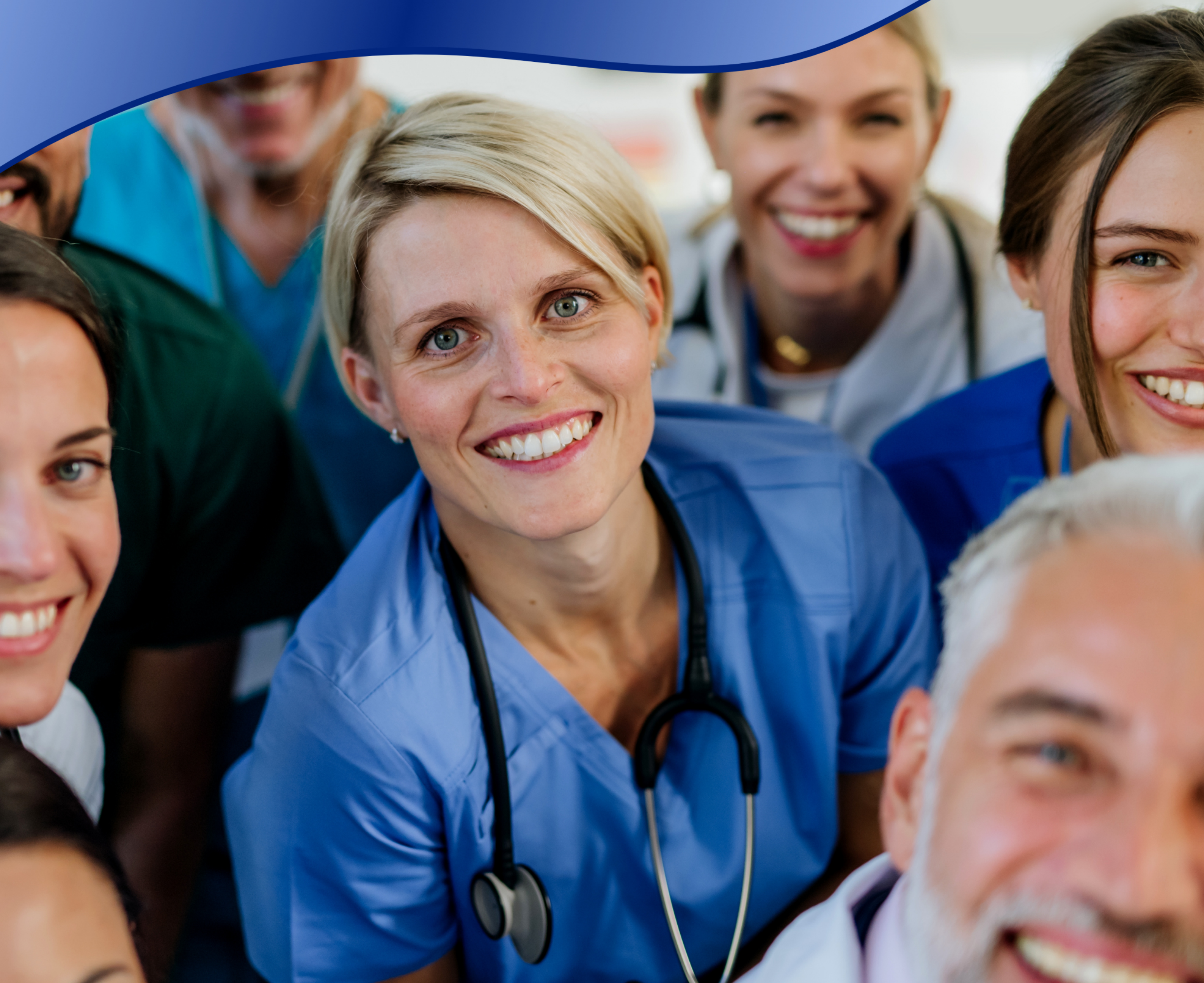
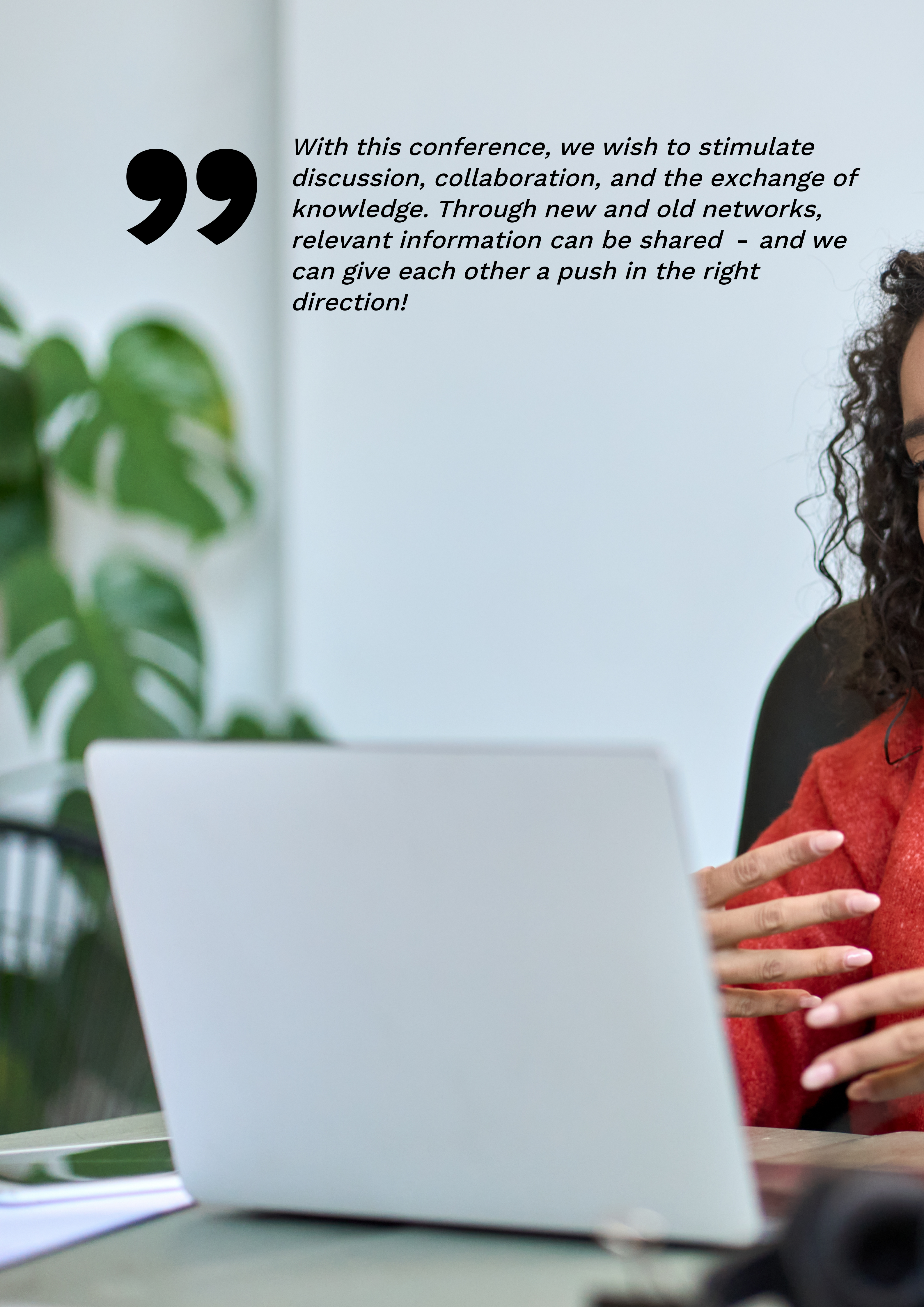
