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# FOIA MARKER

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**Record Group/Collection:** Donated Historical Materials  
**Collection/Office of Origin:** Frieden, Lex, Collection  
**Series:** Printed Materials  
**Subseries:** Miscellaneous

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**OA/ID Number:** 52165  
**Folder ID Number:** 52165-013

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**Folder Title:**  
5-27-99 [To Do Lists, Personnel Policies, Meetings, Independent Living - 1998-1999]

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**Stack:**

**Row:**

**Section:**

**Shelf:**

**Position:**

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From: "Funchess, Roxy" <FunchR@TIRR.TMC.EDU>  
To: "Ifrieden@bcm.tmc.edu" <lfrieden@bcm.tmc.edu>  
Subject: Phone calls 1-21-99  
Date: Thu, 21 Jan 1999 15:29:36 -0600  
X-Mailer: Internet Mail Service (5.5.1960.3)

Thursday, January 21, 1999

Lex:

- 1) Peter Pfaelzer called. Have you had any luck on funding for the sci project? Can leave a message on his voicemail. (510) 841-1238
- 2) Kathy Martinez called. She started getting too detailed, so I put her in your voicemail.
- 3) Dr. Maureen Nelson called. 770-5205. She'll be available late afternoon today.
- 4) Wendy called. She wanted to know if you could speak for the attorneys at her CLE: she said ILRU should really come before some trip to Kuwait.
- 5) June called. (310) 821-7080 She'd like to have a real conversation with you instead of these one liners over the e-mail



United States of America

0000-000000

To Do

get a copy of Simon Haskels paper  
on employment

remember to carry straw in little black bag



THINK SOCIAL SECURITY'S BROKE? GET A REALITY CHECK.

United States of America

0000-000000

To Do

thank Esra El Soadi

thank Dr El Adnan

thank Ashua

thank Addan

send info on the conference to Adnan, Faleh,

two blind guys and lady from Lebanon



THINK SOCIAL SECURITY'S BROKE? GET A REALITY CHECK.



شيراتون الكويت  
SHERATON KUWAIT  
KUWAIT

للشؤون المطلوب (انجازها اليوم)

Things To Do Today

American Standard

6 jets 1Hp \$350.00

skirt = \$92

Jacuzzi 6jet .5HP

\$300 CT \$532.00

Quincy Extra

6 jet 1.5Hp

built in skirt

\$600.00



THE LUXURY COLLECTION  
SHERATON



شيراتون الكويت  
SHERATON KUWAIT  
KUWAIT

للشؤون المطلوب (انجازها اليوم)

Things To Do Today

Vantage 412 898

Vantage shower 922

Pulsar 2 - 2462

J-shower 3500

J steam shower 5000

Surround  
Vantage ~~Surround~~

\$482

1987 with spray



THE LUXURY COLLECTION  
SHERATON

TIRR  
EXECUTIVE COUNCIL  
May 24, 1999

**PURPOSE:** To work as a high performance team addressing hospital-wide issues, including operational planning, budgeting and policies.

**INTENDED RESULTS:**

1. We will have talked about Spasticity management revenues and the possibility of raising prices.  
(Donna)
2. We had a dialog about the leadership of the Outcomes Project.
3. We revisited the responsibilities of the Maintenance Department.
4. We reviewed the practice of reserving beds for ITB trials and Day Surgery Patients.
5. We discussed anesthesia and OR charges.

*[Handwritten scribbles and initials]*

*[Vertical handwritten notes and signatures on the right side of the page]*

Marie Oser (512) 465-1553; mobile: 828-3714

John Nelson (202) 205-9362 home: (202) 554-3499

Linda Kontrier (202) 219-6001 - X-165  
if you don't hear from Michaela Melhan  
in int'l labor affairs

Jean Pollidino (713) 665-0517

Alan Reich  
(202) 293-5960

Margylyn Hammond  
Home 435-750-6781  
Hk. 435-797-3811

From: "Funchess, Roxy" <FunchR@TIRR.TMC.EDU>  
To: "lfrieden@bcm.tmc.edu" <lfrieden@bcm.tmc.edu>  
Subject: Calls and calendar  
Date: Wed, 24 Feb 1999 15:54:04 -0600  
X-Mailer: Internet Mail Service (5.5.1960.3)  
X-MIME-Autoconverted: from quoted-printable to 8bit by hermes.bcm.tmc.edu id PAA29010

Wednesday, February 24, 1999

Lex:

- 1) Dr. Sam Poole's number: (281) 483-7109
- 2) Mitch called. (713) 541-0688. Wants to get started on this formal proposal. ~~Thinks that is what the hold up is.~~
- 3) Alissa Berrol from WID called. (510) 251-4306 wants to know if you know of any good reliable conference planner for the DC area.
- 4) Steve Linder with the SCI Center at the VA at Palo Alto, CA (650) 493-5000 X-65872. called about the electric stimulator for cough. I hinted that you didn't have anything, but he seems to want more of an answer.
- 5) Doug Drey called (713) 284-1973; home: (713) 785-1896 to see if you knew of any organizations to go to for funding for the HERC (equipment). They are losing volunteers and will need paid staff positions.
- 6) Mary Schiflett called today. We received the packet of materials, but is already planning the merit review meeting for Monday or Tuesday, March 8 or 9 at 1:30 p.m. (She already has 4 people that can do it on Monday). Do you want to be on the panel or have someone else in mind?
- 7) Ray Jones called. (713) 529-7887. Referred to you by Marty Green. He was vague when I asked what he wanted to talk about. Told him you'd be tied up all-afternoon. ~~Want me to call and get more info?~~
- 8) Mary Ann wants to meet with you tomorrow at 1:00 to discuss the details of your request--this will give you your meeting after Bruce Robinson
- 9) Marc at WID called and said he sent you some more e-mails-probably with the virus-not to open, but he has figured out where it is. Call if you have questions (510) 251-4308.

Calendar:

Wednesday, February 24 Lex to do Administrative Rounds



ILRU Program  
2323 S. Shepherd, Suite 1000  
Houston, TX 77019

FAX SHEET

DATE: 1-25-99

PLEASE DELIVER THE FOLLOWING PAGES TO:

