

# **Bionics and Cybernetics: Not Just for Movies or Books Anymore**

By Jen Payne  
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Being struck down by a fatal disease is not something anyone wants to think about, but it does happen. The human body is a complex system with checks and balances that helps to keep it healthy. One of the things our body has to help keep it going at optimum is a Negative Feedback Control System. This system is inhibitory and opposes a change such as body temperature. This helps maintain a constant internal environment. For example, if the temperature decreases, the receptors in the skin will send a signal to the brain, which then sends a message to the muscles to shiver that works to restore equilibrium in the body.

Yet sometimes the body cannot handle an illness on its own. When this happens, we often seek our doctors looking for a cure. The doctors set up tests to help determine the problem, and if possible, they can prescribe anti-biotic medication or suggest surgery to rectify the condition. Although doctors have at their disposal an arsenal of things that they can do to help patients, there are also diseases that have no cure, no corrective therapy and a gruesome prognosis.

Amyotrophic Lateral Sclerosis is a fatal degenerative disease that affects the motor neurons, leaving the patients with a life expectancy of 3-5 years. It is referred to as ALS, though it is more commonly known as “Lou Gehrig’s Disease” after the baseball player who was diagnosed with it in 1939 and died in 1941. Other times ALS is referred to as (MND) for Motor Neuron Disease as it affects both upper and lower motor neurons. It does not matter if you are diagnosed with familial ALS in which a genetic factor is involved, or Sporadic ALS where there seems to be no genetic factors. Both have the same prognosis, incurability.

If there is no cure, how can we help those with ALS live as much of a normal life as possible until a cure is found? Men and woman living with ALS in 2009 between the ages of 35-75 years of age in northern New Hampshire who suffer from the isolation and frustration caused by the loss of motor neurons, and bodily functions can find that the use of bionics and cybernetics today can help with communication, self-reliance, independence,

and dignity while alleviating some of the burden off their loved ones and caregivers.

A little over 5,600 people in the U.S. are diagnosed with ALS each year or about 15 new cases each day (Amyotrophic Lateral Sclerosis Association, 2009). That is 1-2 people per 100,000 that have or will develop ALS per year. ALS is most prevalent in men and women between the ages of 40 and 70, although the disease sometimes affects those in their 30's.

The symptoms of ALS either tend to start as muscle weakness or muscle fasciations in any part of the body, although usually in the legs or arms depending on which of the upper or lower motor neurons are affected. When the motor neurons stop sending impulses to muscles, the muscles begin to waste away, causing increased muscle weakness. Patients might also suffer from muscle twitching or cramping as the motor neurons die. Often times there are bulbar and spinal muscle involvement in which cranial nerves are affected (Caroscio 1986). This causes patients to suffer from problems with swallowing, difficulty in chewing, and slurred speech (wiki/bulbar palsy, 2009). About 43% might experience unstable emotions where a patient will have uncontrollable bouts of laughter or crying when pseudo bulbar palsy is evident (Caroscio 1986). Although ALS affects physical movement, eating, talking and eventually breathing, it does not effect eye movement, sexual function and bladder and bowel control (Carocio 1986.)

Unlike a common cold, in order to diagnose ALS patients who go to the doctor with weakness or muscle twitching need to be referred to a neurologist who can properly administer the test Electromyelography (EMG.) There are two kinds of EMG in widespread use: surface EMG and needle (intramuscular) EMG (Electromyography, n.d). To perform intramuscular EMG, a needle electrode is inserted through the skin into the muscle tissue. Intramuscular EMG a surface electrode may be used to monitor the general picture of muscle activation, as opposed to the activity of only a few fibers as observed using a needle (EMG, n.d). X-Rays, MRI's and CT scans can also be performed to help properly diagnose ALS.

Jenifer Estes wrote in *Tales from the bed* "The phrase itself-motor neuron disease-didn't conjure up anything specific. But I knew it was bad. Instinct ordered me to leave my body and supervise from above. My spirit hovered over the scene, trying to make sense of a new phrase-and what I sensed was going to be a whole new life" (p 11, 2006).

