

Dear

**Usher syndrome All Party Parliamentary Group (APPG)**

I’m writing to ask you to lend your support to the All Party Parliamentary Group for Usher syndrome.

This vital vehicle for change, advocacy and empowerment needs your support **now** more than ever before - the estimated **11,000+** strong family touched by the condition living across the UK, who have engaged with the group with passion and promised participation in the future are relying on you to ensure the continuation of the group.

With a view to increasing Officers and to bring to MP’s attention our collective mission to improve the quality of life for all those living with the leading cause of dual sensory loss - Usher syndrome, we are asking you to consider the following:

Usher syndrome is a**genetically inherited condition** that causes combined hearing loss and progressive visual impairment - sometimes, problems with balance.  Those of us that are born with the condition experience this differently -**we are not defined by it - but are all connected by Usher syndrome.**

Currently there is low awareness of Usher syndrome.  But, registered charity and the APPG Secretariat, **Cure Usher** are trying to change that.

**Now, we need your help.**

**People know nothing about Usher syndrome. And that means people know nothing about Us.**

Since the formation of the APPG for Usher syndrome in 2022, and hosting three very well attended Drop-In Events at Portcullis House - the group has successfully contributed to:

* **Connecting** - the APPG has actively been involved across existing Government departments and projects, including the national Disability Action Plan and consulting with the Cabinet Office at the Dept. for Disability Health and Work.  In addition, Cure Usher support the 2022 BSL Act which further cements a commitment to ensure those with deafness/hearing loss are recognised - we want to expand this to include those living with a dual sensory loss too.
* **Community** - 'An estimated 11,000 *individuals across the UK live with Usher syndrome, with 650 constituencies across Parliament, on average, that makes for 17 people in each constituency that you represent*' and as our work continues, attendee lists are expanding and participation from families, charities and patient-led organisations is becoming ever more important.
* **Recognition** - the work of Cure Usher has been recognised by Prime Minister Rishi Sunak, through the Points of Light Award.  Northumbria and Newcastle NHS Foundation Trusts launched an official Usher syndrome awareness day on 2nd of March, the birthdate of British opthalmologist Charles Usher after which the syndrome eponymously bears his name

I am asking for *your* help and to ask you to please consider becoming an Officer and/or Member of the APPG and to email the **Chair**;

**[alex.norris.mp@parliament.uk](mailto:alex.norris.mp@parliament.uk)**

If you would like more information, please visit;

**[www.cureusher.org](http://www.cureusher.org/)**

Please note, for your diary -  there will be a Drop In event held on;

**June 10th, 2pm-4pm, Jubilee Room, Portcullis House**

It is more important than ever to have *your* representation there at this crucial time for people like us living with Usher syndrome, **let**’**s not let another child with hearing loss - lose their sight** **too,** let's create a world that *does* recognises them - and for their families too, let's not let them be faced with such uncertainty - simply due to a lack of awareness - a lack of investment and **let's find a Cure for Usher syndrome**

Yours faithfully, and with hope