Dear Readers,

The purpose of this letter is to help you understand ALS and the people this disease affects. A couple of years ago the famous Ice Bucket Challenge raised over $100 million for the purpose of research, raising awareness, and helping those afflicted by this fatal disease. Sadly, many people participating in the Ice Bucket Challenge had no knowledge of the disastrous nature of ALS or the tremendous physical, emotional, and financial burden this disease places on its victims, family members, and other caregivers who step up to help.

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. The progressive degeneration of the motor neurons in ALS eventually leads to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose the ability to speak, eat, move and breathe.

There are approximately 30,000 people living with ALS in the United States at any given time; the number worldwide is estimated at around 450,000. These numbers are hard to estimate accurately because the disease takes time to diagnose. Accurate diagnosis is somewhat dependent upon the type of insurance and financial means a patient has at his disposal, and the fact that availability and quality of medical care for neurological diseases varies from country to country. One of the reasons for the low number of people living with ALS is that the disease usually kills its victims within two to five years after diagnosis.

ALS typically begins in a limb then spreads to other parts of the body. Bulbar onset ALS starts by attacking the muscles that control swallowing, speech, and respiration. Pseudobulbar affect (PBA) is a symptom that affects 15 percent to 45 percent of people with ALS, especially those with bulbar onset. It happens when ALS or certain other neurological diseases or injuries damage the area of the brain responsible for controlling what we typically consider to be the normal expression of emotion. The damage can affect brain signaling, short circuiting the normal system and causing episodes of involuntary crying or laughing.

Even though ALS is a disease that affects motor neurons, it is not without pain throughout the course of the disease. Pain is often something overlooked by the medical community when dealing with people with ALS. One of the most common types of pain that can come early in the disease is cramping. A muscle cramp is a sudden and involuntary contraction of a muscle. If you've ever been awakened in the night or stopped in your tracks by a sudden charley horse, you know that muscle cramps can cause severe pain. Some people with ALS experience severe cramping in various muscles. Another type of pain in ALS is caused by spasticity. Spasticity is a condition in which there is an abnormal increase in muscle tone or stiffness of muscle, which can interfere with movement, speech, or be associated with discomfort and pain. Spasticity is usually caused by damage to nerve pathways within the brain or spinal cord that control muscle movement. Symptoms may include *hypertonicity* (increased muscle tone), *clonus* (a series of rapid muscle contractions), exaggerated deep tendon reflexes, involuntary crossing of the legs, and fixed joints (contractures). The degree of spasticity varies from mild muscle stiffness to severe, painful, and uncontrollable.

I've visited ALS forums where people with ALS and their caregivers were willing to provide me with suggestions, feedback, and ideas of helpful things to say and do; things that aren't so helpful; and general comments on what life looks like as a person with ALS (PALS) or a caregiver (CALS) of someone with ALS.

The following comments came from these brave people. Understand that some of them type with one finger, use eye gaze technology to communicate, or some other unconventional method of posting on these forums. Their caregivers are tired, stressed, worn out, and unsure of what comes next.

These are some of the things people with ALS want you to know:

- Some of my doctors know more about this than I do. But not many, and virtually no one else. So, if you are a medical professional, consider that in this situation the patient living the disease might know as much as or more about it than you do.

- I am not likely to get better. That is a fact accepted by a few people I know but disregarded by the masses. Telling me I look better is certainly a friendly thing to do, but I also know that it is not the truth.

- I have lost a lot of weight. I started out on the chunky side. Now I am described as thin. Quite a few of those around me comment on how great I look because of the weight loss. What they don't understand is how much effort I have put into keeping my weight up where it is.

- Back when I was walking, I often received comments about how slowly I walked. Yep. I walked slowly, but I still walked.

- My voice is weak, but that does not affect my intellect. I am still the same person inside, even though I have difficulty communicating at times.

- My capacity to do things is extremely limited. I have about two good hours on a good day. I want to get the most out of life during those times.

- I have no intellectual impairment and I can hear just fine. Please don't shout.

- Yes, I am young. It is rare, but it happens. I worry for my children.

- The little cold or tummy bug you have could kill me.

- My life is not over. I have a lot left to offer. If something is hard to do today, I want to do it. Next week it may not be possible.

- Please speak to me. I can hear even though I cannot talk. If I need to write the answer to your question on my communication board, please give me the time to do so.

- Talk to me about things. If you want my opinion, please ask. If there is something I can do to help you, please ask.

- If you are a caregiver outside the family (therapist, visiting nurse, hospice care) find out about me and talk with me about things I find interesting or important. Please do this even if I appear unaware.

- Ask me if you can pray for me or with me. Take time to find out my spiritual needs and also the spiritual needs of my caregiver(s). If you feel comfortable in doing so, help support those needs.

- If you're visiting me and find it difficult, try bringing over a movie or offer to read to me.

