PROJECT TITLE: MyA: Multi-Biometric Vest for People Living with Angelman Syndrome

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Project Description

Angelman syndrome (AS) is a neurogenetic syndrome associated with severe developmental and intellectual disability. Symptoms of AS include very limited speech, difficulty sleeping, and poor motor function. AS is caused by a mutation or deletion of the UBE3A gene on the maternal chromosome 15 and is typically diagnosed in the early childhood period using genetic testing. At present, there is no cure for AS. Treatment is focused on supportive therapies and pharmaceuticals to manage seizures and reduce behavior problems. The AS community is motivated to find a cure, and several major gene therapy trials are underway to reduce or potentially reverse symptoms.

Despite increased investment in clinical trials, functional outcomes that impact the lives of people living with AS and their families remain widely variable. A major barrier to clinical trials is the lack of available outcome measures suitable for AS. Wearable devices that monitor physiological and behavioral output are promising solutions because they provide objective metrics of physiological function without requiring verbal or motoric input from the patient. However, typical wearable devices in form factors such as smartwatches and headbands are often not tolerable by AS patients. Using
input from AS caregivers from extensive focus groups (N = 8) conducted by our research team, we have designed MyA, a biometric vest that will measure several key signals relevant to AS (heart rate, respiration, vocalizations, temperature, and sleep), while meeting the unique sensory and tactile needs of the AS population. For our preliminary developments, we sewed conductive fabric and conductive silicone into separate commercially available athletic vests composed of primarily nylon, polyester, or polyamide. Our preliminary measurements of the electrocardiogram demonstrate the ability to capture key biosignals using our textile prototype. We were able to measure heart rate from the electrocardiogram within 2.4 beats per minute of a commercially available reference chest strap heart rate monitor with high correlation between the two devices (r = 0.88, p

For the proposed project, the student researcher will work closely with a senior member of the lab to integrate audio and video capabilities into the vest. Audio and video are important behavioral inputs that allow us to understand levels and styles of communication in people with AS. We would also like to understand how people with AS interact with others and their environment, and vice versa. The student will work with the senior member of the lab to validate each sensor on the benchtop and develop code that can be integrated seamlessly into the biosensor prototype.

This project is in collaboration with Purdue University Department of Psychological Sciences.