repeated the test from the first day, and found out that ME pasients are not able to perform as well as on the second day as on the preceding day. In this study, the researchers intentionally caused Protein-energy malnutrition (PEM), to see how the ME pasients react to two consecutive days of physical activity. In the test subject with ME, the test creates a passing setback of the function level, a phenomenon that is not found in other disease groups. In the autumn of 2020, Katarina Lien and others published a new science article, containng the key words heart funcion and echocardiography.

At Oslo University Hospital they are working with the ImmunoME study. The purpose of ImmunoME is to understand the ME disease better from a genetic and biological perspective. They particularly want to examine whether the immune system plays a role in the development of ME, and will go through with a thourough mapping of genes that are essensial to the immune system to look for differences between ME pasients and people in the control group. They also want to examine the occurrence of antibodies in ME pasients. – One of our ongoing studies is about a meticulous mapping of genetical associations in the HLA complex on chromosome 6, that contain hundreds of immunologic important genes in addition to the HLA genes. An HLA association is one of several characteristic traits to an auto immune disease, and any findings that might turn up in this study is motivation for further immuno genetic studies on CFS/ME. The research group published a science article in the spring of 2020.

In a collaboration between the medicinal and physical medicine department at UNN Harstad a new major study focused on ME pasients will be conducted. The project received grands from the Research council the spring 2017. At the medical department UNN Harstad dei recently conducted a study on treating irritable bowel syndrom with fecal transplant. Through this work, they got on the trail of finding out that the same treatment principle coud also work regarding ME. When looking at studies concerning other diseases, we now know that an unbalanced intestinal flora can be normalized through transplantling bacteria from a healthy donor to the intestines of the pasient. Finding have shown increased markers in the immune system that can be a sign of bacteria leaking from the intestines.

The research group at Haukeland University Hospital were also collaborating internally with the Children's clinic. Kristian Sommerfelt's experience with ME is with pasients that are children and young, up until the age of 18, that were diagnosed before they turned 15. He has over 20 years of experience with ME, and have some sound advice to give to pasients, their next-of-kin and health care professionals.

Due to the fact that school attendance is obligatory, it is easy to get an overview over all below the age of 15, in what was called Hordaland county earlier, since the physician referred to the Children's clinic. According to Sommerfelt, brain fog might be the most worrying and delimited symptom of ME. – This manifests in the pasient not being able to use the head to think or communicate in a normal way. During a consultation, the pasient might be ablo to answer questions well, but then the quesitoner has to pay close attention. The pasient might start moving the hands a little, to sit in an uneasy way and start giving answers that aren't clear. Sommerfelt then usually ask about whether or not it is difficult to concentrate to think, and then he often gets the confirmation that the brain fog has begun. Sommerfelt encourages health care personell to remember that the pasients might have from 20 to 40 minutes where they are able to follow a conversation in a regular way.

A research team at Karolinska Institutet and the Bragée clinics in greater Stockholm published a study in a prestigeous neurologic journal in the fall of 2020, that's showcasing formerly unknown underlying causes. The physicians at the specialist clinic were taken aback from seeing so many cases of simultaneous hypermobility and constriction of the neck column as an indication of neck damages. They initiated a study with all the willing participants out of the first 229 admitted pasients diagnosed with ME. This study showed that half of the pasients had general joint mobility, which is way above average. In a magnetic-field camera probe (MRI) of the brain and the upper part of the spine the resarchers found a higher occurrence of constricton of the upper part of the spine than they had expected. In addition to this, they found changes in the optic nerve that might indicate an increased pressure in the fluid surrounding the brain in many of the pasients. The researcher Björn Bragée will be a part of the ME Conference Stryn 2021, and talk about these findings.

The ME Conference Stryn wants to contribute to public institutions in Norway getting better knowledge about and increased to, the ME disease. It's about time that ME pasients and their next-of-kin getting the help they need. To be able to do this, you need the right knowledge and to understand the ins and outs of the disease. We are hoping that health care professionals will prioritize to hear what these important lecturers, that we have been as fortunate as to get to participate with their lectures, have to tell us. It is important that both politicans and the health care autorities are up to date on the latest in biomedicinal research. As is the case with every other illness, there is a need to coordinate the effort from the scientific community to understand the biological causes behind the ME disease. It is also important to increase the funding for biomedicinal research on ME.

BINDING REGISTRATION BEFORE THIS DEADLINE: MARCH 15TH, 2021

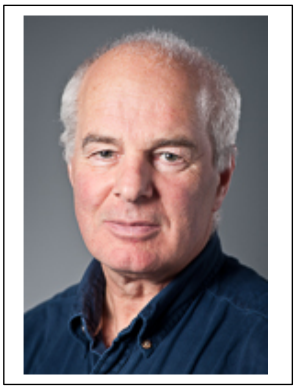
ABOUT THE LECTURERS

JØRGEN JELSTAD

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

Jelstad has an education as a physioteraphist, 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 bokk 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 pasients, next-of-kin, researchers, physicians and nurses, physiotherapists, lawyers, activists, politicans and academics. After the book came out in 2011, Jelstad has written updates from the research field on his blogg 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 lates 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 pasients, 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, thorugh the ImmunoME study. Blood samples from pasients 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 severly ill ME pasients. Saugstad has described this experience as shocking. The ME pasients er 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 pasients with encephalitis (inflammation of the brain). – The biggest betrayal done by the Norwegian health care services is the lack of curiousity in finding out the ins and outs regarding this disease, especially considering the severeness of the disease for a lot of the pasients in this group. A lot of Norwegian ME pasients have been treated poorly, says Saugstad.

