Your address

Date

MP’s name and address / email address (*find title / name / address / email by clicking on this link:* [*https://members.parliament.uk/FindYourMP*](https://members.parliament.uk/FindYourMP))

*You may want to also write your letter to:*

*Matt Hancock MP -*[*mb-sofs@dhsc.gov.uk*](mailto:mb-sofs@dhsc.gov.uk) *Lord Bethell of Romford -*[*PSLords@dhsc.gov.uk*](mailto:PSLords@dhsc.gov.uk) *Justin Tomlinson MP -*[*minister.disabledpeople@dwp.gov.uk*](mailto:minister.disabledpeople@dwp.gov.uk) *Marsha de Cordova MP -*[*marsha.decordova.mp@parliament.uk*](mailto:marsha.decordova.mp@parliament.uk)

Dear (Title and Name of Minister): [*https://members.parliament.uk/FindYourMP*](https://members.parliament.uk/FindYourMP)

As a constituent of yours, I wanted to contact you about something that is very close to my heart. I am hoping you will be able to encourage the government to invest in research for inherited retinal diseases.

I / my child / my family member *[delete as appropriate]* have been diagnosed with a rare degenerative inherited eye condition called Stargardt’s Disease.

Stargardt’s disease is the most common juvenile macular dystrophy affecting one in 8,000 to 10,000 people. It is most commonly diagnosed in children and young adults (although people can have late onset). People typically lose their vision over a few years. Currently, there is no treatment or cure for Stargardt’s. However, with continuing scientific advances and research, there is growing hope that various treatments such as drug, gene and stem cell therapy can stop the condition.

As a person with Stargardt’s / parent of a child with Stargardt’s *[delete as appropriate]*, I would be so grateful for anything you are able to do to encourage the government to invest in research into genetic retinal diseases and provide your support to the new report ‘Time To Focus’ published by the charity, Fight For Sight at: <https://www.fightforsight.org.uk/our-research/timetofocus/>

Currently, 2.5 million people live with sight loss in the UK with a consequent significant cost to the economy and the public purse. An earlier Fight For Sight report identified that less than half of 1% of total medical research expenditure is devoted to eye research, and consequently, far less than this for inherited retinal diseases. With adequate funding for research, we believe that my / my child’s *[delete as appropriate]* quality of life and others affected will be enhanced and costs to the economy will decrease.

On February 28, we celebrated Rare Disease Day, and we would have so much more to celebrate if we could have your support.

With Kind Regards,

(Your name)