NAME: Lex

FROM: Lawie

TIME: \_\_\_\_\_

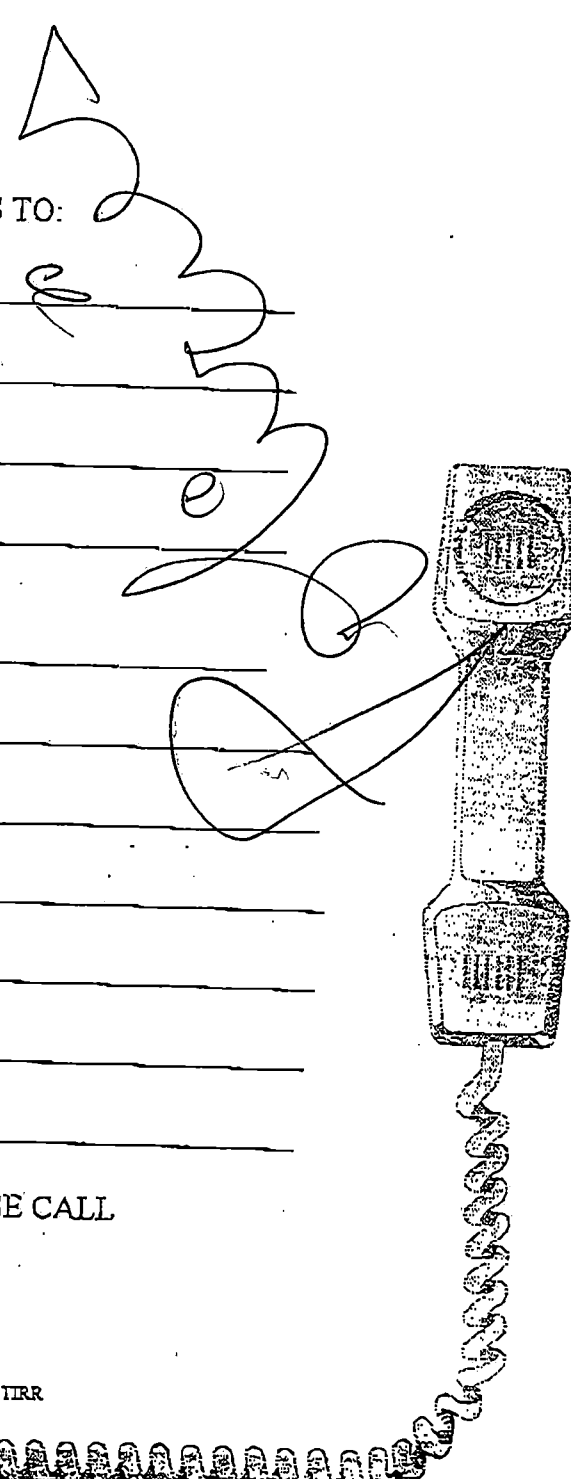
NUMBER OF PAGES: \_\_\_\_\_  
(Including Fax Sheet)

MESSAGE: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

IF YOU DO NOT RECEIVE ALL PAGES, PLEASE CALL  
(713) 520-0232  
(713) 520-5136 (V/TTY)  
(713) 520-5785 (FAX)

ILRU Program at TIRR



TO: Lex  
FROM: Wendy  
RE: Commentary on personnel policies and procedures  
DATE: March 5, 1993

Following is my commentary on personnel policy number TS1.16;

re: post-offer alcohol/drug screens

These can be conducted but it is important to keep in mind that alcoholics are also protected by the ADA so they should not be screened because of their alcoholism. You can require that employees not drink on the job but can't exclude them from a job because of their alcoholism.

re: Medical examinations of employees

Medical examinations of employees have more stringent requirements. For medical examinations to be conducted of employees they must be "job-related" and consistent with business necessity. An examination would be job-related when the employee is having difficulty performing their job, when an employee becomes disabled, when necessary to determine reasonable accommodation or when required by Federal law or state and local laws which are consistent with the ADA.

The scope of an employee medical examination must also be job related. If an employees job involved lifting and they develop a back impairment they can be seen by an orthopedist but they cannot also be tested for HIV. So it would probably be illegal to request an employees medical records as this would be too broad an inquiry.

Employers may also conduct voluntary medical examinations and inquiries which are part of employee health programs. These programs must be:

- 1) voluntary;
- 2) information gathered must not be used to discriminate;
- 3) information subject to ADA confidentiality requirements.

These records should also be kept confidential subject to the following exceptions:

- 1) Supervisors where necessary to apprise them of work restrictions and accommodations.
- 2) First aid and safety personnel where

appropriate if emergency treatment might be required or if specific procedures needed for fire or other evacuations.

3) To government officials investigating compliance with ADA and other laws prohibiting discrimination based on disability.

4) Where required to provide information to state worker's compensation offices in accordance with state law.

5) Where required to provide information to insurance companies providing life or health insurance to employees.

# Memo

**To:** Kathleen DeSilva  
**From:** Wendy Wilkinson  
**Subject:** Personnel Policy Revision #TS1.16: Post-offer Employment Screening

**Date:** January 19, 1998

**CC:** Lex Frieden

*Beverly Harrison Adley*

In reviewing the policy referenced above I became concerned about the legality of a portion of it. The portion I am referring to concerns medical examinations of employees, specifically the language, "As a condition of continued employment, employees may also be required to undergo periodic medical examinations...In connection with these examinations, employees are required to provide...access to their medical records."

I am concerned about its legality in light of the prohibitions in the Americans with Disabilities Act (ADA) governing the medical examinations of employees. The Act does allow for employee medical examinations, but only in certain circumstances. Where a medical examination is permissible, it must be strictly limited to eliciting information an employer needs to know for the purposes of providing an accommodation, assessing direct threat or evaluating an employees ability to continue to perform a job. The inquiry must be triggered by a specific event-- something which indicates that the employee is having difficulty performing their job. If there is such a trigger, again, the scope of the examination must be strictly limited to eliciting information necessary for providing the accommodation.

Following are the applicable provisions from the regulations and technical assistance manual promulgated by the Equal Employment Opportunity Commission; *(i)*

**"(c) Examination of employees**

A covered entity may require a medical examination (and/or inquiry) of an employee that is job-related and consistent with business necessity. A covered entity may make inquiries into the ability of an employee to perform job-related functions.

A covered entity may conduct voluntary medical examinations and activities, including voluntary medical histories, which are part of an employee health program available to employees at the work site."(29 CFR, part 1630.14)

The analysis accompanying the regulations goes on further to clarify:

Policy Distribution Committee

Page 2

January 19, 1998

"The ADA's requirements concerning medical examinations and inquiries of employees are more stringent than those affecting applicants who are being evaluated for employment after a conditional job offer. In order for a medical examination or inquiry to be made of an employee, it must be job related and consistent with business necessity. The need for the examination may be triggered by some evidence of problems related to job performance or safety, or an examination may be necessary to determine whether individuals in physically demanding jobs continue to be fit for duty. In either case, the scope of the examination also must be job-related."

One could argue that the personnel provision referenced is not illegal on its face because, arguably, there are circumstances where a comprehensive medical examination of an employee may be conducted. The key factor will be in assuring that these "triggering" events are understood. This section should be premised with an explanation of legitimate medical inquiries and a description of how extensive they may be. For instance, there could be a scenario where an employee is having difficulty performing his or her job and is subjected to a fairly comprehensive medical examination which includes an evaluation of their medical records in order to determine the appropriate accommodation. To leave this provision in the policy manual as it is, without clarification of and reference to the ADA "triggering" requirements is dangerous and not something I would be comfortable signing off on.

I just wanted to alert you to my concern and let you know that I am available if you have any questions or if I can be of any assistance.

<b>PERSONNEL POLICIES AND PROCEDURES</b>	<b>TITLE</b> Post-Offer Employment Screening	<b>DATE</b> 09/02/97	<b>PAGE NO.</b> 1 of 3	<b>TIRR</b>
	<b>AUTHORIZATION NO.</b> PP97-107	<b>POLICY NO.</b> TS1.16	<b>REVISION NO.</b> 3	

**POLICY**

As part of TIRR Systems employment procedures, an applicant is required to undergo a post-offer medical examination, including alcohol/drug screening, that is conducted by a physician designated by TIRR Systems. Any offer of employment that an applicant receives from TIRR Systems or its affiliated facilities is contingent upon, among other things, satisfactory completion of this examination and a determination by the hiring facility and its examining physicians that the applicant is capable of performing the essential functions of the position that has been offered.

