



CREATIVE CHOICES

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The newsletter of the Austin Memorial and Burial Information Society (AMBIS), a nonprofit, nonsectarian, educational and consumer association working since 1964 to encourage informed planning about end-of-life issues. AMBIS is a member of the Funeral Consumers Alliance.

What you should know about body and tissue donation to give informed consent

Recently, more consumers have become interested in whole body donation to entities that make body parts, organs, and tissue available for research, bio-product development, and demonstration of new devices. A crucial element of this donation process is the informed consent of the family, which should, at an absolute minimum, include a voluntary decision based on full disclosure of the facts. To facilitate a fully informed decision, Funeral Consumers Alliance of Texas (FCA of Texas) offers the following background and informed consent recommendations for consideration.

Background: According to a 2001 report from the Department of Health and Human Services, most of the American public believes that all body, organ, and tissue donation is done with the humanitarian aim of helping the living and the critically injured. However, with respect to whole body tissue donation, most specimens are used in medical research, for demonstration purposes by pharmaceutical companies and device manufacturers, in other educational activities, and in the manufacture of therapeutic and cosmetic products.

Because of the recent proliferation in the use of such tissue for both therapeutic and cosmetic purposes, the financial incentives and profits have risen dramatically. While the Uniform Anatomical Gift Act (UAGA) prohibits the sale of body parts for transplantation or therapy, the Act does not define what consti-

tutes "reasonable payment" for procuring, processing and distributing tissue. This provision leaves a loophole allowing some tissue banks, procurement organizations, and for-profit companies to exchange large sums of money for processed skin, bones, tendons, heart valves and other body parts. They do so by referring to the transaction as the collection of "fees," rather than as an outright sale.

Current biomedical technology has created far more uses for donated tissues and body parts than mere organ transplantation. Donated tissue can be processed and formed into products far different from the tissue's original form. Consequently, some biomedical companies are making large profits on products derived from donated tissue, a practice that seems to subvert the intent of the Act. In addition, the sale of body parts for medical research was not addressed in the Act.

There is also no mandated system by which to allocate donated tissue and body parts to those in the greatest need. Another report from the Department of Health and Human Services in 2001 found many burn centers had difficulty obtaining skin for grafting when it was needed. By contrast, newspaper and television investigations found many cosmetic or elective surgery clinics were able to obtain skin quickly and easily.

The public considers donation an altruistic act that benefits

Continued on p. 3, Body Parts Donation

AMBIS fund-raising time—please be as generous as you can

This is the annual fund-raising issue of *Creative Choices*. Because of your past generosity AMBIS has been able to help 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, charitable 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 from which we can produce and distribute the educational materials that so many have found useful in planning for the future and dealing effectively with the deathcare industry. To simplify the donation process, a donation envelope is enclosed.

AMBIS BRIEFS

Annual Meeting

Our annual AMBIS informational meeting will be held on February 21, beginning at 2 pm. This year Gethsemane Lutheran Church (200 W Anderson Lane, located near Hwy. 183) generously offered their facility for us to use, without a set charge. We will give a donation, but the church's generosity will conserve our limited resources.

Advance Planning Workshops

More Advance Directives/Advance Planning workshops will be offered in the greater Austin area. The October 3 workshop had 25 participants who were helped to draft their own documents, so they are ready for that unknown future time. Preparedness is so valuable! Designating an agent to direct the final actions with your body may seem unnecessary, until complications arise at the time of your death. To insure that your wishes for cremation or body burial can be followed without a hitch, or to verify that you would like body parts to be donated to a person in need of them, have your documents in order. These are some of the benefits of the workshop. Call AMBIS today at 480-0555 to express your interest in a future workshop to be held near to you. New workshops will be scheduled as soon as we have enough people signed up.

Notaries needed

Notaries are needed this coming year to be present at Advance Directives/Advance Planning workshops at a variety of locations. If interested, please send an e-mail to <mail@ambis.info> or call the office to leave a message any time. Volunteers are at the office Mondays, Wednesdays and Fridays between 10 am and 2 pm.

AMBIS Outreach schedule for Fall

- * September 4—Kathy Boas & Chauncey Ashburn spoke to seniors at St. Matthew's Episcopal Church
- * September 10—Lamar Hankins spoke to San Marcos Association of Retired Teachers-28 people attended and received AMBIS information packets
- * September 12—CareGivers Seminar (sponsored by AGE) – materials distributed
- * September 16—InterAgency Council on Aging, "End of Life Planning as a Gift to Your Family and Community"; Amy Praskac, Rodger Ericson and others on panel
- * September 19—Annual Symposium—Area Medical Transcriptionists—Tom Twiss presented for AMBIS
- * September 24—St. George's Court Annual Health Fair—Barbara Tuttle volunteered for AMBIS
- * September 25—Retired State Employees Association Annual Fair—Chauncey Ashburn attended for AMBIS
- * October 11—Austin Ethical Society—Gary Barnhart presented and Chauncey Ashburn passed out materials for AMBIS
- * October 13—Retirement & Social Security Forum – Daesene Willmann presented for AMBIS and Helen Burnette provided materials to those in attendance
- * October 26—Rodger Ericson and Lamar Hankins spoke to a Death & Dying class at the Seminary of the Southwest
- * November 1—Prime Timers at Austin History Center –

