



CREATIVE CHOICES

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Fall

2006

The newsletter of the Austin Memorial and Burial Information Society (AMBIS), a nonprofit, nonsectarian, educational and consumer association organized to encourage informed planning about end-of-life issues. AMBIS is a member of the Funeral Consumers Alliance.

A different kind of whole-body donation program

AMBIS members are familiar with the whole-body donation program that has been available in Texas for the last thirty years or so: soon after death, one's body is transported to one of eleven medical and chiropractic teaching institutions that participate in whole-body donation through the Texas Anatomical Board. Now, there is a new approach to whole-body donation being offered in Texas through nonprofit organizations headquartered in other states. They include LifeLegacy, BioGift, and Genesis, among others.

These organ and tissue specimen procurement programs are not yet well-regulated at the national level, and state regulations vary. The stringent controls we now expect with respect to transplantable organs and tissue do not apply to non-transplantable specimens. As a result, there have been abuses reported from New York to California, from North Carolina to Texas. Consumers are often not well-informed about how the programs work. Because there are no effective, comprehensive controls of their operations, neither Funeral Consumers Alliance nor AMBIS has endorsed these programs, but consumers should know about them in order to make informed decisions.

LifeLegacy, with offices in Tucson, Arizona, is the first such program about which we have extensive information. The LifeLegacy Foundation is a nonprofit 501(c)(3) tissue and organ procurement organization. It acquires non-transplantable tissues and organs only for research and education use by participating hospitals, clinics, medical schools, pharmaceutical companies, and medical research institutions and programs. In this program,

the whole body is not used during a teaching process, as it is in most medical schools for a semester or two. Instead, needed body parts and specimens are removed from the donated body for use by LifeLegacy's participating clients.

A brain may be needed by a brain research program, such as one studying Parkinson's disease or Alzheimer's. An elbow may be needed for demonstrating a new surgical technique. An artificial joint (a knee, a shoulder) may be needed for determining its effectiveness and resilience. Kidneys may be needed in a study being conducted elsewhere. The lungs of a smoker may be studied by lung disease researchers. Arthritic hands are studied by those working on treatments and cures for arthritis.

The procurement process works fairly simply. LifeLegacy pays a funeral home (or mortuary service in some cases) in the area where the donor has died to refrigerate and ship the body to their facility in Tucson as quickly as possible after death. Dry ice is used for the shipment. LifeLegacy receives some donated bodies as soon as eight hours after death, but most out-of-Tucson donations take longer.

The funeral home or mortuary service obtains the necessary transit permits and files the death certificate, which is completed by the appropriate authorities. LifeLegacy staff obtain disease and health information on a medical and social history form in a telephone conversation with a family member. The conversation is recorded in accord with Arizona law. Based on this information, a preliminary evaluation is done concerning what speci-

Continued on p. 3, LifeLegacy

Fund-raising time for AMBIS

This is the annual fund-raising issue of *Creative Choices*. Because of your generosity last year, the FCA Biennial was substantially subsidized by AMBIS and was termed a great success by first-time visitors, as well as old hands. Our member donors deserve a lot of the credit for that success.

Now, AMBIS needs to raise sufficient funds to replenish its accounts to carry out the local work that you have found helpful to both members and the community at large.

The number of AMBIS volunteers has increased along with outreach efforts. More churches, hospice programs, civic groups, service clubs, and individuals have received the information AMBIS provides, and many more are waiting for our educational programs, brochures, and advance planning forms.

Please give what you can today, while it is still on your mind, before we all get involved with the holiday season and forget to send in that donation, which is vital to the success of AMBIS. And don't forget that AMBIS is a 501(c)(3) nonprofit organization, which means that your contribution is tax deductible. In addition, it will be used to help others in our community by maintaining an office to which all have access and to produce and purchase the educational materials that so many have found useful in planning for the future and dealing effectively with the deathcare industry. A donation envelope is enclosed. **Ω**

AMBIS BRIEFS

Receive newsletter electronically

If you would like to receive *Creative Choices* by email, please send the request to <mail@ambis.info>. A copy will be posted on the AMBIS website, also. If you would like to receive both a hard copy and the electronic copy, please tell us to leave you on the newsletter mailing list. Those who receive the newsletter electronically will also receive periodic notices of interest.

Board member vacancy filled

Jim Brittnacher, a retired Mental Health Mental Retardation (MHMR) Social Worker, who is now working part-time as a chaplain at Hospice Austin, has been named to the AMBIS Council to replace Leah Cohen. One other vacancy remains—that of recently-resigned Council member Chauncey Ashburn.

Cemetery survey volunteers needed

Volunteers are needed to gather information for the next periodic cemetery survey. The last one was completed two years ago. A volunteer is needed, also, to coordinate the project. The costs of cemetery goods and services are taken from a sampling of cemeteries in Bastrop, Hays, Travis, Caldwell and Williamson counties. If you are interested in participating in this vital survey work, please contact Donna Belk at <dbelk@austin.rr.com> or by phone at 922-8043, or by leaving a message at the AMBIS office at 480-0555.

