

Working group appointed by the Director of Health in Iceland

Healthcare services for ME/CFS,
Post-COVID Syndrome, POTS
and environmental illness

Key findings and recommendations

SEPTEMBER 2026



On the working group and its tasks

In August 2025, the Icelandic Minister of Health tasked the Director of Health with establishing a working group to address the organisation of healthcare services for individuals suffering from Myalgic Encephalomyelitis (ME), Post-COVID-19 Syndrome (PCS) and Postural Orthostatic Tachycardia Syndrome (POTS). Environmentally acquired illness was later added to the group's remit.

The final report was prepared by the following members of the working group:

- Freyja Imsland, PhD in genetics, representative of The ME Society of Iceland
- Friðbjörn Sigurðsson, physician at The Akureyri Clinic
- Hugrún Vignisdóttir, psychologist, Vice Chair and representative of the Icelandic POTS Association
- Kristín Sigurðardóttir, emergency medicine physician and member of the Public Health Council of Icelandic Medical Association
- Linda Gunnarsdóttir, physiotherapist, representative of SUM – The Icelandic Association of Environmental Impact on Health
- María Heimisdóttir, Director of Health
- María Guðlaug Hrafnisdóttir, Medical Director at Iceland Health Insurance
- Nanna S. Kristinsdóttir, Chief Medical Officer at Primary Health Care Centres of the Capital Area
- Sigríður Elín Ásgeirsdóttir, International business specialist, now disabled due to long COVID-19, representative of Ský - The Post Covid Association in Iceland
- Sigurveig Þ. Sigurðardóttir, Chief physician Immunology, Landspítali – University Hospital
- Una Emilsdóttir, resident physician in occupational and environmental medicine
- Unnur Anna Valdimarsdóttir, Professor of Epidemiology and Dean of the School of Health Sciences, University of Iceland

Kjartan Hreinn Njálsson, Assistant to The Director of Health, served as secretary to the working group.

The working group was established in response to increased awareness of these conditions in Iceland in recent years, and the need to improve services for the affected patients.

The working group submitted its final report to the Director of Health on September 22, 2026.

The key findings and main recommendations are summarized below.

Key takeaways

- Patients with ME, Post COVID-19 syndrome, environmentally acquired illness, POTS, and related conditions experience a high disease burden when compared to patients with other serious illnesses. Despite this, the level of healthcare and support available to these patient groups is not in accordance with the severity of their illness and its impact on their lives.
- These conditions also impose substantial costs on patients, their families, and society, including through reduced capacity for education and employment and withdrawal from schools or the labor market.
- Healthcare and social services for these patient groups need to be extensively strengthened.
- The social security system must provide better support to these patient groups, including disability benefits, medical aids and coverage of medicine costs.
- Appropriate rehabilitation services need to be established, and it must be ensured that potentially harmful rehabilitation approaches are not employed.
- Clear safeguards are needed to prevent these conditions from being dismissed, classified, or treated as psychological or psychosocial disorders.
- Research on these diseases must be strengthened and funded. With strategic and targeted approach, Iceland has the potential to take a leading role in research and treatment of long-term consequences of infections and environmental exposures.
- Funding for this field must be increased to reflect the scale and severity of the problem.

Main recommendations

To Health Authorities

- Awareness needs to be raised within the healthcare system about the nature and severity of these illnesses.
- Education for healthcare professionals needs to be significantly strengthened, to improve their understanding of how serious these illnesses are and the very real impact they have on patients.
- Diagnosis codes need to be standardised and utilised with consistency, so that prevalence and incidence can be recorded more accurately.
- Primary healthcare is the first point of contact for assessment and initial treatment, however most patients in these groups require greater specialist support and follow-up than the primary healthcare services can provide.
- The operation of The Akureyri Clinic needs to be strengthened. The clinic already serves all of these patient groups, but the demand far exceeds what can be provided with current staffing levels. It is proposed that avenues to support the uninterrupted operation of The Akureyri Clinic for the future will be explored. The collaboration between The Akureyri Clinic and Landspítali – University hospital should be formalised.
- It is proposed that the Clinical Care Guide from Bateman Horne, USA for ME, Long COVID, and related illnesses be used to support the assessment and treatment of patients in Iceland.
- It is proposed that ME should be defined as a serious chronic neurological disease, for which conventional rehabilitation is not indicated.
- It is proposed that the expert guidance on the diagnosis and management of POTS from the Heart Rhythm Society and the Canadian Cardiovascular Society, as well as guidelines from the Bateman Horne Center, be used as reference in the assessment and treatment of POTS in Iceland.
- It is proposed that electronic medical record systems within the public healthcare services be unified as soon as possible, and that privately practicing specialists and treatment facilities that are publicly funded be required to use a common and coordinated medical record system with the public health care medical record system.
- It is proposed that a prospective study be conducted in Iceland on the benefits of intravenous fluid therapy for these patient groups.
- It is proposed that a clinical study be conducted at Landspítali – University Hospital on the efficacy of Hyperbaric Oxygen Therapy in the treatment of these diseases, preferably in international academic collaboration.