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 pasients 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 pasients, 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 kan fit into a certain theory. It does not seem that certain personaliy types are re-occuring as victims of ME. Kristina Sommerfelt has developed a method that he calls The Sorcerer's Hat. This is an efficient method for healt care personel to map out the main problem for their pasients. Sommerfelt is saying he pretends to be a sorcerer with a hat. He kan then place one symptom after the other in the hat, to metaporically make them magically disappear. The method is about starting with the mot severe symptom first, and then the second-most severe sympton and so on....

Sommerfelt has been working with a lot of different extreme diseases and severe disabilites. He's pointing to an odd peculiarity when comparing ME to other pasient 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. Pasients 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 pasients when their sickness is that severe. It is of the essence that health care personell turns a new leaf and starts visiting this pasients in their homes. It is also important to take care of the next-of-kin of these pasients. Sommerfelt thinks that the ME pasients might overreport how much they are able to do. It is important to have clear, objective measuring parameters, or at least ask the pasient's next-of-kin about the function level of the pasient.

KARL JOHAN TRONSTAD

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

In collaboration with Øysten 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 pasients with ME/CFS. His research group are focusing on how metabolic deviations can contribute to diseases, by, among other thins, studying the functions of the mitocondria (the power plant within the cells). By looking for metabolical changes in pasient 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 pasients, to then look for a connexion that can explain symptoms, the severity degree and the of the duration of the disease.

They have found changes to the components in amino acids, and the results indicates 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 particula functions, like vitamins. In addition they are looking for genetical changes, and possible connections with deviances 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 kan build the foundation for the development of biomarkers and a new treatment.

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

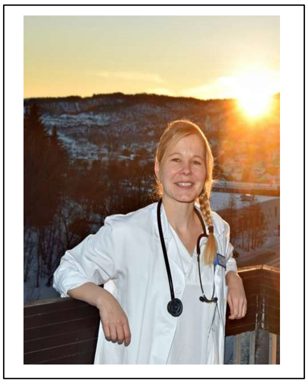
Chief physician at the Department for cancer treatment and medicinal physics, Haukeland University Hospital, and professor at the University of Bergen.

Since 2008, Øysten Fluge and Olav Mella has shown interest for ME pasient 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 cauing 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 contucted a study with continuous registration of acitivity with the help of the activity wristwatch Fitbit. The participators did not receive any treatment, but the goal was to find out whether this was a good method for assessing pasients participating in future studies. They have mapped out the natural cause of symptoms and activity through a 6 month period.

Ingrid Gurvin Rekeland 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 har been working in the ME research group and with laboratory work and anlyses 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.



LINN CHRISTIN SKJEVLING

Physician in specialization at UNN Harstad

In a collaborational project between the medical department and the physiatry 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 Kjevling 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 contucted a study treating irrital bowel syndrom with fecal transplants. Through this work, they got on the trail of the theory of applying the same treatment principle on CSF/ME pasients. – 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 pasient. 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 pasient 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 pasients and the study is to develop new knowledge with the goal of create good, public services that corresponds with the needs of ME pasients and their next-of-kin. The researchers are going to study the demographic and socioeconomic background of the ME pasients 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

Resarcher 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 pasients have had with services within rehabilitation, work try-out programs and the Norwegian Children Protection Services; how the employees in the services have assesed and tried to understand the pasients and hope and optimism in an everyday life riddled with challenges. She will touch on prevalence across diagnose boundaries, based on her project in collaboration with Leonard Jason and DePaul University.

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.

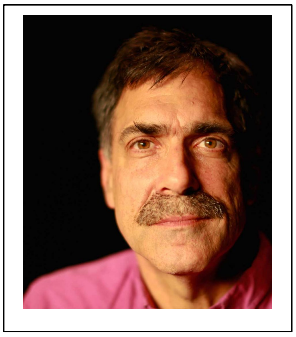
Today, Björn Bragée is also fighting for pasients with ME/CFS. This is a group that currently often is being questioned, and many pasients find themselves being offered going to therapy, even though they themselves feels this doesn't help them. – Time and time again, the pasients are proven right, Bragée 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.

JONAS BERGQUIST

Professor of Analytrical chemistry and Neurochemistry at the Institue of chemistry - Biomedical Center at Uppsala University in Sweden

Open Medicine Foundation (OMF) are financially backing the creation of a third ME/CFS related resarch 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 detbortgjemte.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».