

# Face to Face

## Prosopagnosia Research & Community



Welcome to our fifth edition of *Face to Face*! We are excited to bring you our Summer 2012 issue, full of updated news on research and events, and interesting stories about the past and present alike. We hope to continue receiving your valuable feedback to these newsletters – tell us what you'd like to see in the Winter 2012 issue! Warm and sunny thoughts to you from Cambridge, MA; Hanover, NH; and Minneapolis, MN.

-Prosopagnosia Research Center (faceblind@faceblind.org)

### First Annual ProsoKids Weekend held at UMN

In the Fall of 2012, Sherryse Corrow, graduate fellow of the Yonas Perception Lab at the University of Minnesota, was on the phone with the parent of a child with prosopagnosia. The parent had an interesting suggestion – what if families of children with prosopagnosia came together to meet one another, share experiences, learn more, and provide support? After all, wouldn't it be easier if parents had the opportunity to know other parents who have been through some of the same struggles? And wouldn't it be great if these kids had the opportunity to meet other children who also experience face blindness?

After months of planning and dedication from undergraduates in the lab, this goal finally came to fruition. From Friday July 27<sup>th</sup> to Sunday July 29<sup>th</sup>, the Yonas Visual Perception Lab at UMN hosted the first ever ProsoKids Weekend 2012, which took place in Minneapolis. Eight families who all have a personal connection to prosopagnosia traveled from across the...

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Children who attended ProsoKids Weekend with Research Assistants (left to right) Tobias Donlon, Jordan Mathison, Kelly Gregg, Annie Undis, & Lauren Haas

### How Citizen Scientists Discovered Developmental Prosopagnosia

Prosopagnosia research has made a lot of progress over the last decade. That progress has critically depended on the interest and engagement of people suffering from prosopagnosia and their family members - people like many of you. In this article, I want to talk briefly about the way citizen science has driven prosopagnosia research. Citizen science is science done by everyday people rather than professional scientists. Citizen scientists generally have less training and access to resources compared to professional scientists, but they have their own unique set of observations that can contribute to scientific progress in sometimes unexpected and critically important ways. Many of you who read this newsletter are citizen scientists. You take part in experiments, share information about yourselves, but most importantly you pay attention to and share your experiences. Our understanding of prosopagnosia took a leap forward at the point that scientists began acknowledging people with face blindness as citizen scientists, who understand their own abilities, experiences, and limitations and are willing to share that knowledge with the community of professional scientists in hospitals and universities. I want to take some time in this newsletter to talk about how the contributions of citizen scientists created the field of prosopagnosia research as we know it today.

There are probably many versions of this story, beginning in many homes across the world when people with face blindness began connecting with fellow sufferers through the internet. The version of the story I'd like to tell starts with Bill Choisser. Bill Choisser is a self-described "long-haired man in jeans" who lives in the San Francisco Bay Area, who has suffered from deficits in face recognition his entire life and spent many years as an advocate for prosopagnosia awareness. Bill grew up in an Illinois coal-mining town and found that he often recognized other kids by their jeans. He also found when making friends as an adult that he tended to gravitate to other long-haired men in jeans.

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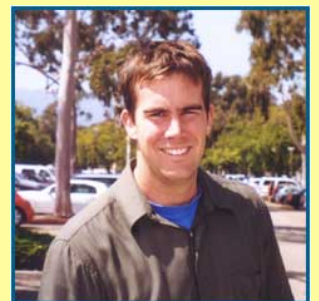
Bill didn't realize he had problems with face recognition until he was in his 40s, sitting in front of the television one day with his partner Larry. They were watching a television program together and Bill expressed frustration that t.v. programs never showed enough of a person's body and clothes. It was impossible to keep track of characters! Larry looked at Bill and said, "You don't need all that, you recognize the characters by their faces." To Bill, this bordered on absurdity; faces were impossible to recognize and all tended to look the same. So Bill took it upon himself to start asking around and observing others to see if they relied as heavily on faces to recognize other people as Larry suggested. This made Bill realize that he was relatively unique in his inability to recognize faces. He went to his doctor and asked whether he might have some sort of neurological problem that meant he couldn't recognize faces. "There's no such thing" his doctor said.