- It is proposed that home healthcare services for severely ill patients be improved, including home visits, mobile phlebotomy, and telehealth services.
- It should be ensured that all premises where health care services are provided are wholesome and free of environmental health hazards so that patients with environmentally acquired illness do not suffer health consequences when seeking healthcare.
- It should be ensured that patients who are at risk of experiencing post-exertional malaise (PEM) and have markedly reduced tolerance to exertion are not harmed by excessive physical, cognitive, or other demands when accessing healthcare. This applies equally to rehabilitation, disability assessment, inpatient care, and all other forms of healthcare.
- Despite the challenges involved, there is great need for appropriate rehabilitation services. It is proposed that a specialised rehabilitation centre for these conditions is founded, in close collaboration with The Akureyri Clinic and patient advocacy groups. This centre must operate in a wholesome environment free of environmental health hazards.
- A biobank for these illnesses needs to be established in collaboration between Landspítali – University Hospital, the University of Iceland, and The Akureyri Clinic.
- International cooperation should be further strengthened, and it is proposed that the Minister of Health and the Minister of Nordic Cooperation use the Nordic Council as a forum with the aim to support Nordic collaboration in this field.
- High-quality data registries are essential prerequisites for research. Work should be undertaken to implement standardised registration systems and develop a database to support research on these diseases.
- It is proposed that a working group be established, with participation from the health authorities, the construction industry and other relevant professions to develop proposals on how to reduce the incidence of environmentally acquired illness due to unwholesome buildings.
- Psychological services should be funded within the social security system, and coordinated with primary healthcare, The Akureyri Clinic, and other specialised services.
- A campaign should be organized to eradicate prejudice among healthcare professionals towards these illnesses, and to ensure that patients are treated appropriately and receive suitable support in every instance throughout the system.
- Recruitment needs to be strengthened and the numbers of healthcare professionals with expertise in treating these illnesses must be increased.
- These illnesses have been under-researched relative to the number of patients affected and the substantial disease burden they impose. As a result, it is not always possible to

rely on well-established evidence-based treatments to improve patients' health and quality of life. Clinical experience and patients' lived experience should therefore be considered alongside the best and latest available scientific evidence.

To Social Affairs Authorities

- It is proposed that the patient group be offered the same social rights and benefits as other individuals living with serious chronic neurological diseases.
- Household assistance should be made available to homes where individuals with these diseases live, regardless of household composition.
- It is proposed that the Ministry of Social Affairs fund one full-time social worker position at The Akureyri Clinic. The social worker would support patients and their families, provide advice to municipalities and other service providers, help coordinate social support services, and strengthen continuity between healthcare and social services for this patient group.
- Action is needed to ensure that preschools, schools, workplaces, and healthcare facilities have healthy indoors air.
- Attention should be given to children whose parents live with these illnesses, to ensure that they are not adversely affected by a parent's illness. In some cases, additional social support may be needed, such as a support worker, counselling, or other family support services.
- It should be ensured that children and youths are not removed from their parents due to lack of belief in the existence of these diseases amongst professionals within the social systems.
- It should be ensured that children and youths with these illnesses receive strong support in pursuing their education despite the hindrances created by their illness. Account should be taken of the fact that the sensory environment in schools can make the attendance difficult for children with severely reduced exertion tolerance and that some school buildings may be affected by dampness and mould.
- Awareness needs to be raised within the social services about the nature and severity of these illnesses.

To Higher Education Authorities

- Health sciences programmes at Icelandic universities should place greater emphasis on ensuring that students receive accurate and up-to-date education about these illnesses. The same applies to postgraduate training and continuing professional development for healthcare professionals
- It is proposed that an academic position focused on teaching about and research upon these illnesses be established at the University of Iceland.

- Funding should be secured for patient registry, a biobank and research. With a targeted effort Iceland has the potential to become a leader in research on these diseases.
- “*Research Centre on the Long-Term Consequences of Infections and Other Stressors*” should be formally established in collaboration between the University of Iceland, Landspítali – University Hospital, and The Akureyri Clinic.

To the Social Insurance Administration and Iceland Health Insurance

- It is proposed that the Social Insurance Administration and the Iceland Health Insurance work together with patient organisations to prepare information materials on the rights and entitlements of individuals with these illnesses within the social and healthcare systems in Iceland.
- It is proposed that a working group be established, comprising representatives from the Icelandic Medicines Agency, Iceland Health Insurance, and healthcare professionals with expertise in treating patients with these conditions. The purpose of the working group would be to review reimbursement for pharmaceutical treatment, while recognising that, in under-researched illnesses, the same level and type of evidence may not always be available as for better-researched conditions.
- It is proposed that Regulation no. 1143/2019 on Iceland Health Insurance reimbursement of cost of medicines be reviewed, with the aim to ensure appropriate coverage of pharmaceutical costs for these patient groups.
- It is proposed that the annex to Regulation no. 760/2021 on assistive devices be reviewed with the aim of ensuring that patients have access to assistive devices and support solutions that can reduce exertion and help prevent worsening of their condition.
- It is proposed that Regulation no. 722/2009 be amended so that the Iceland Health Insurance may contribute to the cost of removing implants when a patient has been diagnosed with Autoimmune/Inflammatory Syndrome Induced by Adjuvants (ASIA), such as from silicone breast implants.
- The health, functioning and participation in society of patients with these illnesses can be significantly impaired by unsuitable, inaccessible or unwholesome housing. Patients should be supported to live in housing that supports their health and reduces their disability burden.

To Financial Authorities

- Funding for this area needs to be increased in line with the scale and severity of the challenges involved.