Summer 2016

ISLRR View

Inside this issue

News:

A Word from the President

I am very pleased that the ISLRR Newsletter is back! It last appeared in the Spring of 2010 and had been, at best, a sporadic publication throughout the history of the organization. I firmly believe that we can breathe new life into this important means of communication and I thank Michael Crossland and the rest of the editorial team for taking on the task. A special "Welcome Back" to Iris who was so instrumental in the success of Vision 2008 by being the go-to person when anyone had a question or concern. In this expanded capacity, we expect great things from Iris as inquiries and requests for advice arrive from all around the globe. Michael Crossland has described the type of content that we would like to see in his Editorial. I would like to add my own encouragement for those of you in developing countries to use this as a forum for keeping the rest of us apprised of what you're working on or of what is going on in your corner of the world regarding Low Vision; be that research, service delivery, professional or patient education, etc. I believe that we all appreciate that your circumstances do not always allow you to publish articles in the standard journals but we all believe that you have interesting and informative stories to relate.

So, please let us hear from you! Whether you write a news article, an announcement for an event, a description of a study that you did or want to do, or a request for advice or information from Iris, keep the communication flowing and let's make this Newsletter a must-read publication in our global Low Vision community. Along with Michael and the editorial team, I wish you a good summer.

Olga Overbury, President

ISLRR View: News

Editorial

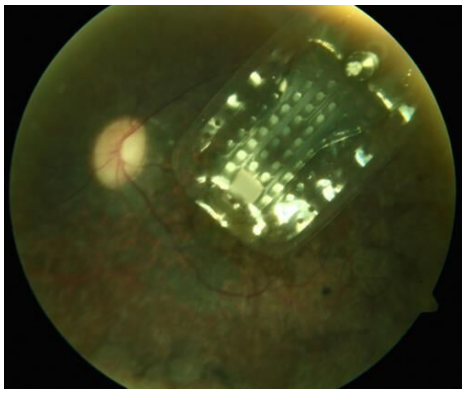
Welcome to the first issue of ISLRR VIEW: the newsletter for members and friends of the International Society for Low Vision Research and Rehabilitation. This is a new quarterly publication which we hope will interest, inform and inspire you all. In this issue we have submissions from Europe, Asia, and North America describing challenges and successes in low vision rehabilitation. In the first of our "**LETTERS FROM**…" series, Jianmin Hu describes the massive improvements in low vision care in China in recent years. We welcome further submissions to this column: please let us know what is happening in your corner of the planet! Our **NEWS ARTICLES** include descriptions of social media groups for researchers in the area of dual sensory impairment, priority setting work in the UK, an exciting course announcement from Montreal, an analysis of the community low vision scheme in Wales, and an update on retinal prostheses. Those of you who were at the 2008 ISLRR meeting in Montreal will be pleased to see the return of "Iris" in the form of our lighthearted low vision problem column, **Ask Iris**. We've also squeezed in an **App review**, in the first of a regular series. In the future we will also have sponsored content from companies producing exciting products or services which may be of interest. We will always make it very clear when you are reading "paid for" content. ISLRR VIEW is your newsletter so please let us know what you would like to see more of (or less of) in your newsletter. And please send your submissions in the form of photos, news items, "letters from" and questions for Iris.
Our email address is islrrview@gmail.com.

Michael Crossland

With best wishes for the summer, from your editorial team: **Michael Crossland,** London, U.K., **Rand Allabade**, Montreal, Canada, **Hilde van der Aa,** Amsterdam, the Netherlands. Special thanks to Wouter Schakel for technical assistance.

Retinal Implants: the Toronto Experience

Samuel Markowitz and Colleagues, Toronto, Canada



Technological advances in the last decades in engineering and medical technologies made possible the introduction of retinal prosthetic devices aimed at rehabilitation of minimal residual native vision (MRNV). Many studies are currently in progress around the world testing various methods for providing prosthetic visual input into the visual system in cases with MRNV. The Argus II epiretinal prosthesis is such a device. It is currently available for general use in cases with retinitis pigmentosa (RP) and first cases were implanted in Canada with the device in 2014. We report here first impressions and results on MRNV assessments for visual functions from our centre. We are currently summarizing rehabilitation therapy outcomes separately and elsewhere.