At the time, the internet was in its preteen years (young, awkward, but with lots of potential) and people were increasingly becoming connected with others in growing online communities. Bill decided to post a message on a forum for neurological disorders. The message said: "I have trouble recognizing faces. Anyone else have this problem?" Then he waited. Soon, he was contacted by someone who reported the same difficulties. Then a second and third person contacted him. A year later there were about 30 people communicating over the internet who reported lifelong difficulties with face recognition with no clear medical explanation. Glenn Alperin, an active member of the group, eventually came across the term "prosopagnosia" in the medical literature. The word seemed to describe the kind of problems that Bill, Glenn, and the other members of their online community were experiencing. But "prosopagnosia" is an unfortunate word: complicated, difficult to remember, and impossible to spell. Bill decided that since people who can't recognize certain colors are known as "color blind" it made sense that people who couldn't recognize faces should be called "face blind". So, in 1997, the term face blindness was coined and is now an accepted term among scientists and sufferers alike.

At the time, the research community was virtually unaware of developmental prosopagnosia / face blindness (that is, face blindness not caused by brain damage in adulthood). The disorder, if it existed at all, was considered very, very rare. There were a handful of reported cases, and it was unclear to researchers whether their deficits may be explained entirely by some form of early brain damage that was difficult or impossible to see on standard CT or MRI brain scans.

To any researcher studying prosopagnosia or face blindness, Bill Choisser, Glenn Alperin, and their growing face blind community offered a significant opportunity to learn about face blindness, face recognition, and the way the brain develops. When they approached research scientists who studied face blindness, however, the response was discouraging. Bill Choisser reflects: "None of the researchers we found had any interest in communicating with us. Some ignored us and some were condescending, while from their responses we could tell...we already knew much more about [face blindness] than they did."

So Bill and others decided it was up to them to learn about the disorder and create web resources for fellow sufferers. For example, in 1997 Bill created a website called "Faceblind!" that described his own experiences with the disorder and his ways of coping. Time passed, the community grew, but developmental prosopagnosia continued to be thought of as an extremely rare, virtually unknown phenomenon. In 1999, Dr. Brad Duchaine (then a graduate student) came upon Bill Choisser's website and got in touch with him. "I want to work with you to learn about this disorder," he said. Dr. Duchaine saw the opportunity, but, more importantly, recognized the importance of learning about face blindness with the community of sufferers. People with face blindness were collaborators: citizen scientists who could partner with professional scientists to learn (together) how and why face recognition was different for people with face blindness.



*Dr. Brad Duchaine, circa 1999*

In the intervening years we've learned a lot about face recognition and face recognition deficits: that face blindness runs in families, how variations in other abilities seem to be related to face recognition deficits, and how face recognition is just different for people with face blindness. We are also beginning to understand how face blindness might arise from differences in the way the brain develops. Most startling, however, is the realization...

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...that developmental prosopagnosia or face blindness is surprisingly common. Based on recent data, Dr. Nakayama and Dr. Duchaine estimated that up to 1 in 50 people have face recognition deficits severe enough to qualify them for a diagnosis of face blindness. It's not quite as rare as scientists thought! And all of these insights began with the face blind community and people like Bill Choisser and Glenn Alperin: people with a unique set of experiences, a healthy dose of insight, and the willingness to break new ground as citizen scientists.

We believe that scientific research works best when it involves a conversation between professional scientists and citizen scientists, like many of you. In the case of our work, this is a conversation between face recognition researchers and those of you at the front lines who have first-hand experience of face blindness.

So, in summary, thank you for making our work possible. To help us understand this disorder, we ask for your continued collaboration: by observing yourself, observing your own experiences, and (when you get the chance) sharing those observations with us. ▽ - *Dr. Laura Germine, Ph.D.*

## ProsoKids Weekend... continued from pg. 1

...country to attend this event, representing the states of California, Texas, Wisconsin, Minnesota, Illinois, and more. Guest speakers also attended the weekend-long meeting to give perspective on how prosopagnosia is recognized within the community, and what kind of research is being conducted to better understand the disorder. Guest speakers included: Stephanie Chase (an adult with prosopagnosia); researcher Sherryse Corrow M.A., Doctoral Candidate (2013), University of Minnesota; researcher Kirsten Dalrymple Ph.D., Post-doctoral Fellow, Dartmouth College; Kimberely Fletcher, Ph.D, UK Clinical Psychologist, University of British Columbia; Laura Hughes, Master of Social Work 2013, University of Wisconsin-Madison; Assistant Professor and Pediatric Neuropsychologist Dr. Kelly King Ph.D., L.P.; Albert Yonas, Ph.D., Professor, University of Minnesota; and school psychologist Jason Welch.