From the President—

Why promote and support AMBIS and our parent, the national Funeral Consumers Alliance (FCA)? We are advocates for the public in matters of death, funerals, and cemetery and related needs. Josh Slocum, FCA Executive Director, has been giving testimony for a bill in the US Congress to support The Bereaved Consumer's Bill of Rights Act of 2009. This bill sets national standards for the protection of funeral and cemetery consumers. The Act will direct the Federal Trade Commission to strengthen and expand the Funeral Rule, which currently applies only to funeral homes, but not cemeteries. I have shared stories with him about abuses I knew.

The Bill also requires the FTC to enact rules that will compel cemeteries to give consumers the right to buy only the goods and services they really want and provide consumers with accurate prices before the sale of a burial plot. It aims to prevent monument dealers and casket sellers from misrepresenting legal requirements, and bars cemeteries from falsely claiming that state laws "require" vaults to surround in-ground caskets or cremains, a cemetery practice recently explained to me by a cemetery in our area.

Have you had success in recruiting memberships for AMBIS? Some of us have. Work on it, spread the word, and help the general public, who are often ignorant of their options. I just read about a clergyman who did not realize that embalming was optional. Be sure your friends and pastors join AMBIS and know what we can do for them.

To those not volunteering, can you give a few volunteer hours a month? Help us to support the greater Austin area. All Board members, officers and workers are volunteers. On behalf of AMBIS, I express thanks to our current volunteers for your work this quarter, no matter how much you do.

MAKE A DONATION TO AMBIS, so we can continue our work for you and the greater Austin area. Consider leaving a legacy gift to AMBIS - donate a bond, the interest from which will go to AMBIS after your death. Do the same for other charities that you want to support when you can no longer give an annual gift.

To prevent fraud and misrepresentation plan ahead before your own death, know Texas laws and options, and contact AMBIS when you feel you are "being sold a bill of goods" or hear of improper pressure tactics. Always call the office when problems arise so we can address them for you and maybe help you or the others in the future.

Rodger Ericson,
President, AMBIS Governing Council

Daesene Willmann to present for AMBIS

- * November 6—Georgetown Unitarian Universalists—Gary Barnhart and Rodger Ericson to present for AMBIS

AMBIS Volunteers met August 19

AMBIS volunteers held a regular meeting on August 19 to discuss indigent burial, which is the responsibility of all counties in Texas, and discussed the need to organize information in the AMBIS office for easy access by volunteers.

Body Parts Donation, from p. 1

those most in need. But in a May 19, 2003, Boston Herald article, the chairman of the Health Law Department of Boston University's School of Public Health said, "The market for body parts has become very lavish—skin, brain, heart valves are not just used for research but are part of a for-profit industry now. People need to be informed of this."

What constitutes "valuable consideration" and "reasonable payment" for the removal, processing, disposal, preservation, quality control, storage, transportation or implantation of donated tissue and body parts is not regulated and is determined by the individual procurement organization.

Informed consent recommendations: (These recommendations may not be exhaustive. Additional elements of fully informed consent may emerge from further discussion among the stake-holders.)

1. There is no requirement that donated tissue be allocated in order of medical priority. Such a system might allocate tissue in the following order: a) to those in danger of dying if they do not receive imminent treatment, b) to those in need of reconstructive surgery to correct such conditions as congenital birth defects or damage from disease (such as cancer) or injury, c) to organizations doing medical research, d) to entities providing educational services with donated tissue and body parts, and finally e) to those who want purely cosmetic surgery unrelated to a medical condition. However, at present, there is no regulated order of priority for donated bodies to be used for these or other purposes.

2. There is no requirement for disclosure to the family of the identification of specific organs and/or tissues (including cells) that are being requested for donation, nor for providing subsequent information about the use of specific gifts recovered. A donor family should receive such information from the procurement organization.

3. Donor families should receive an explanation from the procurement organization about how the retrieved organs/tissues may be used, including, but not limited to, use for transplantation, therapy, medical research, or educational purposes.

4. Donor families should receive from the procurement organization a description of the recovery process, including how tissue is recovered, processed, stored, and distributed; the duration of storage; and the possibility that the tissue may not be used.

5. Donor families should be told by the procurement organization what medical information will be needed, including labo-

ratory tests and a medical/social history that may be needed to determine the medical suitability of the donor, including whether blood samples or other biological material from the donor will be tested for certain transmissible diseases and suitability for donation.

