

Face Blind UK - First Open Meeting

1st July 2015

Summary & Feedback

The First Open Meeting - for members with face blindness - was also the hottest July day on record. It's aim was to provide Face Blind UK members with face blindness with an opportunity to receive an update on both the organisation and the current research, to be part of workshops looking at resources that might be developed and to meet together.

The meeting was held at Birkbeck, and a total of 12 people attended, including members with face blindness, directors of Face Blind UK and Birkbeck researchers.

Face Blind UK Presentation:

Hazel Plastow and Jo Livingston gave an overview of Face Blind UK and its achievements to date, including the development of the website, newsletter and leaflets, and a growing number of members.

Suggestions were made regarding fundraising including applying to NHS Innovations; direct donation via web.

Research Presentation:

John Towler with fellow researchers - Joanna Parketmy and Katie Fisher gave a presentation on the current n overview of research - covering a wide range of work in progress from the basic test materials to the

Questions were raised related to association with topographical agnosia, the link between autism and prosopagnosia, and face blindness running in families.

Tour of the Birkbeck Laboratories

Birkbeck kindly provided tours of their laboratories, plus the opportunity for some people to complete tests and receive their results on the day.

Workshops:

We divided into two groups to look at the current resources that Face Blind UK has developed and the priorities for future work:

Leaflets

Agreed that leaflets were good for providing practical advice and also for raising awareness. However, Group 1 felt the audience should primarily be people with prosopagnosia + peers (particularly younger people), while Group 2 felt that the main audience for leaflets were professionals. Discussions covered:

- The need for additional leaflets for parents, police and social workers
- Lots of suggestions for the current leaflet for schools (and the offer of input from a parent).
- Concern regarding the cost of printing and distributing leaflets.
- The current size of the booklet and use of bullet points both work well.

Newsletter

Discussions on the newsletter included:

- Criteria on which publications, research etc are included
- Need to be clear that we are reporting but not endorsing publications, research etc.
- Quotes etc need to be fully referenced
- An outline on face blindness is to be prominent on each issue
- Good to include anecdotes (e.g. have you ever...., can you tell....)

Website

Suggestions for developing the website included:

- An attachment summarising face blindness and its impact that can be printed off/emailed with college application etc
- Possibility of linking up with self-reporting 20 item test (John may be able to provide link/intro)
- Include link to Facebook support group run by Eileen from USA
- Include dyslexia analogy as this can work well to explain prosopagnosia

There was also a discussion about having online testing on the site itself, but this may be beyond both the resources and the remit of Face Blind UK at present

Twitter & Social Media

Face Blind UK currently only has a Twitter account. It was felt that this was fine for a younger audience, but that it was also important to have a presence on Facebook for the older, more established users of social media.

Talks to groups & Interviews with the Media

The talks and interviews seem to be gradually helping to raise awareness. Ways to develop this area of work were discussed:

- Scope for creating templates for talks (e.g. PowerPoint)
- Would be good to be able to offer talks nationally
- Interviews with media - wanting to spread the word but guarding against sensationalising

ID cards, badges etc

ID card - It was felt that this would be useful for people to use with police or visiting hospital

- Needs to look official
- Include NHS Choices with link, NHS Read Code, www.faceblind.org.uk
- Suggested wording "I have prosopagnosia this means I find it difficult to recognise and remember faces" ... "this is a neurological condition"

Badges - these would be welcomed as a good way of reminding others that you've told that you're face blind and possibly as an opening to explaining to others or to legitimize your difficulties -

- Small pin badge with just the logo
- Logo plus words - 'Please introduce yourself' - would need larger badge and discussed the problems this could present if complete strangers responded
- Different design for children - again discussed potential difficulties and vulnerabilities

Summary

The fact that this was a small gathering, enabled us to provide an friendly, informal meeting, with lots of opportunity for participation. Attendees reported that they had enjoyed the day, found the research update informative and were impressed by the achievements of Face Blind UK in its first year.

We plan to make this an annual event and will look forward to welcoming more members in 2016.