

'Working together across London for people with a visual impairment'

LVIF E-Bulletin: 28 January 2020

Please send articles for inclusion to: lvif@londonvision.org

NB: The views and opinions expressed in this bulletin are those of the contributors. They do not purport to reflect the opinions or views of the LVIF or its members.

2020 meeting dates are:

Friday 27 March

Friday 26 June

Friday 25 September

Friday 11 December

Introduction

Welcome to the latest bulletin. I would like to take this opportunity to thank you all for helping me edit this LVIF Bulletin over the last few months. Going forward, Liam O'Carroll will return to editing and compiling the LVIF Bulletin. Please continue to send articles for inclusion.

Best wishes

Courtney Nugent.

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NEWS

MEDICAL RESEARCH

Article 1: **Scientists investigate the healing process**

The scientists injected collagen into tiny channels the width of a human hair within transparent plastic.

The resulting material is similar in structure to the fibrils found in the cornea. Bioengineer Dr David Schmidtke, from the University of Texas at Dallas, highlighted that how corneal keratocytes repair tissue, and why scar tissue

is left behind in some cases, is not well understood.

“We came up with a way to mimic an injury model, so we can look at how the cells respond when there is a wound,” he said.

Scientists plan to investigate how the density, elasticity and dimensionality of fibrils affect keratocytes.

The study could assist efforts to develop new methods of reducing corneal scarring and develop tissue replacements.

© Optometry Today, 18 January

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Article 2: **Genetic risk of AMD examined**

Researchers from the University of Manchester have received funding from eye research charity Fight for Sight to investigate the genetic risk of age-related macular degeneration (AMD).

Led by Dr Rachel Taylor the researchers will utilise new biotechnologies, including bacterial molecular tools, to analyse gene changes in families where multiple generations suffer from AMD.

Dr Taylor explained that some forms of AMD affect multiple generations of the same family, which implies a genetic component.

She added that this research could ‘allow for the development of genetic tests so that doctors can more accurately predict an individual’s likelihood of developing macular degeneration, estimate how it may affect their vision and allow the development of a personalised treatment plan.’

Fight for Sight's head of research Dr Rubina Ahmed commented: 'We are pleased to fund this valuable piece of research which could lead to a genetic model for age-related macular degeneration and develop more targeted treatment, helping families that are affected by the condition.'

© Fight for Sight 22 January

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TECHNOLOGY

Article 1: “Game-changing” educational coding tool launched by the RNIB

The Royal National Institute of Blind People (RNIB) has launched an educational tool to help primary school children with vision impairment learn how to code.

The Code Jumper tool was designed by Microsoft and developed by the American Printing House as a tactile teaching aid. It is formed of a series of pods that each contain a single line of code, which represents a set of commands that can be joined together in different sequences to create a programme. RNIB explained that coding and programming are part of the national curriculum and it is hoped that Code Jumper will help children from the age of seven in the subject.

Principal researcher at Microsoft Research, Cecily Morrison, said: “The idea for Code Jumper was inspired by working with children who were blind or visually impaired who were excited to create their own technological future, after my son was born blind. The team wanted to create something that excited the hands of blind or visually impaired children as well as their mainstream peers.”

Code Jumper was described as a “game-changer” in accessible education by the director of services at RNIB, David Clarke. He explained that many teaching aids for virtual skills are based in a virtual space and are therefore intangible and inaccessible to those who cannot see and feel it, whereas Code Jumper makes virtual ideas tangible. “By helping children with a vision impairment learn how to code, this product is opening up coding and computer programming as a viable career path to thousands of young people who might otherwise not have considered it. RNIB is delighted to be a part of bringing Code Jumper to the UK and breaking down barriers to learning for children across the nation,” Mr Clarke added.

