

FAQ: bit.listserv.transplant, Organ transplant ng (Part 1 of 4)

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Part 1 of bit.listserv.transplant FAQ

Last updated 3/23/02

Updated subscribe information for DIALYSIS email discussion list Part 1, section I.

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About this FAQ

This FAQ is archived at rtfm.mit.edu and available by anonymous ftp under [pub/usenet–by–group/bit.listserv.transplant](ftp://pub.usenet-by-group/bit.listserv.transplant). Its available by gopher from any site with a link to the MIT ftp archive, such as ccsun42.csie.nctu.edu.tw where faqs are listed under newsgroup hierarchy. URL: <http://www.lib.ox.ac.uk/internet/news/faq/bit.listserv.transplant.html> or [http://www.faqs.org/faqs/medicine/transplant–faq/part1/index.html](http://www.faqs.org/faqs/medicine/transplant-faq/part1/index.html)

The subjects treated in this FAQ are, for the most part, specific for the state of organ and tissue transplantation in the United States. If anyone would be interested in providing information that might be helpful

to people of other countries please let me know. If anyone has other information they would like to have included in this FAQ please send it along.

Many thanks to the people who have contributed information and otherwise helped with the FAQ: Alex Bost, Dan Flasar, Kimberly Montgomery, Arthur Flatau, Katherine Eberle, Anne Treffeisen, Rosalie Katchen, Joel Newman, Gerald Huber, Ken Lifton, Dale Ester, Jim Warren, Jeff Punch, Fritz Dolak, Julio Real, John Abbott, Marion Leska, Karen Couture, Lou Bushfield, Lisa Carroccio, Kandy Darroch, Dorothy Bourdon, and Luis Enrique Acero.

Mike Holloway
mike_holloway@hotmail.com

I. Description of the TRNSPLNT mail list and bit.listserv.transplant

The Usenet newsgroup bit.listserv.transplant is a bi-directional echo of the listserv mail list TRNSPLNT. If you have an interest in transplantation, and think that the posted news and discussions are of interest, it may be more convenient for you to subscribe. Be sure to save the instruction file that is sent to you automatically when you subscribe. To have a list of listserv commands sent to you, send mail to LISTSERV@WUVM.D.WUSTL.EDU and place either HELP or INFO REFCARD on the first line of text. This list includes commands for unsubscribing, setting your subscription to "nomail", and other useful commands. To remove yourself from the list, send SIGNOFF TRNSPLNT.

All posts to TRNSPLNT or bit.listserv.transplant are archived by the listserv system at Washington U. You can get an index of the archive by following the directions below in Dan's introduction. You can search the archive as a database and retrieve individual articles via a keyword search by following the directions in the file obtained by sending INFO DATABASE to LISTSERV@WUVM.D.WUSTL.EDU

Below is the introduction to TRNSPLNT written by Dan Flasar. Since Dan started the group early in 1993 the posts have been on everything from copies of news and information to recipes for low salt diets. It has been a useful electronic support group for some participants who are either waiting for a transplant, recovering from a transplant, or just getting on with life after a transplant. We encourage recipients, caregivers and medical professionals to introduce themselves to the group. The list is also a tool for organ and tissue donor education.

TRNSPLNT on LISTSERV@WUVM.D.WUSTL.EDU

TRNSPLNT is a discussion list for organ transplant recipients and anyone else interested in the issues, experiences and realities of

living with an organ transplant.

Over the last 30 years, the number of transplants performed each year has grown steadily in both absolute numbers and type of organs transplanted.

Though there are hospital, clinical and pharmaceutical industry-sponsored newsletters, there are few, if any, completely independent discussion forums for those who have experienced this oftentimes dramatically effective therapy.

There are many life issues for the transplant patient that are simply not covered in medical literature or by medical personnel. TRNSPLNT will provide a way for members to share information on such things as as travel, both domestic and abroad, how to deal with a compromised immune system, stories about transplant experiences, and anything that the members feel is worth discussing.

Archives of TRNSPLNT postings can be listed by sending an INDEX TRNSPLNT command to LISTSERV@WUVMD.WUSTL.EDU.

To subscribe, send the following command to LISTSERV@WUVMD.WUSTL.EDU via email:

SUB TRNSPLNT Your Full Name

where "Your Full Name" is your name. For example:

SUB TRNSPLNT Billy Rubin

Owner: Dan Flasar SYSFLASAR@WUGCRC.WUSTL.EDU

A web page form is also available for subscribing at <http://trnsplnt.tsx.org>

NOTE: This is NOT a medical forum! Though advice may be offered, you should, as with any medical issue, check with your physician before you accept anything said in this forum as a basis for doing anything that might affect your physical condition!