Article continued on the next page.

Retinal Implants: the Toronto Experience (cont.)

The Argus II Retinal Prosthesis consists of a camera and transmitter mounted in eyeglasses, a video processing unit and an implanted portion. The implanted portion includes a wireless receiving antenna and an electronics case, fixed outside the eye with sutures and a scleral band, and a 6x10 electrode array that is placed epiretinally over the macula. The Argus II device was surgically implanted in one eye (worst seeing eye) under general anesthesia.

Main outcome measures for visual functions were measured by using three different high contrast, objective, computer-based tests: square localization (SL), moving grating visual acuity (MGVA), and grating visual acuity (GVA). Visual function tests were performed at baseline, 3 months, 6 months and 1 year. SL measures the ability to locate and touch a target (white square on a black touchscreen monitor). MGVA measures the ability to perceive the direction/ trajectory of a moving object (white bar on a black touchscreen). GVA measured visual acuity in the range of 1.6 to 2.9 logMAR by using black and white gratings.

A total of 6 patients with diagnosis of RP were implanted (50%male and 50% female), average age was 58 years old. All implanted eyes had light perception poorer than 2.9 logMAR as tested with GVA at baseline. Visual function tests (SL and MGVA) showed twice as good improvement on performance (number of correct from total trials) with the implanted device ON compared to OFF at 3, 6 and 12 months compared to baseline. We don't have as yet the rehabilitation therapy outcome measures summary to compare with.

Discussion:

The introduction of prosthetic devices for vision rehabilitation in cases with MRNV brought to the fore the issue of the usage of suitable outcome measures for assessment of such cases. In general outcome measures for low vision are divided into three groups: physiological measures such as mfERG, visual function measures such as visual acuity, contrast sensitivity and fields of vision and skills based functional measures such as reading or activity of daily living estimates. Due to the complexity of the cortical vision processing, subjective measures such visual function and functional vision measures are viewed as the preferred outcome measures in low vision rehabilitation. Whereas such outcome measures are currently defined, standardized and validated for mainstream low vision cases, most if not all are not suitable for assessment of cases with MRNV. The Argus II set of tests for SL, MGVA and GVA that we used in our cases is a proprietary approach to provide a measure of utility in such cases with regard to visual functions.

Article continued on the next page.

Retinal Implants: the Toronto Experience (cont.)

Other similar proprietary measures with other devices were publicized as well. Ian Bailey introduced to us a modality to standardize levels of very low vision, still not sufficient for those with MRNV. From our results we see that SL and MGVA where significantly better with the device turned ON, yet these results did not correlate accurately in some cases with the initial impressions we collected on actual functional vision obtained. Also these results cannot be compared for equivalency with results from other studies using different technologies, since other studies use also proprietary specific outcome measures. This is probably the biggest challenge MRNV rehabilitation faces today. We still need to define, standardize and validate outcome measures for assessment of visual functions and of functional vision in cases with MRNV. Technological and research efforts need to be directed by our community to solve this conundrum sooner rather than later.

Beatrice Patino MD, **Michelle Markowitz** OD, OT, **Robert Devenyi** MD, **Samuel N Markowitz** MD

Mainstreaming Low Vision Services in Wales

Barbara Ryan and Rebecca John

Around the world, it is clear that despite the development of more holistic, person-centred low vision rehabilitation services, in many areas the extent of provision is not adequate or low-vision services are not currently available. In Wales, a small devolved country in the United Kingdom with a population of approximately 3 million people, Government funded National Health Service (NHS) low vision services have been mainstreamed and are now available in almost every town and city in 200 optometry practices. In 2014-15 the Low Vision Service Wales assessed 8,049 people. This article describes how this service is delivered and some of the recent service developments are outlined.

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Mainstreaming Low Vision Services in Wales (cont.)

