

Hi all,

I hope you are all doing well as we near the end of 2020.

As we reflect on the year, 2020 has most certainly been a year like no other and presented many challenges to us all. As a charity, we have unfortunately had to cancel our face to face meet ups, and postpone our Stargardt's Connected Conference and think of different ways to fundraise.

Despite the difficult circumstances we have been faced with, I always try to think of what positives we can draw out from the situation. For our charity, it has undoubtedly been having our Zoom sessions where we have been able to reach out to more of our community than before. We are so excited to see our global community growing as we have had people from all around the world join these sessions, many who have never met anyone with Stargardt's before. If there is anything the pandemic has brought, it has given the opportunity for people to connect virtually where we wouldn't have thought possible a year ago. We will be holding more Zoom sessions in 2021 and hope you can join us. Of course, we do miss our face to face events and long for those to resume sooner rather than later.

As we enter a new year with continuing uncertainties, Stargardt's Connected are really passionate to continue to support and build our growing global community, to fundraise and to raise awareness of Stargardt's.

Please do feel to reach out to us anytime, you are never alone.

### **Stargardt's Connected News**

For our last Zoom session, we were very grateful to have our Medical Adviser, Professor Michaelides, to join part of our session and talk about Stargardt's Research. The recording is now available on our website on this link:

<https://stargardtsconnected.org.uk/research/latest-research/>

### **Fundraising**

If you are shopping online there are ways to raise money for our charity without an extra cost to you. If you shop on Amazon, please shop through Amazon Smile selecting Stargardt's Connected and they will make a donation to our charity. Simply log in to Amazon with your existing account and then click on this link to start your shopping: <https://smile.amazon.co.uk/ch/1183570-0>

We are registered with EasyFundraising where over 4000 shops/sites will donate to us if you shop online. It is free to sign up and only takes a moment. You can find our easyfundraising page at: <https://www.easyfundraising.org.uk/causes/stargardtsconnected/>.

### **Thank you**

We would like to say a big thank you to Rachael Shorthose and her family for their fantastic fundraising efforts- they have started a fundraising Justgiving page for their daughter Evie who has Stargardt's and raised over £900 so far! Here is the link if you wish to donate:

<https://justgiving.com/fundraising/evie-shorthose>

Rachael has also managed to get Evie's old secondary school to choose Stargardt's Connected as their chosen charity this year and they have raised £1000 which is an amazing amount.

THANK YOU so much to ALL of you who have donated and continue to support us through any form of fundraising- it is very much appreciated. Every penny counts!

Our fundraising ideas page on the website gives lots of ideas on how you may wish to raise money for our charity: <https://stargardtsconnected.org.uk/fundraising/>

### **BBC Children in Need Documentary**

My son Ethan who has Stargardts recently featured in a BBC Children in Need special documentary called Life in Lockdown. We felt really honoured to be chosen and share part of our story amongst 3 other families.

If you would like to watch the documentary, you can catch it on BBC iplayer:

<https://www.bbc.co.uk/iplayer/episode/m000pfn5/bbc-children-in-need-2020-life-in-lockdown>

### **GeneVision**

Professor Mariya Moosajee from Moorfields Eye Hospital and her team have launched a brilliant website, which is a one stop shop on rare genetic eye diseases, their interventions, research and support.

Here is the link: <https://gene.vision/>

### **Macular Society Counselling Service**

The Macular Society runs various counselling sessions with details below.

#### **CBS Group**

This is a 6 session group for people who are experiencing visual hallucinations caused by eye disease (Charles Bonnet Syndrome).

The group allows for people to share their experiences and together come up with strategies and ways of coping. The topics discussed are led by the group members themselves and what they feel they would benefit from working on.

The Macular society is running two telephone groups.

The criteria for both groups is that participants have a form of Macular Disease, and our age range is 16 plus. Everyone who is referred will be offered a telephone assessment to make sure that group work is going to be helpful. If this is not the case they will look into alternative sources of support, such as individual sessions or signposting to another agency.

Their groups are facilitated by a counsellor who will help to keep the focus of the group and enable everyone to have an opportunity to share should they wish to do so.

If you decide to join a group you will be given the joining details which involves dialling a telephone number to access a conference call. Each group runs for 6 weeks. You can refer yourself online <https://www.macularsociety.org/form/counselling-referral> or by calling 0300 3030 111.

### Adjusting to Sight Loss

This is a new group which is being trialled and is open to anyone with a form of Macular Disease who would like to speak with others who are navigating the changes brought about by sight loss. This could be practical issues as well as the emotional impact.

Lastly they have expertise within their counselling team in providing counselling to young people & families within a wellbeing setting.

If there is anyone who is 16 plus who needs emotional support, or would like a one off assessment, please make contact to number below. The same goes for parents of children who have a form of Macular Disease.

To request to join these groups, you can ring the Macular Society on:  
0300 3030 111

### **Fight for Sight**

Fight for Sight have been raising awareness of the disproportionate impact people with eye conditions are facing as a result of the pandemic. In June they released the findings of their survey of people with eye conditions/sight loss in the UK which showed that 73% of people were having difficulty accessing treatment as a result of the lockdown, with 4 in 10 people fearing their eyesight would further deteriorate as a result. With the ever-changing landscape and lockdown restrictions, they are asking for people to take part in a follow-up survey about how the pandemic is continuing to affect them.

Here is a link to the survey - <https://www.surveymonkey.co.uk/r/GF5DQRV>

Finally, the Stargardt's Connected team would like to wish you all a Merry Christmas and a Happy, Healthy and Safe 2021.

Thank you all again for your continued support, we really appreciate it!

**Best wishes,**

**Bhavna Tailor**

**Chief Executive Officer**

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