DIALYSIS

(from Julie <clarify@alum.mit.edu>)

To subscribe to the list see http://groups.yahoo.com/group/dialysis_support/ or email dialysis_support-subscribe@yahoogroups.com

Chat groups

The Lung Transplantation Page Chat

<http://homestead.deja.com/user.lungtxpsych/index.html>

WEEKLY TRANSPLANT CHATS ONLINE

From Kandy S. Florida <Kandysfl@AOL.COM>:

Sunday, 9:00 PM ET, Organ Transplant Chat

Talk City <http://www.geocities.com/~rolo1/community.html>

Contact: gmreilly@snet.net

Sunday, 10:00 PM ET, Kidney/Pancreas Transplant,

AOL: Private Room aol://2719:2-2-kidney%20pancreas%20tx

Contact: OhLarry922@aol.com

Monday, 7 PM ET, Kidney/Pancreas Transplant Chat

OTA: <http://organtx.org/chatroom.htm>

Contact: CarolG@organtx.org

Monday, 8:00 PM ET, Donor Awareness,

AOL: allHealth, aol://2719:3-1453-Helping%20Hand%20Cafe

Contact: BHostMich@aol.com or HOST AHTH Blu@aol.com

Monday, 9:00 PM ET, Liver Disease & Transplant

AOL: allHealth, aol://2719:3-691-Mutual%20Support%20Room

Contact: HOST AHTH Kandy@aol.com or HOST AHTHLiv@aol.com

Tuesday, 8:00 PM ET, Organ Transplantation & 2000 U.S. Transplant Games

Team Minnesota <http://www.sadiehawkins.com/gameschat.htm>

Contact: dick@sadiehawkins.com

Tuesday, 9:00 PM ET, Carols lung tx room

AOL: Private Room, aol://2719:2-2-Carols%20lung%20tx%20room

Tuesday, 9:00 PM ET Bone Marrow Transplant

AOL: Private Room, aol://2719:61-2-bmt%20support%20online

Tuesday, 10:00 PM, Kidney Pancreas Transplant

AOL: Private Room, aol://2719:2-2-kidney%20pancreas%20tx

Contact: HSchrei686@aol.com

Wednesday, 7:00 PM ET, All Organs & Tissues Transplant

DrKoop: Communities: Health Central

https://www.drkoop.com/mem_bin/formslogin.asp?http://drkoop.com/community/chat/chat.asp?room=healthcentral

Wednesday, 9:00 PM ET, Liver Disease and Transplants

OTA: <http://organtx.org/chatroom.htm>

Contact: JamHil@aol.com

Wednesday 10: 00 PM ET, Kidney/Pancreas Transplant Chat & ESRD

AOL: allHealth, aol://2719:3-691-Mutual%20Support%20Room

Contact: HOST AHTH Blu@aol.com or HOST AHTH KLIX@aol.com

Thursday, 7:00 PM ET, Heart Transplant

AOL: allHealth, aol://2719:3-193-Health%20Conference

Contact: HOST AHTH Max

Thursday, 8:00 PM ET, Organ Transplantation & 2000 U.S. Transplant Games

Team Minnesota <http://www.sadiehawkins.com/gameschat.htm>

Contact: dick@sadiehawkins.com

Thursday, 9:00 PM ET Bone Marrow Transplant

AOL: Private Room, aol://2719:61-2-bmt%20support%20online

Thursday, 9:00 PM ET, Lung Transplant Chat

SecondWind: <http://www.2ndwind.org/main.htm>

Contact: luckylungsforjo@aol.com
Thursday, 10:00 PM ET, Children's Liver Chat
Children's Liver Alliance <http://www.livertx.org>
Contact: Livers4Kids@earthlink.net or call 718-987-6200.
Friday, 8:00 PM ET, Kidney Disease & Transplant
AOL: Private Room, aol://2719:2-2-Kidney
Contact: BLUBFLY@aol.com
Friday, 9:00 PM ET All Organs & Tissues Transplant
AOL: allHealth, aol://2719:3-49-Positive%20Reflections
Contact: HOST AHTH Kandy@aol.com or HOST AHTHLiv@aol.com
Saturday, 7 PM ET, Dealing with End-Stage Disease and Death
OTA: <http://organtx.org/chatroom.htm>
Saturday 9:00 PM ET, Parents of Bone Marrow Tx Recipients
AOL: Private Room: aol://2719:61-2-bmt%20support%20online
Saturday 9:00 PM ET, Transplant Pre n Post Support Community
Talk City: www.tnpn.org/community.html, #Transplant channel
Contact: gmreilly@snet.net

Caregivers Support Group

From Evelyn Heering (ev48@aol.com):
This list is for the spouses, family members and caregivers of lung disease patients, lung transplant recipients and of those waiting for lung transplants only. We are here to help each other cope with the waiting and the post transplant times as well. To subscribe to this list send your request to: ASSIST-request@HOME.EASE.LSOFT.COM Please include the diagnosis of your loved one, your relationship (spouse, parent, sibling, etc.) and whether the person has been transplanted or is waiting.

