IIMEC18 | International ME Conference 2026

20 Years of Investing in ME Research to Discover ME

In Pursuit of the Mechanisms and Treatment Strategies for Myalgic Encephalomyelitis

---

29 May 2026, Wellcome Genome Campus, Cambridge, UK

Conference Summary Report

The 18th Invest in ME Research International ME Conference of 2026 was part of the International ME Conference Week that is organised annually by the charity.

It is now the only 5 day conference week dedicated to ME in the world - something quite remarkable for a volunteer-run charity, and testament to the wonderful support that we receive from our friends and colleagues.

In recent years Invest in ME Research has been involving the European research networks formed by the charity - the European ME Research Group (EMERG) and the European ME Research early-career network, Young EMERG - in moderating the events.

EMERG has celebrated our twentieth anniversary by leading a consortium that has achieved a first in the history of EU research funding - forming the project **DISCOVER-ME**, funded under EU Horizon call HORIZON-HLTH-2025-01-DISEASE-07. This is the first European research call ever to name ME explicitly as a priority condition. For a disease long marginalised within mainstream medical research, this is not merely a funding announcement - it is a historic, landmark moment for people with ME, and the culmination of twenty years of sustained, volunteer-driven effort to build European biomedical research into this disease - https://www.investinme.org/horizon2026.shtml

This report gives a brief summary of the presentations given at IIMEC18 and presented in the order in which the talks were given. It is intended as a short companion to the full presentation videos, which show each talk in full and are available via the conference page at https://investinme.org/iimec18.shtml#pres

1. Simon Carding

Quadram Institute, UK

Opening and BRMEC15 Days 1 to 2 Summary

Simon Carding, Quadram Institute, opened the conference with a personal summary of the preceding two days of the BRMEC15 researchers' colloquium and the Young EMERG early career workshop. He described a shift towards single cell genomics, systems and network biology, and AI assisted analysis to handle the complexity and heterogeneity of ME/CFS, alongside growing interest in patient stratification and precision medicine. He drew on talks covering immune dysregulation, viral triggers and reservoirs (including EBV, enteroviruses and endogenous retroviruses), and mitochondrial physiology.

He cautioned against losing sight of whole body context in an increasingly reductionist, cell level research landscape, and highlighted the continuing lack of disease relevant animal models, insufficient computational infrastructure, and the unresolved question of what actually triggers the disease.

https://www.investinme.org/iimec-simoncarding.shtml

---

2. Hans Kluge

WHO Regional Office for Europe

Why This Work Matters

Dr Hans Kluge, WHO Regional Director for Europe, gave the opening address marking twenty years of Invest in ME Research. He described ME as a serious, complex, multi system illness that WHO classifies as neurological, and called for accurate diagnosis, belief, and access to care for those affected. He linked the conference to the WHO European Programme of Work, which calls on countries to strengthen diagnosis, care and rehabilitation for people with ME within primary health care and universal health coverage. He closed by urging collaboration between researchers, clinicians and patient organisations so that progress can accelerate.

https://www.investinme.org/iimec-hanskluge.shtml

---

3. Andrew Wilson

University of East Anglia, UK

A Platform for Clinical Trials in ME

Andrew Wilson, University of East Anglia, opened the day's session on therapeutics with an overview of clinical trial design. He explained the hierarchy of

evidence from case reports through randomised controlled trials to meta analyses, and introduced umbrella, basket and platform trial designs that allow multiple treatments or diseases to be studied efficiently within a shared infrastructure. He showed how enrichment strategies, using genetic or clinical markers, can identify patients most likely to respond to a given treatment, and discussed factorial and adaptive (SMART) designs for testing drug combinations. He argued that platform trials offer the most efficient route to testing the many candidate therapies now emerging for ME, given the limited time and funding available.

https://www.investinme.org/iimec-andrewwilson.shtml

4. Gitendra Uswatte

University of Alabama at Birmingham, USA

Brain Fog Treatment: Preliminary Findings from Cognitive Rehabilitation Trials in Adults with Post-Viral Syndromes