Unfortunately, the first signs of having ALS mask themselves as fatigue or stress, and doctors usually recommend exercise and relaxation without realizing that there is a bigger underlying problem. My father, Nick, was very active when his symptoms of muscle twitching started to manifest. We often shrugged it off when he would complain that he could not push the lawn mower, or use the nail gun building his shed. Since he was in his early 70's, we figured that it was his age, and not ALS. When he finally did go to the doctors, he was sent home with a prescription for rest and lots of it. Months went by, and he continued to get a little weaker every day, but his doctor continued to send him home with no answers. This situation is extremely common. Albert Robbilar, who wrote *The Meaning of a Disability; the Lived Experience of Paralysis*, went to three different doctors before he got a definitive ALS diagnosis months later. Even 7 years after the book was published, with all the new technology at a medical practitioner's disposal, my father was misdiagnosed several times before finally being sent to a neurologist and getting a diagnosis in 2006.

I spoke with Dr. Cohen, a neurologist at Dartmouth-Hitchcock Medical Center in Lebanon N.H., who is also my father's doctor, on May 27, 2009. I asked him what is it like for him to give grave news to patients. He sighed, took a breath and said, "It is always hard, very hard, but I feel it's important to develop a doctor-patient relationship first so I hold off on telling patients for as long as possible. This way they can feel that I am able to help them better cope with the news." He went on to say, "Most the time, the patient goes right into denial, asking for their records and even second opinions."

I went on to ask him how many patients he is dealing with now, and how that affects his job. He sighed again, "I work with about 50 patients, all with different degrees of ALS, and get about 2 new patients a month. I don't want to give patients false hope, this disease has no cure as you know. It does not affect my job as I try to do my best for them. I also try to refer them to our physical therapists, psychologists, and nutritionists to help patients deal with the disease as it progresses. There really is not a whole lot more that I can do."

After speaking with Dr. Cohen I thought about the other end of the spectrum. How did my father take the news that he has a fatal disease with no cure?

I called my father and asked him when his first symptoms started, and his reply was, “I had my first symptoms in the fall of 2004, and in 2006 I was diagnosed with PMA or Progressive Muscular Atrophy, but by 2008 Dr. Cohen said it was predominately ALS.”

I went on to ask him how the news affected him. He said, “I denied it. I thought it has to be something else. I have always led a healthy lifestyle, never smoked or drank, daily exercise, eating vegetables, vitamins and supplements, how could this happen to me?” I said, “So you were angry?” He replied, “Yeah, I guess I was, but more so as the disease progressed and I have lost more and more functions.”

I went on, further asking him about his doctors and his reactions to them. My first question was about his primary doctor and how this person helped him understand and cope with the disease. He said, “Dr. Kate Smith of Summit Medical Group in Littleton, New Hampshire, has been totally useless and uncompassionate to the extremes of not pointing me in the right direction, and making appropriate referrals to the doctors who could give me the help I needed, when I needed it.” The frustration of not knowing for so many months made my family angry, but even worse was the diagnosis. Nick was losing functions in his arms, and he could no longer write his own signature by the time he was diagnosed with ALS. So, I went on to ask about Dr. Cohen. He replied, “The doctor and I knew I wasn’t ready to hear the diagnosis but your mother insisted. When he did finally tell me, he suggested I take anxiety, depression, pain and spasm medications, and suggested I go to the monthly support groups.” I knew about the support groups so I went and asked him how his first one was. His response, “Once, and it was difficult because there was a 31 year old man, hooked up to breathing machines. He was so young, and so I could not bear to see that. To know that one day I will be in that same position is dreadful.” As difficult as it is for patients to understand their diagnosis and have physician-patient relationships it brings up another issue. Support groups can both be beneficial and painful. Mrs Payne, who I also spoke to briefly said, “It might be comforting to understand what another ALS patient is going through, but it also is a gateway into seeing your inevitable future.”

This is essential information about support group, and how patients and families view other victims of ALS. My last question was if he would ever consider the use of bionics or cybernetics. His answer was, “No, I don’t think I would. I just don’t know enough about them, and I doubt if they

would help.” His answer brought me up short, as I did not expect him to say no. I explained what I knew about them, but he just said, “I don’t know Jen” repeatedly. Again, this was not the answer I thought my father would give, so I knew I had to interview people who were more positive about the possible helpful aspects of Bionics and Cybernetics.

Knowing how my father feels about bionics got me into thinking about where the research was at this point in history. “Research is to see what everybody has seen, and to think what nobody else has thought” (Albert Szent-Gyorgyi n.d).

Research into what causes, stops, and prevents ALS has been a very difficult road. French doctor Jean-Martin Charcot first described ALS in the late 1800’s as a progressive Motor Neuron Disease. Since then, research has gone into overdrive with hospitals and clinics working together to find the root of the disease.

