

ALS SOCIETY OF BC

3rd ANNUAL AWARDS FOR EXCELLENCE IN DESIGN TO IMPROVE THE QUALITY OF LIFE WITH ALS

August 1, 2009

A. Eye-Gaze Tracking Project Ideas

Introduction:

“Eye-gaze tracking technology is being developed for a variety of promising commercial applications. Eye-gaze tracking also has great potential for use as a primary communication technology for individuals in the advanced stages of ALS (Amyotrophic Lateral Sclerosis). In the later stages of this disease, neuromuscular control is progressively lost, resulting in a progressive loss of speech and body movement and control, but there is minimal loss of sensory perception, mental ability, brain function and eye-gaze. Unfortunately, eye-gaze tracking technology at present has some major limitations which have prevented its widespread use by persons living with ALS. Many of those limitations could be overcome by design improvements, and some design limitations/challenges are given below. We believe that the availability of improved eye-gaze technology could greatly improve the quality of life of those living with ALS, and if combined with mechanical ventilation and other assistive technologies could possibly extend life of a meaningful quality for a number of years, perhaps until the discovery of more effective treatments or even a cure.”

- Jim McEwen, Immediate Past President, ALS Society of BC

Commercial and prototype eye-gaze tracking systems are in use at Simon Fraser University (Tobii - <http://www.css.sfu.ca/sites/mcl/>), at the University of British Columbia (Prototype - <http://www.ece.ubc.ca/~craigah/>, <http://www.ece.ubc.ca/~peter/>), at the University of Victoria (CanAssist; Nigel Livingston), and by persons living with ALS who are members of the ALS Society of BC (Erica; www.eyeresponse.com) and Tobii (www.Tobii.com).

Project funds for appropriate materials and supplies are potentially available from the ALS Society. Projects are eligible for consideration in the 2nd ALS Excellence in Design Awards sponsored by the ALS Society of BC (with design awards of \$5000, \$2500 and \$1000). Details on the 2nd ALS Excellence in Design Awards can be found elsewhere.

A.1 Low-Cost Eye-Tracker Project

Issue: Current commercial eye-gaze tracking systems cost thousands to tens of thousands of dollars. The high cost of eye-gaze trackers prevents potential users from accessing eye-

gaze tracking tools. The hardware components required for eye-gaze tracking do not justify the price and a lower-cost alternative is desirable. Webcams may be used for low-cost imaging, along with simple infrared diodes for system lighting. Alternatively, visible light systems may also be investigated. Opensource eye-gaze tracking software is also available: <http://thirtysixthspan.com/openEyes/>

Goal: The goal of this design project is to develop a low-cost and usable eye-gaze tracking system based on simple commercial-of-the-shelf hardware.

Deliverables: A working prototype of a functional, low-cost (< \$200), eye-gaze tracking system.

A.2 Eye-Glasses Compensation Project

Issue: The use of eye-glasses can cause considerable problems in eye-gaze tracking. The issue stems from reflections off the eye-glasses due to the use of controlled infrared lighting (on and off axis light sources) used to highlight features of the face. The key features of interest are the pupils and glints (or reflections of the surface of the cornea). Incorrectly identifying the pupils and glints then results in invalid estimation of the point-of-gaze.

Goal: The goal of this design project is to develop techniques for either: 1) avoiding image corruption with eye-glasses on a commercial eye-gaze tracker, or 2) developing a controlled lighting scheme to ensure valid pupil and glints identification are identified in the presence of eye-glasses.

Deliverables: Two forms of deliverables are possible: 1) A working prototype illustrating functional eye-gaze tracking in the presence of eye-glasses with a commercial eye-gaze tracker, or 2) A working prototype illustrating accurate real-time identification of the pupil and glints using controlled infrared lighting (on and off axis light sources) in the presence of eye-glasses.

A.3 Innovative Selection With ALS and Eye-Gaze Tracking

Issue: As mobility steadily decreases in the more advanced stages of ALS, alternative techniques for selection are required. Current solutions include head switches, sip and puff switches and dwell time activation depending on the degree of mobility loss to name a few. The use of dwell time requires no mobility other than eye motion, however, this technique suffers from 'lag' in that the user must wait the dwell time duration for each selection, as well as the 'midas touch' problem in which unintended selection if the gaze point is stationary for too long.