As Al Yonas, professor at UMN, and Sherryse Corrow guided the informational sessions, families were given the opportunity to share their experiences and struggles with prosopagnosia and how it affects their lives - both in positive and negative ways. The major goal of the ProsoKids Weekend was to foster a sense of community and support among the families in attendance. This goal was successfully met as one parent remarked, "It was comforting to be in a group of parents who were all struggling with the same concern." Parents also had the opportunity to ask questions about the state of the research today. More importantly, they shared their experiences with one another. They discussed topics such as what has worked for them regarding getting the special education system to understand and recognize prosopagnosia, how to discuss prosopagnosia with their child, and whether or not to discuss this disorder with others in their life.



*ProsoKids Weekend attendees &  
RA Bethany Israelson*

In addition, the eight children who attended were able to get to know each other, play games, make arts and crafts, and go on a fun trip to the local zoo under the supervision of Yonas Lab staff. At the end of the weekend, one child remarked, "When is the next ProsoKids Weekend?" The children seemed to have a wonderful time and the researchers were thrilled to meet them!

Overall, the weekend was an overwhelming success. Sherryse Corrow stated, "This weekend was truly amazing. It was so amazing to hear the experiences of all of these families, meet them face-to-face, and discuss areas of future research with them. It is my hope that these types of events will continue in the future so that families can continue to learn from one another's experiences and the research can move forward based on the needs of these children."

The Yonas Lab would like to thank all the local businesses that donated food, money, goods, etc. to the ProsoKids Weekend event. They were blown away by the generosity and compassion shown by everyone involved who helped make the weekend so wonderful. ▽

## What's Going On...

**60 Minutes, the American television news magazine, recently featured a report on prosopagnosia, presented by Lesley Stahl.**

If you missed it on television, you can access it on the 60 Minutes website using this link:

<http://www.cbsnews.com/video/watch/?id=7417242n>



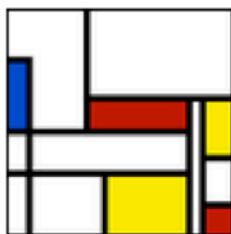
As many of you know, we conduct a lot of our experiments using the web as it lets us test lots of people from all over the world. Through our website, TestMyBrain.org, you can participate in an experiment and learn a bit about

yourself and your abilities, while contributing to advancements in our understanding of face recognition and other cognitive abilities. Since 2008, we've collected data from 600,000 volunteers – people just like you – who are interested in science and self-discovery.

This summer, TestMyBrain.org is getting a makeover. In addition to the usual set of cognitive tests, we will soon allow participants to create user accounts, save test results in their “brain profiles,” and share results on Facebook. We are also updating the look and feel of the site to make it easier to navigate and find information. We're hoping that TestMyBrain.org can provide a fun way for citizen scientists to learn about their own abilities, while also promoting public participation in science, and research awareness.

If you have feedback over the coming months on how we are doing, please let us know at [testmybrain@testmybrain.org](mailto:testmybrain@testmybrain.org). And if you know anyone who you think might enjoy contributing to research and learning about themselves, please send them the link!

## Test of Multiple Memory Types



2065 brains

How good is your memory? Are you better at remembering certain types of information?

Estimated time to complete: 25 minutes

Go!



## Where are YOU on the web?

Are you a member of the Faceblind group on Yahoo (<http://tech.groups.yahoo.com/group/faceblind/>) or Prosopagnosia group on Facebook (<https://www.facebook.com/groups/117013401655030/>) ?

Are there any other groups, blogs, or sites about face blindness that you visit on a regular basis? Please share with us at [faceblind@faceblind.org](mailto:faceblind@faceblind.org)!