Documents training workshop planned

Sandy Booth has volunteered to teach a workshop early in 2007 to review the advance planning forms that are in the AMBIS member packets. The workshop will last about two hours and will be held at the AGE building, 3710 Cedar Street in Austin. If you have questions about any of the documents found in the freezer pouches, want assistance to fill out the forms for yourself, or are interested in helping new members complete these forms, please email <alana50@grandecom.net> or call 453-3091. Once enough people express interest in a workshop, Alana Carpenter will contact members who are interested.

Annual funeral costs survey planning underway

Planning has begun to produce the 2007 survey of Austin area funeral costs. To volunteer to help with this project, contact Lamar Hankins at <lamarhankins@mac.com> or 512-396-0317.

SAVE THE DATE for the 2007 Annual Meeting

The annual meeting for 2007 will be held at First English Lutheran Church (3001 Whitis Avenue, Austin, Texas), Sunday, February 11 from 3-5 p.m. We will have a presentation about organ and tissue donations. We will hear from organ and tissue donor families, recipients, and an organization that matches donors with families. Discussed will be some myths about organ and tissue donation, and there will be time for questions and answers. Additionally, we will have a wide variety of snacks to share with one another. At the annual meeting we will also provide a notary public to enable you to complete or update your advance planning documents.

Referral sources for new AMBIS members

Affordable Caskets (Bill Collier) - 5
American Way of Death - 1
AMBIS members - 35
AMBIS Council member -12 (excludes presentations by Council members)
Compassion & Choices - 1
Church of Glad Tidings - 1
Clark Howard Radio show -2
Disabled American Veterans -1
Employees Retirement System of Texas Fair - 1
FCA (national) - 1
Gray Panthers - 1
Hospices - 43
Low Vision Club - 2
Newspaper article on Annual meeting - 1
Marketplace Chaplains USA - 2
Methodist CareGivers Fair - 2
Margie Jenkins book - 1
Minister - 1
Not Known - 1
Pflugerville Care Center - 2
St. Peter's Episcopal Panel - 1
Texas Home Health - 3
UTMB Mini Med Series - 1
Usher Syndrome program - 3
Web page - 12
Wildflower Unitarian Universalist Church - 5

Outreach activities

An Advance Directives workshop for Volunteers was led by Sandy Booth in August and was well-received. More are planned for early next year, with help from Alana Carpenter.

AMBIS advertisements are appearing monthly in the *Senior Advocate* and *Good Life* magazine.

Sandy Booth and Daesene Willmann were interviewed by freelance writer Robyn Ross, who is writing an article for submission to the *Austin American-Statesman* for publication in the "Lifestyle" section.

Daesene Willmann was interviewed and her photo taken for an article which appeared in the September issue of the Travis County RSVP monthly newsletter.

On September 14, AMBIS Outreach Coordinator Daesene Willmann attended a Case Manager Expo to meet with hospital, nursing home, and hospice case managers to discuss AMBIS and its services.

On October 6, Daesene Willmann and Tom Twiss attended the Round Rock Parks & Recreation Senior Health Fair to promote AMBIS.

AMBIS volunteer Kathy Boas attended a Care-Giver's Conference on October 14 to provide information about AMBIS.

On September 28, AMBIS volunteer Tom Twiss was the guest speaker at a meeting of a post-polio survivor group in Georgetown to promote AMBIS and its benefits.

On October 25, Daesene Willmann spoke at Bethany United Methodist CareGiver's group.

George and Carole Hawkins and Daesene Willmann attended a "Spirituality of Death and Dying" seminar to provide information about AMBIS and its services on October 28.

LifeLegacy, continued from p. 1

mens can be taken from the donor body and which are needed by LifeLegacy's approved recipients or clients, which pay LifeLegacy for its services in procuring and processing the specimens.

As soon as the body arrives in Tucson, the evaluation is completed and the specimens are removed and treated according to the protocols requested by the intended research or education recipients. Often LifeLegacy sends blank medical/social history forms to hospice, hospital, or funeral home staff to help families understand the information that will be requested in the telephone interview.

LifeLegacy maintains records of the chain of custody of the body and the specimens that are removed, from the time they are contacted until the remains are cremated and returned to the sending funeral home or mortuary service. After two to three weeks, what remains of the body at the Tucson facility is cremated by LifeLegacy and returned to the funeral home or mortuary service, which is then responsible for returning the cremated remains to the family.

LifeLegacy pays all of the costs for picking up the body and protecting it by refrigeration and dry ice, shipping it to Tucson, filing the death certificate, obtaining permits, and cremating the remains. The cremation of the remains is an ancillary benefit of the donor process and not a direct benefit offered to the family, though it does result in a financial savings on disposition costs for the family. LifeLegacy also will pay for the cost of an urn, with a value of up to \$150, selected by the family from the sending and receiving funeral service. Because organs and tissue may not be sold or traded for anything of value under federal law, some have questioned the propriety of the urn benefit.