Research teams are focusing on genomes, genetics, brain and spinal cord neuronal defects, protein levels, metal toxicity, and environmental elements such as locations that could cause ALS.

Some of the most recent studies that have been focusing on the genome have found certain markers that correlate with shorter or longer survival with those with sporadic ALS.

John Landers from the Massachusetts Medical School and colleagues from around the world have conducted a “genome-wide association” looking at genes to determine ALS risk and survival factors (Muscular Dystrophy Association[MDA.org], 2009). The research conclusion is that they have found a Survival Gene.

The research was conducted in the United States and Europe and comprised of 1, 821 patients with sporadic ALS, 2,258 without ALS, and 1,014 people who have died from ALS. They found a single variant in the gene for KIFAP3 (Kinesin Family-associated protein 3) that significantly correlated with ALS survival time (mda.org, 2009).

The study concluded that patients with the chromosome 1[which are in pairs] with protein KIFAP3 on both had a survival time of 14 months longer, than those with the variant on just one or none. The researchers believe that

having this variant helps reduce toxic molecules from entering nerve fibers. They note that lowering KIFAP3 production or changing the interactions of this protein with other proteins might be worth investigating as an ALS therapy (mda.org, 2009).

Another study which is ongoing by Dartmouth-Hitchcock Medical Center in Lebanon New Hampshire, working with the University of New Hampshire, Wyoming-based Institute for Ethnomedicine and the New Hampshire Department of Environmental Services is looking at a possible link between algae found in Lake Mascoma, and a significant increase in patients with ALS living around the lake.

Elijah Stommel, a DHMC neurologist who has been mapping cases of the disease in New Hampshire, Vermont and Maine, says, “There's clearly a cluster of ALS around that lake.”

The algae is known as cyanobacteria, a photosynthetic, single-celled organism that commonly occurs in New Hampshire and Vermont lakes and ponds... forming a blue-green scum on the water surface, according to the DES Web site (Gregg, Cox, 2009).

It has been researched that cyanobacteria has a neurotoxin amino acid BMaa (B-Methylamino-L-alanine) which has been found in the brains of dead ALS patients, further strengthening the link between cyanobacteria and ALS. Paul Cox, the executive director of the ethnomedicine research institute in Jackson Hole, Wyo, said “a small percentage of the population might be vulnerable to the neurotoxin... the hypothesis is that in those people it can trigger neurodegenerative diseases, including ALS.” This is very important when you consider the men and women living in Northern New Hampshire who spend their summer days in and around the lakes.

Cyanobacteria exposure is believed to potentially occur through a variety of means, including drinking, showering, swimming, boating or eating fish from infected waters (Gregg, Cox, 2009).

Dr. Stommel's research team will be seeking a federal grant from the National Institute of Environmental Health Sciences in order to analyze water, and hair samples from other surrounding lakes in NH and VT for a link. Dr. Stommel said, “Brain and spinal cord tissue samples from some of the ALS patients who died would also be analyzed for the study.”

The men and woman living in northern New Hampshire between the ages of 35-75 who have ALS could greatly benefit from the knowledge of what possibly caused them to develop this disease. It will not be enough to alleviate the isolation, or frustration of having this disease, but it might be enough to put their minds at ease that it is not their fault. I know that my father feels responsible for getting the disease, but if this research can prove the link between cyanobacteria and ALS, perhaps he and others can stop blaming themselves.

Studies like these are just two of hundreds that are going on all over the world. So much more research is needed in order to understand the disease, and to develop therapies that can help in either in stopping or slowing down the disease.

Learning about the investigation being done at Lake Mascoma, I decided to head home to New Hampshire to interview people at Dartmouth-Hitchcock Medical Center's ALS Clinic in Northern New Hampshire. On Wednesday July 8<sup>th</sup> I arrived at DHMC with my father, who also had an appointment there, and together we headed inside to 3C – the neurology department.

I presented myself to the nurse who said I could sit in the lounge. Not long after, a man in a wheelchair followed by a woman came in and sat across from me. I introduced myself, and my purpose to interview patients. The woman agreed to participate and introduced herself as Mary, and her husband Fred.