Goal: The goal of this design project is to develop a technique for improved selection with eye-gaze for individuals with only eye-motion available. Possible solutions may

involve novel HCI designs for interaction, including various adaptive and predictive technologies, the consideration of contextual cues, and the introduction of ancillary inputs, such as EMG, EEG.

Deliverables: A working prototype illustrating eye-motion only selection with a commercial eye-gaze tracking system.

A.4 Novel and valuable eye-gaze tracking applications and application enhancements

Issue: To date, relatively few gaze-tracking applications have been developed. These include relatively simplistic applications such as the tedious typing of words, and even in such systems, little is done to ease the effort required, e.g., systems typically do not allow for the saving and reuse of words and sentences.

Goal: The goal of this design project is to develop one or more novel applications or application enhancements that take gaze as input, and that provide new efficiencies or capabilities that could significantly improve the quality of life of those living with ALS.

Deliverables: A working prototype illustrating one or more novel applications that take eye-motion as an input. The prototype must be developed and implemented to the extent that an evaluation of the potential efficiencies and/or reductions in effort can be evaluated by persons living with ALS and others on an evaluation panel.

B. Other Project Ideas (for Mechanical, E-Mech, Electrical and Computer Engineering, Engineering Physics, Engineering Science and Biomedical Engineering)

Introduction:

Reasonable funding assistance for appropriate materials and supplies for the projects outlined below is available from the ALS Society of BC. Project results are eligible for consideration in the 2nd ALS Excellence in Design Awards sponsored by the ALS Society of BC (with design awards of \$5000, \$2500 and \$1000 available). Details on the 2nd ALS Excellence in Design Awards can be found elsewhere.

B.1 Integration of Breathing and Voice Technology for ALS

Background: In the later stages of ALS (Amyotrophic Lateral Sclerosis, see www.alsa.org/als/what.cfm or www.als.ca/manual-whativals.shtml) neuromuscular control is progressively lost, resulting in a progressive loss of the ability to move, to speak, and to breathe. Many people living with ALS increasingly use BiPAP masks for

breathing assistance (eg see www.tpals.org/bipap.htm). These masks muffle the patients' already weak voices, and the 'wind noise' further impairs audibility. An SFU prize winning team from the first ALS Design Competition demonstrated signal processing techniques that do a good job of removing 'wind noise' and amplifying weak voices, but were hampered by the inability of the microphone to pick up clear voice sounds from behind the BiPAP mask.

Issue: Current designs of BiPAP breathing masks and prongs assist the breathing of persons living with ALS, but they also stop or limit their ability to communicate easily and naturally with their caregivers, family and friends. Although amplification and signal processing can improve intelligibility, a microphone apparatus that captures intelligible voice sounds from behind the BiPAP mask is a primary requirement.

Goal: The goal of this project is to develop, implement and demonstrate an integrated breathing/speech system suitable for use by persons living with ALS.

Deliverables: A system developed with and for persons living with ALS, having the following characteristics: it should integrate BiPAP and voice technology; it should substantially increase the volume and intelligibility of speech during periods of BiPAP assisted breathing; it should extend the period of time during which a person living with ALS can communicate well with caregivers, family and friends, as that person becomes increasingly dependent on BiPAP ventilation. In designing the deliverables, it is suggested that particular attention be paid to high-fidelity capture of voice sounds from behind a BiPAP mask.

B.2 Development of a Powered ALS Neck Brace

Background: In the later stages of ALS (Amyotrophic Lateral Sclerosis, see www.alsa.org/als/what.cfm or www.als.ca/manual-whativals.shtml) neuromuscular control is progressively lost, resulting in a progressive loss of the ability to move, to speak, to swallow, and to breathe. As neuromuscular control is lost by a person living with ALS, the ability to move his or her head to desired positions and keep it there becomes increasingly difficult and eventually impossible.

Issues: The progressive loss of head control in ALS creates progressive problems in breathing and speaking (airway is partially blocked), in swallowing and thus drinking and eating, in seeing objects (eg TV, computer), in seeing and communicating with others, and in moving in vehicles where a hazardous bobble-head situation may exist. Many designs of neck braces have been developed, eg for spinal-cord injured patients, but these braces tend to fix the head in one position, are not inherently dynamic to adapt to activities of daily living, and have many limitations from the perspective of a person trying to live life as normally as possible while coping with the progressive effects of ALS.

