Dear **XXX** MP,

Firstly, may I congratulate you on your ***election/re-election*** to Parliament as MP for **XXX**.

I am writing to you about my child **XXX** who is **XX** years old and has Batten disease. This disease has led to the rapid loss of ***his/her*** neurological function which leaves ***him/her* (*insert details of impact of disease*)**. **XXX** was diagnosed when ***he/she*** was **XX** years old.

Batten disease is rare. It has an estimated incidence of approximately 1 in 200,000 and there are currently between 100 – 150 children living with a diagnosis in the U.K. today.

For families like us, who live with this disease, the impact is huge. Children and young people with Batten Disease will develop childhood dementia, resulting in learning difficulties, unusual behaviours, confusion and memory loss. This is in addition to blindness, epilepsy, seizures and increasing difficulties in motor skills like speech, language and swallowing.

Due to its rare nature, a child is often only diagnosed with Batten disease after the characteristic irreversible symptoms have manifested, typically 1 – 4 years post onset. Symptoms are also often mistaken for other diseases. Onset of the disease usually starts between 2 and 4 years old, preceded in the majority of cases by language development delay, and is followed by rapid deterioration of motor skills. The disease progresses quickly, and the devastating reality is that affected children usually only have a life expectancy of 8 – 12 years old.

Given the rate of deterioration, early diagnosis is absolutely crucial. Only with early diagnosis can you access specialist care, clinical trials, palliative support, genetic testing and counselling for other members of the family.

Sadly, not all children have access to the right standard of care. There is currently no national service specification for the treatment and care of children living with Batten Disease. There are no services available outside London. This means we have to travel long distances to enable **XXX** to get the care they need. This is costly in both time and finances, but more importantly has a huge impact on us as a family.

Until recently, this lack of national service has been matched by a lack of treatment options. We are now hopeful that this is about to change.

The European Medicines Agency recently provided marketing authorisation for Brineura™ (cerliponase alfa), the only approved treatment for Batten disease. The EMA made this decision in an unprecedented timeframe, recognising the urgent need, moving rapidly to a positive decision. We now hope that this momentum is maintained as Brineura™ goes through the NICE process. It is vital a decision is made as quickly as possible so that these children can receive the treatment they so urgently need in the UK.

As a family, we are lucky to have the support of the Batten Disease Family Association (BDFA). It is a national charity that supports us and other families affected by Batten disease. They will be holding a Family Conference from the 24th-26th November in Stratford-upon-Avon and if you are able, please do come along. You will learn more about the impact of this debilitating disease and discover ways in which you can show your support to ultimately help us to improve the treatment and care available to these children.

I would also welcome the opportunity to meet with you personally to share more of our experiences of this disease, and how we might work with you to make the case for a nationalised service specification that will ensure children are diagnosed at the earliest possible opportunity and have access to the very best treatment, care and support.

Please do let me know your availability to meet with you in your constituency office.

Best wishes,

**XXX**