As a condition of continued employment, employees may also be required to undergo periodic medical examinations, at times specified by TIRR Systems, which may also include alcohol and drug screening. In connection with these examinations, employees are required to provide the designated TIRR Systems facility with access to their medical records, if requested. Further, it should be understood that the designated TIRR Systems facility receives a full medical report from its examining physicians regarding the applicant's or employee's state of health. TIRR Systems post-offer and drug/alcohol screening medical examinations, as well as continued employment exams, are paid for in full by the appropriate TIRR Systems facility.

Questions about TIRR Systems-required medical examinations should be directed to your Supervisor, the facility's Personnel Department, or the TIRR Systems office.

**PROCEDURE**

- I. After an applicant has successfully completed the interview process the Personnel Department at the hiring facility will arrange an appointment for a physical exam with a TIRR Systems designated physician.
  - A. The health examination will consist of at least the following:
    1. Medical history
    2. Physical examination
    3. TB skin test/chest x-ray (TB skin test will not be required for known positives); a chest x-ray will be performed when candidates/employees indicate that they test positive.



## PERSONNEL POLICIES AND PROCEDURES

SUBJECT Drug Free Workplace/Substance Abuse DATE 5/93  
 POLICY NO. TS3.16 REVISION NO. 1  
 AUTHORIZATION NO. PPM120 PAGE NO. 3 of 8

### GENERAL POLICY PROVISIONS

Any of the following actions constitutes a violation of the policy and may subject an employee to disciplinary action including immediate termination:

1. Using, selling, purchasing, transferring, possessing, manufacturing, or storing an illegal drug or drug paraphernalia, or attempting or assisting another to do so, while in the course of employment or engaged in a TIRR Systems sponsored activity, on TIRR Systems premises, in TIRR Systems owned, leased, or rented vehicles, or on business.
2. Working or reporting to work, conducting work related business or being on TIRR Systems premises or in a TIRR Systems-owned, leased, or rented vehicle while under the influence of an illegal drug, alcohol, or in an impaired condition.
3. Switching, adulterating, or attempting to tamper with any sample submitted for medical testing, or otherwise interfering or attempting to interfere with the testing process.

### PREVENTIVE ACTS


1. Employees taking drugs prescribed by a physician must advise their direct supervisor in writing of the possible effects of such medication regarding their job performance and physical/mental capabilities. This written information must be kept confidential and communicated to the direct supervisor prior to the employee commencing work. All medical information will be kept confidential and the employer, without exception, will punish any breach of privacy and confidentiality in this regard. All prescription drugs must be kept in their original container.
2. Any employee involved in a work related accident or injury where alcohol or drugs are believed to be a contributing factor may be referred to an employee assistance counselor in addition to any other investigation activities.

### CORRECTIVE ACT

Although employees will not be subjected to random fitness for duty examinations as a result of this policy, any employee involved in a work-related accident or injury may be subject to urine/blood and breath testing.

### SEARCHES

We reserve the right to conduct searches or inspections of an employee's person or personal effects including (without limitation) purses, briefcases, and motor vehicles located on TIRR Systems property based on reasonable cause, as well as TIRR Systems property used by an employee, including (without

  <b>POLICY AND PROCEDURE</b>	<b>SUBJECT:</b> <b>RESEARCH</b>		<b>POLICY NUMBER:</b> <b>A-31.T,L</b>
	<b>MANUAL:</b> <b>Administrative</b>	<b>DATE:</b> January 1999	<b>REVISION NUMBER:</b>
	<b>APPLIES TO:</b> <input type="checkbox"/> TIRR SYSTEMS <input type="checkbox"/> TIRR FOUNDATION <input checked="" type="checkbox"/> TIRR <input checked="" type="checkbox"/> TIRR LIFEBRIDGE <input type="checkbox"/> TIRR REHABILITATION CENTERS		<b>PAGE:</b> 1 OF 2

POLICY

Purpose

To insure effective coordination and appropriate management and support for all research endeavors.

Rationale

In order to provide monitoring and assurances required by Federal Regulations, and to ensure protection of patient rights and appropriate care and use of institutional facilities, we must have certain standards and policies for the conduct of research within the institution. Additionally, effective coordination and management of research will insure best use of institutional resources and synergistic linkages with clinical programs.

PROCEDURE

Definition


For the purpose of this policy, the term "research" shall be broadly defined to include all research, service demonstration, technical assistance, training, and related grant funded or externally sponsored activities at the hospital.

Policy Outline

1. All research concepts for which serious efforts are needed or for which serious planning is undertaken shall be filed in the form of a concept memo with the TIRR Office of Grants Administration.
2. The TIRR Office of Grants Administration will provide feedback on the research concept as it may relate to other research, educational, or clinical programs which may be in a conceptual stage or which may be underway. The Office of Grants Administration will also provide assistance in reviewing funding possibilities for the concept, and may recommend consultation pertaining to research design and methodology, if necessary.
3. At such time as one or more investigators decide to mount a formal proposal, the Office of Grants Administration should be notified to insure coordination with


I have made minor changes to both policies so they could apply to both hospitals. Example - "Will instead of "Time"

Rev, please review this (2) policies and make changes. Can they apply to TIRR + LifeBridge? Return by 1/15/99 Kathleen

  <b>POLICY AND PROCEDURE</b>	<b>SUBJECT:</b> <b>RESEARCH</b>		<b>POLICY NUMBER:</b> <b>A-31.T,L</b>
	<b>MANUAL:</b> <b>Administrative</b>	<b>DATE:</b> <b>January 1999</b>	<b>REVISION NUMBER:</b>
	<b>APPLIES TO:</b> <input type="checkbox"/> <b>TIRR SYSTEMS</b> <input type="checkbox"/> <b>TIRR FOUNDATION</b> <input checked="" type="checkbox"/> <b>TIRR</b> <input checked="" type="checkbox"/> <b>TIRR LIFEBRIDGE</b> <input type="checkbox"/> <b>TIRR REHABILITATION CENTERS</b>		<b>PAGE:</b> <b>2 OF 2</b>

other groups which may be responding to the same concept or program solicitation to insure that all possible support resources are organized and made available.

4. All proposals for external funding shall be submitted for administrative review to the Office of Grants Administration prior to the date of submission to the granting agency. Such proposals also shall be submitted simultaneously to the TIRR Grant Accounting Office and to the institutional research offices of affiliated institutions, as appropriate. A routing sheet should be prepared for each proposal, and should be signed by the TIRR Office of Grants Administration, the TIRR Grant Accounting office, and the TIRR CEO prior to final submission of the proposal.
5. A TIRR institutional review board for research will be maintained as required by Department of Health & Human Services regulations for the protection of human subjects under 45CFR46, as amended, and by other applicable federal and state policies and regulations. All research initiatives and proposals involving human subjects must be approved by the TIRR Institutional Review Board prior to the administrative review process. In certain circumstances, the IRB may provide a letter indicating that review is pending and will be completed prior to initiation of the proposed activity.
6. Copies of all official notices of grant or contract awards shall be filed in a timely manner with the Office of Grants Administration where they shall be maintained as an institutional record, along with copies of relevant grant proposals, budgets, and other documentation.
7. A TIRR Research Committee appointed by the Senior Vice President for Grants Administration shall: 1) advise the Senior Vice President for Grants Administration on research policy, programs, procedures and practices; 2) assist in the production and implementation of a strategic plan for the development of externally sponsored programs; 3) engage in mentorship and training programs related to research for staff members; 4) develop policies and procedures relevant to the dissemination of research findings; and 5) assist with coordination of the TIRR institutional review board and other research related committees and subcommittees.