Fred is a 58-year-old man, diagnosed in 2005 with Sporadic ALS. He does not look his age as his hair still has tufts of brown in it, and his skin is remarkably smooth for being almost 60. I asked him how the diagnosis has affected him emotionally. He heaved a big breath and said, "At first the fear of losing the ability to move was gripping. I set out to do as much as possible while I could." I asked him what kind of things he set out to do. Mary laughed and said, "Everything – golfing, swimming, hiking, and spending weekends on his four-wheeler, he was never home, until his legs weakened too much." He continued saying, "the isolation now is sometimes unbearable, but I have my wife to keep me company which helps" He smiled, and looked at her in adoration. She patted his hand and said, "We do what we can to get him outside, but it's hard, especially when it is raining,"

I asked Fred how he was feeling today, and his wife decided to answer for him: "We are having an okay day. The morning was rough, and the drive here is long, but we both seem to be in good spirits." I nodded and smiled and went on to ask Fred about Bionics and if he has done any research on it. They both just shook their heads no, so I continued on relating the information that I have learned so far about bionics and cybernetics and how scientists are working on using brainwaves, or "thoughts," to help patients regain some mobility. Mary said, "It sounds fascinating, but a little too science fiction, yet if it would help my husband, we would try anything." Fred bobbed his head up and down in fervent agreement. I then asked my last question of what would you want bionics to do for you to make your life easier. Mary looked thoughtful for a moment, then looked at her husband, turned back to me and said "breathing." To me, this is a strange answer since all he wanted to do before was walk and be outside, so it is interesting that he would choose breathing as his bionic choice. I didn't get a chance to further elaborate another question on this newfound knowledge as he was called into his appointment. This is a disappointment, as it is an answer I can only guess at.

After a few minutes another man named John sat in a chair down from me. I turned to him, and asked if I could ask him some questions about ALS. He smiled a very sad smile and said okay.

John is a 51-year-old male, diagnosed on April 21, 2009 and is currently residing in St. Johnsbury Vermont but has lived in Whitefield, NH for years. I asked what were his first signs that something was wrong. He said, "difficulty breathing and my right arm and shoulder hurt, and I couldn't lift it with out straining." I smiled an encouraging smile in hopes to make him comfortable, but he just continued to look gloomy. I asked him how he was feeling today. He shook his head, and his ears turned a bit red. He said, "I'm angry, I have no hope, and I resent God that I have this disease." The anger in his voice was very apparent and also understanding. I asked him if he has heard about bionics. He shook his head no, so again, I went into the details about the research I have done. He actually looked a little happier, and when I asked him if he would consider a bionic if it were available, he replied that he would. I gave him my best smile, and asked what would he want it to help him with? He quickly replied, "I guess walking. That is what I fear losing the most. Yeah my breathing and eating are important, but to be able to go for walks. I can't bear to lose that, even with a wheelchair I will someday have." I was about to thank him when he said, "I'm more than

willing to help out, and apologize if I came off upset, I'm just having a rough day. Everyday is rough, but today I had a hard time getting up to come here." I told him that it was fine, and not to worry about it. He seemed pleased and even a little bit more hopeful now that I told him about the bionics that someday might be available.

My dad was called into his appointment a moment later, and so I thanked John and went over to the magazine area when I noticed a man in a wheelchair and a woman dressed in scrubs come in. I almost ran out of the room at that point. This person was strapped in completely to a wheelchair, and had a tracheotomy to breath. I had to close my eyes to clear my head as I thought of my father having all that equipment attached to him someday. I turned around when I heard a computer-animated voice speak up and say, "Hello Everyone, I'm Dwayne." My heart started to thump a little as I heard and saw he was using a computer to speak. I shook my head in fear that I would be offending them in some way by looking back at him. I took a brave breath and approached him, and quietly asked him if I could interview.

I watched him move his eyes around his computer screen, and listened for his reply, "Timely process, but okay." I quickly told him, I have time if he has time as his nurse just looked at me before taking a seat. Dwayne was diagnosed when he was 39, and is now 50 year's old, living in Lebanon NH. Wow, he has had the disease for 11 years, that is very impressive, and I could not help but tell him that. I asked him how he was feeling today and his reply was "excellent." Again, I am blown away by his good-natured attitude, like when he came into the room and introduced himself. Perhaps this is a key reason why he has lasted so long with the disease. It is no secret that if you give up on yourself when you're ill you might not get better as quickly, so maybe with ALS if you have a happy attitude you'll last longer. Moving on, I asked him about his machine, and he said, "It [EyeMax system] has helped with talking to my caregivers and doctors." I pretty much had that idea when starting this report so I headed onto the next question; what kinds of things has he done to fight ALS. He said. "China, 5 years ago for stem cell implants, but it did not work." This shocked me because of the controversy surrounding stem cell research and I became extremely disappointed in this new knowledge; I was betting all my chips on it being the future cure for ALS. It is still early in stem cell research so there is still time for a cure to be found. Dwayne did not seem upset and after a few minutes he said "Its okay, there is still hope."

