

Statement by Patricia O'Byrne and Reinhard Schäler

13 March 2014

We acknowledge the receipt of the letter by Taoiseach Enda Kenny, T.D., of 10 March 2014, in answer to our open letter to him, and would like to thank him for the time he took trying to address the questions raised in our letter.

We are awaiting officials from the Department of Health to make contact with us without delay as per the Taoiseach's assurance.

The Taoiseach unequivocally states in his letter that we *"are right that Pádraig should be able to receive care here in his own country, the place where his parents and friends live"*. He continues to say that *"the health system that we have here at the moment is unsatisfactory; it is not able to provide health care for its patients when they need it most"*.

Unfortunately, instead of proposing concrete measure to address this unsatisfactory situation, he refers to a number of reports, plans, and strategy papers, some of them published, some of them still under consideration, all aiming to improve health care in Ireland. These include a plan to *replace*, but not to expand, existing rehabilitation facilities, as well as a reference to the *National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011 – 2015* which also explicitly states that all policies described in the plan will be *cost neutral*. – All this on the background of a well-known, well-documented, and well-established shortage of adequate rehabilitation care facilities. In addition, and based on our own knowledge, experience, and contact with the NRH, we believe that the Taoiseach's statement that waiting times have decreased at the NRH since 2011 is factually wrong.

What is worse, although there is no dispute over the lack of adequate rehabilitation services in Ireland, and although Irish Citizens have a right to receive treatment abroad if the treatment in question is available in the home country but cannot be provided without undue delay, we have been told in no uncertain terms by an NRH consultant that it would be a waste of time trying to apply to the HSE under the E112 scheme for treatment abroad. It had been tried before, was rejected, and would just be "a waste of time".

Of course, our case is not unique. Many patients with severe brain injuries are neglected by the state's health service that does not exercise its duty of care to these patients. In their desperation, they resort to desperate measures that include lobbying local politicians to help their loved ones, fundraising and remortgaging their homes to cover the cost of urgent treatments, spending their days at their bedside to protect their physical well-being in acute wards providing inadequate care. Policy papers and reports have not and will not change this intolerable situation. The state cannot negate its responsibility to care for its most vulnerable citizens, ignore their needs, and leave them to look after themselves. The ongoing, very concrete, immediate, and human scandal that this constitutes was not addressed by the Taoiseach in his reply. We look forward to talking to James Reilly and officials in the Department of Health to identify ways in which relief for us and the many families like ours who require immediate and adequate care for their loved ones can be found in the short term, and ideally in their own country.

Patricia O'Byrne and Reinhard Schäler