- **How the Low Vision Service Wales is delivered and funded**

Traditionally in the UK, the majority of individuals with low-vision have been seen in hospital low-vision clinics and this was also the case in Wales until 2003. Whilst there were benefits of having a service in a hospital department to facilitate the continuum of care from an ophthalmologist to a rehabilitation programme, due to the growing number of people with a visual impairment and the resultant pressures on hospital low-vision services, the Welsh Government funded a programme of change to a community-based service in optometry practices. All the funding for the examination fees, together with the cost of the low-vision aids (which are loaned free of charge) and administration is met from an NHS budget.

- **Training and equipment**

Ophthalmic medical practitioners, optometrists and dispensing opticians provide the service. To do so they undertake training and an assessment provided by Wales Optometry Postgraduate Centre, School of Optometry and Vision Sciences, Cardiff University. Since 2013 this has aligned with the College of Optometrists Professional Certificate in Low Vision (http://www.college-optometrists.org/en/CPD/hq/low-vision-hq/index.cfm). About 130 practitioners were accredited in the first year. Each subsequent year another 10–20 practitioners have been accredited and now over 190 practitioners provide the service in over 200 practices. The majority had not previously provided low-vision services. The distribution of participants is widespread and consistent with the general population distribution in Wales (http://gov.wales/statistics-and-research/eye-care/?lang=en). Every three years practitioners have to attend further training and this enables service development and quality assurance. On becoming accredited, practitioners are provided with a kit that includes a range of demonstration low vision, devices a contrast sensitivity chart, logMAR charts for distance and near assessment and high cross cycles (±0.75, ±1.00). Beyond the range of low-vision aids in their kit, practitioners can order from a much larger catalogue which includes pocket electronic devices, optical devices, lamps and tints (http://www.eyecare.wales.nhs.uk/low-vision-lvsw-).

- **An accessible community based service**

The person can refer themselves or be referred by a friend, an optometrist, an ophthalmologist, general practitioner, rehabilitation worker, teacher, social worker or from a voluntary organisation. Anyone accessing the Low Vision Service Wales must have had a sight test in the previous year and have a best-corrected binocular distance acuity of 6/12 or worse or N6 or worse with a +4.00D near addition. If it is considered by an low vision practitioner that a person who doesn't meet this criteria may benefit from a low vision assessment, then individual requests for inclusion in the service can be made to the clinical lead. The majority of people seen are over 65 years (over two thirds are over 80 years), but many practitioners have seen children or those of working age.

Article continued on the next page

Mainstreaming Low Vision Services in Wales (cont.)

Many practices also offer a domiciliary service and about 20% of patients are assessed in their own home. Waiting times are typically less than two weeks. Follow-up appointments are performed if required, sometimes by telephone, and an annual appointment is offered for re-assessment.

- **Centralised administration**

An administration team, based in Hywel Dda University Health Board in Carmarthen, administer the Low Vision Service Wales for the whole of Wales. A standardised record card is faxed to the administrators and this also acts as an order for the low vision devices. The administration team also enter key information from the record cards into a centralised database for audit purposes. The low-vision aids are delivered to the practice in about 1 week. The contract for low vision devices is procured centrally by the service through an open tender process for one supplier and, as it is the largest low vision service in Europe, this bulk buying ensures a competitive price. Within the contract is a recycling element so that if a device is no longer of use it can be returned. The company checks and cleans those in good working order and puts it on the recycling shelf to be issued the next time that device is ordered.

- **Low Vision Aids prescribed**

The most commonly prescribed visual aids are a 3.5x/10dioptre hand held illuminated magnifier, a 5x/20 dioptre hand held illuminated magnifier, a desktop magnifier lamp and an electronic pocket magnifier. An average of 2 visual aids are given per low vision assessment. Hand held and stand magnifiers form the vast majority of visual aids dispensed accounting for 64% of all aids given. The remaining aids dispensed are made up of accessory aids (17%), lights (10%), distance aids (5%) and spectacle mounted aids account (0.7%).

