

Improving standards of care in Chronic Intestinal Failure

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Event Coverage

Much more needs to be done to reduce inequalities of care for people suffering from Chronic IF, a rare disease and organ failure, MEPs have been told.



The event's main speakers, from left to right: Professor Palle Jeppesen, Professor Simon Lal, José Inácio Faria MEP, XChronic IF expert patient Marek Lichota, Cristian Busoi MEP & Professor Stéphane Schneider | *Photo credit: Jean-Yves Limet*

Much more needs to be done to reduce inequalities of care for people suffering from Chronic IF, a rare disease and organ failure, MEPs have been told

This was the key message from a recent event bringing together EU policymakers, rare disease experts, healthcare professionals and patients at the European Parliament on 28 March to discuss the launch of a call to action for improving standards of care for patients suffering from Chronic intestinal failure (Chronic IF).

Chronic IF patients lose much of their capacity to absorb nutrients via their intestines and rely on Home Parenteral Nutrition (HPN), a form of external feeding that is administered intravenously in the home.

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The event, organised by the Parliament Magazine in association with Shire, heard that compared to the political attention received by some rare diseases at European and national level, Chronic IF remains overlooked. Host MEP, Cristian Busoi, said health practitioners faced two problems in tackling a rare disease with low prevalence such as Chronic IF; “limited treatment options” and “high medical needs.”

He said, “Chronic IF is treatable but there is inequality of access to treatment between and within countries and a lack of specialists. The lack of data makes addressing the disease burden challenging.”

It was to address these inequalities and unmet needs that a group of leading clinicians, policymakers and patient representatives decided to create the ATLAS Programme. Initiated and funded by global biopharmaceutical company Shire, the programme aims to improve the health outcomes of Chronic IF patients. Attendees heard a call to action directed at Europe’s policymakers.

[The ATLAS Programme policy paper, 'Transforming the vision: Giving chronic intestinal failure patients the care they need - a call to action'](#), [7] provided a disease overview and six unmet needs that need to be addressed urgently.

Busoi explained that Chronic IF is not in the WHO’s International Classification of Diseases (ICD) and therefore not defined as a chronic condition.

“This makes it difficult to collect data on disease prevalence and has other implications for funding, access and reimbursement at national level. As policymakers, we MEPs should fight to recognise and classify Chronic IF as a rare disease and encourage WHO to include it in the ICD. We should also encourage member state governments to integrate Chronic IF in national plans and strategies”.

He explained how the EU-wide “European Reference Networks”, virtual networks involving healthcare providers across Europe that aim to facilitate discussion on complex or rare diseases and conditions requiring highly specialised treatment and concentrated knowledge and resources, could help ensure patients get the best available treatment.

“Chronic IF is treatable but there is inequality of access to treatment between and within

countries and a lack of specialists. The lack of data makes addressing the disease burden challenging” **Cristian Busoi MEP**

He added, “It’s our duty to encourage and support expansion of the Chronic IF reference networks throughout the European Reference Networks.” Portuguese MEP José Inácio Faria echoed Busoi’s comments, saying, “We need member states to step up and do more.”

He hoped the ATLAS Programme policy paper would “shed further light” on Chronic IF and on the plight of those “showing tremendous courage” in living with the condition. “I do not suffer from Chronic IF but I know those that do and they deserve a good quality of life.”

He cited the case of a 39-year-old Romanian woman highlighted in the policy paper. Cristina was unable to obtain the treatment she needed in Romania so had to be treated in a clinic in Paris. After five months of treatment, she was well enough to return home; however there are still neither the facilities nor access to specialist nurses to properly care for her in Romania.

“Cristina desperately wants to return home but sadly until HPN is available in Romania she is forced to live away from her family and friends,” the policy paper explains. With most key health-related decisions taken at national level, Faria argued, “Member states need to be pressed to fully implement rare disease strategies and increase awareness of Chronic IF.”

Increased harmonisation of health policies would help tackle the discrepancies highlighted in the ATLAS programme. The policy paper, illustrated the “daily problems that patients with Chronic IF face in all member states. It knows no borders, with inequalities in access and quality standards among member states.”

