Who should get a brain autopsy and why?
A brain autopsy is the only definitive way to diagnose Lewy body dementia. Anyone who desires confirmation that a clinical diagnosis was accurate should arrange for a brain autopsy to be done soon after the time of death.

Will an autopsy delay the funeral or disfigure the individual’s face?
No, an autopsy does not delay the preparation of the body for burial. The physician who performs the autopsy, called a pathologist, will remove the brain through an incision in the back of the head. That leaves the face entirely untouched during the procedure, allowing for an open casket viewing if desired.

Where do I get one?
Most major university and hospital programs can confirm a diagnosis with a brain autopsy. If there is not one in your community, ask your physician or local hospital for referral to an appropriate resource. (If the brain is being donated to research, you will need a board-certified neuropathologist, because preparing brains for research purposes requires a higher level of expertise than one examined during a routine autopsy.) Brain autopsies must be arranged in advance in order to provide legal authorization for the autopsy and give prior notification to the treating physicians, hospital, and/or long term care facility so that the brain harvesting can be done shortly after time of death.

Who should donate their brain to research?
Brain donation is the ultimate gift and may provide researchers with information to better understand LBD. People with LBD, their family members, and the general public should seriously consider brain donation. Individuals who are on a respirator or life support shortly before they die may not be good candidates for brain autopsy or brain donation, so a physician should make a recommendation in that situation.

How far in advance do I need to plan the brain donation?
Families are encouraged to participate in research studies years in advance of making a brain donation, in order to assure a complete diagnostic work up is performed in a specialty setting. For those who arrange for brain donation apart from a research study, it is usually necessary to make arrangements several months in advance to allow for identifying the necessary resources, arranging the legal paperwork, and notifying the appropriate people in advance.

Who accepts donated brains?
Sometimes autopsies are included as part of participation in a clinical trial. While there are not many clinical trials specifically on LBD, there are certainly many on dementia in general. Visit www.clinicaltrials.gov and enter your state and the word ‘dementia’ to find a trial near you. If there are no clinical trials near you, the next step is to find a brain bank who does research on neurological disorders. The National Institute of Neurological Disorders and Strokes, which is funded by the federal government, has a list of a number of brain banks that specifically seek brains of people with neurological disorders.
conditions. That can be found at the National Institute for Neurological Disorders and Strokes Web site.

**What information will be needed for brain autopsy or donation?**
The best donated brains are those that come with the medical records from a comprehensive work-up and treatment by a specialist. Provide any clinical records based on evaluations by neurologists, psychiatrists, neuropsychologists and brain imaging tests. Without those records, the autopsy will not be able to determine whether the individual had Lewy body dementia that included parkinsonian symptoms or Parkinson's disease that later developed into dementia. Specialty evaluations are most helpful when they begin early and run throughout the entire course of the disease process. Families can have very good historical records that they personally documented at home to describe the disease progression.

**Who can harvest the brain?**
The brain bank will provide information on what specific procedures must be followed at the time of death. Some funeral homes can do brain harvests, which typically cost about somewhere between $1,000 and $1,500 and must be privately paid by the family if done outside of a research study. If the individual is also donating organs for transplant, tissue procurement agencies will do brain harvests too and will not charge the family. Instead, they bill the organization who is receiving the brain tissue. The brain then needs to be re-directed to the appropriate brain bank.
To learn more about LBD, visit www.lbda.org

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By supporting the work of LBDA, you too will be

Increasing Knowledge
Sharing Experience
Building Hope

Lewy Body Dementia Association
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