Gitendra Uswatte, University of Alabama at Birmingham, presented Constraint Induced Cognitive Therapy (CICT), a 30 hour outpatient intervention combining speed of processing training, in lab practice of everyday tasks, and behavioural techniques to transfer gains into daily life. He showed results from a pilot RCT in adults with long COVID brain fog, in which the CICT group had large improvements in processing speed, brain fog severity and everyday task performance compared to treatment as usual, with four of five participants returning to work. He described a larger trial now under way comparing CICT plus vagus nerve stimulation against brain fitness training, with interim results replicating the earlier benefit, and played recorded participant testimony describing regained confidence and independence. He closed by outlining a forthcoming pilot RCT of CICT delivered by telehealth in people with ME/CFS, incorporating blood and MRI measures of inflammation.

https://www.investinme.org/iimec-gitendra-uswatte.shtml

5. Rikke Katrine Jentoft Olsen

Aarhus University, Denmark / EMERG

Hypoxia-Induced Mitochondrial Stress-Signaling: A Randomised Controlled Trial for ME

Rikke Katrine Jentoft Olsen, Aarhus University/EMERG, presented the rationale and protocol for the Re-Energize ME trial, a placebo controlled study of intermittent hypoxia therapy in ME. She explained the working hypothesis that immune dysregulation and autonomic or vascular dysfunction create local

hypoxia and mitochondrial stress that drives post exertional malaise, and showed evidence from long COVID studies and her own pilot data that intermittent hypoxia therapy can improve quality of life and pain scores. She described the trial design, including 104 participants, individualised hypoxia sessions, biobanking, and mechanistic endpoints such as microvascular responsiveness and small fibre neuropathy. She thanked her collaborators and funders, including the Independent Research Fund Denmark and the new EMERG Horizon Europe grant, for enabling the study to begin recruiting this summer.

https://www.investinme.org/iimec-rikkeolsen.shtml

---

6. Caroline Dalton

Sheffield Hallam University, UK

Digital Tools for a Complex Disease: Harnessing Wearable Data in ME Research and Trials

Caroline Dalton, Sheffield Hallam University, gave practical guidance on using wearable devices in ME research, drawing on her group's work adapting sports science wearables for long COVID studies. She discussed trade offs between device types, warning that fitness focused algorithms in devices such as Oura rings can misread rest as inactivity, and stressed the importance of minimising patient burden and resolving data sharing and GDPR issues before a study begins. She showed her own data on attempts to capture post exertional malaise objectively via accelerometry, heart rate variability and sleep tracking, noting that a clear activity to symptom relationship was identifiable in only around 10% of participants, since wearables cannot capture cognitive or postural triggers of PEM. She concluded that wearables are promising for objective outcome measures, particularly for pacing and sleep, but that noisy data and confounding factors mean they should be used thoughtfully rather than as an automatic substitute for patient reported outcomes.

https://www.investinme.org/iimec-carolinedalton.shtml

---

7. Vicky Whittemore

National Institutes of Health, USA

Data Standardisation and Data Sharing for ME/CFS Research

Vicky Whittemore, National Institutes of Health, described the development of common data elements (CDEs) for ME/CFS research, explaining how standardised objective measures and patient reported outcomes allow data to be compared and combined across studies. She outlined how the original set of over 160 CDEs was reduced to 68 core items, and described three working groups that have recently revisited standards for post exertional malaise, cognitive measures and functional severity, each involving people with lived experience

alongside clinicians. She gave examples of trials undermined by inadequate outcome measures, including a long COVID cognition trial that failed because participants were not screened with validated neuropsychological tests before enrolment. She closed by describing NIH's ME/CFS data and biospecimen portals, Map ME/CFS and Search ME/CFS, and encouraged researchers to deposit and make use of shared data, noting the added complexity GDPR brings to sharing data between the US and Europe.

https://www.investinme.org/iimec-vickywhittemore.shtml

8. Eva Untersmayr-Elsenhuber

Medical University of Vienna, Austria

Emerging Research for the Discovery of ME Mechanisms

Eva Untersmayr-Elsenhuber, Medical University of Vienna, gave delegates a first look at the newly funded DISCOVER-ME project, a Horizon Europe study built on the European ME Research Group network. She described the project's origins in an EU call targeting under researched, high burden diseases, and outlined its aims to harmonise diagnostic criteria, identify patient subgroups, and discover immune, cellular and metabolic biomarkers across a large, geographically diverse set of European biobanks. She explained that the findings will feed into an AI based ME/CFS disease map and computational and in vitro models intended to identify and validate drug repurposing candidates. She thanked Invest in ME Research and the wider consortium for their support, introduced the project team, and invited young researchers to apply for opportunities within it.