I went on to thank him as my father came back from his appointment. I learned so much through this experience, and talking with others who have the disease. Each one has their own unique idea on what they would want out of bionics, and it shows me the value they put in what would make their life better. The patients completely mesmerized me, and the information I gained from them really nailed it in for me on how much bionics or could mean to someone who once had little hope.

“It is of practical value to learn to like yourself. Since you must spend so much time with yourself you might as well get some satisfaction out of the relationship” (Norman Vincent Peale n.d).

One of the challenges of bionics and cybernetics in today’s world is not just about cost, or availability, but the values of the people choosing to use bionics or cybernetics. As humans, we place so much value on materialistic items, and what we can accomplish like running a marathon or building skyscrapers that we do not stop to think about what we would do if we were to get a disease like ALS. Likewise, if a person is diagnosed with ALS, does he or she have family support, friends, or something they are striving to accomplish like writing a book? On the other hand, are they alone with little to no family, and have nothing left they feel they need to do? If you are an accomplished hiker, or swimmer, then slowly losing your body to the disease can be the scariest thing of all. If you cannot fathom losing the ability to walk, and do not believe in using bionics or cybernetics, then you might choose to die before that disease strips you of walking. It is a personal choice to use bionics or cybernetics, and not something someone should jump into lightly. It is something to discuss with friends and family, but it is ultimately your choice alone to make.

One might also ask themselves, “What does it mean to be human?” If you decide to use bionics or cybernetics, does it make you less human? This is one of the most difficult questions to answer. Sean, who writes the blog [EverythingIknowiswrong.blogspot.com](http://EverythingIknowiswrong.blogspot.com), has a good idea of what it means to be human. He writes, “How can people be so blind as to be able to ask questions about “quality of life,” as if only a certain quality of life makes one human. Are people human only when they have full use of all of their limbs and faculties? What about paraplegics? Quadriplegics? People with low IQ’s? People with blue eyes; brown skin? When a stroke victim cannot speak, are they less human; when they re-learn speech, have they somehow regained their lost humanity; when they are paralyzed in one half of their

body, does that mean that the value of their life is cut in half? Or is their life, as I believe, just as valuable as ever, but a little more difficult?” (Sean, 2005) Although this does not answer the question of what it means to be human, it does bring up the idea of how one values a human life. It is a question with no clear-cut definition and many interpretations, but it is something to consider when choosing a bionic or cybernetic that is more than just a computer. You have to decide if bionics or cybernetics is the right course of action.

“Affliction of the tongue and throat and the inability to talk is especially depressing for the whole face becomes merely the imprint of that despondency” *The Cancer Ward* by Solzhenitsyn (p 161, line 25).

Speech is our most primitive means of communication. Even before words, there were grunts from our caveman ancestors, which slowly evolved into coherent sentences. We use our ability to speak to share our thoughts, concerns and to increase our understanding of the world we live in. Children who do not learn to speak are at a disadvantage emotionally, socially, and academically, but when you are an adult, it can cut you off from the world.

It is one thing to be born a mute because there are avenues like sign language that can be used effectively for communication. ALS patients on the other hand not only lose their ability to speak over time, but they also lose the ability to use their arms, so sign language is not viable. This brings up more frustration, anger, and isolation as the patient can no longer effectively communicate with their doctors, loved ones, and friends.

Communication allows us to be a part of the world, not just a bystander watching the world move. We all want to be an active participant in our life and communication is a key element in being able to do so. It can give back some joy, and some hope to go on living, even when you know the disease eventually will win.

“The essence of isolation, at least for me, resides in the inability to indicate through my own bodily behavior and speech the analysis of others’ preceding and subsequent utterance and bodily behavior” (Robbilard, 1999).