  <b>POLICY AND PROCEDURE</b>	<b>SUBJECT:</b> <b>MISCONDUCT IN RESEARCH</b>		<b>POLICY NUMBER:</b> <b>A-32.T,L</b>
	<b>MANUAL:</b> <b>Administrative</b>	<b>DATE:</b> <b>July 1998</b>	<b>REVISION NUMBER:</b>
	<b>APPLIES TO:</b> <input type="checkbox"/> <b>TIRR SYSTEMS</b> <input type="checkbox"/> <b>TIRR FOUNDATION</b> <input checked="" type="checkbox"/> <b>TIRR</b> <input checked="" type="checkbox"/> <b>TIRR LIFEBRIDGE</b> <input type="checkbox"/> <b>TIRR REHABILITATION CENTERS</b>		<b>PAGE:</b> <b>1 OF 2</b>

**POLICY**

We expect all of our staff and collaborators in research to adhere to the highest standards of conduct in pursuing their research and other activities. Any form of misconduct, whether involving falsification of data, plagiarism, abuse of confidentiality, use of unacceptable clinical practices, violation of regulations or standards governing research or any other form of scientific fraud is contrary to the principles upon which TIRR was founded and adversely affects the reputation of TIRR and its programs and staff. Misconduct violates the trust of agencies, foundations, and other entities which sponsor research at TIRR, and it may also constitute a violation of law.


**DEFINITION OF MISCONDUCT IN RESEARCH**

"Misconduct in Research" means fabrication, falsification, plagiarism, or other practices that seriously deviate from those that are commonly accepted within the scientific community for proposing, conducting, or reporting research. It does not include honest error or honest differences in interpretations or judgments of data. (Source: U.S. Public Health Service Regulations).

TIRR has adopted standing policies regarding misconduct in research that are consistent with those in use by academic and clinical research facilities nationally. These policies comply with regulations issued by the Public Health Service (Responsibilities of Awardee and Applicant Institutions for Dealing with and Reporting Possible Misconduct in Science, effective November 8, 1989). Following is a brief summary of the procedures by which allegations of Misconduct in Research are reported to and investigated by TIRR.

**PROCEDURE**

1. Allegations of misconduct in research must be reported in writing and in confidence to the Senior Vice President ("Senior VP") for Grants Administration, TIRR, 1333 Moursund Avenue, Houston, Texas 77030.
2. The Senior VP shall promptly refer the matter to the TIRR Research Committee (the "Committee"). The Committee shall undertake an inquiry into the allegations. The

  <b>POLICY AND PROCEDURE</b>	<b>SUBJECT:</b> <b>MISCONDUCT IN RESEARCH</b>		<b>POLICY NUMBER:</b> <b>A-32.T,L</b>
	<b>MANUAL:</b> <b>Administrative</b>	<b>DATE:</b> <b>July 1998</b>	<b>REVISION NUMBER:</b>
	<b>APPLIES TO:</b> <input type="checkbox"/> <b>TIRR SYSTEMS</b> <input type="checkbox"/> <b>TIRR FOUNDATION</b> <input checked="" type="checkbox"/> <b>TIRR</b> <input checked="" type="checkbox"/> <b>TIRR LIFEBRIDGE</b> <input type="checkbox"/> <b>TIRR REHABILITATION CENTERS</b>		<b>PAGE:</b>  <b>2 OF 2</b>

Committee shall promptly submit a written report of its findings to the Senior VP within sixty (60) days of initiation.

3. If the results of the inquiry indicate that there is a reasonable basis for more thorough study, within thirty (30) days the Committee will undertake a formal investigation of the allegations. The investigation must be completed and a report of the results of the investigation submitted to the Senior VP within one hundred twenty (120) days of initiation.
4. A final finding of misconduct may be appealed to the Chief Executive Officer ("CEO") of TIRR within five (5) days of receipt by a respondent of the report of the Committee. The CEO may delegate the handling of the appeal to a person or persons whom the CEO deems qualified.
5. The Committee shall prepare and maintain records of its proceedings and documentation concerning its activities.
6. The privacy of persons who in good faith provide information concerning misconduct in science will be protected to the maximum extent possible.
7. Federal regulations and reporting requirements must be followed strictly.
8. TIRR must impose appropriate sanctions on individuals when allegations have been substantiated.

The foregoing summary is qualified in its entirety by reference to relevant Federal and non-Federal regulations that apply to research carried out with sponsorship from other than hospital sources.

Kay Daugherty

1720 So. Memorial

Tulsa, OK 74112-7043

January 25, 1999

Lex Frieden  
3634 N Braeswood Blvd  
Houston, Texas 77025

Dear Lex and family,

You may not have the slightest remembrance of me, but, believe me, I remember you, Brooke and your Mom and Dad very well. The names of Fred and Chuck Daugherty you may recall. We knew you and your family at First United Methodist Church and our families always sat near one another in the sanctuary. Now, that tells you who I am.

Thru a wonderful coincident, I received the article from the Houston paper that was written about you and your family. I was given it on the premise I would share it with the Joynor Class which your parents were members of and so many remembered you also.

One day, Annette Parks who used to be treasurer at the church called me and said that her son, Bruce, had just sent her this clipping about Lex and remembered his mom knew the family. So, he sent it to her and then Annette passed it on to me.

I loved every word of it and am still in awe yet not surprised at your achievements. Just being disabled doesn't effect your mind.

Lex, I have a grandson who became totally blind at age 19 and he is a real achiever as you have been and are. Brent was born with only one eye that had very little vision. His problem is Reiger's Syndrome and doctors know the name but no research has ever been done on it. After 12 surgeries in 20 months trying to save what little sight he had, he lost it all. Like you, tgat has never stopped him. If I can find a clipping that our paper here did on him, I will enclose it as I want Brent to call you sometime.

At present, Brent is working on his masters in juvenile justice. He made the honor roll several times in colleg enad was so upset if he missed his 4.0. He claims, which is so true, there is nothing wrong with him--he just can't see.

Last May, he married a gal he met at school and she is studying to become a teacher. Brent has done some wild things in his young life such as rock climbing, jumping out of a plane, etc.

Am so glad you met a lovely gal to be a companion. Also, know you love having Trey there. I have a 7 yr old grandson also so know what fun they are. Do believe God put you and Mac together. You both are a real team.

In time, Brent may want to call and talk toyou. He may need

some advice as to how is the best way to get around in Wash. Brent is a go-getter as you are.

I made umpteen copies of your article and the Joynors took everyone of them to take home and read. See, you never know who is reading about you.

do you ever get to Tulsa? If so, you are welcome to come to my house and the Joynors would love to see you.

