### FACE TO FACE Prosopagnosia Research Center at Dartmouth

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WALKING THROUGH A WORLD OF WHERE'S WALDO: AN OT'S EXPERIENCE OF PROSOPAGNOSIA

#### RESEARCHER SPOTLIGHT

# What are your strategies for managing prosopagnosia?

In this issue, occupational therapist (OT) Maggie Tai Tucker discusses her experiences with prosopagnosia and the coping strategies she uses at work and at home. If you have strategies of your own to share, please send us a paragraph describing them. In a future newsletter, we'll publish a selection of strategies contributed by readers.

### Update on Developmental Prosopagnosia Project

Following COVID-related delays, our large-scale behavioral and neuroimaging study finally started to test people with DP this month. We can't wait to bring you updates on our findings in future newsletters!

### CLICK ON THIS IMAGE TO VIEW A NEW YORK TIMES VIDEO ON









### Walking Through a World of Where's Waldo: An OT's Experience of Prosopagnosia By Maggie Tai Tucker

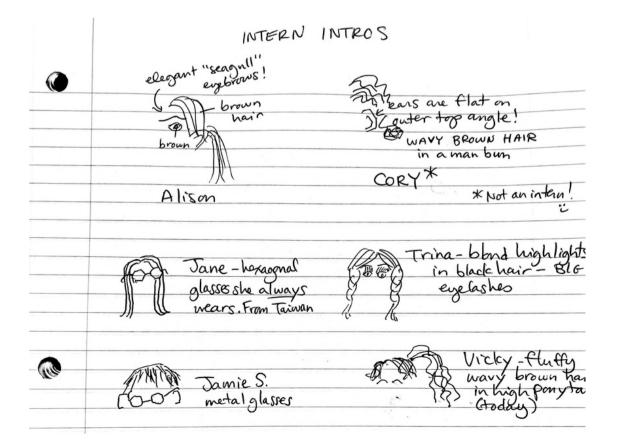
I first learned about prosopagnosia in 2000 as a student at the University of Washington. A biology professor mentioned facial recognition in a lecture, sending me searching online. I found a website titled "Prosopagnosia and Stones" that used boulders shown in different light and weather conditions to show how people's appearances can change in a way that stumps prosopagnosics. It was a lightbulb moment for me – other people can recognize each other just from their FACES?! It seemed wild. I was 29 years old at the time.

In terms of facial recognition, I had been blundering along for most of my life. Originally, I worked as a newspaper reporter, which was manageable as a prosopagnosic because every story's subjects were new to me, so I had to ask them their names no matter what. The people I interviewed were usually where I expected them to be, for instance behind the counter in a shop or sitting in their own offices. I didn't develop a lot of specific workplace coping skills during those years. I did okay identifying my colleagues, in part because they were diverse in age, hair color, clothing style, etc. And also because in a newsroom, everyone has their own little territory and pretty much stays in it.

In 2004, I returned to school for a Master's in Occupational Therapy. As an OT, I began working at a busy children's hospital doing feeding therapy. Again, patients were usually where I expected them to be. I could walk into the waiting room and call out their name as if I didn't see them, watching out of the corner of my eye to be sure of their reaction. In general, I don't have as much difficulty identifying children as I do adults. Children are all slightly different sizes and, at the hospital, they usually come as a set with parents, providing a greater number of traits overall to recognize the family by. With both outpatients and inpatients, there are many opportunities to confirm identity – charts, hospital ID bracelets, and so on. For the record, I never made an identification error as a journalist or as an OT.

I did have trouble identifying my hospital colleagues -- most of whom were white women in their late 20s to mid 40s. Fortunately, they wore ID badges. During meetings, I would sketch my colleagues and scribble notes about their features, something that I continue to do. Looking at my recent sketches, I noticed for the first time that I don't draw the person's facial features, only their hair type, eyebrows, and ear shape, the main items I focus on memorizing. I also forget the content of the drawings pretty quickly. So the sketches are mainly useful as a reference later. I keep my sketches (see sample below) in my work binder. I'll see someone in the office, say hi without attempting a name, think, "Hmm ... that's the woman with blond streaks in her hair," then peek at my binder and follow up a few moments later with a casual-sounding, "How's your day going, Trina?" Everyone likes to have that moment of connection, being recognized for who they are.

I'm married and have three children, non-identical twin boys, 18, and a daughter, 9. I used this same sketch reference trick for my older kids' friends when they started coming over en masse to watch movies, etc. I collected their names and parents' contact info the first time a bunch of them slept over, partly for safety reasons, but also so that I could sketch them to look up later as necessary. I can identify my kids' closest friends, and my closest friends' kids, without this type of aid. But the boys' more casual high school acquaintances remained friendly mysteries to me.



