

24<sup>th</sup> October 2018

**To whom it may concern:**

My name is Niamh Corcoran and my niece is Grace O'Malley. Grace has Spinal Muscular Atrophy (SMA) Type 2 and is 9 years old. We come from Mayo. In August of this year (2018) I made contact with some families affected by SMA in Ireland and proceeded to set up a Whatsapp group as a means of communication and support. We have currently over 30 people with SMA and their families on this group. We have also set up a website [smaireland.ie](http://smaireland.ie) where there is a registration section.

On behalf of SMA Ireland and Friends of Grace we are presently campaigning for access to the clinically proven and licensed drug Spinraza for all types and ages of SMA which has yet to be reimbursed. We believe there are approximately 70 individuals in Ireland with SMA. In order to represent the voice of each of these, we would like to gather as much information on people with SMA as possible and we need your help please. We are aiming to get in contact with everyone in Ireland with SMA so that we can ensure the maximum impact for our work towards this campaign and future support.

We would therefore really appreciate it if you could please contact us either by website, text, phone or e-mail with the following information:

**Name, Age, Location, Type, Clinically Diagnosed, Telephone Number, E-mail address**

Please do not hesitate to contact me if you have any questions.

Kind Regards

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