Source: Northern Ireland Assembly Date: May 12, 2025 URL: https://www.theyworkforyou.com/ni/?id=2025-05-12.3.26&s=%28chronic+fatigue%29+2025-04-30..2025-05-14#g3.27

[Members' Statements]

ME Awareness Week

Robbie Butler

I rise to mark the beginning of ME Awareness Week and highlight the ongoing, often invisible, suffering of those living with myalgic encephalomyelitis. That complex and debilitating neurological condition affects thousands across Northern Ireland but remains chronically under-recognised and, in some cases, underserved in our health system. ME can leave individuals housebound or bedroom-bound for years. It causes profound fatigue, pain, cognitive dysfunction and hypersensitivity to light and sound. Sadly, many patients still face disbelief, stigma and a lack of appropriate care. Despite its severity, there are no specialist services for ME patients in Northern Ireland.

There will be an event tomorrow in room 115 that Members are more than welcome to drop into. For over 14 years, Hope 4 ME & Fibro NI has worked to fill the gap. Through its advocacy, education and efforts, it has kept ME on the public health agenda. I have been proud to support and work alongside the group over the years, recognising the essential advocacy that it provides for a community that is too often overlooked. It has hosted 17 international medical conferences, contributed to biomedical research and collaborated with Queen's University and Ulster University to educate the next generation of healthcare professionals. That work is driven by dedicated volunteers but is ably led by the group's founder, Mrs Joan McParland MBE. Joan's personal resilience and leadership have made a lasting impact, ensuring that ME patients are not forgotten.

As we begin this important week of awareness, I pay tribute to all who continue to shine a light on this devastating illness. I also encourage

Members to spend some time in room 115 tomorrow with us.

(c) 2025 Northern Ireland Assembly