Australian Transplant and Dialysis discussion list

RALPH NEWMAN <rnewman@tpgi.com.au>:
Announcing the establishment of a new email listserver (actually Majordomo - Ed.) in Australia, open to all, set up for both Transplant and dialysis discussion. It is still a small group and we would welcome your input. It can be found on the web, where there is an automatic subscribe site, found at
<http://www.wagga.net.au/transplant>

Second Wind discussion list

(see Second Wind National Lung Transplant Patient's Association web site in section II below <http://www.2ndwind.org>)
Messages concerning lung diseases, lung transplants, problems, solutions, and life in general.
Subscription form:
<http://www.2ndwind.org/join.htm>

Kidney/Pancreas Support Group

Since dealing with the long term chronic condition and complications

from years of Diabetes, still affects people after a transplant, we formed this group a few years ago to deal with those issues. Many people stay on both lists. We now have about 75 people participating in the KPTX group.

To subscribe, Send a blank email to:
kptx-subscribe@makelist.com

If you have questions or problems, write to me at:
alangluc@soca.com

HTX, Heart and Lung Transplant Support Group

Chris Molnar (StephenKyl@aol.com)

HTX – An online mailing list for support and information sharing for families and individuals dealing with heart or heart-lung transplants due to childhood-onset heart disease. Subscribers facing the possibility of transplant or otherwise interested in the issues surrounding transplanted survivors of childhood-onset heart disease are also welcome.

To subscribe:
send email to: majordomo@tchin.org
message: subscribe htx

LiverSupport-L

from Ron Koestler [koestler@ix.netcom.com]

LiverSupport-L@onelist.com. The list owner can be reached at LiverSupport-L-owner@onelist.com. People can subscribe by sending mail to LiverSupport-L-subscribe@onelist.com.

The Organ Transplant Support Group Chat

<http://www.jensoft-cs.com/icqlist.html>

We encourage all members to get ICQ and provide us with their ICQ numbers. We will list the ICQ numbers of all members, allowing quick contact with members for anyone who may visit this page. ICQ empowers members with a means to chat whenever they like and enables them to share ideas, discuss similar interests or anything else.

II. Selected organ and tissue transplant info via gopher and WWW

There is no attempt here to make a comprehensive list of web resources for transplantation. Instead, the sites below are meant to provide some of the best resources for patients and the general public, with particular reference to information on organ donation.

Gopher

Yale Biomedical Gopher
<gopher://info.med.yale.edu/11/Disciplines/Disease/Transplant/>

Contents:

Bone Marrow Transplant Information (U. Penn. Med. School)
Gallup Poll on Attitudes Towards Organ Donation
HRSA organ transplantation fact sheet
Directory Issues of UNOS Update
Legislative history of organ donation
Live kidney donor information
National Resource Directory for transplant patients (updated 3/94)
Organ trafficking myths
 Critique of French film "Organ Snatchers"
 Organ trafficking myths
 Report to UN on Child Organ Trafficking Rumor
 UNOS paper on organ theft myths
Organ transplants increase; donation shows little change
Relevant articles from National Kidney Foundation Newsletter
Religious and cultural views on donation
Transplant ethics
Transplant fund raising (from BMT Newsletter, 11/93)
UNOS Brochures
Xenograft transplantation: "The Transplant Gap"

World Wide Web

American Liver Foundation disease information brochures

<http://www.gastro.com/liverpg/livdz.htm>

American Share Foundation WWW page

<http://www.asf.org>

maintainer: jsabbott@ix.netcom.com (JOHN S. ABBOTT)

Partial list of contents:

 Kid's Space=20
 1995 Transplant Desk Reference
 Questions a Patient Should Ask
 Answers to Commonly Asked Transplant Questions
 What Every Patient Needs to Know about UNOS
 Transplant Centers
 OPOs – Organ Procurement Organizations

The American Society of Transplant Physicians

<http://www.astp.org/>

ASTP is a multidisciplinary group of physicians and scientists dedicated to the promotion of education and research relating to transplantation medicine and immunology. News and abstracts of the journal "Transplantation" available.

Biliary Atresia & Liver Transplant Network

<http://www.asf.org/balt.html>

(see Part 3, section IIe)

BODY British Organ Donor Society

<http://www.argonet.co.uk/body/index.html>

This site covers topics on organ donation and transplantation, both in the UK and Worldwide. Your requests for topics you would like to see included are welcomed. Please send them to body@argonet.co.uk

Coalition on Donation

<http://www.shareyourlife.org/>

Slick web page with donor education and myths information.

"The Coalition on Donation is a not-for-profit alliance of local coalitions and national organizations who have joined forces to promote organ and tissue donation. The Coalition has created national education/action campaigns for distribution by our 50 local coalition affiliates."

The Delaware Transplant Program (DVTP)

<http://clever.net/wwwmall/dvtp/index.html>

The Delaware Valley Transplant Program is the non-profit organ tissue donor program serving hospitals and patients in the eastern half of Pennsylvania, southern New Jersey and the state of Delaware. Founded in 1974, DVTP is one of the federally designated organ procurement organizations in the U.S. The program coordinates the recovery and allocation of organs and tissues for transplant and is a part of the nation's organ procurement and sharing network. DVTP is also the primary source for donor cards in the region and conducts hundreds of community and professional education programs each year.

