



Registrant Enrollment and Renewal

Approved by

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This policy applies to the initial and subsequent renewal of enrollment in the United States Transuranium and Uranium Registries.

Initial contact mechanism is by group contact or referral

Registrants for the USTUR are normally obtained through one of the following mechanisms:

- a. Self referral by persons with known or suspected exposures to actinides;
- b. Referrals to the Registries of potentially suitable individuals by health physicists, physicians, or other persons acquainted with the purposes of the Registries, with prior permission obtained from the potential registrant;
- c. Postmortem referral soon after death directly by the surviving spouse or next-of-kin, or by individuals acting in their behalf;
- d. Group recruitment, in which the initial contact is initiated by the Registry through a mailing or oral presentation to a group of individuals with known experience with actinides; this is normally done by or with the concurrence and assistance of the employer or former employer in the case of retirees.

Prospective registrants are provided with full information regarding the Registries

All prospective Registrants shall be provided with detailed specific information regarding the Registries and their activities prior to initial enrollment, reenrollment or renewal of registration. No Registrant shall be accepted without voluntary informed consent.

Valid registration requires informed consent and other forms

Premortem enrollment as a Registrant shall be contingent upon:

- a. Informed consent, as indicated by a signed, dated and witnessed form;

- b. Receipt of permission for autopsy or whole body donation or surgical specimen donor form or participation in special study not involving tissue donation, suitably signed by the individual or other legally authorized person; duly dated and witnessed, and accepted by the Registries as indicated by the dated signature of a faculty member of the Registries;
- c. Receipt of signed authorization or release form for medical and radiation exposure records.

In addition, Registrants will be requested to complete and return to the Registries individual Personal History forms.

Postmortem consent may be granted by the next-of-kin of the deceased Registrant. That person thus becomes the tissue donor to the Registries. This applies only to those Registrants who previously participated in the program and, for various reasons, were not current or their forms had expired before the time of death. Postmortem enrollment of a Registrant shall be contingent upon:

- a. Informed consent as indicated by a signed, dated and witnessed form completed by next-of-kin or other legally authorized person;
- b. Receipt of permission for autopsy or whole body donation or surgical specimen donor form, suitably signed by the next-of-kin or other legally authorized person; duly dated and witnessed, and accepted by the Registries as indicated by the dated signature of a faculty member of the Registries;
- c. Receipt of signed authorization or release form for medical and radiation exposure records completed by the next-of-kin or other legally authorized person.

- d. *Previous classification of the Registrant as Cat-*

egory 1 or 2, based on dosimetry information.

Evaluation of Registrant exposure and dosimetry

When the exposure history/dosimetry information for potential Registrants are received from their sites of employment, they will be classified as Category 1, 2, or 3 as indicated by bioassay results and other dosimetric information. Criteria for this classification are included in USTUR P202—Criteria for Registrant Acceptance. Only those individuals assigned to Categories 1 and 2 will be accepted as USTUR registrants; those in Category 3 will be rejected.

Renewal of registration is on a quintennial basis

Registration shall be renewed at five year intervals. Registrants shall be sent new forms as indicated above, and requested to sign, date, have witnessed and return same to the Registries to maintain active or current registration.

In the event that the Registrant is incapacitated and unable to complete the renewal forms, a person with durable power of attorney for the Registrant may complete and sign the renewal forms for continuation in the program. A copy of the durable power of attorney documentation must be included and returned with the renewal forms.

Individual files are kept for each Registrant

An individual separate file shall be maintained for each Registrant, and shall include all authorizations, whether current or expired, as described above, medical and work history forms, correspondence, medical, health physics and analytical data, and other pertinent documents, and should be as complete and accurate a record as possible.

A copy of the authorization shall be sent to the Registrant

After acceptance by the Registry, each Registrant shall be provided with a signed copy of the Authority for Autopsy or Authorization for Use of Whole Body for Research form, Authorization for Release of Medical and Radiation Exposure Information form, and the Registries Information and Informed Consent form.

Privacy of registrants shall be maintained

To protect and maintain the privacy of the Registrants, each Registrant shall be assigned a unique four digit identification number which shall be used in lieu of names or other personal identifiers. Registrants shall not be identified by name or other personal identifiers unless signed permission has been received, or unless required to do so by law, regulation or legally constituted authority.

Registrants are provided with suitable identification

Each Registrant shall be provided with a wallet sized identification card and/or as desired or needed, other suitable means, such as a Medic Alert bracelet or necklace, identifying him/her as a Registrant and providing the 24 hour telephone number of the Registries.