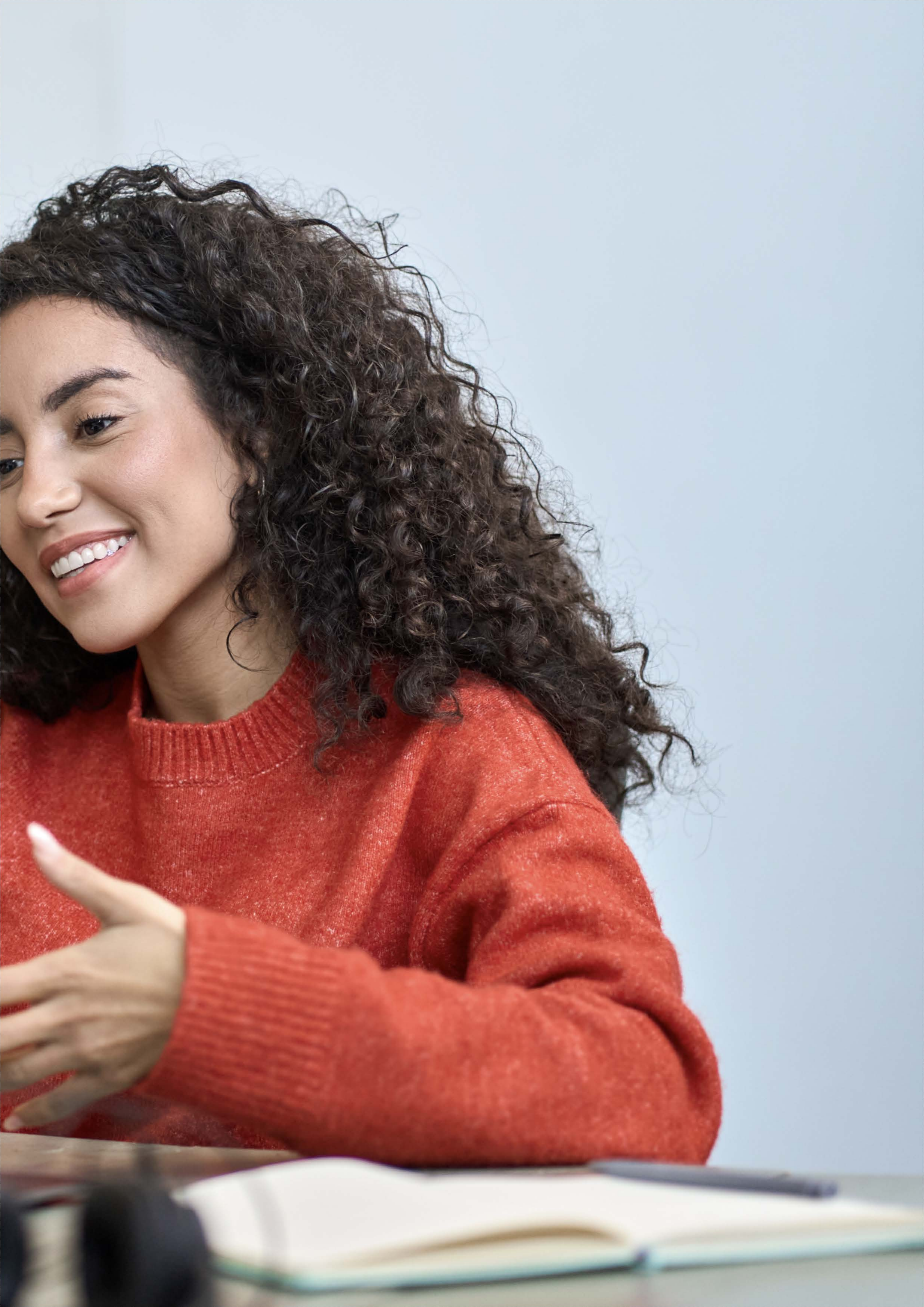
RIKSFÖRBUNDET
FÖR ME-PATIENTER