Keep up the fine work, Lex.

Oh, I have kept in touch with Petie. She is lovely.

My husband, Joe, has been gone for 3 years now so I am alone. So many Joynors have passed away in the last few years but--we are up there in years and that is God's plan.

Remember, you are welcome here anytime.

Sincerely,

Kay Daugherty

Brent married a sighed girl--  
Brent & Angela Harbolt

Brent is Diana's  
youngest son. She is  
older than the boys.

P S Lex, I have macular degenration and near legally blind. Mine has nothing to do with brent's problem. Mine is strictly ole age!!!!

February 8, 1999

Lex Frieden:

It is noted in the December, 1998, issue of the Contemporary Rehab publication that you were presented the Ninth annual Henry B. Betts award. I take this opportunity to offer my congratulations to you for such a prestigious award.

We, in Oklahoma, are proud of your many accomplishments on behalf of the disabled.

It is further noted by the 1999 Disability Calendar that your birthdate is March 5.

I wish also to take this opportunity to wish you a Happy Birthday!!


Keep up the good work!!

Sincerely,

Pat Eidschun

9032 E. 35th St.

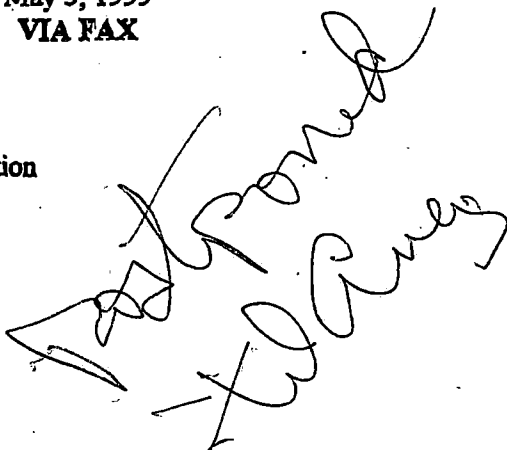
Tulsa, OK 74145-3402



**INSTITUTE OF MEDICINE**  
NATIONAL ACADEMY OF SCIENCES  
2101 CONSTITUTION AVENUE WASHINGTON, D. C. 20018

May 5, 1999  
VIA FAX

Lex Frieden, M.D.  
Professor of Physical Medicine and Rehabilitation  
Baylor College of Medicine  
1333 Moursund  
Houston, Texas 77030  
tel: 713.797.5283  
fax: 713.799.7095



Dear Dr. Frieden:

On behalf of the Institute of Medicine, I would like to invite you to participate, as an external reviewer, in the review of the Institute's report from the Committee on Improving Quality in Long-term Care. The statement of task is attached for your information.

The review process plays an important role in assuring that every IOM product will be accurate, effective, and credible. Members of the review panel should expect to receive the review manuscript and reviewer kit on or about Wednesday, May 26, 1999 and are asked to complete their comments by Monday, June 21, 1999. Reviewer comments are considered confidential and are sent without identifiers to the project staff.

**NOTE: Confidentiality and Anonymity.** To encourage reviewers to express their views freely, the review comments are treated as confidential documents and are given to the authors of the report with identifiers removed. After submitting their comments, reviewers are asked to return or destroy the draft manuscript and to refrain from disclosing their comments or the contents of the draft. The names and affiliations of participants in the review will be made public when the report is released (usually by acknowledgment in the published report), but their comments remain confidential. Even after release of the report, reviewers should not divulge their comments or any changes made to the draft manuscript. These restrictions are imperative in safeguarding the integrity of the institutional review process.

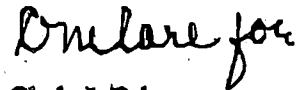
The draft manuscript is approximately 300 double-spaced pages, plus signed appendices that are not subject to external review. This manuscript should be considered confidential until its official release by the Academy. You will receive a complimentary copy of the report upon completion of the project.

Please fax Claudia Carl your response to our invitation at (202) 334-1412 or e-mail to IOMREVU@NAS.EDU. Should you agree to participate in this review, we will mail you the *Guidelines for the Review of National Research Council Reports*. This document will help guide you through the report review process.

Lex Frieden, M.D.  
Page 2  
May 5, 1999

I hope you can assist the Institute in this important endeavor. Please call Ms Carl at (202) 334-2352 if you would like further information. If you have any questions about the review process, please feel free to contact me at (202) 334-3666.

Sincerely,



Clyde J. Behney  
Deputy Executive Officer

Enclosure

cc: K. Shine  
S. Stoiber  
C. Carl

## Project Scope

✦ [More Project Information](#)

**Continuing to Improve Quality in Long-Term Care**  
**Project Identification Number: HCSX-H-97-02-A**

**Responsible Staff Officer: Marilyn Field**

**Major Unit: Institute of Medicine**

**Sub Unit: Division of Health Care Services**

### **Project Scope:**

#### **IMPROVING QUALITY IN LONG-TERM CARE**

The Institute of Medicine (IOM) has established an expert committee to examine the means for assessing, overseeing, and improving the quality of long-term care in different settings and the practical and policy challenges of achieving a consistent quality of care regardless of the site of care.

Since the IOM issued its 1986 report, *Improving the Quality of Care in Nursing Homes*, many changes have occurred that have significantly altered where long-term care is received and by whom. In addition, the methods and tools for assessing the quality of care and measuring health outcomes have advanced and have become more patient-oriented. Unlike the earlier IOM study, the current study will examine the full range of long-term care settings and services, including nursing homes, assisted living facilities, and community-based home health care.

Among the questions the new study will consider are:

1. What are the demographic, health, and other characteristics of individuals requiring long-term care and how are they changing?
2. What are the roles of the various long-term care settings in community health care systems, and how do they relate to other components of community care systems?
3. What are the strengths and limitations of existing methods and tools to measure, oversee, and improve quality of care and outcomes in nursing homes and other long-term care settings? How can these methods and tools be improved to promote better quality of care and other outcomes regardless of setting?
4. What is known about the currently quality of long-term care in different settings and the extent to which care has improved or deteriorated in the last 10 to 15 years? What is known about the impact of long-term care regulation, especially the Nursing Home Reform Act of 1987, on such matters as: the use of physical and chemical restraints; advance care planning; provision of adequate nutrition; identification of substandard facilities or programs; and public access to information on quality of care?

**Project Duration: 18 months**

**Funchess, Roxy**

**From:** Lex Frieden [lfrieden@bcm.tmc.edu]  
**Sent:** Thursday, June 03, 1999 3:23 PM  
**To:** Funchr@tirr.tmc.edu  
**Subject:** Fwd: A Request

**From: "Hudgins, Nancy" <Hudgin@TIRR.TMC.EDU>**

**To:** "frieden, lex (E-mail)" <lfrieden@bcm.tmc.edu>  
**Cc:** "Funchess, Roxy" <FunchR@TIRR.TMC.EDU>  
**Subject:** A Request  
**Date:** Tue, 1 Jun 1999 13:20:35 -0500  
**X-Mailer:** Internet Mail Service (5.5.2448.0)

We were discussing TIRR Year 2000 in a meeting this morning (June 1) and Ashley asked if we could get a meeting with President Bush to ask him if he would serve as Honorary Chairman (or whatever we might decide to call it) of our TIRR Year 2000 celebration. He feels we have a good chance to make this happen because of the Bush Medal Luncheon, etc. Can you see about making such a meeting happen. Ashley has an idea of who might be good to attend the meeting and you might want to discuss this with him.