Donor Network of Arizona

<http://www.donor-network.org/dnet/>

We are located in downtown Phoenix, Arizona

3877 N. 7th Street, Suite #200

Phoenix, Arizona 85014

(602)222-2200

1-800-94-DONOR

-Organ Donation for Transplant and Research

-Donation of Bones and Tissues for Transplant and Research

-Eye Donation and Corneal Transplant

-Public Education (General Donation & Transplant Information)

-DNA'S Vital Link (A Quarterly Publication)

-DNA'S Legislative Update

The Friends' Health Connection

<http://www.48friend.com>

The Friends' Health Connection is a non-profit organization and the premiere organization that provides customized, one-to-one support for individuals and/or their families with health-related problems. We now have a national toll-free phone line that you can call Monday through Friday, 9:00 AM-5:00 PM to speak directly with a representative from our organization. It is 1-800/48-FRIEND or 1-800/483-7436.
e-mail: fhc@pilot.njin.net

Gift of Life Trust Fund of South Carolina

<http://www.giftoflife-sc.org/>

Site includes information on organ donation, support groups and programs for transplant patients, patient stories, and links to other information sites.

HCFA, The MEDICARE and MEDICAID Agency

<http://www.hcfa.gov>

Health care financing news, Information about the Medicare Program, etc.

HHS organ donation information

<http://organdonor.gov/>

Wide array of information on organ donation and organ donor education. Current statistics. National Donor Sabbath information. Donor card.

HHS/HRSA Solid Organ Transplantation Information

<http://www.hrsa.dhhs.gov/osp/dot/solid.htm>

Technical Data – Includes statistics on the Waiting List, Number of Organs Recovered and Transplanted, Survival Rates, etc.

Fact Sheets

Glossary of Terms

Commonly Asked Questions about Organ Donation – Includes excerpts from Questions & Answers about Organ Donation, as well as links to Steps Involved in Donation and Transplantation, How are Recipients Matched to Donor Organs, and Why Should Minorities be Particularly Concerned about Organ Donation?

History of the OPTN and Scientific Registry – Includes summarized organ allocation policies, Scientific Registry information, and a brief history of UNOS and its role in the OPTN and Scientific Registry.

Organ Procurement Organizations (OPOs) by State

List of UNOS Member Transplant Programs by State

Life Connections of Ohio

<http://www.mco.edu/hosp/lifeconn>

Contains excellent information on donation and transplantation, as well as extensive answers to frequently asked questions about donation.

Mission

Life Connection of Ohio is dedicated to increasing and facilitating the recovery of high quality organs and tissues for transplantation.

London Health Sciences Centre Multi-Organ Transplant Program

Has several informative articles on organ donation and transplant information, with references.

<http://www.lhsc.on.ca/transplant/index.htm>

Missouri Kidney Program

Contact person: David Patterson < mokpdave@muccmail.missouri.edu >

<http://www.missouri.edu:80/~mokpwww>

The Missouri Kidney Program in Columbia Missouri (MoKP). We are developing an End Stage Renal Disease (ESRD) and related issues web site for patients, providers and others who are interested.

Currently our web site houses our most recent annual report detailing who MoKP is as well as some statistics about patients in Missouri. We also maintain to links to other related areas.

National Donor Sabbath Resource Kit 1997

<http://www.transplantawareness.org/sabbath/CONTENTS.html>

Jennifer Grant at the HHS Division of Transplantation has assembled opinions from all religious organizations in the US regarding organ donation, and give suggestions of how congregations can participate in the National Donor Sabbath (Nov. 13-15, 1998).

NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD),INC.

<http://www.pcnet.com/~orphan/>

This organization manages a drug cost share program for individuals who cannot afford Sandimmune (cyclosporine). See Part 3, section I.

National Transplant Assistance Fund

<http://www.LibertyNet.org/~txFund>

Formerly National Heart Assist and Transplant Fund

e-mail: txFund@LibertyNet.org

VOICE 800-642-8399 / Fax 610-527-5210

National Transplant Assistance Fund is dedicated to providing financial, social and emotional support to transplant candidates. NTAF counsels patients regarding location and cost of transplant centers and other possible sources of financial assistance. NTAF helps the patients' families organize fundraising in their communities while assuring fiscal accountability as trustee. The organization is also deeply committed to educating the public about the critical need for organ donation, lecturing community groups on organ donor awareness and distributing free organ donor materials upon request.

New England Organ Bank

One Gateway Center

Newton, MA 02158

800/446-6362

Contact address: info@neob.com

<http://www.ultranet.com/~neob/index.html>

Very nice on-line donor card available.

Information on donation and transplantation

Organ and Tissue Donation

Transplantation

Attitudes toward organ and tissue donation

Deciding on organ and tissue donation

The Gift of Life!

Information on becoming an organ and tissue donor

Print a donor card to sign. Tell your family.

We will send you information. Just fill out this form.