At the conclusion of the use of specimens from a body, LifeLegacy provides a "tissue-taken report" to the family that describes what tissues and organs were taken and what areas of research were involved with each specimen. In most cases, specimens are cremated at the location of the research or educational use and are scattered in a garden maintained by the research or educational program. Occasionally, specimens are returned to LifeLegacy for cremation, but by that time the rest of the remains have been cremated and returned to the family. If the family does not want to receive these cremated remains, LifeLegacy scatters them in a garden in Tucson.

As a result of this process, most of the cremated remains can be returned to the family, except for the specimens used by researchers and cremated elsewhere by the researchers, so the total volume of cremated remains is less than would be normally received after a cremation.

Autopsied remains are accepted for donation if a blood sample can be provided to LifeLegacy. All bodies are screened for various infectious diseases which would preclude the use of the body for specimens. Whole bodies are used by a few LifeLegacy researchers, but most donated bodies are used to harvest specimens for specific research and education purposes.

LifeLegacy has associations with research programs around the country, such as the National Neurological Brain Bank and the Harvard Brain Bank. In addition, LifeLegacy accepts bodies from which transplantable organs have been removed. This situation requires close coordination between LifeLegacy's medical

staff and the organ procurement team so that LifeLegacy can properly evaluate the remaining useful organs and tissue which can be recovered for use by its program.

LifeLegacy does not participate in trauma research, in which bodies are subjected to such traumatic conditions as automobile crashes, bombings, etc., to study the effects. It also does not accept bodies of those under the age of 18 or those in excess of 300 pounds. LifeLegacy does not process tissue for use in surgeries or medical treatments. Its sole purpose is to provide specimens only for research and educational purposes.

When the donation is made, a family member receives a consent form. Although the consent form is not entirely clear that not all cremated remains can be returned to the family because of specimen disposition at the location of the research, it is an otherwise adequate consent form.

If you are interested in learning more, or participating in the program, you can contact LifeLegacy at its toll-free telephone: 888-774-4438. Preregistration by the prospective donor is available, as well as donation by family members after death. Email may be sent to <info@lifelegacy.org>. LifeLegacy's website can be found at <http://lifelegacy.org/>.

At the present time, both Austin Peel & Son Funeral Home and All Faiths Funeral Service have contracted with LifeLegacy to work with its program in the Austin area. Ω

What the funeral industry has planned for families in 2007 Texas Legislature

According to the Texas Funeral Directors Association (TFDA), it will renew its efforts in the 2007 session of the Texas Legislature to prevent Texas families from arranging a cremation for a family member directly with a crematory. TFDA claims that crematory operators are too untrained and unreliable to make sure that all the forms are completed correctly, something only a funeral director can do, TFDA claims. By law in Texas, anyone may serve as a funeral director if they do so without being paid for their services. When serving in such a capacity, it is that person's responsibility to make sure that all forms are completed correctly, a task many have done. AMBIS and similar funeral consumer groups have provided such "how to do it" information for years to interested families. Now, newer nonprofit organizations, such as Crossings Care Circle, conduct workshops to help families learn how to do what is needed to handle a funeral or cremation.

Although TFDA admits that few families use this option, they may be worried that the practice reveals that following regulations may not be so complicated that it is worth thousands of dollars to pay a funeral director to take care of the process.

The Funeral Consumers Alliance of Texas, an umbrella group representing all five of the funeral consumer organizations in Texas that are affiliated with the Funeral Consumers Alliance, will be working through its volunteers to make sure legislators know that we do not need more regulations that increase the cost of funerals. If you can help in any way, including just calling or writing a letter to a legislator, please let us know of your willingness to help. More information will appear in the next issue of *Creative Choices*. Ω

Please Help Us Keep Our Mailing List Current

Be sure to let AMBIS know if your address changes. It will help us keep our mailing costs down. If you move out of the area, we can help you transfer your membership. Send changes by email, call the AMBIS office at 512-480-0555 or send this form with the old address to AMBIS

My new or corrected address is:

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New or correct address

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AMBIS CONTRACTED FUNERAL HOMES

The following funeral homes offer to AMBIS members a 15% discount off of the costs shown on their General Price List:

- All Faiths Funeral Services
8507 North IH 35 (512-339-8878) and
4360 South Congress Ave. (512-326-8878)
- Austin-Peel & Son Funeral Home
607 E. Anderson Lane (512-419-7224)
- Harrell Funeral Home
4435 Frontier Trl. (512-443-1366)
- King-Tears Mortuary
1300 East 12th Street (512-476-9128)
- Wilke-Clay-Fish Funeral Home
2620 S. Congress (512-442-1446)
- Weed-Corley-Fish Funeral Home
3125 N. Lamar (512-452-8811)

When contacting one of these funeral homes, please provide proof of your AMBIS membership by showing a copy of this newsletter addressed to you or your new membership letter. Membership can be confirmed also by calling the AMBIS office at 512-480-0555.

www.ambis.info

CREATIVE CHOICES

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