I was at UofH Law School this a.m. and Mark Rothstein said he has a meeting with you June 10, 10 a.m. Is this a meeting I should attend? Maybe not, but Mark wanted me to ask.

**Funchess, Roxy**

**From:** Hudgins, Nancy  
**Sent:** Wednesday, June 02, 1999 2:17 PM  
**To:** Smith, Ashley  
**Subject:** FW: A Request

This is where we are on your suggestion we try to set something up with President Bush re: Honorary Chair, TIRR Year 2000. You know this – but the Bushes are in Maine a lot during these summer months. Plus whatever they are doing to help George W. So Lex will have to do some fancy footwork to make this meeting happen. He can do that.

-----Original Message-----

**From:** Funchess, Roxy  
**Sent:** Wednesday, June 02, 1999 2:02 PM  
**To:** Hudgins, Nancy  
**Cc:** Frieden, Lex  
**Subject:** RE: A Request

Nancy: Lex is in Washington presenting at a reverse site visit today. He'll get your e-mail when he returns, but I did ask him about the meeting on June 10. He intended to invite you to the meeting, but got tied up preparing for this site visit. It's on the 10<sup>th</sup>, with Laura and Mark at 10:00. I'll let you know where as soon as the room is confirmed.

--Roxy

-----Original Message-----

**From:** Hudgins, Nancy  
**Sent:** Tuesday, June 01, 1999 1:21 PM  
**To:** frieden, lex (E-mail)  
**Cc:** Funchess, Roxy  
**Subject:** A Request

We were discussing TIRR Year 2000 in a meeting this morning (June 1) and Ashley asked if we could get a meeting with President Bush to ask him if he would serve as Honorary Chairman (or whatever we might decide to call it) of our TIRR Year 2000 celebration. He feels we have a good chance to make this happen because of the Bush Medal Luncheon, etc. Can you see about making such a meeting happen. Ashley has an idea of who might be good to attend the meeting and you might want to discuss this with him.

I was at UofH Law School this a.m. and Mark Rothstein said he has a meeting with you June 10, 10 a.m. Is this a meeting I should attend? Maybe not, but Mark wanted me to ask.

*from  
Laurie*

**Subject: [NIC-981229.7081] Modify Registration ILRU.ORG**

**Date: Tue, 29 Dec 1998 16:08:03 -0500 (EST)**

**From: rereg@internic.net**

**Reply-To: hostmaster@internic.net**

**To: cdresden@bcm.tmc.edu, rshepard@bcm.tmc.edu**

THIS IS NOT AN INVOICE, PLEASE DO NOT PAY UPON RECEIPT OF THIS NOTICE. YOUR BILLING CONTACT WILL RECEIVE AN INVOICE APPROXIMATELY 30 DAYS BEFORE YOUR RENEWAL PAYMENT IS DUE.

*hex*



The purpose of this notice is twofold;

- 1) to inform you that you will be invoiced for your annual maintenance fee shortly.
- 2) to give you an opportunity to update any information on your domain registration agreement.

This notice is being sent to the Technical, Admin and Billing Contacts.

Please review the agreement below and complete any sections which are blank or need to be updated as soon as possible. Please pay particular attention to the Billing Contact (Section 6), as this is where invoices will be sent. If no Billing Contact exists, the invoice will be sent to the Admin Contact.

After updating the agreement, please e-mail it to hostmaster@internic.net so that we can process your updates.

Your Billing Contact (or Admin Contact if no Billing Contact exists) will be sent an invoice 30 days before your maintenance fee is due. The invoice will detail the domain name for which renewal is due, and the associated fee.

For additional billing information, please read the billing FAQ at [HTTP://rs.internic.net/announcements](http://rs.internic.net/announcements). Billing questions may be directed to [billing@internic.net](mailto:billing@internic.net) or 703-742-4777.

[ URL <ftp://rs.internic.net/templates/domain-template.txt> ] [ 01/98 ]

\*\*\*\*\* Please DO NOT REMOVE Version Number or Sections A-Q \*\*\*\*\*

Domain Version Number: 4.0

\*\*\*\*\* Email completed agreement to hostmaster@internic.net \*\*\*\*\*

NETWORK SOLUTIONS, INC.

DOMAIN NAME REGISTRATION AGREEMENT

A. Introduction. This domain name registration agreement ("Registration Agreement") is submitted to NETWORK SOLUTIONS, INC. ("NSI") for the purpose of applying for and registering a domain name on the Internet. If this Registration Agreement is accepted by NSI, and a domain name is registered in NSI's domain name database and assigned to the Registrant, Registrant ("Registrant") agrees to be bound by the terms of this Registration Agreement and the terms of NSI's Domain Name Dispute Policy ("Dispute Policy") which is incorporated herein by reference and made a part of this Registration Agreement. This Registration Agreement shall be accepted at the offices of NSI.

## B. Fees and Payments.

1) Registration or renewal (re-registration) date through March 31, 1998: Registrant agrees to pay a registration fee of One Hundred United States Dollars (US\$100) as consideration for the registration of each new domain name or Fifty United States Dollars (US\$50) to renew (re-register) an existing registration.

2) Registration or renewal date on and after April 1, 1998: Registrant agrees to pay a registration fee of Seventy United States Dollars (US\$70) as consideration for the registration of each new domain name or the applicable renewal (re-registration) fee (currently Thirty-Five United States Dollars (US\$35)) at the time of renewal (re-registration).

3) Period of Service: The non-refundable fee covers a period of two (2) years for each new registration, and one (1) year for each renewal, and includes any permitted modification(s) to the domain name record during the covered period.

4) Payment: Payment is due to Network Solutions within thirty (30) days from the date of the invoice.

C. Dispute Policy. Registrant agrees, as a condition to submitting this Registration Agreement, and if the Registration Agreement is accepted by NSI, that the Registrant shall be bound by NSI's current Dispute Policy. The current version of the Dispute Policy may be found at the InterNIC Registration Services web site: "<http://www.netsol.com/rs/dispute-policy.html>".

D. Dispute Policy Changes or Modifications. Registrant agrees that NSI, in its sole discretion, may change or modify the Dispute Policy, incorporated by reference herein, at any time. Registrant agrees that Registrant's maintaining the registration of a domain name after changes or modifications to the Dispute Policy become effective constitutes Registrant's continued acceptance of these changes or modifications. Registrant agrees that if Registrant considers any such changes or modifications to be unacceptable, Registrant may request that the domain name be deleted from the domain name database.

E. Disputes. Registrant agrees that, if the registration of its domain name is challenged by any third party, the Registrant will be subject to the provisions specified in the Dispute Policy.

F. Agents. Registrant agrees that if this Registration Agreement is completed by an agent for the Registrant, such as an ISP or Administrative Contact/Agent, the Registrant is nonetheless bound as a principal by all terms and conditions herein, including the Dispute Policy.

