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[Members' Statements]

ME: Support for Patients

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Orlaithi Flynn

I will highlight a meeting that Sinn Fein representatives held recently with ME Support NI to hear about the invaluable support that it is providing to ME patients. ME, also known as chronic fatigue syndrome, is a long-term chronic and painful neurological illness. Over 7,000 people in the North are living with ME, with many so severely affected that they are unable to leave their homes or even their beds. This disease of the central nervous system can have a debilitating impact on people's lives.

A few weeks ago, the Sinn Fein health group MLAs met volunteers from ME Support NI. The people in the support group, who set up the charity, have direct experience of living with this awful disease. They are doing amazing work in supporting people — young and old — who are living with ME, many of whom are living without a diagnosis or a treatment plan and, sadly, feel stigmatised, ignored and not believed when they end up in hospital as a result of that debilitating disease. I sincerely hope that we can make more progress to support the work of ME Support NI to help secure better services, receive proper diagnoses and, generally, raise more awareness of what the disease is and how it affects people.

Patients who suffer from ME deserve to have access to appropriate and quality healthcare. People should not have to travel to hotel rooms to have specialists from overseas diagnose them, which is the situation currently. I will continue to work and speak up for those who are suffering from ME and, hopefully, do all that I can, along with colleagues, to bring about positive change for patients.

ME Support NI is a fantastic charity that does fantastic work for people who are often at their lowest point when they have been struck down by this relatively unknown illness. The charity was originally founded by a brave mother from west Belfast who found herself in the terrible position of having a very sick young child with no diagnosis, no answers, no care pathway and nowhere to turn. Her efforts and perseverance gave rise to a group of people that now provides invaluable support to everyone who lives with ME. I commend that mother, Antoinette, and her son David from west Belfast. They run the charity alongside other board members. Keep up the great work, and, hopefully, we will soon see the appointment of a specialist in this healthcare field.

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