In 2016, I had a moderately severe concussion, but my facial recognition didn't get any worse. It's hard to get worse than very poor. I had to leave my OT job because I couldn't drive safely and was getting headaches from computer work. It took two years to recover, during which time I did volunteer work and cared for my family.

My level of prosopagnosia is such that I recognize my family members individually, but have trouble picking them out of a crowd. My favorite photo from the twins' graduation is of me and one of my sons taken backstage, right before the seniors entered the auditorium. I'm smiling widely in the photo because I'm proud of him, of course – but also because I'm relieved that I found him. I knew he was going to be among the first 10 students in the line up. I wasn't able to find his brother in time to take a photo with him. With more than 400 kids in black robes in the crowded backstage area, it was a lost cause.

Once, on a beach vacation, my husband stepped off the boardwalk with one of the kids and shouted back that I should come and find them when I was done shopping. I burst out laughing because it was literally a Where's Waldo page for me, down to the beach packed with blankets and striped umbrellas. Eventually, they had to come find me instead. Another time, I took a writing class that met three hours every Monday evening for eight weeks. On week seven, I was in the hall getting a drink of water when a woman started chatting with me. I politely asked if she was new to the class. It turned out that she was the instructor, who had been standing in front of us teaching for more than 20 hours at that point.

In 2019, I ran for local office and was elected to our city's school board. This role was a challenge for me because I met a lot of people who expected me to start recognizing them fairly quickly. That's when I started routinely explaining that I was more than just ordinarily bad with faces. The stakes were too high for me to pretend to recognize someone, for example if a parent or teacher came up to me after a meeting to discuss a district policy. One of my favorite regular Zoom meetings during 2020 was run by a principal who would put up a slide with photos of everyone with their names and roles listed, and keep it up for most of the meeting. That was so helpful to me.

My school board role forced me to get serious about adaptive strategies. If I know I am going to meet someone new at a coffee shop, for example, I create an entry for them in my phone address book. Then I find a photo of them on Facebook or

Google and save it to that entry. I glance at the photo right before walking in. I can usually retain enough about their appearance to recognize them within about 30 seconds. If I'm the first one there, I have to keep re-checking the photo because it fades from my mind after that. If I'm meeting several people, I might print their photos on a single sheet of paper as a cheatsheet, because if I look at a different address book entry, I will forget the first one. I sometimes intentionally arrive a little late so the group will already be clustered together and call out when they see me. I have a funny hat with a cow print, so sometimes I'll wear that and tell them, "I'll be the one in the cow hat," which makes it their job to recognize me.

When the pandemic hit, I returned to school to get a Master's of Social Work to help me address the mental health aspects of my professional specialty, pediatric feeding therapy. Online school is great for prosopagnosics because nearly everything is done on Zoom, so everyone's face is labeled. It's my ideal scenario. But halfway through my program, I started my practicum at a children's services agency. I had a hard time at first, because many of the staff worked in unlabeled cubicles. Someone would send me an e-mail saying "stop by my desk at 11 to discuss this case" and I would struggle to find them. When I told my supervisor this, she was very supportive. She got numbers and names added to the outside of the cubicles, and had everyone's badges reprinted with names on the back as well as the front. (Flipped-over badges are the bane of my existence!) She has also asked me to do an inservice training about this condition and how it might affect the occasional client. Due to Brad Pitt's disclosure of his face blindness, more people are now realizing that they may have this disorder while still in their teens.

Last year, I found a great support group for this topic on Facebook. It's the private group, not the public one. People in the group are quick to offer suggestions or sympathy, with a sprinkling of appropriately dark humor. That's where I learned about the research being done at Dartmouth and at Harvard. That's also where I learned that on Etsy you can buy badges that say "Let's start a conversation on … face blindness" and "Hello, I am faceblind, if I don't recognize you it isn't personal". I bought one of each and wear them at different times on my lanyard at the office.

Coming out publicly about this disorder has mostly been empowering for me. Even though my husband has known about it for decades, he still doesn't always think of it. We were at his company picnic recently and he kept saying, "Maggie Tai, have



you met so-and-so?" as he introduced me to his colleagues. After four or five repetitions, I pulled him aside to ask quietly, "Why are you asking ME that? Why don't you ask THEM if they've met MF?" That worked better. Since I've shared about my prosopagnosia on my personal social media, people have started identifying themselves to me when they see me out in the community. Even though this is exactly what I always thought I wanted, decades of faking recognition and covering up my uncertainty leaves me feeling mortified that they now know I probably don't recognize them on sight. But I'm sure I'll get used to it over time.