Information for Donor Families and Recipients

NEOB Donor Family Services

Donor Family Quilt

Corresponding with donor families and recipients

Novartis Pharma (formerly Sandoz) Transplant Square

<http://www.transplantsquare.com/index.htm>

Just as the town square used to be the central meeting place where people exchanged information and ideas, the Transplant Square from Novartis Pharma Ltd. is being offered on the Internet as a service to the worldwide transplant community — patients, healthcare professionals, support networks, and other interested audiences. We are committed to advancing the science of transplant medicine, and to providing you with up-to-date information in the field of transplantation.

Organ Transplant Association

<http://organtx.org/>

A web site organized by patients, families, and volunteers for the purpose of providing resources and support over the Internet. Contains the archives Kandy Darroch's "Medical Meanderings" newsletter. Medical Meanderings contains informative articles on transplantation topics. The site also contains a list of organizations providing financial support, or counseling, to transplant patients, a well maintained list of transplant related chat groups, information on laptop lending to patients in the hospital, and other useful resources.

Organ Transplant Patient Home Page

<http://www.hooked.net/users/chartsf/txp/txphome.htm#chrono>

Carl Hart <chartsf@hooked.net>:

There are numerous sites with transplant information; some pages are dedicated to health care practitioners, others to patients and their

families. However, I found the information to be piecemeal, in no logical order. I began to think back to my own experience with my father's heart transplant: What information could I have used, and when could have I used it? Thus, I recognized that one way to present this information logically was to present it in a chronologically based Table of Contents:

- after the shock of the diagnosis and prognosis;
- becoming informed about the procedure;
- determining where the transplant may take place;
- qualifying for the treatment (i.e., meeting the medical and insurance/financial criteria);
- entering the transplant program;
- undergoing the transplant procedure; and,
- complying with the aftercare instructions and addressing complications.

The Partnership for Organ Donation

<http://www.transweb.org/partnership/index.html>

The Partnership is an independent, non-profit organization dedicated to saving and improving lives by closing the gap between the number of organ transplants that are possible and the number of organ transplants that actually occur.

If you would like more information about us and the work we are doing to help solve the organ donor shortage, please contact us at info@organ-donation.org or call (617) 482-5746.

Contents:

- How the Partnership Fulfills Its Mission
- Progress Notes: The Partnership's newsletter
 - Progress Notes Archive
- Public education: A Different Kind of Love Letter and the Gallup Survey
- A brief history of The Partnership for Organ Donation
- A list of our Board members and Advisory Board members
- Recent press releases
- The Partnership's Bibliography
- The Partnership for Organ Donation Scientific Abstracts (accepted)
- Job opportunities (when available)
- Sponsors

Renalnet Home Page

<http://ns.gamewood.net//renalnet.html>

Partial contents:

- Dialysis Clinical Information
- ESRD Program Financing
- ESRD Providers
- ESRD Vendors and Manufacturers
- Government & Education Healthcare Resources
- Nephrology Professional Organizations
- Nephrology Research Presentations
- Organ Transplantation

Featured General Healthcare Resources

Second Wind National Lung Transplant Patient's Association

<http://www.2ndwind.org>

A Network of General Information and Support For both pre and post lung transplant patients and their families.

- Members Network E-Mail Address Listings
- Financing Transplantation
- Members Stories & Letters
- Information on Specific Lung Transplant Related Diseases
- Member profiles E-mail Addresses ,homepage links
- "AirWays" Newsletter
- Articles & Items of interest
- Nutrition Center
- Organ Donation Information

Stadtlanders' Pharmacy

<http://www.stadtlander.com>

Transplant National Resource Directory

Article Archives: These articles have been adapted from Stadtlanders' magazine.

Surviving Transplantation

Dr. John Craven <jcraven@julian.uwo.ca>:

Surviving Transplantation is intended as a guide to coping for persons undertaking major organ transplant. Any ideas contained within this book should be considered in the context of your personal health circumstances. As you will read in several places in Surviving Transplantation, we recommend that you consult a physician or another health professional before undertaking to make any changes in your personal health care.

<http://www.stjosephs.london.on.ca/SJHC/programs/mental/survive/st.htm>

Transplant Awareness Inc.

Transplant Awareness Inc. sells T-shirts, car license plate frames, pins, and other items, which have slogans that promote organ and tissue donation. TAI is a nonprofit corporation run and operated by volunteers who are all organ transplant recipients. Our objective is to market products that will promote organ donation by increasing awareness among the general population. It is our hope that TAI's efforts will result in more organs being donated and more lives being saved and prolonged in the manner that our lives were. Since we are all non-paid volunteers, 100% of the profit from the sale of our merchandise goes to increasing organ and tissue transplantation awareness. We thank our donors for the lives we can now live and we thank you for your patronage of our efforts. Wide variety of donation and patient resources listed under "Other Transplant Resources "

<http://www.transplantawareness.org/>

Transplanthealth.com

<http://www.transplanthealth.com>

is an educational Web site that offers transplantation information, message boards, and interactive features for kidney, liver, and other organ recipients and donors. Features patient education information, a message board, and information links. On-line registration required.