G. Limitation of Liability. Registrant agrees that NSI shall have no liability to the Registrant for any loss Registrant may incur in connection with NSI's processing of this Registration Agreement, in connection with NSI's processing of any authorized modification to the domain name's record during the covered period, as a result of the Registrant's ISP's failure to pay either the initial registration fee or renewal fee, or as a result of the application of the provisions of the Dispute Policy. Registrant agrees that in no event shall the maximum liability of NSI under this Agreement for any matter exceed Five Hundred United States Dollars (US\$500).

H. Indemnity. Registrant agrees, in the event the Registration Agreement is accepted by NSI and a subsequent dispute arises with any third party, to indemnify and hold NSI harmless pursuant to the terms and conditions contained in the Dispute Policy.

I. Breach. Registrant agrees that failure to abide by any

provision of this Registration Agreement or the Dispute Policy may be considered by NSI to be a material breach and that NSI may provide a written notice, describing the breach, to the Registrant. If, within thirty (30) days of the date of mailing such notice, the Registrant fails to provide evidence, which is reasonably satisfactory to NSI, that it has not breached its obligations, then NSI may delete Registrant's registration of the domain name. Any such breach by a Registrant shall not be deemed to be excused simply because NSI did not act earlier in response to that, or any other, breach by the Registrant.

J. No Guaranty. Registrant agrees that, by registration of a domain name, such registration does not confer immunity from objection to either the registration or use of the domain name.

K. Warranty. Registrant warrants by submitting this Registration Agreement that, to the best of Registrant's knowledge and belief, the information submitted herein is true and correct, and that any future changes to this information will be provided to NSI in a timely manner according to the domain name modification procedures in place at that time. Breach of this warranty will constitute a material breach.

L. Revocation. Registrant agrees that NSI may delete a Registrant's domain name if this Registration Agreement, or subsequent modification(s) thereto, contains false or misleading information, or conceals or omits any information NSI would likely consider material to its decision to approve this Registration Agreement.

M. Right of Refusal. NSI, in its sole discretion, reserves the right to refuse to approve the Registration Agreement for any Registrant. Registrant agrees that the submission of this Registration Agreement does not obligate NSI to accept this Registration Agreement. Registrant agrees that NSI shall not be liable for loss or damages that may result from NSI's refusal to accept this Registration Agreement.

N. Severability. Registrant agrees that the terms of this Registration Agreement are severable. If any term or provision is declared invalid, it shall not affect the remaining terms or provisions which shall continue to be binding.

O. Entirety. Registrant agrees that this Registration Agreement and the Dispute Policy is the complete and exclusive agreement between Registrant and NSI regarding the registration of Registrant's domain name. This Registration Agreement and the Dispute Policy supersede all prior agreements and understandings, whether established by custom, practice, policy, or precedent.

P. Governing Law. Registrant agrees that this Registration Agreement shall be governed in all respects by and construed in accordance with the laws of the Commonwealth of Virginia, United States of America. By submitting this Registration Agreement, Registrant consents to the exclusive jurisdiction and venue of the United States District Court for the Eastern District of Virginia, Alexandria Division. If there is no jurisdiction in the United States District Court for the Eastern District of Virginia, Alexandria Division, then jurisdiction shall be in the Circuit Court of Fairfax County, Fairfax, Virginia.

Q. This is Domain Name Registration Agreement Version Number 4.0. This Registration Agreement is only for registrations under top-level domains: COM, ORG, NET, and EDU. By completing and submitting this Registration Agreement for consideration and

acceptance by NSI, the Registrant agrees that he/she has read and agrees to be bound by A through P above.

#### Authorization

0a. (N)ew (M)odify (D)elete.....: M  
0b. Auth Scheme.....:  
0c. Auth Info.....:

1. Comments.....:  
2. Complete Domain Name.....: ILRU.ORG

#### Organization Using Domain Name

3a. Organization Name.....: Independent Living Research Utilization (ILRU) Pro  
3b. Street Address.....: 2323 S. Shepherd, Suite 1000  
3c. City.....: Houston  
3d. State.....: TX  
3e. Postal Code.....: 77019  
3f. Country.....: US

#### Administrative Contact

4a. NIC Handle (if known).....: CJD16  
4b. (I)ndividual (R)ole.....: I  
4c. Name (Last, First).....: Dresden, Cynthia J  
4d. Organization Name.....: ILRU  
4e. Street Address.....: 2323 S. Shepherd, Suite 1000  
4f. City.....: Houston  
4g. State.....: TX  
4h. Postal Code.....: 77019  
4i. Country.....: US  
4j. Phone Number.....: (713) 520-0232  
4k. Fax Number.....: (713) 520-5785  
4l. E-Mailbox.....: cdresden@BCM.TMC.EDU

#### Technical Contact

5a. NIC Handle (if known).....: CJD16  
5b. (I)ndividual (R)ole.....: I  
5c. Name (Last, First).....: Dresden, Cynthia J  
5d. Organization Name.....: ILRU  
5e. Street Address.....: 2323 S. Shepherd, Suite 1000  
5f. City.....: Houston  
5g. State.....: TX  
5h. Postal Code.....: 77019  
5i. Country.....: US  
5j. Phone Number.....: (713) 520-0232  
5k. Fax Number.....: (713) 520-5785  
5l. E-Mailbox.....: cdresden@BCM.TMC.EDU

#### Billing Contact

6a. NIC Handle (if known).....: RMS50  
6b. (I)ndividual (R)ole.....: I  
6c. Name (Last, First).....: Shepard, Rose M  
6d. Organization Name.....: ILRU  
6e. Street Address.....: 2323 S. Shepherd, Suite 1000  
6f. City.....: Houston  
6g. State.....: TX  
6h. Postal Code.....: 77019  
6i. Country.....: US  
6j. Phone Number.....: (713) 520-0232  
6k. Fax Number.....: (713) 520-5785  
6l. E-Mailbox.....: rshepard@BCM.TMC.EDU

Prime Name Server

- 7a. Primary Server Hostname....: TMC.EDU
- 7b. Primary Server Netaddress...: 128.249.1.1

Secondary Name Server(s)

- 8a. Secondary Server Hostname...: GAZETTE.BCM.TMC.EDU
- 8b. Secondary Server Netaddress: 128.249.2.2

END OF AGREEMENT

For instructions, please refer to:  
"<http://rs.internic.net/help/instructions.txt>"

# RIL Research Information on Independent Living

## The RTC/L

4089 Dole Building  
University of Kansas  
Lawrence, KS 66045  
(785) 864-4095 (Voice or TDD)  
(785) 864-5063 (Fax)

## The ILRU Program

2323 South Shepherd, Suite 1000  
Houston, TX 77019  
(713) 520-0232 (Voice)  
(713) 520-5136 (TDD)  
(713) 520-5785 (Fax)

Dear IL Advocate,

**Your vote will result in the access of research information that you feel is the most important for independent living (IL).**

Please vote for or rate the types of research information that you feel are most important for IL. Also rate how satisfied you are with what is available. It will take you about 10 minutes to complete the survey. All information will be kept confidential. Note that recognized IL leaders have selected the survey items.

**Please return the survey by June 10, 1999.** A self-addressed, stamped envelope is enclosed for your convenience. You can also return the survey through our fax number (785) 864-5063.