© RNIB 17 January

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Article 2: RNIB provides advice through Amazon Alexa

The sight-loss charity RNIB has teamed up with Amazon to provide information through the tech giant’s voice assistant Alexa about living with

sight loss. The charity today announced that users would be able to access this information by asking Alexa voice commands such as: “Alexa, what should I do if I think I'm losing my sight?” Other questions featured include “Alexa, what assistive technology do blind people use?” and “Alexa, how do I register as sight impaired or severely sight impaired?” The charity says that 54 per cent of blind and partially sighted people cite their sight loss as a barrier to using the internet, and almost two-thirds feel unable to make the most of new technology as a result of their condition. The charity has been providing advice and assistance to Amazon about Alexa on an ad hoc basis for a number of years, Third Sector understands. The announcement follows a number of charities in the past two years that have looked at how Alexa could enable greater engagement with their charitable work and allow people to easily donate. In 2018, the British Heart Foundation was the first UK charity to allow donations through Alexa, with other charities having since followed suit. David Clarke, director of services at the RNIB, said: “Voice assistant technology is playing an ever-increasing role in transforming the lives of blind and partially sighted people. “Voice assistants can enable independence, helping to break down accessibility barriers to a more inclusive society. "By using this technology to increase the reach of our own resources, we are ensuring that people can immediately get essential information about sight conditions, their rights, and the support available, simply by asking out loud.”

© Third Sector, 24 January

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STUDIES AND SURVEYS

Article 1: Transport for All: Dockless Bikes

Calling disabled and older Londoners! Are you affected by Dockless Bikes? We are conducting research to gauge the impact of Dockless Bikes, so we can work with operators to improve the service. Take this short survey

<https://www.surveymonkey.co.uk/r/C3MD9G9>

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Article 2: **DWP accessible customer communications needs survey**

DWP wants to improve www.gov.uk. We are focussing on helping customers with a disability who need us to adjust the way we communicate.

We created a survey about this. It will only take a few minutes to complete.

We need feedback from anyone who needs this additional help, or from the people who support them.

We would be very grateful if you would complete the survey. Please also share the survey link with anyone you think appropriate. This invaluable feedback will help DWP to ensure www.gov.uk meets these customers' needs.

This Survey is open until the 9 February.

It can be found here:

<http://www.lothiancil.org.uk/dwp-accessible-customer-communications-needs-survey/>

For further queries please email cat.communicationsurvey@dwp.gsi.gov.uk

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Article 3: **Cycleway between Greenwich and Woolwich - Consultation and Drop-in Sessions**

Transport for London's consultation on the first phase of the new cycleway connecting Greenwich and Woolwich is open until Sunday, 16 February. Please respond to the consultation and encourage your members to do the same through the link <https://consultations.tfl.gov.uk/cycling/greenwich-to-woolwich/>

Please also share with your members that TfL are hosting drop-in sessions, on the below dates and times. These events are a great opportunity for residents to learn more about the scheme directly from the people who are developing them. It is a valuable chance to provide first hand feedback to TfL and help shape how the borough will look like in the future. Please share these dates via social media and other channels you may have.

Saturday 25 January 2020 (12:30 - 17:30) Greenwich Room, Clockhouse Community Centre, Defiance Walk, Royal Arsenal, London SE18 5QL

Tuesday 28 January 2020 (12:00 - 19:00) Greenwich Suite, The Valley,
Floyd Road, Charlton, London SE7 8BL

Saturday 8 February 2020 (11:00 - 16:00) Greenwich Suite, The Valley,
Floyd Road, Charlton, London SE7 8BL

If you have any questions please email AndrewMiles@tfl.gov.uk or
AyoOsideinde@tfl.gov.uk .

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CHARITIES AND CAMPAIGNS

Article 1: Thomas Pocklington Trust awards Visionary £1.3m

Visionary are thrilled to kick-off 2020 by sharing the news that Thomas Pocklington Trust have awarded Visionary funding of £1.3m as part of a three-year agreement.