Goal: The goal is to develop, implement and evaluate a powered, dynamic neck brace for a person living with ALS. The powered ALS neck brace should overcome some of the major limitations of existing non-ALS neck braces, the powered features should supplement the natural but limited movement abilities of the person with ALS (eg to nod ‘yes’ or ‘no’, to locate ‘sip and puff switches for environmental control) and should adapt as the disease progresses, the brace might optionally serve as a useful platform for other assistive capabilities (eg voice pickup, eye-gaze tracking, mouse-like switches to complement gaze tracking) and the brace should represent a significant improvement of a prototype non-powered dynamic ALS neck brace developed previously by a team of 4th year mechanical engineering students.

Deliverables: A prototype of a powered, dynamic neck brace ready for demonstration and actual evaluation by person living with ALS. The demonstration and evaluation will be the key part of project completion. The assistance and advice of one or more persons with ALS will be available during the project.

B.3 “Design for manufacture” of a low-cost dynamic neck brace for persons living with ALS

Background: In the later stages of ALS (Amyotrophic Lateral Sclerosis, see www.alsa.org/als/what.cfm or www.als.ca/manual-whativals.shtml) neuromuscular control is progressively lost, resulting in a progressive loss of the ability to move, to speak, to swallow, and to breathe. As neuromuscular control is lost by a person living with ALS, the ability to move his or her head to desired positions and keep it there becomes increasingly difficult and eventually impossible.

Issues: No low-cost dynamic neck brace that overcomes these problems is available commercially, to allow persons living with ALS to move their head into a variety of desired positions, and to support the head in those positions for desired periods of time. The unavailability of suitable neck braces for ALS may be because any suitable braces that have been developed to date (eg one designed last year by a 4th year team of UBC mechanical engineering students) have not progressed past the prototype stage, and have not been designed or re-designed to be suitable for larger-scale, low-cost manufacture.

Goal: The goal is design a dynamic neck brace for persons living with ALS, so that the neck brace is “designed for manufacture” as a low-cost, larger-scale product that could be made available to every patient with ALS for improve the quality of life in the advanced stages of the disease. This might be accomplished by re-designing or by adapting the design resulting from a project completed last year by the 4th year team of UBC mechanical engineering student, or it might be designed more simply from scratch.

Deliverables: A prototype of a dynamic neck brace for persons living with ALS and suitable for large-scale, low-cost manufacture so that it could be made available widely. The prototype should be ready for demonstration and actual evaluation by person living with ALS, and should be suitable for evaluation by biomedical design engineers in the

meditech industry. The demonstration and evaluations will be the key part of project completion. The assistance and advice of one or more persons with ALS will be available during the project.

B.4 Design of improved, low-tech communication for ALS as speech and movement are progressively lost

Introduction: What simple design improvements could be made to existing low-tech, low-cost devices and strategies to allow quickest and easiest communication between someone living with ALS and their family, friends and caregivers? How could such design improvements best take into account gradual deterioration and loss of speech with ALS, and the progressive loss of movement and thus a progressive inability to operate a keyboard, mouse or switch?

Typically, at present, a person with ALS must have a way to hit a switch, blink an eye or otherwise make an indication. Present low-tech communication systems generally involve using a communication grid (letters) which can simply be virtual - an air scan - where letters which begin desired words are identified (a to g? h to m? n to z?), then scan through the identified group of letters to find the target letter, then attempts to predict the word or go to the next letter in the word with attempts to predict; a word is nailed, then the next, generally with ongoing guessing at the intended word, sentence or phrase; if not, return to letter scan to find the next word. This is readily demonstrated to students by professional staff, by a caregiver and/or by a person living with ALS. Many times caregivers must stand around for a long time while PALS using communication boards spell out a message letter by letter. Sometimes it is frustrating and not always possible for the caregiver to wait for the entire message. It has been suggested that a low tech device that could store a message until a caregiver could come and see the completed message would be beneficial.

This is currently the most common approach used to communicate when speech is lost, together with increasing loss of movement, as ALS progresses. It takes a great deal of time to learn and carry out, and requires a dedicated group of caregivers and family members who have taken time to learn a system. The result is time-consuming, tedious, imperfect, very limited in scope (ie, meeting basic needs comes first, quality of life second) and is very tiring for all involved.

Goal: To design a significant improvement to an existing, commonly used, low-tech communication device or strategy so that, based on an evaluation by one or more persons living with ALS, the improvement results in communication that is significantly faster, easier, more accurate, and/or requires less learning/training effort.