Transplantweek

<http://www.transplantweek.org>

Latest news about transplanation.

The Transplant Week online newsletter, presenting the latest news and views on developments in transplantation, is one of a family of specialized medical newsletters brought to you by Medical Week, LLC

TransWeb

TransWeb is a world wide web page for sharing information on organ donation and transplantation. The page is continuously seeking contributions of new material, as well as ideas for making it a more useful forum for the transplantation community. TransWeb can be found at

<http://www.transweb.org>

and suggestions and contributions can be sent to transplant.webmaster@umich.edu

Partial list of contents:

- Focus on Transplant Patients

 - Ask TransWeb

 - Frequently Asked Questions

 - Experiences with Transplantation and Donation

 - Transplant Medications

 - New Developments in Transplantation

 - Policy and Legislative Updates

 - Support, Advocacy, and Educational Groups & Resources

 - The Transplant Memorial

 - Reading List, Articles, Videos, etc.

Information for Medical Professionals

- New Developments in Transplantation

- Political/Legislative Updates

- Ask TransWeb

- Cybercongress: Transplantation in the Next Millennium

- Congress on Xenotransplantation

- UNOS's Calendar of Events

Organ and Tissue Donation: A Gift of Life

- Test Your Knowledge of Organ Donation! The Donation Quiz

Frequently Asked Questions:

Top Ten Misconceptions about Donation

Can well-connected people like Mickey Mantle get transplants faster?

How many people need organs? See also the waiting list statistics at UNOS.

Does my religion approve of donation?

What kinds of tissue can be donated?

What do I do if I want to donate?

Can I donate NOW?

Where can I register to be a bone marrow donor?

Articles About Donation:

The Tissue Shortage

From Oncolink: Measures to Safeguard Human Tissue Transplants

Experiences With Donation:

Feelings of a Living Kidney Donor

A bone marrow donor's experience

A special thank-you letter

"The Gift That Lives On"

Promoting Donation:

The Wendy Marx Foundation

The Transplant Memorial

Transplantation Resources on the Internet

(A comprehensive list of links for related sites on the net.)

Transplant News

<http://www.trannews.com/>

The only independent newsletter offering timely news on Organ, Tissue, Eye and Bone Marrow Procurement and Transplantation. Find out how to receive a FREE copy of the Transplant Video Journal.

TRIO (Transplant Recipients International Organization, Inc.)

<http://www.primenet.com/~trio/>

TRIO is a major transplant patient support, and government lobbying, organization. This site offers recipient and donor family support.

Large available publications list.

Current news. Local chapter information. Email: trio@primenet.com

UCLA Transplantation

<http://www.medctr.ucla.edu/dept/xplant/default.htm>

So far available is a description and statistics of the Dumont-UCLA Transplant Center. Other things under construction:

Abstracts not Currently under Copyright

A Moderated Newsgroup on Issues in Liver Transplantation

Static and Video Images of Procedures

Slide Show Presentations

University of Colorado's Organ Transplant Web Page

<http://www.uchsc.edu/ctrinst/organtx/>

UNOS Transplantation Information Site

(See also section VII for more information on UNOS.)

<http://www.unos.org>

UNOS is a non-profit organization responsible for promoting, facilitating, and scientifically advancing organ procurement and transplantation throughout the United States while administering a national organ allocation system based on scientific and medical factors and practices.

Issues of the very informative news magazine UNOS Update have begun to be posted.

The site also has up-to-date transplant statistics, resources available, and calls for public comment on policy changes.

World Children's Transplant Fund

<http://www.wctf.org/>

The World Children's Transplant Fund (WCTF) is a unique and special organization. Our mission is to provide as many opportunities as possible for lifesaving pediatric transplant surgery to children of the world. Our goal is to assist nations in developing and then sustaining independent pediatric organ transplant programs. Coordinating and sharing of our medical resources enables children of lesser developed countries access to the chance which children of the United States routinely have...the chance for life. The Strategy of the World Children's Transplant Fund focuses on developing World Children's Transplant Centers attached to preexisting medical facilities in each of the selected site locations.

World Children's Transplant Fund

16000 Ventura Blvd.

Suite 103

Encino, California 91436

Phone: (818) 905-9283

Fax: (818) 905-9315

E-Mail to: info@wctf.org

III. Organ donation and transplantation, frequently asked questions

contributed by Alex Bost, alex@unx.sas.com

*** Commonly Asked Questions About Being an Organ Donor:

– Where can I get an Organ Donor Card?

Many organizations, including the NKF and AAKP will provide donor cards free of charge. Many physicians, pharmacies, and hospitals will also provide them.

[Free cards and pamphlets also available from (800)24-DONOR]

– Should I mention being an Organ Donor in my Will?

No. Your will may be read too late to take your organs. However, you should definitely mention Organ Donation in your Living Will.

– What is a Living Will?

A Living Will is a document where you stipulate what kind of medical attention you will receive if you are unable to make decisions for yourself. You may state your wish to become an organ donor in a Living Will.