Socially, the biggest impact of this disorder for me has been feeling disoriented at parties. Imagine 30 or more people walking around whose faces are indistinguishable from each other after a moment or two. It would be a little nauseating if you saw it

depicted in a movie, for instance in a scene where someone has been drugged or poisoned. That's pretty much my experience at large parties. So I tend to just find one person to talk to and just stick with them. I do enjoy hosting parties of my own. I ask all guests to wear name tags. And I post a conversation starter question next to the name tags and markers so that there's an extra reason for people to use the name tags. Most of our parties are themed (for instance, a costume party to accompany the finale of a TV show), because then I have a built-in conversation starter, whether I know who I'm talking with yet or not.

I can recognize a lot of people I know once I hear them speak more than a couple of sentences or see their body language at the right distance (depending on the trait).

It helps that I know a fair amount about gait as an OT. I'm always watching how people stand and walk. Occasionally, this gets me into social trouble. The other day I commented that a friend had started limping, embarrassing her, which I felt bad about. It's just something that I take note of because that's part of my recognition system. Where I live, a lot of people have dogs with them out in public, which is great, since like many prosopagnosics, I have no problem recognizing individual dogs. It's still like doing a math problem for me to figure out who the human is, even if it's a quick one – "if this is Rocky, that must be Gloria."

I realized recently that I've always been drawn towards activities that don't require me to recognize people by face. I was active in Rotary Club before the pandemic. I loved that Rotarians wore 4-inch-diameter badges with their name and profession printed on the front. When I hear from prosopagnosics online who feel socially isolated, I encourage them to consider joining Rotary. In fact, I volunteered at the Rotary check in desk because people would come up and say their full name to help me find their badge, allowing me to have a friendly chat with each of them ahead of the meeting. I have also done a lot of volunteer work with dogs, such as dog training at a shelter and, currently, volunteering with my specially trained crisis response therapy dog in the aftermath of disasters.

If I had known I had developmental prosopagnosia in my teens, my life would have been different in some respects. I wouldn't have thought of myself as such a wallflower in college and my early 20s. I would have sought out smaller group social activities, and work settings where colleagues could always be found in specific locations. I would also have asked openly for support earlier in my working life, and probably avoided leaving a lot of colleagues with the impression that I was stand-offish. It might not have helped as much then as now, though, since workplaces weren't especially welcoming to non-neurotypical coworkers in the 1990s, when I entered the workforce.

How do I think my life would be different if I had typical facial recognition skills? Mainly, I think, wouldn't have to put so much effort into figuring out people's identities on a day-to-day basis. I love being around people, but I'm exhausted after dealing with large groups of them or with a series of them one after another. Not because I'm an introvert -- I'm not -- but because I'm processing information much more consciously than a non-prosopagnosic is. Imagine if you had to think about every single muscle movement to walk across a room without falling on your face. That's what it feels like for me to move around in the world identifying people. Everyone has their own way of conceptualizing this experience. For me, it's like everyone has a QR code on their face and I lack the built-in scanner that most people have. It's an amazing feat of processing that most people are performing when they take in, interpret, and recall facial data. And they don't even know that they're doing it.

*Maggie Tai Tucker* is an occupational therapist, currently pursuing her MSW, who lives on Mercer Island, Wash. She is a school board director and community volunteer. Her hobbies are baking, dog training, and urban chicken keeping. She recently started learning to play taiko (Japanese drums) and is enjoying the fact that a) it's not an activity that requires greeting people and b) her instructor requires every student to wear a big, bold nametag in class.

## **Recent Media Coverage**



(Elizabeth von Oehsen/The Washington Post)

Here's a recent article about prosopagnosia in the Washington Post. <u>https://www.washingtonpost.com/health/2022/09/17/what-face-blindness-</u> <u>means/</u>

### **Researcher Spotlight**

Three members joined our lab in Fall 2020. They have been working on the DP project for two years now. Get to know more about them below.

#### **Daniel Stehr**



Daniel joined our lab as a postdoctoral fellow. He received his PhD from the Department of Cognitive Sciences at the University of California, Irvine. There, he used behavioral and neuroimaging techniques to investigate how social perceptions are shaped by movements of the face and body. His interests are (broadly construed) action observation, face and speech perception, and attentional modulation of high-level vision. Daniel is originally from Canada and enjoys hiking and backpacking.

Alexis is a third-year PhD student in our lab. She graduated from the State University of New York at Geneseo with a B.A. in Psychology, and then spent three years in Chris Baker's lab as a research fellow at the National Institutes of Mental Health. Her research interests focus on using neuroimaging techniques to explore the interaction of vision and memory processing underlying facial recognition, and understanding the neural correlates of abnormal visual processing.

### **Alexis Kidder**



### Yiyuan Zhang



Yiyuan is our lab manager. He grew up in China, received a B.S. in Neuroscience from Baylor University, and followed by a M.S.E in Biomedical Engineering from Johns Hopkins University. During his master study, he worked with Michael Bonner and Janice Chen. He is broadly interested in the neural and computational mechanisms of high-level vision. He is also keen on building tools to help make cognitive research easier.