- I really appreciate leg and foot massages. Even though I am paralyzed, I still have working sensory nerves. Massage also helps circulation and is good for both my health and comfort.

- Try to find time to understand the technology I'm using (breathing devices, power wheelchairs, speech technology for the computer, transfer equipment.) You might be able to help my caregiver and provide her with a break.

- Some of us can be in a lot of pain from muscle spasms and loss of muscle and fat around nerves and joints. If you are one of our health care providers, please address the needs associated with pain. Decreasing the level of pain can mean the difference between a good day and a horrible day.

- Medical marijuana should be legalized in all States for ALS. I have to travel across state lines to get the type of medical marijuana that helps my pain. It doesn't even have much THC in it so I don't get high.

- When I was first diagnosed, many people offered to help. Please make good on your promise. The more I progress, the more help I will need. There are so many things you can do to help me. Here are just a few: Cook and deliver a meal for my caregiver and me; go grocery shopping for me; do a few loads of laundry; help clean the house; drive me to the doctor, to a park or the beach, to church, or to visit someone; take my dog for a walk or to the vet; ask my caregivers what they need.

- Have a listening ear. No advice needed, just listen. You may hear me cry and lament at times or you may hear me laugh. Just sit there and listen while I can still talk. Converse with me when you have the words. When I can't talk anymore, come talk to me. Bring a friend and talk to them in my presence. I may not be part of the conversation speaking-wise, but just to listen to something other than the TV or books on tape is a good thing. Break apart the monotony of my existence with tales from the outside world. Keep electronics out of it. My world consists of electronics and I don't want to see things on your phone. I want to see your face, hear your voice, see a live, fully dimensional person instead of a flat-faced, unmoving photographed Facebook face and typed words. I get enough of that. Bring me flowers to look at. Bring your pet for me to see. By all means, bring your baby! I want to see babies. Put their cheek on mine so I can smell their newness. Take me outside, if you can, so I can see the trees and feel the air and listen to the birds.

- Please ask my permission or my caregiver's permission if you plan on bringing someone or something (pet) with you.

- Please don't tell me about magic cures, lotions, and potions. Discussing this with me just uses up my very limited energy. Energy we could be using doing something valuable.

- I can still feel everything. Massage my feet, legs, hands, and arms.

- Please, please educate yourself on ALS. You can be such a value to me if you understand this disease.

- Each one of us with this disease is different. What might be a critical need for one PALS might not be necessary for another. Take time to understand my needs and know that they will change as I progress.

- Many people with ALS have other health issues that complicate treatment such as diabetes, depression, or heart disease. Some people with ALS cannot tolerate various medicine because of the side effects. Something as simple as constipation can be a medical emergency to a person with ALS.

- If you have a special skill, please make it available to us. ALS is financially devastating, even with the best of health care insurance. My caregiver can only do so much and it breaks my heart to see her worry so much about my needs while neglecting her own. She needs someone to help her with our money, do light cleaning around our apartment, and cook a few crockpot meals a week.

- I have waited months for a BiPAP machine to help me breathe at night. I am on Medicare with the richest supplement plan money can buy. Over half of my monthly income goes to health insurance premiums, drug co-

pays and supplements. The wait on top of the financial burden makes my suffering so much worse. I have no idea how I will be able to afford home health care of any kind. I tried to get long-term care insurance years ago but was denied due to an insignificant pre-existing condition. If you are reading this and have any influence with legislatures, please help us.

- I am afraid of being abandoned by my family and friends. Some have already left. I feel like I need to walk on eggshells and put on a happy face for people to want to be around me. I feel like I can't complain because I will be considered negative. When people leave, I cry. Please let me be real with you. It's the only way I can get through this disease.

- I'm terrified my caregiver will get sick or leave. The pain in his eyes breaks my heart.

- I can't get comfortable in my chair or in my bed. Sleep is my only relief. I've tried all the muscle relaxants and most of the pain medications. I get furious when I read ALS does not affect sensory nerves, only motor nerves. Constant spasticity and muscle cramps prevent me from enjoying my family.

- Our local ALS Chapter doesn't support the needs of its patients and caregivers. We make a huge effort to get to the meetings but clueless speakers are brought in to waste our time and our important questions go unanswered. Why can't someone approach hospitals, doctors, and medical equipment suppliers in our area to organize fundraisers where the money directly benefits the patients? We need to raise funds for in-home help, remodeling as to provide a safe place to live, vans that accommodate our chairs, and other necessities to keep living. As a PALS, I cannot do this. My CALS is too busy and worn out that he can't do this. Somebody must be able to help us. Perhaps someone could write a grant.

- If your PALS belongs to a church, please get the congregation involved. Most of the members won't understand what ALS does to a person. Take the lead and help them to understand and get involved volunteering. Talk to the priest, pastor, or other religious leader to find out if he or she has suggestions that might help your PALS.