- **Working with others ensures a holistic approach**

To ensure a holistic approach, low vision practitioners are expected to refer people to other services; for example, people eligible to be registered as sight-impaired are referred to an ophthalmologist. Of particular note is the strong link that has developed with visual impairment rehabilitation teams in local authorities. If a low vision practitioner is concerned about a person losing independence, or worried the person or someone they care for is unsafe, if the individual consented, practitioners share the low-vision record card with rehabilitation workers who then visit the individual at home. The rehabilitation worker will provide advice, equipment, mobility or daily living skills training to ensure the person can live safely and independently, thus reducing the need to further help. In many areas voluntary organisations also provide a range of vital support including social groups and advice on benefits.

Barbara Ryan is Chief Optometric Advisor to Welsh Government. **Rebecca John** is Clinical Lead for the Low Vision Service Wales

Announcement!

New Master Program in Low Vision
at the University of Montreal

École d'optométrie
Université de Montréal

We are pleased to announce a new option in the Master of Science program. This option, offered in English and in French by the School of Optometry at the University of Montreal, is called Visual Impairment & Rehabilitation.

There are three concentrations (or tracks) in the program, enabling one to specialize in Low Vision, Orientation & Mobility, or Vision Rehabilitation Therapy.

The first English cohort will begin the program in September, 2016. Given the very recent approval of the program, we will work with potential candidates to accelerate the admission process. Anyone who is interested in applying should contact the Graduate Program Director, Dr. Olga Overbury, as soon as possible. We will accept applications until June 30th or until we have a full cohort.

FOR MORE INFORMATION, CONTACT :

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Dual Sensory Loss Research Network

Walter Wittich, Montreal, Canada

Dual sensory loss is a very important but challenging area of low vision rehabilitation and research. Deafblind International is the world association promoting services for deafblind people. Last year, they established their Research Network, which can be accessed at research.deafblindinternational.org. The purpose of the Research Network is three-fold:

1) First, it creates an opportunity for researchers to build networks across countries and continents, thereby facilitating collaboration and exchange of ideas.

2) Second, within Deafblind International, it is now possible to facilitate knowledge exchange from researchers to individuals with deafblindness, clinicians, service providers, administrators, policy makers and other stakeholders.

3) Third, all stakeholders have a direct line to researchers in order to inspire and initiate research that is relevant for them, and that can make a difference in the lives of persons with combined vision and hearing loss.

Walter Wittich

DbI
DEAFBLIND INTERNATIONAL

In order to participate in any of the activities of the DbI Research Network,

- you can join our e-mail list by contacting walter.wittich@umontreal.ca,
- or join us on our Facebook page https://www.facebook.com/groups/158743377516989/?ref=bookmarks,
- or join our LinkedIn group to make professional contacts https://www.linkedin.com/groups/8339092,
- or send us a 200-word summary of a project on which you are looking for collaborators, to have it posted on the DbI Research Network web page http://research.deafblindinternational.org/collaborative_opportunities.html

VISION 2020 UK update: Setting Priorities for Low Vision in the UK

Mary Bairstow and Niall Ryan, UK

VISION 2020: The Right to Sight is the global initiative for the elimination of avoidable blindness. This is a joint programme of the World Health Organization (WHO) and the International Agency for the Prevention of Blindness (IAPB). VISION 2020 UK was established in 2002 as part of the global initiative. It is a unique, cross-sector collaboration, which enables public, private and charitable interests to work together, to strengthen national health-care systems and facilitate national capacity-building. The **purpose** is clear: (1) To improve the eye health of the UK, prevent avoidable blindness and ensure inclusion of people who have sight loss in society. (2) To lead the collaboration of organisations involved in eye health and sight loss in the UK to work together to achieve the outcomes of the UK Vision Strategy. Each year the IAPB supports a day of celebration focused on the global initiative – 'World Sight Day'. This takes place early in October and in the UK has been the focus of a number of local activities. This year's theme clearly reflects the mechanism for change by which VISION 2020 UK operates – 'Stronger Together'. The strength comes from the ability to be the unifying voice leading collaboration and co-operation between organisations with an interest in eye health and sight loss.

