

(W22) MS CAREGIVERS CAN HELP BASIC SCIENCE RESEARCHERS

GOAL: To provide information to caregivers about our MS postmortem research brain bank so they can talk in detail to their patients which should assist patients to arrive at an informed decision about registering with our donor program.

BACKGROUND: Unlike postmortem human organ donation programs which use donated organs to treat living patients; such as, the Lion's Club Eye Bank (cornea transplant) or other organ transplant programs (heart, lungs, liver, kidneys, skin, joints, stem cells), our MS Research Bank distributes donated postmortem brain tissue to scientists to conduct basic research on multiple sclerosis searching for the etiopathogenesis; i.e. the cause. Of great concern to our MS Bank is that epidemiology studies have shown that the diagnosis of MS is made 10,000 times per year in the USA and since incidence and prevalence is at a steady state, 10,000 MS patients die per year. Nevertheless, the average collection of MS brains to our Bank is less than 25 per year. Why is this the case? Based on our experience we have concluded that MS caregivers (MD, PhD, RN and family members) as well as patients are not aware of our MS Research Brain Bank. So it is the goal of this poster to educate caregivers and patients about our MS Bank.

METHODS: MS Patient's caregiver can help by distributing to MS patients and their family members our MS Gift of Hope brochures. Our Gift of Hope brochures should be in every Neurology office located in an easy access area; for example, the waiting room. All MS caregivers should read our Gift of Hope brochure, so they can answer patients' questions. When patients ask, they should be encouraged to participate in the MS Gift of Hope Brain Donation Program and they should be given a copy of our MS Gift of Hope brochure. In addition, they should be encouraged to phone our coordinator for a more extended discussion. Registering before death is important so that arrangements can be in place for our technicians to receive the brain tissue as soon as possible after death for our quick freeze processing. If the patient contacts our Bank and expresses the desire to be a registered donor, the Bank Coordinator then takes the responsibility to furnish details via a Patient Donor Packet and to sign up the patient.

RESULTS: Based on a small survey we have found, on the average, 90% of caregivers and patients have no knowledge of our MS research brain bank for basic scientists. Further, when the NMSS "Inside MS" or "Connections" publishes a feature article about our Bank or the local NMSS Chapter does likewise, we get a few new donors. But this is not enough because we have great need, since we have an over abundance of requests for active demyelinating lesions. To make the matters worse there are only an average of 13 plaques in the cerebrum and only 30% of these plaques have active demyelination.

CONCLUSION: To fulfill the great need to basic scientists for postmortem MS brain tissue, we must educate MS care givers and their patients that our Bank is a critical resource for basic scientists to search for putative new treatments, diagnostic tests and a test for active demyelination (disease activity). Our practical suggestion is to distribute our Gift of Hope brochure to educate every caregiver and patient and if a patient is interested to call the Bank Coordinator at (310) 268-3536 for an extended discussion and to request a donor packet or at our website: www.loni.ucla.edu/~nnrsb/NNRSB.

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