Conference Program 2023



> *With this conference, we wish to stimulate discussion, collaboration, and the exchange of knowledge. Through new and old networks, relevant information can be shared - and we can give each other a push in the right direction!*





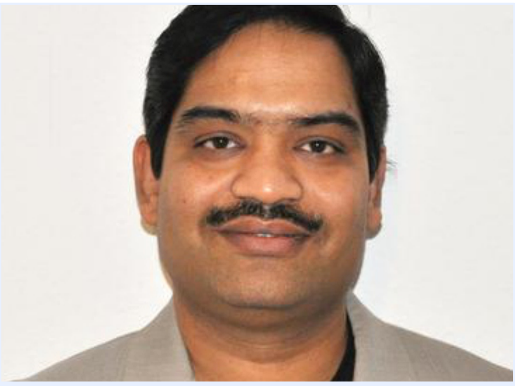
By joining forces, we increase both knowledge and awareness of ME/CFS.

For many years, the Nordic associations for ME patients have collaborated by mutually sharing information and experience, translating informational material, and sharing invitations to national events and conferences. This year we are expressing our unity in the form of a pan-nordic conference that highlights some of the issues we have in common.

We share the experience of not being respected and not receiving adequate care in healthcare systems where both knowledge and resources are lacking. We are used to having to inform healthcare providers and decision-makers about international research and clinical experience, since ME research in the Nordic countries is (with a few brilliant exceptions) often neglected.

We all carry out intensive advocacy work in our respective countries to improve the lives of people affected by this complex and severely debilitating disease. Now we join forces to make ME a known and recognized disease!