I personally cannot relate to this, but those with ALS do. This is the hardest part for people who suffer from ALS because over time they lose their ability to move and speak. They become locked in to their body, while their

mind remains sharp and focused. It is a terrifying experience as the body becomes a prison for the mind. They have lost what we take for granted every day. Things like walking, stretching, talking, and breathing. Activities that we enjoy like singing, swimming, running, hiking, and sports like baseball and basketball become impossible. How then does one deal with the constant state of not being able to move unless they rely on family, friends. The values of having bionics or cybernetics now and into the future can greatly improve a patient's outlook on life. The mind is a fascinating network where possibilities are nearly endless, and so we need to continue to understand how the mind works.

"I think it is fair to say that personal computers have become the most empowering tool we have ever created. They're tools of communication, they're tools of creativity, and they can be shaped by their user" (Bill Gates, n.d.).

Although, there is no cure, there are ways in which our new technology can greatly improve the quality of life for those living with ALS, loved ones, and caregivers. The investigation about bionics and cybernetics has been a fascinating and enlightening experience that I see so much potential in.

Bionics and Cybernetics were once nothing more than a good read in a science fiction novel, but the times have changed. Now a day such things are possible with our ever evolving technology and understanding of the human body and its mechanisms. It is often portrayed in movies and books that having bionics would enable a person to be faster or stronger than an average human, which is really just a misconception. Our technology has not yet reached that point, but it has come far enough that we can now use the idea to further research and to help those that otherwise are at a disadvantage.

Bionics is a term which refers to the flow of ideas from biology to engineering and vice versa (bionics-history n.d.). On the other hand, Cybernetics refers to the science of communication processes and automatic control systems in both machines and living things: a study linking the working of the brain and nervous system with the functioning of computers and automated feedback devices (encyclopedia.com n.d.). There is a rapidly growing interest in bionics and cybernetics with the development for real time interaction with computers in which people with disabilities gain functions, such as talking, and moving limbs. The brain is still very much a

mystery to researchers, but great strides have been made in the last 10 years.

A neurobiologist, in 2000, Dr. Miguel Nicolelis, implanted electrodes into a monkey's brain that could move a robotic arm using thoughts. Dr. Miguel Nicolelis told Christine Soares, editor of *Scientific America*, "... What we were doing was to record the brain activity that Aurora [the monkey] was producing to generate arm movements and after a little bit of training, both Aurora and I, we were able to basically get these signals to be decoded in real time and translated into digital commands that could be used by a robotic arm to generate movements that Aurora was imagining" (Soares, 2008).

Dr. Miguel Nicolelis is a leader in neurobiology research into how the brain transmits and receives information by thought, rather than by action. His research has paved the way for new and improved technology for those with diseases such as ALS or spinal trauma. Although there is nothing on the market that you have to implant electrodes, research is ongoing by doctors and researchers such as Miguel Nicolelis to help those with debilitating neurological diseases.

The research teams over at BrainGate, Dr. John Donoghue, Dr. Leigh Hochberg, and Dr. Arto Nurmikko have crossed another milestone for neurologist in the BrainGate2. This new system records brainwaves turning thoughts into action. (BrainGate, 2009). It comes with 3 major components, the sensors and a decoder, which "sends the information to a computer or communication device which then can move a powered wheelchair, a prosthetic or robotic limb, or, in the future, a functional electrical stimulation device that can move paralyzed limbs directly" (BrainGate, 2009).

The potential to restore function after paralysis is only one benefit of harnessing the power of intracortical signals (BrainGate 2009). At this point and time though, this is not available to the public, and who knows how much it will cost, and how well it will work. Right now its just speculation, but they have come a long way in advancing how bionics could one day be used.

One of the most advanced technology companies today actually has a riveting history to it. The 1984 hit sci-fi movie *The Terminator*, where the world goes apocalyptic in the future from nuclear war perpetrated by artificially intelligent computers and cyborgs has a hair of truth to it. The

companies in the movie that were responsible for the world's damnation were Skynet and Cyberdyne systems. What we create today is just a stepping-stone for the future and that is exactly what these two companies were. If not for those companies, than the future in *The Terminator* never would have happened.