https://www.investinme.org/iimec-evauntersmayr.shtml

9. Douglas D. Fraser

Western University, London, Canada

A Global Platform Trial of Repurposed Drugs for Long COVID

Douglas Fraser, Western University, presented progress on a precision medicine, Phase 3 adaptive platform trial for long COVID, building on omics and AI-driven drug repurposing work from a prior 5,561-patient cohort across three continents. He explained that 13 hallmark biological pathways were found across all geographical areas and symptom clusters, leading to two repurposed drugs, upadacitinib and pirfenidone, being tested against matched placebos in a double-blind, adaptive design with a full omics work-up on every participant. He described a ten-site global trial, including sites in Canada, the US, Brazil, Italy and several low and middle income African countries, and set out in detail the regulatory, manufacturing and logistical challenges of running a trial across such

varied jurisdictions, from EU-mandated stability testing to a sevenfold rise in drug supply costs. He closed by stressing that an adaptive trial design demands equally adaptive operational infrastructure, and answered a patient question on treatment duration by explaining how the trial's phased, evidence-led structure allows the protocol to be revised if early signals warrant it.

https://www.investinme.org/iimec-dougfraser.shtml

10. Rowan Gardner

Precision Life, UK

Expanding Mechanistic Insights in ME: Analysis of the DecodeME Population and What's Next

Rowan Gardner, Precision Life, presented findings from the LOCOMBE study, which combined genetic and clinical data from the patient population with Precision Life's combinatorial analysis methods. She described identifying over 22,000 disease associated SNP combinations mapping to more than 2,300 genes, of which 259 were considered core drivers linked to neurological, inflammatory, cellular stress and calcium signalling processes, and showed that 76 genes were significantly enriched in both ME and long COVID, pointing to shared underlying biology. She outlined plans to translate these findings into patient benefit through stratification tools for clinical trials, a low cost whole genome sequencing pathway, and a planned direct to consumer genetic report offering six mechanism based risk profiles. She invited clinicians interested in drug repurposing candidates or patient stratification to contact her team.

https://www.investinme.org/iimec-rowangardner.shtml

11. Leo Tamariz

University of Miami, USA

Cardiovascular Phenotyping Across Fatiguing Syndromes: Comparative Findings from ME/CFS, Long COVID, and Gulf War Illness

Leo Tamariz, University of Miami, compared cardiovascular findings across ME/CFS, long COVID and Gulf War illness. He showed that dysautonomia, including orthostatic hypotension and postural tachycardia syndrome, is common to all three conditions, and demonstrated how a simple NASA lean test combined with end tidal CO2 and cerebral blood flow monitoring can identify autonomic dysfunction without access to a tilt table. He presented echocardiogram data showing that, unlike long COVID, ME/CFS and Gulf War illness do not cause structural heart damage, but do involve reduced diastolic filling volume that limits

the ability to raise cardiac output on standing. He also described endothelial dysfunction driven by spike protein and senescent endothelial cells across all three conditions, outlined practical treatments including salt, compression stockings, IV fluids, and vitamin C or arginine for endothelial support, and announced plans to revive an international clinicians' group to discuss difficult patients.

https://www.investinme.org/iimec-leotamariz.shtml

12. Ana Palacio

University of Miami, USA

COVID-UPP Baseline Findings and the Measurement Gap in Long COVID

Ana Palacio, University of Miami, presented preliminary baseline results from the COVID-UPP cohort study, a community recruited, longitudinal study of post-COVID recovery designed with a deliberate focus on Hispanic representation. She showed that classifying participants using a validated CDC symptom inventory, rather than a single self-reported recovery question, revealed a distinct 'boundary' group, and that around 55% of people who met criteria for being unrecovered would have been missed by the single-question approach. She identified post exertional malaise as the sharpest and most reliable marker distinguishing recovered from unrecovered participants, and showed that financial strain was the strongest predictor of under-reporting illness, raising concerns about undercounting the most disadvantaged patients in surveillance data. She concluded that screening tools which do not capture PEM risk missing genuinely unwell patients, and called for more nuanced, longitudinal approaches to classifying long COVID recovery.