Deliverables: An improved prototype low-tech, low-cost communication device and strategy, suitable for evaluation by those living with ALS to determine the extent of any reduction in training time, reduction in time per use, improvement in accuracy and ease of use.

C. Creative Ideas, Solutions and Designs Developed By Those Living With ALS and Their Caregivers, Families and Service Providers

Background: Some of the most creative ideas, solutions and designs to significantly improve the quality of life with ALS can – and do – originate directly with those who have ALS, and with their caregivers, family members and professional providers of services and technologies.

In this spirit, anyone who has developed, implemented and used technology creatively to improve the quality of life with ALS may submit that solution for consideration for an Award for Excellence in Design. The Awards are also open to any such person who wishes to develop, evaluate, submit and be recognized for, a creative solution to a real and practical problem that is currently limiting the quality of life with ALS. Detailed information on the 2nd Annual Awards for Excellence in Design to Improve the Quality of Life With ALS can be found elsewhere.

Goal: The goal is to produce a creative design solution to a real and practical problem that currently limits the quality of life with ALS.

In a recent survey of needs conducted on behalf of the ALS Society of BC (copies of the detailed survey results are available on request), a number of specific ALS-related needs and opportunities for design solutions were identified and are summarized in Appendix A. They are not meant to be exclusive, but only to serve as good examples.

Deliverables: The design solution must be capable of demonstration to, and independent evaluation by, persons living with ALS and others on an evaluation panel.

Example: “Energy Management”

Background: People with ALS typically spend much of their lives in powered wheelchairs, supplemented with devices that control or assist with breathing, suctioning, communication, and other aids. Most of devices are battery powered, and it can be a challenge to assure there is sufficient energy reserve to assure mobility and support for critical functions, throughout the PALS daily activities, travel to appointments, etc..

Goal: The goal is to design safer, more flexible portable power systems, perhaps defined as "Integrated energy management". This would offer improved mobility and safety, perhaps prioritizing power distribution with run-down protection to preserve energy supply for critical items.

Appendix A – Additional Needs Identified in 2008 ALS Client Survey

1. Mobility

Wheelchair footrest repositioning:

The position of the foot rests on a wheelchair can be awkward for someone trying to get in and out of the wheelchair independently if they are unable to lean down and release the foot rest. It would be useful to have an automated system that would move the footrest out of the way when the user wanted to stand up.

Adaptable wheelchair back:

The positioning of chest straps on a wheelchair is variable, depending on the person using it. It would be beneficial to have a wheelchair back with adjustable positions for chest straps so that the wheelchair back can be shared in an equipment bank.

Door closer:

It can be difficult for people in wheelchairs to close inward swinging doors behind them as the handle can be out of reach once they pass through the door. One thing that was suggested was a hinge-mounted door closing mechanism that would extend out from the hinge edge of the door to allow someone in a wheelchair to close the door easily by pulling on it. *(A person in BC who has ALS is currently getting a prototype built and if it proves useful would like to find a way of getting it into production.)*

Alternative braking system for a walker:

People who have ALS and weakness in their hands can have difficulty using the hand-operated brakes on a walker. An alternative (foot operated?) braking system is desirable.

Automatic body turner:

Some individuals with ALS are waking their caregivers every 2-3 hours to turn them. If they don't get turned, they feel very uncomfortable, are at risk of longer-term pain and wake up feeling sore. Additionally, there may be a psychological need to turn. Rolling mattresses exist that can turn the patient 30 degrees to either side but often this is not sufficient, and an improved, automatic turner would be desirable.

2. Communication

Handheld writing pad (based on a PDA) with voice output

(A prototype has been built by the son of an individual in Kamloops who is living with ALS, and that prototype may be available for demonstration and evaluation.)

A method for a person living with ALS to communicate while lying down, when he/she is unable to speak.

Adaptable switch:

Finding a control switch that works with individuals in more advanced stages of ALS can present a challenge. An adaptable switch that could be altered as the individual's condition changes, without necessitating an orientation to a completely new device, would be useful. Applications are numerous: an example would be to help the PALS signal their caregiver of the need for suctioning, or other simple communication.

