DATE

*TD name*

*By email*

Dear [TD]

*[Insert paragraph about who has PKU in your family or use this sentence]*

My child …… was born in ….. and was diagnosed with phenylketonuria or PKU, through the standard newborn blood screening test.

PKU, is a rare genetic disorder that affects my child’s metabolism. People with PKU are unable to break down an amino acid called phenylalanine (phe). This is a natural substance found in food but in people with PKU, phe builds up in the blood and in the brain and can cause serious problems, including if untreated, severe brain damage.

While there is no cure for PKU, there is a way to prevent the build up of phe in the blood and brain. This involves a very challenging, highly restricted, low protein diet.

*[Insert your own explanation of what the daily diet and supplements is like]*

Living with PKU is a constant daily challenge and has a significant impact on [my/my child’s / my family’s] quality of life. It also means that [I / my child] is at risk of many other health complications associated with this diet.

Like many other families living with PKU and numerous other rare diseases, I would like to see more resources invested in improving our treatment and care. In particular, I want to know that I have access to the full range of low-protein food products that offer [me/my child] the best chance of eating a healthy diet.

I also would like to be given the opportunity to discuss with my paediatrician whether the medicine Kuvan would work for my child and if so for it to be reimbursed by the HSE.

As well as these two specific asks, which both have the potential to improve significantly the quality of life of PKU people and improve our overall health outcomes, I would like to see a generally more strategic approach to the management of rare diseases in Ireland. I understand that a National Rare Disease Plan (2014-2018) is in place but that there is little transparency or accountability on the progress being made.

I would appreciate you taking these points up with the relevant government minister on my behalf, and I look forward to hearing your own, and the government’s thoughts on the matter soon.

Should you require any further detail from me or information about PKU, please let me know.

Yours sincerely

[NAME, ADDRESS].