A short presentation of our speakers and their backgrounds:



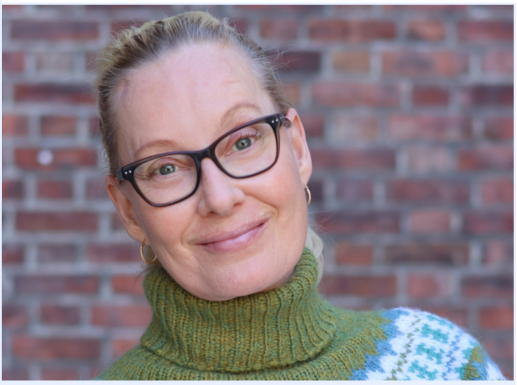
Bhupesh K. Prusty

Eirini Apostolou

Amy Proal

Diane O’Leary

Nigel Speight



Anne Kielland

Understanding infectious origin of ME/CFS

PhD, Dr Bhupesh K. Prusty

Dr. Bhupesh Prusty is a well-established researcher at the Julius-Maximilian University in Würzburg, Germany. Dr. Prusty describes himself as a "passionate virologist" and he has long been interested in herpes viruses. Already around 2014, Dr. Prusty realized that human herpesvirus 6 (HHV-6) could in some cases cause dysfunction in the mitochondria. This in turn raised the question whether the virus might also play a part in the development of diseases such as ME/CFS.

Since then, Dr. Prusty has continued to investigate closely related viruses such as HHV-7 and the Epstein-Barr virus (EBV) and sought to explain the mechanisms behind their reactivation. In a study, published in *Immuno Horizons* in the spring of 2020, Prusty and his co-authors found that HHV-6 not only appears to fragment mitochondria, but also reduces the availability of the substances needed for their proper functioning.

In recent years, Dr. Prusty has expanded his work by investigating the connection between ME/CFS and post-covid in relation to herpes viruses. Dr. Prusty also suggests that a new biomarker for ME/CFS may have been found as a result of this research.

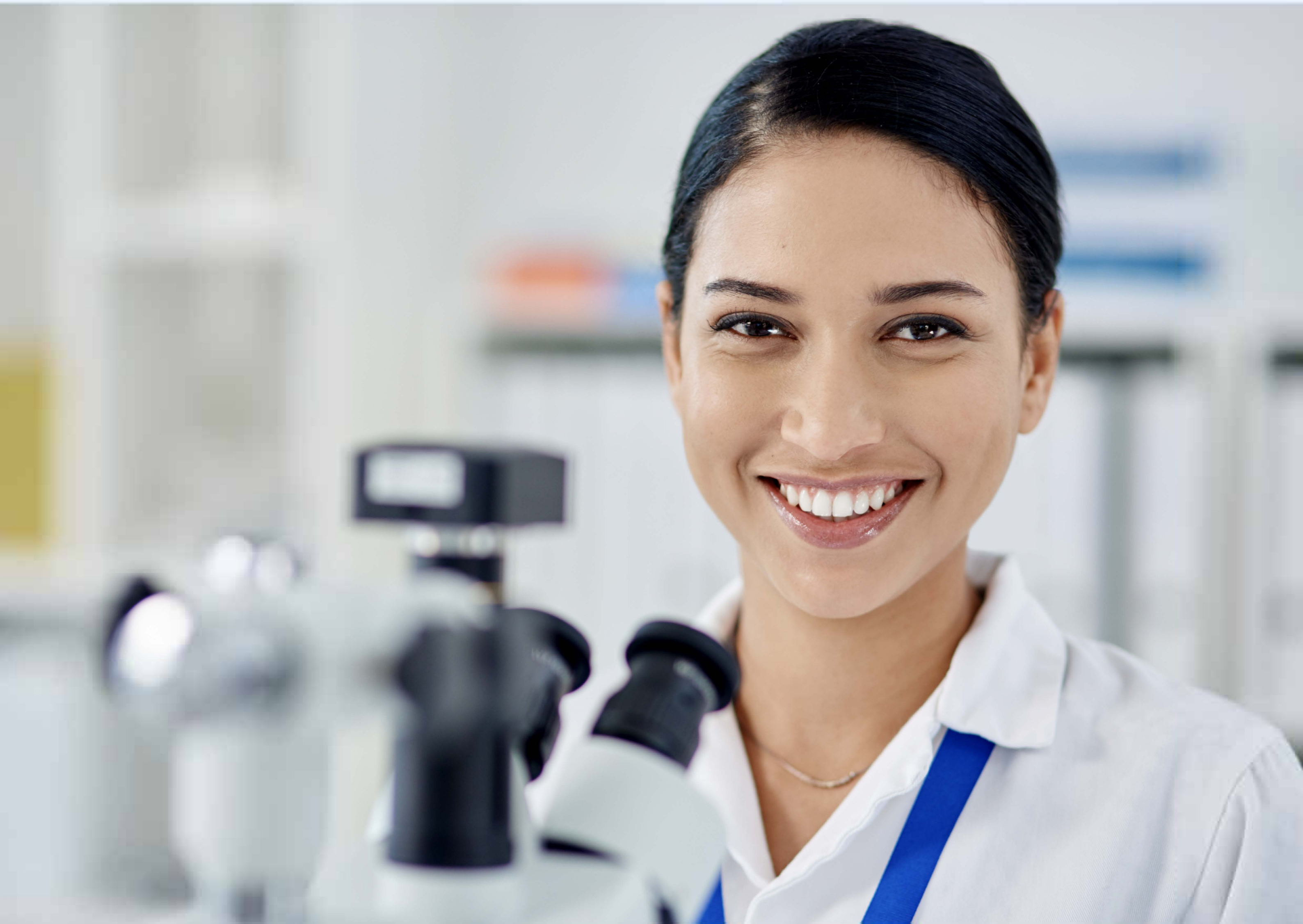
SARS-CoV-2 induces differential reactivation of latent viruses in ME/CFS