Low vision services: How can this unified voice add to a multitude of voices seeking to improve low vision services and ensure the participation in society? Over the last twenty years there has been a strong history in the UK of collaborative working to effect change. Most recently the baton has been taken up by the VISION 2020 UK Rehabilitation and Low Vision Committee. Inspired by the success of the development of the UK Eye Health and Sight Loss Pathway – a tool to ensure people get the right support at the right time and from the right person - the committee has begun to develop its thinking around low vision services. Work with key professionals, service user groups and individuals have enabled UK wide priorities to be identified. The first is the need for national guidance / standards. The second is to address inequalities of access and provision across diverse and vulnerable groups. Many people recognised the positive role VISION 2020 UK could bring to this in co-ordinating a national piece of work and developing Department of Health accreditation. The next stage will be to consider the actions required and to work with the VISION 2020 UK Rehabilitation and Low Vision Committee to consider mechanisms to take these forward. Already a number of people have volunteered support and this will be invaluable resource as VISION 2020 UK will be using their expertise to drive change. (Resources – UK Eye Health and Sight Loss Pathway: http://www.vision2020uk.org.uk/adult-uk-eye-health-and-sight-loss-pathway-revised-january-2015/).

Mary Bairstow

Mary Bairstow and **Niall Ryan**, UK VISION 2020 UK PO Box 70172, London WC1A 9HH
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ISLRR View: Letter from China

Where There Is a Dream, There Is a Way.

- "Look, this is a photo of Jack, my son from Tsingtao. He's a junior in a Medical University. Very handsome, isn't he?"
- "Your boy? Isn't it a girl?"
- "My apology! Actually, in my eyes, my boy is just a blurred figure. I have low vision. Maybe the boy next to the girl is my son. Would you please tell me what they're doing?
- "Seems that they are singing"
- "Oh, I got it. He told me he's preparing for school art festival as a music director. It must be that. I'm so proud of him," said the father in tears. "To be a teacher once seemed impossible, but he got closer and closer. After years of treatments, he can see, but still not clearly. My son told me that he wanted to be a teacher, so that he can teach children to enjoy the beauty of music. However, he couldn't see the world clearly and thought his dream may NEVER come true. Every time I recall his childhood talk, depression sets in hard and strong."
- "Why?"
- "His dream was once mine, you know?" whispered the father in tears "Poor sight, little money, few schools for people in the same situation as me forty years ago. I had no opportunity to go to school. Illiterate children like me had to make a living as labourers. But my lucky Jack, he went to Quanzhou School for the Blind at the age of 7 years, where he could learn Braille. I still remember the smile on his face when he told me he had learned to read in Braille. He even told me how he wished he could learn to read Chinese characters one day! I told him that it will come true eventually, if you don't give up your dream. I told him that, though even in my own deep heart, I never believed that day would come."

Everything changed in 2008: The Second Affiliated Hospital of Fujian Medical University China Assistive Devices and Technology Centre for persons with disabilities (CADTC) and Quanzhou School for the Blind (QSB) worked together and started exploring a new suitable low vision rehabilitation (LVR) model for the persons with low vision. The Low Vision Rehabilitation (LVR) centres on combining education and medicine. The CADTC offered funds (mainly for rehab trainings and transport fees) as well as different kinds of suitable aids to patients with low vision. Ophthalmologists and optometrists from the Second Affiliated Hospital of Fujian Medical University, provided the technical support on LVR, and teachers from QSB were in charge of LVR training. The LVR training seeks to train individuals with LV to learn some simple Chinese characters, how to browse the internet and do some on-line shopping. In addition, some even achieved reading music in Chinese, and not in Braille. As a successful LVR work model, that is becoming more widespread in China, more and more people are benefiting from these services every day. During the period of 2010-2014, over 600,000 people with visual impairment have received free aids and LVR trainings from the CDPF. We are optimistic in China to see that with all this support, individuals with low vision can have the same bright future as any other person in society. As the saying goes, where there is a dream, there is a way!