The agreement, which came into effect on 1 January 2020, includes funding and other resources for a three-year period, with a view to extension after this period subject to us successfully achieving the ambitious and exciting objectives outlined in the agreement.

This funding builds on the already strong relationship Visionary have shared with Thomas Pocklington Trust. TPT have been instrumental in the success of Visionary over the past 5 years, with us already having been working together for the benefit of blind and partially sighted people and with TPT providing grant funding, support services and seconded staff, since 2015.

Vision UK, 19 January

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Article 2: Fight for Sight Launches '20 Voices' Campaign

Eye research charity Fight for Sight is today launching the '20 voices for 2020' campaign, sharing the stories of 20 people whose lives have been impacted by sight loss.

The campaign hopes to raise awareness of the personal impact of sight loss in the UK and the possibilities of science to make a difference.

Fifteen-year-old Rose Roberts is lending her voice to the campaign. Rose was diagnosed with Stargardt macular dystrophy when she was seven years old. Since then, Rose's eyesight has deteriorated and she no longer has central vision, leaving her severely sight impaired.

Rose said: "When you suffer from an eye condition it's not only your vision that's impaired, it's your ability to live your life as easily as others. Other people don't realise how much they should treasure their eyesight until something happens to it. Eye research brings hope of new treatments to people with eye conditions."

Head of Research at Fight for Sight Dr Rubina Ahmed said: "We believe 2020 is the right time for us all to be investing more in new therapies to treat eye conditions, many of which are already stopping sight loss and blindness at clinical trial. If we can close the '1 to 20' research funding gap, we can help so many more people like Rose."

Currently, only one percent of national research funding is invested in eye research, even though twenty percent of people in the UK will experience serious sight loss or blindness in their lifetime[1]. The prevalence of sight loss is also on the rise – the number of people in Europe with the leading cause of blindness, age-related macular degeneration, is projected to hit 10 million by 2050.[2] Fight for Sight are referring to this as the '1 to 20' funding gap.

The 20 Voices campaign is part of Fight for Sight's wider 2020 campaign, which will include a major research study showing the economic and personal impact of sight loss. The findings, which are due in July 2020, will be used to lobby decision-makers and funding bodies for a national plan on sight loss that will ensure eye research gets the funding it badly needs.

You can listen to Rose's story of living with sight loss on the latest episode of Fight for Sight's podcast Eye Research Matters here – <https://www.fightforsight.org.uk/news-and-articles/podcast/>

If you want urgent action on blindness in 2020, you can add your voice to the campaign here – <https://www.fightforsight.org.uk/jointhefight/>

© Fight for Sight, 14 January

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Article 3: **Guide Dogs and Citi in brand new partnership**

Guide Dogs is pleased to be announced as the new London Charity Partner of global bank, Citi for 2020/2021.

Employees at Citi voted for Guide Dogs after staff visited their offices in Canary Wharf to demonstrate the hard work and dedication that goes into training a guide dog and helping people with sight loss.

Citi employee Patrick Moran was one of a number of people to nominate Guide Dogs as their charity partner, and for a very specific reason.

Patrick, who has been at Citi for 20 years, is also a guide dog owner and has a form of sight loss known as retinitis pigmentosa. Patrick said: "I'm incredibly pleased that Citi have chosen Guide Dogs to be their London Charity Partner, especially as I'm a beneficiary of the fabulous work that Guide Dogs deliver. Citi have been an exemplary employer to me and the willingness to support both me and my guide dog, Yoda means the world to me. The partnership between Citi and Guide Dogs will show what we can do together."

The partnership between the two organisations will aim to raise £350,000 to help people with sight loss get around with greater confidence and independence.

With Citi's support, we will create more life-changing partnerships, by matching people with sight loss with a guide dog or volunteer sighted guide.
Tom Wright, Guide Dogs CEO

James Bardrick, UK CEO from Citi, said: "I'm proud that Citi will be working with Guide Dogs in London to not only raise vital funds but to also promote awareness around sight loss and further our diversity and inclusion efforts. At Citi, we believe in creating quality and equality of life for everyone."

