



ACCRF Joins NDRI's Rare Disease Biospecimen Alliance – August 2007

The Adenoid Cystic Carcinoma Research Foundation (ACCRF) is pleased to announce that it has joined the Rare Disease Biospecimen Alliance (RDBA) of the National Disease Research Interchange (NDRI). NDRI is a non-profit organization with 25 years of experience in obtaining, storing and distributing human cells, tissues and organs to researchers and scientists (www.ndriresource.org). NDRI receives funding for its Rare Disease Biospecimen Alliance from the National Institutes of Health. This new initiative seeks to provide researchers with the appropriate materials to gain insights into adenoid cystic carcinoma (ACC).

The process of donating tissues is fairly simple and very sensitive to the needs of donors and their families. Potential donors will receive a packet of information describing the donation process, including consent and medical history forms. The primary donation option for ACC patients is to give consented tissue samples from surgery. All tissue donations are at no cost to the donors.

NDRI follows strict governmental regulations and guidelines regarding donor consent and confidentiality; tissue samples are provided to only approved biomedical researchers. NDRI has an extensive database of researchers around the world who are seeking human tissues. NDRI matches donors with appropriate requests and then sends the tissues directly to the researchers. Patients' personal details remain strictly confidential and no identifying donor information is given to the scientists.

To receive more information on tissue donation, please contact a Rare Disease Coordinator at raredisease@ndriresource.org, or by phone at 800-222-6374. For further information about NDRI, visit www.ndriresource.org. For further information about ACCRF, visit www.accrf.org.