https://www.investinme.org/iimec-anapalacio.shtml

13. Mari Gamme Sollie / Trine Alm Holterbakken

Røysumtunet, Norway

Specialised Care for Seriously and Very Seriously Ill People with ME

Mari Gamme Sollie and Trine Alm Holterbakken, Røysumtunet, Norway, presented on specialised residential care for people with severe and very severe ME. They opened with a short film about their unit, an eight room, sound and light isolated department within Norway's primary health care system that has operated as a dedicated ME department since September 2025. They described their care model, based on the NICE 2021 severity categories and a structured functional assessment and description plan, covering post exertional malaise, sleep, nutrition, pain and cognitive symptoms, delivered by a multidisciplinary

team of nurses, physiotherapists, occupational therapists and physicians. They shared results from their first published case series of 24 patients with severe or very severe ME, in which 50% showed significant or partial improvement, and explained how they adapt communication, activity pacing and the sensory environment to each patient's tolerance limits to guard against PEM.

https://www.investinme.org/iimec-maritrine.shtml

---

14. Per Julin

Karolinska Universitetssjukhuset, Sweden / EMERG

Karolinska Policlinic for Post-Infectious Diseases: Clinics and Research

Per Julin, Karolinska Universitetssjukhuset/EMERG, described the development and current work of the Karolinska Policlinic for post-infectious diseases, tracing its roots to earlier, under-resourced ME/CFS rehabilitation clinics in Sweden and the clinic's closure and rebirth as a post-COVID, then post-infectious disease, service based within a university hospital. He outlined the team's multidisciplinary assessment model involving physicians, physiotherapists, occupational therapists and psychologists, and stressed the importance of routinely screening for postural tachycardia syndrome (POTS), illustrating this with a patient whose severe breathlessness turned out to be autonomic rather than respiratory in origin. He presented research linking breathlessness and symptom burden to inflammatory markers and functional disability, and shared results from around 80 patients scanned with FDG-PET, of whom roughly 90% showed reduced neural activity in the medial temporal lobe even when routine blood tests and MRI were normal. He closed by describing Karolinska's new post-COVID research network and ongoing immunological and probiotic treatment studies.

https://www.investinme.org/iimec-perjulin.shtml

---

15. Friðbjörn Sigurðsson

Akureyri Hospital, Iceland / EMERG

Clinical Approach to Treatment

Friðbjörn Sigurðsson, Akureyri Hospital/EMERG, an oncologist by background now working full time in ME and long COVID care, opened with the history of Iceland's 1948 to 1949 'Akureyri disease' epidemic and its place among more than 70 historical ME-like outbreaks, including the Royal Free Hospital epidemic that led to the naming of 'benign myalgic encephalomyelitis'. He described Iceland's new national long COVID and ME clinic, established by the Ministry of Health, which has seen 830 patients including children as young as ten, and

outlined its multidisciplinary team, its role providing samples to the DISCOVER-ME project, and Iceland's public awareness work including newspaper articles, symposia and television documentaries. He argued, drawing on his oncology background, that an ME centre needs the same core elements as a cancer centre, including expert multidisciplinary teams, short waiting times, clinical trials, biobanking and international collaboration. He closed by describing growing collaboration between Nordic clinicians, referencing a regional position paper calling for closer cooperation, and inviting delegates to consider Iceland for a future meeting.

https://www.investinme.org/iimec-fridbjornsigurdsson.shtml

Summary

IIMEC18 brought together researchers, clinicians and patient representatives from across Europe, North America and beyond, reflecting twenty years of growth in biomedical ME research. Talks ranged from mechanistic work on immune, mitochondrial and cardiovascular dysfunction, through data standardisation, wearable technology and genetic stratification, to clinical trial design and specialised care for the most severely affected patients. A recurring theme was the shared biology linking ME, long COVID and related post-infectious conditions, and the growing international collaboration this is driving.

The launch of **DISCOVER-ME** under Horizon Europe stands as a fitting marker of this milestone year. The project builds directly on foundations laid by Invest in ME Research over two decades, from establishing the European ME Research Group and the wider European networks that made international collaboration possible, to guiding the discussions, identifying the consultancy support, and funding the work behind the successful submission.
Seen in this light, DISCOVER-ME is not simply a new grant but the culmination of twenty years of sustained effort by Invest in ME Research and its networks, now moving into a new phase of European biomedical research into ME.