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OTHER NEWS

Article 1: 1 in 3 children with vision impairments are missing out on specialist support in school

According to new research we have published today, thousands of children and young people with vision impairments (VI) are being failed by underfunded local authorities across England.

Our new report *Left Out of Learning*, reveals that since 2017, 44 per cent of local authorities have cut or frozen funding for specialist education services. This has affected an estimated 11,000 children across England - representing one in every three.

Despite a rise in the number of children and young people requiring and accessing specialist support, 44 per cent of local authorities have also reported a decrease in qualified teachers of Vision Impairment (QTVI). These teachers are essential in making mainstream education accessible for vision impaired children and young people.

This decrease has resulted in tremendous strain on the remaining QTVI, as the number of local authorities where QTVIs have a caseload of more than 100 students has soared to more than a quarter. Despite this existing pressure on resources, 24 per cent of local authorities have admitted to current or proposed reviews of their VI services, meaning there could be even more cuts.

To read further please see

<https://www.rnib.org.uk/connect-news-and-stories/children-missing-support>

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Article 2: Moorfields Consultation

An update on the next steps and decision-making following the Moorfields consultation, which ended on 16 September 2019.

Moorfields Eye Hospital NHS Foundation Trust and its research and education partner, the University College London (UCL) Institute of Ophthalmology have been exploring the opportunity to move services from their existing premises in City Road to the St Pancras hospital site in Camden.

The final report summarising the findings from the consultation has been published today alongside an Integrated Impact Assessment and report

'Consultation with people with protected characteristics and rare conditions'. All the documents will be available from the Oriel website.

A joint health overview and scrutiny committee (JHOSC) led by local authorities in north central London is to give its view in response to the consultation, as required by national regulations. The JHOSC will consider the proposal at its next public meeting on 31 January 2020. This is a public meeting and if you wish to attend, details can be found on the JHOSC website.

Date for decision-making

You are invited to the CCGs' Committees-in-Common to consider the outcome of consultation and the Decision-Making Business Case. This will be held on Wednesday, 12 February 2020, from 5.30 - 7.00pm at The Wesley Euston Hotel and Conference Venue, 81-103 Euston Square, London, NW1 2EZ.

Thank you for all your support during the consultation; we are grateful to all those who have given feedback. If you have any queries or would like any of the documents in another format please contact the Oriel team on 020 7521 4684 or email moorfields.oriel@nhs.net

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Article 3: **Sandra, 72 will run three marathons in three months to beat macular disease**

Just one marathon would be a challenge enough for most people, but 72-year-old Sandra Orlando is planning to complete three in the space of three months.

Sandra is taking on the fundraising mission to help find a cure for macular disease. It will begin in March when she runs the Washington DC Rock and Roll Marathon, followed by the London Marathon in April and finally the Edinburgh Marathon in May.

"I'm calling it a marathon-a-thon" she said.

Sandra has age-related macular degeneration (AMD), but thanks to monthly injections in her eye her condition is currently stable.

She said: “My sight will never again be normal and there is no guarantee that the deterioration will not return or that my other eye will not be affected.”

Sandra only started running as a New year’s resolution at the age of 64, while she was living in America.

Since then, she has completed a streak of more than 500 continuous days of running at least a mile, and qualified to represent England in her age group at the marathon distance.

Last year she ran the London Marathon to raise money for the Macular Society and has so far raised more than £7,000 for the charity through her various fundraising efforts. She is determined to help find a cure for macular disease.

She said: Although I remain optimistic that I will continue to lead a normal life I want to take the opportunity now, to raise some money towards research into a cure and better treatments, and to provide much needed help for those who have not been as fortunate as I.”

You can sponsor Sandra online via the following link:
<https://www.justgiving.com/fundraising/run4eyes2020>

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Supporting blind and partially sighted people who live, work and study in London

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