6. Donor families should be told by the procurement organization what costs, if any, directly related to the evaluation, recovery, preservation, and placement of the organs, body parts, and tissues will be charged to the family, and what costs will be paid to third parties who assist the procurement organization in the body acquisition process.

7. Donor families should be told by the procurement organization what impact the donation process may have on the return of the donor's cremated remains to the family. In most cases, not all cremated remains will be returned to the donor family. The procurement organization should explain exactly what is done with cremated remains or body parts, including tissue, that are not returned to the donor family.

8. Families must be informed what tissue can be used or modified in various ways for transplantation in a life-saving capacity, transplantation in a life-enhancing capacity, and medical research or education, including a non-technical explanation of the use and modification process.

9. Families must be told that they have the right to limit or restrict the use of the tissue from the donor body.

10. A completed consent form must be reviewed with the family before final consent, and a copy provided to the family. Other written material explaining tissue donation should be offered to the family.

11. Families must be given the option of receiving acknowledgment of their gifts. This acknowledgment should include disposition and any recipient information available at that time, while protecting the anonymity of both the donor and any human recipient. If a recipient is a research program or the purpose is educational, the family should be told the name of the organization, the program, the specific body parts provided, and the location of the organizational recipient.

12. To obtain additional information about the gift, the donor family should be provided with contact information (including phone number and address) for the recovery agency.

NOTE: This article was written by Gere Fulton and Lamar Hankins as part of their work as Co-Chairs of the Legal Committee of the Funeral Consumers Alliance. FCA of Texas is an unincorporated association of the Texas affiliates of FCA.

AMBIS Obituary Writing Seminar Saturday, January 16, 10 am to Noon

If you would like some help putting the last words to be said about you in good order, consider signing up for the 2010 AMBIS Obituary Writing Seminar to be held at the Austin AGE Building on January 16, 2010, 10 am to Noon.

The successful first such event held in 2009 has persuaded seminar leader Ed Nichols to agree to direct the January event, which will be limited to 30 participants. A donation is always appreciated to pay for the cost of materials and facility. For more information or to sign up, contact the AMBIS office at (512) 480-0555 or by email at <mail@ambis.info>.

Magazine article of interest

"Caring for our Dead – A Family Undertaking" is an article written by Holly Stevens, an active member of the FCA of the Piedmont, situated in Greensboro, NC. It was published in the October 6, 2009, issue of *Christian Century* magazine. Rodger Ericson, AMBIS Governing Board President, and Donna Belk, AMBIS webmaster, contributed to the story. You can read it in the AMBIS library or at <<http://www.christiancentury.org/article.lasso?id=7853>>

Please Help Us Keep Our
Mailing List Current

To help us keep our mailing costs down, be sure to let AMBIS know if your address changes. 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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A Funeral Consumers Alliance
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To mail an address correction, please clip and mail to AMBIS at P.O.Box 4382, Austin, TX 78765, or take to AMBIS office in the Austin Groups for the Elderly Bldg. at 3710 Cedar St. (at 38th Street), Room 112. Email an address change to <mail@ambis.info>.

AMBIS CONTRACTED FUNERAL HOMES

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

- King-Tears Funeral Home
1300 E. 12th Street (512-476-9128)
- Harrell Funeral Homes
 - 4435 Frontier Trail (512-443-1366)
 - 100 Heritage Drive & Hwy 290W, Dripping Springs (512-858-5666)
 - 2770 & Kohlers Crossing, Kyle (512-268-8200)
- Fish Funeral Homes
 - 2620 S. Congress (512-442-1446)
 - 3125 N. Lamar (512-452-8811)
- All Faiths Funeral Service
 - 8507 North IH 35, (512-339-8878)
 - 4360 South Congress Ave. (512-326-8878)

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.fcaambis.org

CREATIVE CHOICES

CREATIVE CHOICES is published quarterly by the Austin Memorial and Burial Information Society, a nonprofit, nonsectarian consumer and educational organization formed in 1964 to protect a consumer's right to choose a meaningful, dignified, and affordable funeral.

The ideas expressed in CREATIVE CHOICES are those of the authors and editor and not necessarily those of AMBIS. Address changes, editorial items, letters, and inquiries about the benefits of membership should be sent to:

AMBIS, P.O. Box 4382, Austin, Texas 78765
Office: AGE Bldg., 3710 Cedar Street, Rm. 112, Austin
Telephone inquiries may be made to 512/480-0555
E-mail may be sent to mail@ambis.info

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Leon Lebowitz, Director Emeritus (452-8601, Austin)
Daesene Willmann, Volunteers Coord. (459-6703, Austin)

Editor, Lamar W. Hankins (512-396-0317, San Marcos)
Editorial assistance provided by Dr. June Chase Hankins