PhD, Dr Eirini Apostolou

If COVID-19 activates latent viruses in the body – does it affect ME patients in a different way than it affects healthy controls? In her lecture, Dr Eirini Apostolou tries to answer the question in light of the article that she and Professor Emeritus Anders Rosén et al. published in *Frontiers in Immunology* in the autumn of 2022.

Dr Apostolou is a biologist with a specific focus on immunology. She received her PhD in TGF-beta signaling in lung immune responses from the University of Athens, Greece. After completing her doctorate, she went on to do postdoctoral research at the Medical School of Athens, where she studied Interferon responses and ER-stress (Endoplasmic reticulum-stress) in autoimmune processes and specifically in the context of Sjögren’s syndrome.

Subsequently, in 2019 she joined the lab of Anders Rosén at Linköping University, initially as a post-doc and currently as a principal research engineer, where she is investigating immune responses in ME/CFS. She is assisted by a team with advanced equipment and world-class knowledge for analysis of antibodies and our immune system.



This year's conference theme has a multi-layered meaning

The key concept "The hidden disease" runs like a red thread through the conference.

ME is a hidden disease when seriously ill people don’t get an explanation for their symptoms – and no correct diagnosis.

ME becomes a hidden disease when it is not addressed in healthcare education.

ME is hidden when healthcare providers use "it-is-all-in-your-head" as an all-encompassing explanatory model – instead of seeking medical reasons for the patient’s lack of recovery.

ME becomes a hidden disease when the health insurance system requires *objective findings* to grant financial support to severely disabled patients, who are unable to work or study.

ME is denied and hidden when parents are accused of making their children ill.

Many ME patients have experienced stigma in connection with their diagnosis of ME/CFS, to the point where their disease becomes something they're afraid to even talk about.

Current research presented at the conference suggests that viruses hidden in body tissue can be reactivated by new infections and thus trigger the very specific course of disease that many of us know only too well.

Persistent infection and viral reactivation: a driver of common ME/CFS and Long Covid symptoms

Dr Amy Proal

Microbiologist Dr. Amy Proal leads the Boston based PolyBio Research Foundation, which she co-founded with Dr. Michael VanElzakker. PolyBio conducts research on complex chronic inflammatory diseases and focuses, among other things, on neuroinflammation.

Research into ME/CFS is one of the foundation's core activities and the researchers describe their focus as "innovating neuroscience and NOT psychology". Amy Proal also takes on the role of Chief Scientific Officer in the closely related *Long Covid Research Consortium* (LCRC).

Dr. Proal holds a bachelor's degree in biology from Georgetown University and a PhD in microbiology from Murdoch University in Australia. In her work with PolyBio and LCRC, dr Proal coordinates large-scale collaborative projects between research teams studying infection-related chronic diseases. She has also written several review articles describing the central biological drivers of the disease processes in both post-covid and ME/CFS.

