

## LIVING ~~AND~~ WITH A.L.S

JUST RECENTLY I WAS DIAGNOSED AS HAVING A.L.S AND AM AWAITING CONFIRMATION FROM A SPECIALTY CENTER. FOR A LITTLE OVER A YEAR NOW I HAVE EXPERIENCED A LOSS OF MOTOR CONTROL OF MY LEFT LEG, PRIMARILY BELOW THE KNEE. I CANNOT WIGGLE MY TOES, STRETCH MY CALF REFLEXIVELY, OR WALK WITHOUT MY TOE DRAGGING ON THE GROUND AS I TRY TO BRING THE FOOT FORWARD. SO IN COMPENSATING FOR THIS AFFLICTION I WALK WITH A VERY NOTICABLE LIMP. AS THIS CONDITION PRESENTED RAPIDLY, WITHIN A SPAN OF FOUR MONTHS, I FOUND MYSELF DEPRIVED OF MOST CARDBO EXERCISE AVAILABLE. I CAN NO LONGER DO JUMPING JACKS, RUN, WALK AT A HIGH PACE, OR ANY OTHER THING THAT REQUIRES LEG STABILITY.

DURING THE EARLY STAGES, I WOULD NOTICE MUSCLES IN MY LEFT QUAD TWITCHING SPORADICALLY AND AT TIMES IT FELT AS IF AN INDIVIDUAL MUSCLE FIBER JUST DIED. FOR A LITTLE OVER A YEAR I WAS TOLD THAT I WAS A "MEDICAL MYSTERY", AND BECAUSE THERE WAS NO DIAGNOSIS NOTHING MEDICALLY COULD BE DONE FOR ME. NOW AFTER SPENDING A HALF HOUR OR SO, FACE TO FACE WITH A NEUROLOGIST, I DO NOW HAVE THAT DIAGNOSIS. UNFORTUNANTLY A.L.S IS THE DIAGNOSIS WHICH HAS NO CURE OR TREATMENT. I GUESS I AM BLESSED THAT ONLY MY LEG IS AFFECTED DIRECTLY AT THIS TIME, IT COULD BE WORSE AND WILL GET THAT WAY EVENTUALLY. I AM NOW WAITING TO GO TO THE A.L.S CENTER AT UCSF TO HAVE THE DIANOSIS CONFIRMED OR REFUTED, WHEN THAT WILL HAPPEN I DO NOT KNOW.

MUCH OF THIS AILMENT IS A MYSTERY TO ME STILL, MY MIND

IS FILLED WITH QUESTIONS AS TO HOW, WHAT, AND WHY A.L.S  
ATTACKS THE BODY. HOW DID I GET THIS? WHAT IS ACTUALLY  
CAUSING THE NERVES TO DIE? WHY IS THERE NO TREATMENT? I  
UNDERSTAND THE NO CURE, BUT WHY HAS THERE BEEN NO TREATMENT  
DISCOVERED TO ALIVIAE THE SYMPTOMS OF MUSCLE TWITCHING AND  
CRAMPING?

I LOOK FORWARD TO HEARING BACK FROM ANY AND ALL WHO  
WISH TO OFFER INFORMATION AND ADVISE ON THIS ISSUE.

ALSO I JUST RECEIVED WORD THAT THE REQUEST FOR A  
SECOND OPINION FROM UCSF WAS DENIED BY THE PRISON.  
MY PHYSICIAN SAID THAT IF THE SECOND REQUEST IS  
DENIED, THEN I WOULD HAVE TO PURSUE LEGAL ACTION.  
THIS IS ANOTHER PROBLEM WITH THIS STATE, LEGAL ACTION  
WILL PROBABLY COST THEM MORE THAN THE SECOND OPINION.