

Monday, 24 July 2017

Subject: Charlie Gard case

Dear Members of the Council of National Alliances,

Over the past weeks EURORDIS has been closely following the story of Charlie Gard. Both in the UK and in Italy, the tragic situation this little boy and his family face resonates very strongly within the rare disease community, and also more broadly with the general public.

Charlie's parents have now announced that they are ending their legal battle to take Charlie to the US to receive an experimental treatment. Our thoughts are with Charlie and his family at this difficult time. This situation is something that affects each of us not only on a personal basis, but also because EURORDIS is the voice of people living with a rare disease at the European level.

We felt that any public statement we were to make would be subject to interpretation and would add to the massive confusion that has been created by the mediatisation of Charlie's case. As only the family, Charlie's medical team and the legal teams involved know the full details of his situation, we have refrained from making a public statement on the case.

Moreover, it is our policy at EURORDIS to not take public positions on individual cases that local associations are more familiar with. We have exchanged with Genetic Alliance UK, the UK national alliance for rare diseases, the Lily Foundation, the UK national association for mitochondrial diseases, and UNIAMO, the Italian national alliance. Both Genetic Alliance UK and the Lily Foundation decided not to make a public statement.

We are aware that there are many children, adults and families who go through the same heart-breaking experience as Charlie and his parents. It is our mission to improve their lives and the lives of all those who living with rare diseases: we strive to improve research and to make sure that diagnostics, care and treatments for them are timely, of best possible quality and accessible; we fight to increase awareness of rare diseases, to establish rare diseases as a public health priority, to engage patients at all levels and empower them to be engaged; and, last but not least, to change the political and legal landscape.

This is what we can do on a daily basis, in the hope that children facing similar situations to Charlie in the future will have access to the best possible care and treatment.

Kind regards,



Terkel Andersen
President, EURORDIS-Rare Diseases Europe



Yann Le Cam
Chief Executive Officer, EURORDIS-Rare Diseases Europe