- ALS has affected the part of my brain that controls emotional expression. I may laugh or cry in a way that makes you uncomfortable. I know that my response is inappropriate, but I cannot make my body obey what I am feeling inside. When this happens, I may leave the room or look away from you so that I can regain control. Please ignore these outbursts as they are quite embarrassing.

These are some of the things caregivers of people with ALS want you to know

- If it is too uncomfortable for you to ask the PALS about ALS, please ask me.

- If you are a close friend with the PALS, try to keep that bond until the end.

- Remember that the person with this horrible disease is completely aware of what is going on. His or her mood might reflect fear, anger, or hopelessness. Other times, he or she might be happy, relaxed, and friendly. Please don't take offense, just love them.

- When you first find out about a friend, co-worker, or loved one has been diagnosed with ALS, telling them you're sorry and that you care about them is most appropriate. A gentle hug, a hand on the shoulder, or another warm gesture will be appreciated. Never underestimate the power of human touch.

- If you offered to help when you first found out about the ALS diagnosis, please continue to ask as the disease progresses and make yourself available to the caregiver. We've all heard, "If there's anything I can do, let me know." We've heard it many times. Please don't make empty promises. I tell everyone who has asked this question that we are fine right now, but the day will come when I will need your help. Follow up with the caregiver frequently.

- I've found that most people are shocked when they learn about my husband's diagnosis, so I overlook the blunders that some people make when I first tell them. When people are told of a disease that is always fatal and has no effective treatment, they grasp for something meaningful to say. I realize that these folks have very good intentions. The best thing you can say is, "what can I do to help?" If you feel you cannot help, it's best not to offer.

- I wish all our close friends would research ALS and be prepared to help, even if it is in some small way such as grocery shopping or mowing our lawn. If ten people could donate two hours a week, that would be a blessing. I feel that I'm in over my head and really need family and friends to step up now.

- Never compare ALS to other diseases. ALS is not cancer. With cancer there are many treatments that can prolong or even save lives. Not so with ALS.

- Please don't tell me or my PALS how bad we look. We know.

- We've heard all the stories about alternative treatments and we've tried many of them out of desperation. We have both spent hundreds of hours researching treatments online, in person, through ALS clinics, and communicating with other patients and caregivers. The best thing you can do for us is to find a way to help in our daily struggle.

- The lack of general knowledge by medical professionals about neuromuscular diseases is astounding. We have met emergency room nurses and doctors, primary care physicians, and specialists who have no idea how to treat restrictive airway diseases. I understand that every medical professional cannot know everything but basic information and the ability to assist should be available.

- My PALS has been cleaned and made presentable for your visit. The before and after can be quite different.

- When you visit our home, please understand that things are organized for my PALS' convenience. Please help me keep things organized in a way that promotes effectiveness and efficiency in helping her.

- It takes a minimum of two hours to get my PALS fed, medicated, showered, and dressed in the morning. Then I need time to clean up and get myself ready. Please understand that early appointments are very difficult for us. If you are visiting, we won't be up and going very early.

- My PALS cannot stand and I cannot lift him, so we try to schedule our outings around his bowel movements. If we misjudge, he's stuck wearing a dirty diaper, and that is no way to socialize. We try to be on time when we make plans, but sometimes it's just not possible.

- We often cannot predict when my PALS will need to sleep all day. If you've planned a visit, please don't be offended if your visit is with me.

- Depending on the stage of ALS, a PALS might be able to function pretty well or need 24/7 care. The latter requires continually monitoring him or her, adjusting the bed, repositioning arms and legs on the bed, turning

to avoid bedsores, adjusting the BiPAP mask, feeding, making transfers or emptying urinals and responding to a variety of other issues while he or she sleeps.

- Many caregivers survive on very little sleep because the PALS' breathing alarm goes off, interventions such as cough assist and suctioning must be done throughout the night, and shifting the PALS' position to avoid bedsores has to be done.

- Please don't let me and other caregivers down. You must be reliable no matter how small the task might be.

- Most CALS don't have time for lengthy chats on the phone. They are too busy trying to tend to constant needs throughout the day. Please don't be offended if I have to cut our call short.

- As a caregiver, the things that have helped me the most are cooking meals, buying groceries, and staying with my PALS while I run out to go to my doctor. Someone organized a meal train for us where various neighbors in our condo took turns bringing over a healthy meal each night for several weeks. Another person helped organize a respite time out for me for three hours, two days a week. I was able to go for a massage, get my hair cut, and work out.

- If you are a nurse or other health care provider, please consider donating an hour or two of your time to help someone with ALS.

- While my PALS is sleeping during the day I am very busy trying to get caught up while keeping one eye on her. I often eat on the run or while I'm cleaning. If I sound rushed, irritated, or confused, please understand.