Marek Lichota, a Chronic IF sufferer from Poland, described how the condition affected his daily life. Professor Stephen Hawking, who said, ‘Intelligence is the ability to adapt to change’ had shown that “Disability doesn’t mean you have to be excluded from life”.

“If you don’t receive intravenously what you need in terms of fluids and electrolytes and nutrients, you die” **Gastroenterologist Professor Stéphane Schneider**

Lichota added “I have suffered from Crohn’s Disease since 2002. Due to complications I was diagnosed with Chronic IF and I now receive HPN intravenously.” He now receives around 60 per cent of his calories and nutrients as a liquid mixture through an intrusive intravenous process that can often take most of a day to administer. “However it is the only way I can survive.”

The lack of accredited national reference centres is a fundamental problem in tackling and treating rare diseases such as Chronic IF, said Lichota. It was “important for people with the condition, when travelling for example, to know where they can go in case of an emergency.”

He finished his call for better and more coordinated action across member states saying, “Behind all of these unmet needs are the patients and their families that just wish to live as normal a life as possible.”

Gastroenterologist Professor Stéphane Schneider, described Chronic IF as an “awful disease among organ failures.” Until the development of Parenteral Nutrition in the 1970s, it was fatal. “If you don’t receive intravenously what you need in terms of fluids and electrolytes and nutrients, you die.”

ATLAS has identified six key unmet needs; inequality of access, dissemination of agreed epidemiology and quality standards, stakeholder education, home and social care and quality of life, R&D and accredited reference centres. "These unmet needs cut across different fields, but essentially it's about quality," said Schneider.

He explained that the ATLAS group had gathered data to benchmark care standards in Chronic IF across Europe. The initial results from 10 EU countries showed up "scandalous differences" in equality of access to treatment. "We need to raise standards of care everywhere for patients."

"Chronic IF would benefit from being considered an organ failure and being classified as a rare disease. This could boost European Reference Networks to provide the leadership to improve European wide health outcomes" **José Inácio Faria MEP**

The survey will be refined and populated to provide a full picture of what is happening across the EU. Gastroenterologist Professor Simon Lal, who leads a national intestinal failure unit in the UK, outlined the work he and his colleagues do on some of the complex issues surrounding Chronic IF.

"HPN is a lifesaver. If you have intestinal failure and you can't get it, then you'll die." There are also other complications, some of which can be life-threatening.

"If the catheter line gets infected, that can be life-threatening. The veins around the catheter can become blocked with a clot or a thrombosis. Patients can develop liver and kidney problems, dehydration and even kidney failure needing dialysis. It's also important to remember the psychological burden of this condition. Being connected up to a bag, twelve to fourteen hours a night can be harrowing."

He also shared patient success stories, including Rosemary, "our longest-surviving patient who began HPN in 1980; without it she wouldn't be here."

Another expert, Professor Palle Jeppesen, of the gastroenterology department at Copenhagen's Rigshospitalet said, "Since 1970, Denmark has had a national database for tracking patients and all their complications; how they look, demographics, administration."

He went on, "Because we track using national security numbers, we can access these numbers. It makes Denmark ideal if you want information. It is a haven for clinical and epidemiological intestinal failure research."

The Danish figures suggest Europewide prevalence should be around almost 60,000 patients. The dilemma is, there are currently only 10,000-20,000 identified," said Jeppesen. "It is tragic to think about these numbers, it illustrates how many thousands of people are not being provided with a chance of a life. With referral, we could have saved tens of thousands of lives."

The problem is that Chronic IF is neglected by clinical research. "It's a rare condition, cases are decentralised. There are few true expert centres and in many countries there are unfavourable payment structures. The quality of evidence around Chronic IF is low. Other specialities tend to disregard us because the research is poor."

Jeppesen added, "If we did the research we would have the evidence; we need to up our game. Collaboration is the future. We need centres of excellence and multicentre international studies. The EU is perfect for reaching the people to join these activities; the ATLAS Programme is part of this."

In the Q&A, MEP Faria said, “Chronic IF would benefit from being considered an organ failure and being classified as a rare disease. This could boost European Reference Networks to provide the leadership to improve European wide health outcomes. Research and networking between experts and clinicians, which could come from the European Reference Networks could improve the situation; accredited reference centres have a role to play. I hope that this event takes steps towards realising the ATLAS Programme.”

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