An ethics-based approach to management of ME/CFS and Long Covid

Professor Diane O’Leary

Professor Diane O'Leary describes herself as an independent researcher. She studies medical issues of metaphysical, clinical, or ethical nature. Her research is informed by personal experience. Severe illness forced her to be academically inactive for almost fifteen years. Yet, she still managed to continue some of her studies. Her work during this period laid the foundation for what is now her area of specialization.

O'Leary returned to academic life in 2016 as a visiting scholar at the Kennedy Institute of Ethics in Washington. She then went on to attend the Canadian Rotman Institute of Philosophy and became a visiting fellow at Pittsburg's Center for Philosophy of Science. After her return, O'Leary had her first article published in 2018. Since then, she has continued to publish more articles – and delivered many presentations for philosophers, clinicians, patients, bioethicists and the general public.

In academic contexts, Diane no longer hides the fact that she is periodically handicapped by her illness. On the contrary, she has been committed to raising awareness of research conducted by disabled academics. Especially when it comes to women scientists, whose disabilities are often invisible.

Children with ME taken into custody

Dr Nigel Speight

Dr. Nigel Speight is a hospital pediatrician from the northeast of England who specializes in Pediatric ME/CFS. He has been vocal about the risks to children with ME being misdiagnosed as having a psychiatric condition, and has been involved in fighting many child protection cases in which children with ME/CFS were at risk of being removed from their parents.

In the past, Dr. Speight has served as an honorary pediatric medical adviser for several ME/CFS charities. He is also one of the authors of the 2011 *Myalgic encephalomyelitis: International Consensus Criteria* (ICC) and the 2017 clinical guidance: *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer.*

In the well-known English documentary "Voices from the Shadows", Speight and two other experts, Leonard A. Jason and Malcolm Hooper, talk about the great amount of prejudice that surrounds the disease. The film also describes the consequences for those affected, and their relatives, when necessary care is not provided. Dr. Speight participated in the RME conference in 2014 and we are grateful to have him share his knowledge with us once again.

Patient experiences with public services and interventions in Norway

PhD Anne Kielland

Anne Kielland holds a PhD in Sociology from the University of Oslo. In her home country of Norway she is known for her work in child research. For ten years she worked at the World Bank – mainly with reducing the vulnerability of children in Africa.

Kielland is affiliated with the Fafo research foundation. Recently she has been conducting research into ME patients' experiences of public healthcare in Norway, resulting in a research program called: *"Tjenesten og MEg".* (Roughly - *"The healthcare service and ME"*) It has been funded by the Norwegian Research Council.

One of the main purposes of the program is to find out more about the needs of ME patients and their relatives, and to investigate how ME sufferers experience society's health and welfare services.
Through her research, Kielland has become aware of the situation of ME sufferers, and she has expressed her views on the issue publicly. Dr. Kielland has also collaborated with renowned ME specialist Leonard A. Jason and his team at DePaul University.

BOOK NOW!

Registration

Book via RME's website *www.rme.nu/konferenser*. Registration is also mandatory for the digital conference. The conference fee will be refunded if cancellation is submitted no later than October 5, or if the conference for any reason cannot be held.

Last day to register is October 5, 2023.

Conference fees:

	Stockholm	Gothenburg	Online
Regular ticket	895:-	595:-	495:-
Students*	50:-	50:-	0:-
Members of RME or other Nordic ME / CFS organization	50:-	50:-	0:-

Coffee, tea and refreshments are included at the physical conferences.
*Students at college/university. Members of RME, or equivalent patient associations, may participate subject to availability.
Representatives of the press/media please contact RME.

Date and place

Stockholm	*11 October, 9.30–16.30* Landstingssalen, Landstingshuset, Hantverkargatan 45 (Taxi entrance Pilgatan)
Gothenburg	*12 October 12.30–17.00 (half day)* Matsmak, Drakegatan 1 (by Mölndalsån, just behind Ullevi)

You can participate on site in either city or choose to take part in the conference digitally via a streaming platform on October 11. The link to the event will be attached in a separate mailing just before the conference.

Questions

General questions are answered by Kerstin Heiling (*kerstin.heiling@rme.nu*. Practical questions regarding the physical conferences are answered by our regional associations in Stockholm (*stockholm@rme.nu* and Gothenburg (*vast@rme.nu*.

Target audience

Healthcare personnel, academy, business, politicians, media, and patient representatives are invited to participate in this research conference for the acquisition and exchange of knowledge and ideas.

Presentation language

English.

Organizers and contact information

RME organizes the conference together with our three fellow Nordic ME associations.

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ME FORENINGEN

NORGES MYALGISK ENCEFALOPATI FORENING

ME/CFS