– Who pays for the medical costs of being a donor?

The transplant recipient is responsible for all costs involved in organ procurement. The donor's family will not pay any of the cost.

– Does organ donation disrupt funeral arrangements?

No. Organ donation will not disfigure the body. A donor may still have an "open casket" funeral.

– Will becoming a donor mean a doctor will let me die?

Absolutely not! Medical personnel must follow very strict guidelines before a donor can be pronounced dead. You can expect the same quality of health care as you would if you weren't a donor.

The following was written by Anne Treffeisen of the Long Island Chapter of TRIO (Transplant Recipients International Organization) (516-421-3258). The last week of April is National Organ and Tissue Donor Awareness Week (NOTDAW). She asks that pastors or rabbis include mention of the gift of life in their sermon or bulletin during this week and provides this message as a guide.

ORGAN DONATION AND TRANSPLANTATION FACT SHEET

The donation of organs is a unique opportunity to save lives. It is possible for the organs, tissues, and corneas of a single donor to save or help as many as 25 people.

Transplantation works. As of 1993, over 160 thousand people have been transplanted, and the majority are living full productive lives more than five years after surgery.

Over 28,000 people in the United States, many of them children under 10 years of age, are currently waiting for transplants, and someone is added to the waiting list every 30 minutes. Many will die waiting.

All potential recipients are listed on the United Network for Organ Sharing, UNOS, computer. Organs are assigned as they become available considering the severity of a patient's condition, medical requirements (such as blood type, size, and tissue match), proximity to the available organ, and time on the waiting list.

More organ donors are needed. Only about 20% of the potential donors actually have their organs donated.

Organ donors are healthy people who have died suddenly, usually through accident or head injury. They are brain dead. The organs are kept alive through mechanical means.

No one involved with the life saving care of an individual is involved in the transplantation or organ recovery process. No one on the transplant team has any role in the diagnosis, treatment or declaration of death of a patient.

Organs for transplant must be made available soon after death. Organ removal will not take place without the permission of the next of kin. Therefore, the decision to donate should have been discussed earlier and the next of kin should understand and be prepared to carry out their loved one's wishes. This is the heart of DONOR AWARENESS.

There is no cost or payment to the donor family or estate. All normal funeral arrangements are possible.

All religious groups approve of organ and tissue donation as charitable acts toward one's fellow human beings.

Organ donation is a true gift. In general, the donor family will never know the recipient. They do know that out of their tragic loss, they have given others life and health.

Questions frequently asked by transplant patients:

(see also UNOS pamphlets in Yale biomed gopher, information in TransWeb, American Share Foundation WWW site, section II)

Contributed by Joel Newman <newmanjd@UNOS.ORG>, UNOS Manager of Corporate Communications

*What's my position on the list?

Candidates and donors are matched by data, not rank. The only thing you could be "ranked" by, in theory, is your waiting time. You could be #1 on your local list by waiting time, having waited longer than

everyone else. However, if you're blood type B and a type A organ comes along, you'd automatically be excluded. The same is true for organ size, tissue match, etc. Given that all donors and all candidates differ in some respects, you could be 20th on the list for one offer, 3rd for the next, then 57th, then 1st.

Even if you're at the "top of the list," you may not get the organ. Perhaps you have a complication that would preclude getting a transplant for a few days or weeks. Maybe in reviewing the lab work or donor history the transplant team has cause to defer the offer. Perhaps, if you're highly sensitized, the initial crossmatch is OK but the final crossmatch comes back bad. There are lots of scenarios. Any refusals and the explanations would be submitted to UNOS.

Organs other than kidneys are most often transplanted into one of the first 10 candidates identified on the match run. For kidneys that rate is much lower, particularly because of highly sensitized patients with adverse crossmatches.

With specific, written permission from the patient and from the listing center, UNOS can provide the basic information on patient listing (date of entry, current medical status, etc.). But I'd *beg* you to call the center first on this if you have any questions! And again, for all the reasons above, this would be meaningless as an expression of your "rank" for a transplant.

For more detail:

http://www.med.umich.edu:80/trans/transweb/faq/faq_pos_list.html

*Where is the best transplant center?

We (UNOS) maintain(s) data on center-specific graft and patient survival. The current report covers all transplants occurring between 10/1/87 and 12/31/91. You can request data free on up to 10 transplant programs; after that we recommend you purchase either the set of data or the specific volume you need. I believe the entire report is also available via ftp on some obscure HCFA site; even I don't know the address. (I'd warn you, though — it's a huge report.)

That report will tell you quite a bit, but there's a lot it can't. There are some risk factors we're unable to quantify at this point but might affect outcome. There is also pure chance, which we can never completely eliminate. For example, a recipient with a perfectly functioning transplant who gets run over by a truck is still counted as a death, graft-related or not.

The numbers can never tell you the whole story, either. I think any surgeon or physician would tell you that the patient's outlook and attitude have a great effect on outcome. If you really like (or really hate) the care you're getting, the numbers have less meaning.