Personalization of voice communication devices:

It would be desirable for individuals living with ALS to have the option of being able to choose from a greater variety of different voices on existing communication systems. Ideally, a person living with ALS could record his or her own voice while that was still possible, so that their individual voice could be used later as part of a personalized, humanized voice communication system. *(It might be valuable to investigate the Model Talker. This is free communication software that allows a user to bank voice data. Samples are then used to provide synthesised text to speech which sound like the person who recorded the samples)*

3. Eating, Drinking and Feeding

Squeeze cup:

Many individuals living with ALS need to lean forward to drink (to close off the airway). There is a need for a 'sippy cup' that could be squeezed or pushed from the bottom to force the liquid into the mouth. As this would likely be used by someone with limited dexterity, there also needs to be a way to strap the cup onto the user's hand and perhaps assist with squeezing action.

Arm supports/assist to help with feeding:

It can be difficult for a person with ALS to lift his or her arms up high enough to drink from a cup (particularly the bottom). Existing arm supports (eg. the 'Arm Thing' and mobile arm supports) don't work well for many individuals with ALS. Setup can be difficult and time consuming, and it is often difficult to setup a person to achieve the right angles for feeding himself. 'Robotic' assistance might be useful in some form, but in a low-cost, simple, intuitive manner. There is also a need for effective arm supports that help the user with writing and typing.

Portable gravity bag holder:

Some people who are living with ALS, and who use gravity feeding, would benefit from a collapsible or telescoping feeding pole that could fit on the back of a wheelchair to be used when the individual is away from home. This may involve designing a universal adapter that could allow the pole to be mounted to a variety of different wheelchairs.

Feeding tube holder:

Many people living with ALS who use tube feeding have a feeding tube that is approximately 6-8 inches long extending from their belly. As this often gets in the way, or appears conspicuous, it would be good to have something to contain and hold the tube in place. Some persons with ALS and their caregivers have used creative solutions to hold this into place including: tying the tube around the waist with a piece of gauze; putting it in a Velcro pouch that is attached to a belt; securing it to a piece of elastic attached to a string around the neck (so that the elastic allows for inadvertent movement of the tube). A better, integrated design solution would be desirable.

Sliding refrigerator shelves:

Getting things out of the refrigerator can be difficult for people with limited arm strength and dexterity. A system that would allow a shelf to slide out, similar to how some cupboard shelves slide out, might be useful, especially if it could be retrofitted to existing refrigerators.

4. Breathing and Ventilation

Increased portability of suctioning/ventilation equipment:

Suctioning and ventilation equipment is heavy and cumbersome and needs to accompany a mobile individual with ALS everywhere. It would be desirable to have a rack that would allow the ventilation and suctioning equipment to be quickly and easily positioned onto the back of a wheelchair.

BiPAP masks:

Persons with ALS have stated that existing BiPAP masks are not comfortable and there are often issues with skin irritation and breakdown. Also, saliva buildup can also be a problem. BiPAP masks should be designed to accommodate different shapes of faces and people who wear glasses. Masks should be designed so as not interfere with a user's field of vision (eg. when watching TV). Also, BiPAP mask design should reduce the physical barrier created creates in front of the person's face so that facial expressions and emotional contact are not unnecessarily diminished.

Simulation and Training Aids:

While many people living with ALS eventually require mechanical ventilation support, others do not. They do have in common, the need for clearing their airways regularly as their natural mechanisms such as swallowing, are diminished. In the Home-Care setting, the role of suctioning frequently causes anxiety for the new "lay Caregiver". Training aids which can help to overcome these concerns would have much potential benefit. Ideally, such aids, or "simulators" would be able to represent the airway in both its natural, or "altered" state, (IE by tracheostomy) .

5. Quality of Life

Clothing design:

It is difficult for people with limited hand/arm strength and dexterity to dress themselves. It is also difficult for caregivers to dress people with ALS who cannot help with dressing. There is a need for easy to don/doff clothing designs for people in wheelchairs. There is also a need for clothing designs that would allow a person with ALS to undress for the bathroom more easily. In particular, zip flies and buttons are difficult. Some suggestions have included: man's pants with a front fly opening similar to what is found on men's pyjamas, and pants with an opening in the back with a wrap-around.

Toothbrushes:

Some individuals with ALS who are unable to bring their hands up to their mouth to brush their teeth support their arms on the sink and then lean over the toothbrush. Long handled electric toothbrush with alternative grips might be useful.

Handles for support pole

Holding onto a support pole can be difficult for someone with reduced grip strength. One idea that was suggested was to have handles on such poles that could be adjusted to different heights and then locked into position.