We would like your survey by this date so that your votes can be included in the data that will be discussed at our session, "A Town Meeting," at the National Conference on Independent Living in Washington, DC on Saturday June 26, 1999 from 9:00 AM until noon. We hope that you will attend. A report will also be available at a later date.

**If you need an alternate format (large print or disk), please notify Pam Willits at (785) 864-4095 or e-mail: Pam\_W@Dole.LSLUKANS.EDU**

The "Town Meeting" will involve a discussion and refinement of the priorities that you and other experts will establish through the enclosed survey. The priorities will then be used to identify research studies in the priority areas. The studies will be entered into a user-friendly format and included in the RIL searchable/interactive database that you can access through the Internet. The RIL website and database will also be available for you to review and operate at the "Town Meeting." If you do not have Internet access, brokering services will be available at a later date that you can use to obtain research information.

Sincerely,

*Glen White*

*Lex Frieden*

*Laurel Richards*

*Jim Budde*

# VOTE

## RIL Information for Independent Living Survey

RTC/IL, University of Kansas

ILRU a Program of TIRR

The completion of this survey will result in your votes for research information that you feel is important for Independent Living (IL). Please help your colleagues and us to identify research information that consumers, staff, advocates, planners, and directors need to facilitate IL. The survey results will be used to prioritize the identification and review of research information that will be made available to you and others through an interactive/searchable database that you will be able to access through the Internet.

Please return this survey by June 10, 1999. It will take you about 10 minutes. Use the enclosed envelope or fax it to (785)864-5063.

**If you need an alternate format, please call  
Pam Willits at (785)-864-4095**

Your votes in this survey are important for the IL field. All individual information will be kept confidential and treated as group data. Your contribution will be sincerely appreciated.

Please complete the following questions by rating the importance and satisfaction of each item.

1 Low Importance	2 Fairly Low Importance	3 Neither High or Low Importance	4 Fairly High Importance	5 High Importance
1 Low Satisfaction	2 Fairly Low Satisfaction	3 Neither High or Low Satisfaction	4 Fairly High Satisfaction	5 High Satisfaction

*Research Definition: Careful and diligent inquiry, investigation, or experimentation that produces reliable or factual information or products.*

**1.0 Advocacy Research Information: *Reliable or factual information that enables one to improve advocacy skills or plead a cause effectively to others regarding an issue, individual, policy, environment, etc.***

1.1 Research information for people with disabilities to develop advocacy skills.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.2 Research information on effective advocacy action strategies.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.3 Research information to advocate for accessible and affordable housing.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.4 Research information to effectively advocate for entitled benefits (e.g. SSDI).

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.5 Research information to effectively advocate for personal assistance.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.6 Research information on employment of individuals with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.7 Research information to advocate for barrier free community environments.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.8 Research information for enforcement of accessible parking.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.9 Research information for effective advocacy strategies for rural areas.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

1.10 Research information on effective advocacy for local, state, and federal government.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**2.0 Positive Perception of Individuals with Disabilities Research Information: *Reliable and factual information and procedures that enhance the image of individuals with disabilities.***

2.1 Research information on personal strategies to enhance other's perception of one's self.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

2.2 Research information to enhance the image of individuals with disabilities through media.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

2.3 Research information on effective strategies in changing public perception of people with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**3.0 II. Service Research Information: *Reliable or factual information on the effectiveness of various types of services, service strategies, and procedures***

3.1 Research information on assisting others to develop effective consumer control.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.2 Research information on accessible and affordable homes.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.3 Research information on consumer directed personal assistance.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.4 Research information on accessible and affordable transportation.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.5 Research information on employment and accommodations.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.6 Research information on peer counseling.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.7 Research information for rural service delivery.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.8 Research information on reaching underserved populations.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.9 Research information on effective transition (from schools and nursing homes).

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.10 Research information on service funding trends and impacts on independent living.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.11 Research information on helping to serve children with disabilities in Independent Living settings.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.12 Research information on effectively managing a CIL.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

3.13 Research information on use of assistive technology.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**4.0 Health Care Service Research Information: *Reliable or factual information on the effectiveness of various types of health care services, treatment and procedures.***

4.1 Research information for women with disabilities and accommodations in medical settings.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.2 Research information for men with disabilities and accommodations in medical settings.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.3 Research information on "cures" such as spinal cord regeneration.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.4 Research information on medical service delivery options such as managed care.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.5 Research information on effective rural health care services for people with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.6 Research information on prevention and management of secondary conditions (e.g. pressure sores).

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.7 Research information on health care financing and impact on individuals with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

4.8 Research information on proper nutrition for particular disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**5.0 Disability Policy Research Information: *Reliable or factual information on the effectiveness or cost-benefit of various disability policies (including laws) at all levels of policy-making.***

5.1 Research information on spending patterns and trends for disability programs.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.2 Research information on policies that impede independent living.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.3 Research information on policies that impede employment of individuals with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.4 Research information on policies that impede health care service for individuals with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.5 Research information on the effectiveness of disbursing service funds or vouchers to consumers.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.6 Research information on policies that facilitate personal assistance for individuals with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.7 Research information on the effectiveness of school transition and coordination policies.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.8 Research information on inclusion of individuals with disabilities on policy boards.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

5.9 Research information on the effectiveness of key disability laws (e.g. the ADA).

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**6.0 Accommodations and Supports Research Information: *Reliable or factual information on various accommodations and supports that facilitate independent living.***

6.1 Research information on effective accommodations and supports for various disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

6.2 Research information on barrier free environments.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

6.3 Research information on use of Medicaid and Medicare regulations for durable equipment.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

6.4 Research information on effective communication devices and procedures.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**7.0 Family Research Information: Reliable or factual information that enhances the family unit that includes individuals with disabilities. (Family unit is used broadly)**

7.1 Research information on personal support for families who have members with disabilities.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

7.2 Research information for individuals with disabilities who wish to have or rear children.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

7.3 Research information on encouraging family members to become independent.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

7.4 Research information on cultural differences of families and independent living.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**NOTE: THIS LAST SECTION OF THE SURVEY REQUIRES A DIFFERENT ANSWER.**

**8.0 Barriers to Research Information: Rate the importance and satisfaction with various barriers that hinder acquisition of research information.**

8.1 Research information is difficult to locate.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.2 Research information is not accessible, because accommodations are needed.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.3 Research information is not available, because of the lack of resources (e.g. Computer, Internet).

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.4 Professional conferences where research is presented are not user-friendly for consumers.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.5 Research reviews are not available that present an understandable overview of research.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.6 Research information is not relevant.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

8.7 We have no way of knowing how to influence research that will assist us.

Importance 1 2 3 4 5 Satisfaction 1 2 3 4 5

**9.0 Most Important Research Information Categories:** Please rank the importance of each of the seven major research information categories. Place a 7 in the most important category and a 6 in the next important category and down through 1 for the least important category.

- 9.1  Advocacy Research Information
- 9.2  Positive Image Research Information
- 9.3  IL Services Research Information
- 9.4  Health Care Research Information
- 9.5  Disability Policy Research Information
- 9.6  Accommodation & Supports Research Information
- 9.7  Family Intervention Research Information