I'd advise you to look at the numbers, get some recommendations from people in similar need, and then talk to the people at the program(s).

IV. The organ donor shortage

UNOS statistics reveal that in 1993, on average, 8 people a day died in the US while on the waiting list. As organ transplantation has passed out of the experimental stage, the number of people with end stage diseases seeking a transplant has slowly but steadily increased. The number of donations however, has not increased. Sadly, this is not because there are not more potential donors. Various estimates are that anywhere from 60 to 70% of potential donations are either refused by the next-of-kin or are never requested. These estimates take into account the criteria for brain-dead, heart-beating donors and other contraindications. Roughly half of the missed donations appear to result from failure of physicians to either declare brain death in a timely manner, or their failure to notify their Organ Procurement Organization of potential donors. This is despite enactment in all 50 states of "required request" legislation that mandates that all potential donations be sought. Apparently, there is no enforcement of these laws.

There are a variety of proposals to increase the number of donations. For example: public and professional education, giving people who have registered their support for donation additional points on the waiting list should they ever need a transplant themselves (preferred status), changing the structure of donation from a required opting-in to a required opting-out strategy (presumed consent), and requiring all adults to register their choice of whether they would permit donation in the event of their death (mandated choice or required response).

There are also, on occasion, issues raised in the media that might be of interest to medical ethicists, but which would have little to no positive impact on the number of organs available for transplantation. Organ donation from anencephalic infants and executed convicts, for example, are issues that could possibly distract attention from the more important issue of obtaining wide spread support for donation.

In the 1994 September 14th issue of JAMA, the AMA has finally (after nearly a year of delay after the policy's adoption) made public its recommendation that states enact into law a mandated choice policy. The length of time it has taken to make this policy public indicates the medical community's inability to appreciate that this is a crisis situation for those patients on the waiting list whose lives could potentially be saved. It also indicates that there are individuals who do recognize the seriousness of the situation and are working to move their colleagues toward a feasible solution.

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Note: Some of the conclusions in this study are at odds with those of studies conducted by The Partnership for Organ Donation.

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Lee, P.P., Kissner, P., Organ donation and the Uniform Anatomical
Gift Act. (1986) Surgery 100:867–875.

"Solving the Organ Donor Shortage", The Partnership for Organ Donation,
Inc. (617)482–5746.

UNOS Ethics Committee Reports on alternatives for organ donation:
"Financial Incentives for Organ Donation"
"Preferred Status for Organ Donors"
"An Evaluation of the Ethics of Presumed Consent and a Proposal Based on
Required Response"
– available from UNOS (804)330–8500
– also available through the Yale biomedical gopher (see section II)

Gallup Poll on Attitudes Towards Organ Donation, available in the Yale
biomedical gopher and Transweb (see section II), and from The Partnership
for Organ Donation, Inc. (617)482–5746.

National Donor Sabbath web site

This site contains a wealth of information regarding the positions of
many Judeo–Christian religious organizations toward organ donation.
Organizations' recent position statements, and suggestions to clergy
for participating in National Donor Sabbath Day, or presented.

From Douglas Y. Sur – doug.sur@bigfoot.com:
National Sabbath Day is coming and has been constructed to help
religious organizations help the transplant community.

For those interested in National Donor Sabbath Day, please contact
Jennifer Grant at 301–443–7577. I tried putting up some information
regarding the subject at

<http://www.transplantawareness.org/sabbath/CONTENTS.html>

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V. Transplant and organ donation myths
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As with any new technology, rumors, myths and misunderstandings about
organ transplantation are widespread. Frustration produced by the high
cost, the effect of the organ donor shortage, and the unavailability of
transplantation throughout most of the rest of the world have probably
contributed to this. Since rumors can often be more entertaining than
the truth, tabloid media will often pick up and help spread them, despite
the great harm they cause. Urban legends about organ transplantation are
uniquely dangerous since organ transplantation can not succeed without
the participation and support of the majority of the population. Bad
press, urban legends, even fiction portraying organ transplantation as

somehow evil, all have prevented full support for donation and led to the death of people who might otherwise be leading productive and happy lives now.

Another factor fueling the proliferation of myths is the unfortunate institution in India of payment for unrelated live kidney donation that preys on the poor in that country. While it may be true that the Indian medical community is not required to abide by western standards of ethics, neither is the US medical community required to interact with them, train their physicians, publish their research, etc. Its past time that the US medical community started taking visible responsibility for influencing transplantation ethics in foreign countries.

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Gallup Poll on Attitudes Towards Organ Donation, available at http://www.med.umich.edu:80/trans/transweb/gallup_survey/gallup_index.html and from The Partnership for Organ Donation, Inc. (617)482-5746.

UNOS web site's Top Ten Myths About Donation
http://www.unos.org/Newsroom/Frame_news.asp?SubCat=myth

The "rising from brain death" myth

One of the requirements for solid organ donation from cadavers is that blood remain circulating for a number of hours. This requires a patient that has been declared brain dead, total loss of brain stem function, but whose heart can be kept beating. Unfortunately,