Jianmin Hu, Fujian, China

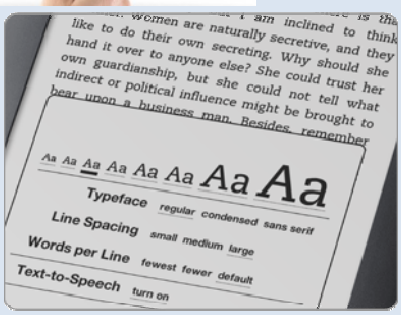
ISLRR View: Columns

Ask Iris: your low vision questions solved!

Dear Iris,

my low vision practice has changed dramatically over the past 10 years. I still issue optical magnifiers, telescopes, but they are being used less and less by my patients. This is because of new technology: people don't use monocular telescopes to look at bus numbers – they use an app on their phone that tells them which bus is due next. They don't use binoculars to look at a train departure board – they take a photo on their iPad and zoom in. They don't use a stand magnifier and large print to read a novel – they use text enlargement on their Kindle and higher power reading spectacles. It isn't just in younger people either, I see plenty of older adults who are very comfortable with these devices. They use a magnifier app on their tablet in between Skyping their grandchildren and ordering their online groceries. Low vision rehabilitation will still be crucial, but is there a place for magnifiers? Will we still be prescribing them in ten years? Should I sell all of my magnifiers on eBay whilst they're still popular? What do you think?

Yours,
"In with the New"



Iris replies

Dear "In with the New",

as I am answering your query, I am of course using modern technologies that did not exist at the time low vision rehabilitation began. However, I also realize more and more that the people who fill our waiting rooms are often of a generation where the memory of "simpler days" is still alive, (sometimes more so than the memory of what they had for breakfast…) and that often forms a barrier to access contemporary rehabilitation tools and toys. High-tech interventions can face considerable resistance, especially with older adults that have a general fear of this technology and the related threats that are being reported in the media in terms of identity theft etc. Taking a world perspective, I would also point out that those in the "developed" countries often forget how varied the situation is around the globe. Even though

communication technology holds great global potential to incorporate assistive functions, such as apps that turn your phone into a magnifier, there are still barriers as to whether your phone is "smart enough" to have a camera and the required processing speed. I agree with you that we will likely need to work in parallel, depending on the context, but unless the entire planet catches up with the state of the art, I think we are safe to continue in bringing all types of rehab interventions, large and small, to those who need them.

Yours,
Iris Clearview

Do you have low vision questions for Iris, ISLRR's very own agony aunt? Email them to ISLRRview@gmail.com

APP REVIEW: ViaOpta Daily

Michael Crossland, London, UK

ViaOpta daily is a free App developed by Novartis pharmaceuticals which is available on iOS (Apple) or Android devices. It combines several standard low vision apps into one platform. These include a magnifier, a colour recogniser, a scene identifier, and various other systems. The colour recogniser is one of the most accurate I have seen and I think this is likely to be useful for many people who struggle to identify colours when matching clothes, for example. It is only as good as the lighting in the room – it works much better under the bright fluorescent lights of a clinic than in a dimly lit bedroom, for example. The magnifier works relatively well but suffers from many of the common problems of smartphone magnifiers: the image smears when the text is moved, autofocussing takes a while, and holding the viewing distance is tricky. I am very impressed by the scene and object recogniser. The app developers don't say whether this uses computer object recognition (as in TapTapSee) or human workers (as in VizWiz), but it seems to be quite accurate even with slightly odd objects – such as a large fruit sculpture in Lille, France! I am not as convinced by the weather module – do we really need rain sound effects when your device reads the weather forecast to you? – and the currency identifier is currently limited to only US Dollars, Euros, Reals and Lyra. The app speaks in 12 languages (English, German, French, Spanish, Arabic, Japanese, Chinese, Greek, Portuguese, Dutch, Italian and Hungarian). Although more work is clearly needed, I recommend downloading this app and demonstrating it to people with low vision. For more see viaopta-apps.com/ViaOptaDaily.html – or download it from your App Store (for iPad, you need to select "iPhone only" in the top left corner of the App Store screen).