The reason I bring up *The Terminator* and the companies involved in the plot of the movie is that in Tsukuba, Japan, there is a company called Cyberdyne, which is a leader in cybernetics. Yes, Cyberdyne is a real company, and not something the world should fear just because it was in a movie. Their focus is on "Robot Suit HAL" (Hybrid Assisted Limb), which is a cyborg-type robot that can expand and improve physical capabilities (Cyberdyne, 2009). Where some people might see malevolent foreshadowing in the fact Cyberdyne in the movies is doing the same thing as in real life, I see potential for the future. What is fascinating about their technology is unlike BrainGate, which attempts to pick up the signals coming from the brain, "HAL" can pick up weak biosignals on the surface of the skin by a sensor attached... to the wearer (Cyberdyne, 2009). "HAL" catches these signals and the power unit is controlled to move the joint... with the wearer's muscle movement, enabling to support the wearer's daily activities (Cyberdyne, 2009). This is what we call a 'voluntary control system' that provides movement interpreting the wearer's intention from the biosignals in advance of the actual movement (Cyberdyne, 2009).

"HAL" is expected to be applied in various fields such as rehabilitation support and physical training support in [the] medical field, ADL support for disabled people, heavy labor support at factories, and rescue support at disaster sites, as well as in the entertainment field (Cyberdyne, 2009).

What makes "HAL" so extraordinary is the computer immediately analyzes how much power the wearer intends to generate, then calculates the adequate amount of power to assist...the process is completed a fraction of a second earlier than the muscles actually move (Cyberdyne, 2009). The implications of this new cybernetic technology are almost unlimited. A person with ALS might actually be able to walk again, if only for a limited amount of time. The battery that comes with "HAL" lasts about 2 hours and 40 minutes, which is amazing.

Now the first question I had was how heavy is it? A person with ALS would not have the muscles to hold the exoskeleton up to use it. The answer is

“HAL” weighs approximately 23kgs, or 50.7 lbs, but the exoskeleton supports its own weight (Cyberdyne, 2009). With the assistance of caregivers, it might still be a pain to strap on the exoskeleton, but to gain back movement is an unbelievable gift to an ALS patient.

According to the Cyberdyne website, “HAL” is unfortunately only available in Japan, and hopefully soon to the EU. In addition, more research is being done on if “HAL” can pick up signals from someone with spinal cord injuries and possibly even ALS, but it is something to look forward too.

With these types of advances in bionics, and neurology, there is a shimmer of hope for those who suffer from ALS. By gaining back some independence, mobility, and communication these patients do not have to see their disease as the end of the road.

One thing that strikes me as worrisome about the use of bionics or cybernetics is the price for such procedures, computer systems, and upgrades. The rich will have no problem facing this challenge, but most ALS patients are on fixed incomes and must rely on the government to help ease the costs of even the most basic home health care costs.

When taking into account the costs of everyday living for patients with ALS it would seem reasonable to overlook the idea of bionics. Patients need anything from powered wheelchairs with tilt, recline, and power leg lifts that can easily cost several thousand dollars, to other important everyday costs such as paying home nurse aids, speech therapists, physical therapists and so on. In the advanced stages, care can cost up to \$200,000 a year (ALS association, 2009).

There are of course ways to help cover some of those costs. Medicare can help cover a good portion, if not all of the basic needs for ALS patients. Once someone is no longer able to work, Medicare can covers in-patient hospitalizations including surgery, treatments and inpatient medications, but will not cover custodial home care and only limited skilled in-home care (Lyon, 2001). Unfortunately, most people with ALS require a variety of adaptive devices around the home to assist with activities of daily living... Medicare does not cover the expenses for most assistive/adaptive equipment (Lyon, 2001).

As for products that are available now with the use of bionics and computer

systems, price range varies from just a few dollars, to the extremes of close to 10,000 dollars. The most used product is the alphabet board that is priced between 5 and 25 dollars. This allows the patient to “eye” certain letters, while another person plays a guessing game, hoping to pick out the right letters to spell words. The problem with this is obviously communication when after spelling something out, the interpreter does it wrong, causing confusion and frustration to both the patient and caregiver. It is also extremely time consuming and impossible to hold a steady conversation.

The higher end devices used in communication, and close to bionics, is the DynaVox Eyemax System. The lowest price is \$7,645 for the DynaVox V. The high end DynaVox Vmax costs \$8,420 and offers 1 GB ram, with screen resolution of 800x600, and the accessories cost \$7,000 dollars alone. What is paramount about this product is that people of all ages and cognitive abilities can use the EyeMax System with direct vision in one or both eyes (DynaVox, n.d). The program calibrates to the eyes and can follow the movement around the screen, much like a mouse. The person then lets their eyes dwell on the screen they want or they can choose to blink. One man, Augie Nieto, a well known fighter of ALS has been using the EyeMax DynaVox system since September 2008 and uses it to generate speech, send e-mails, have video conferences via Skype [Internet phone access] and even write a book (Quintero, A 2009). It [EyeMax] provides freedom for limited head movement, eliminating the need to manually focus the system (DynaVox, n.d.). Individuals can use the EyeMax System with...ALS (DynaVox, n.d).

