



28 March 2020

Dear Sir / Madam

Rett Syndrome is a genetic condition which first strikes healthy young children around the age of 1-2 years old and typically leaves them unable to speak, walk or use their hands.

Rett Syndrome also causes digestive and eating problems as well as breathing irregularities and regular chest infections.

Due to difficulties with digestion and feeding, people with Rett have increased nutritional requirements. Many patients are fed through a feeding tube and live on a regime of blended food.

Some patients with Rett are on a high fat diet, called the Ketogenic diet to help control seizures which are also part of the overall condition.

All these nutritional needs are vital for these patients and will help them stay as healthy as possible in order to fight infection and save lives.

The impact of Rett Syndrome on the digestive system which often necessitates multiple medications and nutritional interventions to manage means that people with Rett Syndrome need greater quantities of wipes, toilet paper and other hygiene products including soap and paper towels.

Due to the increased risk of chest infections, people with Rett Syndrome are at increased risk of complications from Coronavirus and therefore must therefore be shielded through social-isolation for at least 12 weeks.

We are very concerned to learn through our communications with families that many are experiencing great difficulty in obtaining food and other supplies they need to care for their family member with Rett Syndrome.

Here are the key issues:

- Not enough delivery slots for most supermarkets
- Not possible to register as a new customer for some supermarkets
- Not possible to register as vulnerable by some supermarkets
- Item rationing which means that families caring for someone with Rett cannot obtain enough wipes and toilet paper and other hygiene products to manage the effects of the digestive complications of the condition.
- Item rationing which means that families caring for someone with Rett cannot purchase enough food to make batches of blended food to meet the nutritional needs of their family member with Rett Syndrome.

People with Rett Syndrome are strongly advised by medical advisors to Reverse Rett that they cannot leave home for any reason.

For family members in the same household, who are carers for people with Rett Syndrome and necessarily in extremely close contact with the person they are caring for, leaving their home to shop for food and essential supplies, puts them at increased risk of becoming infected with Coronavirus and passing it on to the person with Rett Syndrome, for whom they are caring, which could be fatal.

We request that you take immediate action to ensure that the families of people with Rett Syndrome can shop online for food and other essential provisions as soon as possible and with priority ordering status, including:

- Being able to register as a vulnerable group for online grocery orders
- Being able to purchase additional quantities of essential groceries in order to meet their additional nutritional requirements
- Being able to purchase additional quantities of wipes, toilet paper and paper towels to manage the effects of their condition

With much appreciation,



**Rachael Stevenson**  
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