Another device that can help with using a computer is the Impulse Switch with Bluetooth technology. The price is steep at \$2,100, and a 120 pack of electrodes cost \$90 dollars a pop, but being able to use your computer, hands free has some advantages. This little device uses sensing electrodes that perceive tiny muscle contractions. Combining this wireless power with popular accessibility programs such as EZ-Keys allows users to fully control their computer with the smallest muscle activity (“Impulse“ n.d.).

In this day and age, people use computers for everything, from online shopping to keeping in touch with other ALS patients on the ALS forums. These products can have a huge impact on a patient’s well being because it allows them to communicate with others with less frustration and confusion. It also enables caregivers to understand patient needs by ways of communication.

So then, how would one go about getting monetary assistance for devices such as communication computers or HAL that can greatly improve the quality of life?

The best way to help in covering costs, any costs, is to host a fundraiser in your hometown, or nearby city. This also brings the community together in the fight against ALS and the continued awareness of patients who struggle with the disease. This can also greatly boost moral of all those involved. It can look like hosting a fundraiser would be a daunting experience, but it is as simple as organization. What you really need in order to be successful is a theme with a budget in mind, menu of food, or entertainment, sometimes both, and a presentation on ALS, and how the money will be used. Get friends together to help pitch in, and take some of the tension away when organizing an event.

Another way to help get assistance is through your local hospital. They can help provide avenues in finding product, and sometimes can even offer assistance when available in the means of loaning equipment. Sometimes, its just as simple as getting something small that can greatly help make daily life a little bit easier.

Overall, I propose that the government should team up with a non-profit organization that would work with the companies responsible for making bionics and cybernetics to get patients the equipment needed for free or for a discount, where the government would pay for the rest. Those with ALS who suffer from the loss of movement, communication and independence as the disease progresses can then gain back some of their self-reliance, dignity, and hope for the future. Fundraisers and Medicaid are great in coping with the amount of daily living expenses, but in order for patients to get the new technology they need to have a more fulfilling life then the government and non-profit organizations need to come together and become the solution.

In Addition, when an ALS patient dies the equipment would then go back to the companies to be refurbished and then re-supplied to the next patient. The companies could even go further and upgrade the equipment as our ever-evolving technology expands. Just because a family cannot afford bionics or cybernetics does not mean that the government should not step in and try to help them obtain equipment.

It might be a belief that the government cannot help in this situation. Perhaps it is because our government is approximately 11 trillion dollars in debt as of August 2009 ([usdebtclock.org](http://usdebtclock.org), n.d). Although Medicaid and Social Security are at a surplus, it is estimated that Medicaid will be depleted by 2017, and Social Security by 2037 (Crutsinger, 2009). This is of course the biggest deterrent in not being able to get the government to pitch in with the costs of bionics or cybernetics for ALS patients. The current recession is a truth we have to face every day, and there is no sign of it stopping any time in the near future. This could put a damper on an organization getting together to work on the proposal for the government to chip in.

Then again I think that if an organization should arise to the occasion with a well thought out proposal then the government would listen. The government might not do anything right away since they will pull out all the red tape possible, but with enough persistence this proposal could come to actualization.

There is so much more the government could do to ease the costs of daily living, but also in helping the patient and caregiver with being able to live a more fulfilling life.

So I have come to believe that because this disease is fatal, and there is no treatment to eliminate symptoms, the best possible way to fight the disease is through keeping the patient as mobile and communicative as possible. This allows the patient to become self-reliant and independent again.

Living with this disease is a scary experience, and without hope it can leave the patient depressed, angry, and isolated. With the help of these aforementioned technologies and solutions, it is my hope that at least some of these painful issues can be alleviated. Furthermore, it will allow caregivers some peace of mind because the patient can gradually learn to do some things on his or her own. Since the burden of care usually falls upon the families of victims, the knowledge that they do not have to constantly hover over their loved one to help with every experience can be extremely beneficial for both parties, and the smallest victories can become cause for the greatest celebration.

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