

United States Transuranium and Uranium Registries  
2020 Scientific Advisory Committee Meeting  
Teleconference, Richland, WA, April 23 – 24, 2020

## Registrant Statistics and IRB Changes

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*“Learning from Plutonium and Uranium Workers”*



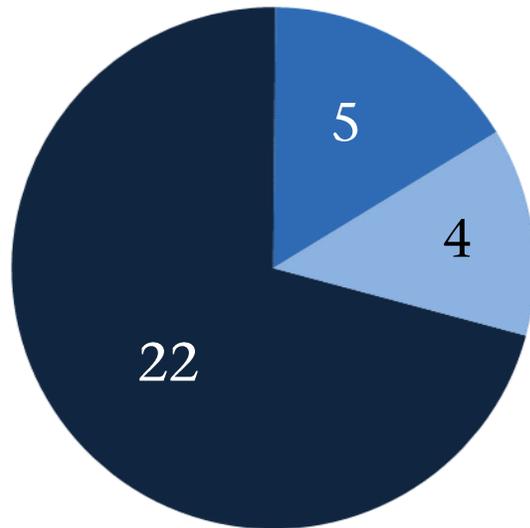
College of  
Pharmacy and  
Pharmaceutical Sciences  
WASHINGTON STATE UNIVERSITY



# Number of Registrants

As of March 31, 2020

Living (31)

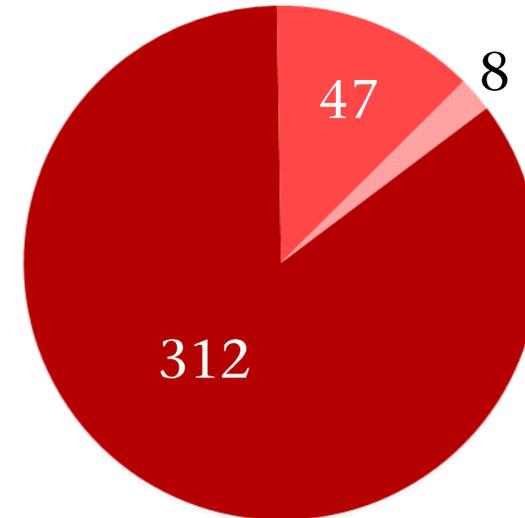


+

Deceased (367)

= 398

- Partial-Body
- Whole-Body
- Special



Inactive Registrants: 482





# Three Registrant Donations

## Whole body

- Worked with actinides for 41 years
- No recorded intake

- Worked with actinides for 37 years
- No documented plutonium intakes
- Extensively monitored for uranium, some >MDA

## Partial body

## Partial body

- Worked with actinides for 40 years
- 2 plutonium inhalations, possible wounds
- Systemic plutonium deposition of ~4nCi



# Institutional Review Board

- Two reviews were submitted to the Central DOE IRB in September 2019
- Continuing review
  - ✓ No changes
  - ✓ Submitted to ensure IRB approval wouldn't expire before modifications were completed
- Modifications
  - ✓ Updated scientific collaboration policy
  - ✓ Added data request forms
  - ✓ Removed periodic personal medical history questionnaire
- Both were approved through September 11, 2020





# Scientific Collaboration and Data Access

- Revised USTUR P106 “Scientific Collaboration and Data Access”
- Formalized changes that were discussed at last year’s SAC meeting
- Policy Summary





# Potential Collaborators Must...

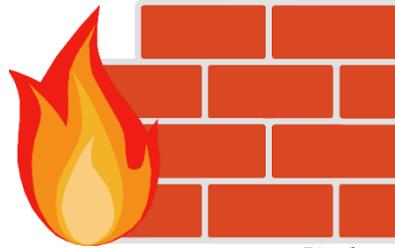
- Submit a written proposal
- Provide assurance that they can receive human samples
- Agree to follow USTUR policies on human subjects and privacy of Registrants
- Receive director approval





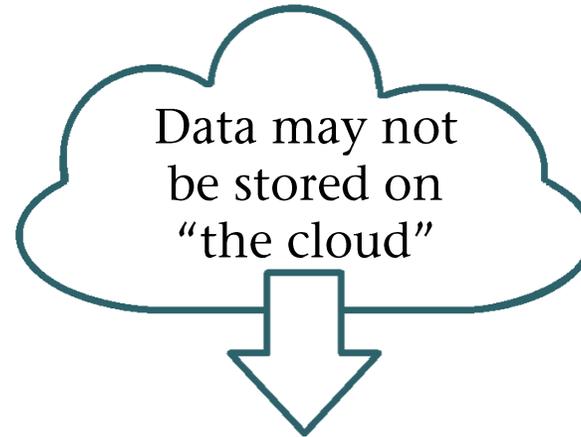
# Stewardship of Data and Tissues

- Once data is received by collaborator:



Pixabay

Computers must be protected by firewall and password



Pixabay

Electronic and paper files must be kept in a secure location

- USTUR data and biological specimens are shared:
  - ✓ With approved collaborators, for specific research purposes
- Prior approval required to:
  - ✓ Analyze specimens or data beyond scope of research approved by USTUR
  - ✓ Share specimens or data with other researchers



# Return or Disposal of Materials



Original Data

AND



Secondary Files



Destroy or Return within  
1 year of publication, or  
5 years of receipt



Tissue Materials

Not destroyed  
during analysis



Return within  
1 year of analysis, or  
3 years of receipt

1-year extensions may be granted





# New Records Request Forms

**F103b**  **Data Request: Deceased Registrant**

Created 09/19  
Revised n/a

Approved by  Sergei Y. Tolmachev, Director  
September 2019

*To request information on behalf of a deceased individual, the requestor must be next of kin and provide a copy of the death certificate.*

*To protect our Registrants' information, we require proof of your identity. To request information by mail, your signature on this form must be notarized OR the person requesting information must provide a photocopy of two identifying documents bearing your name and signature, one of which shall bear your current home or business address and date of birth (e.g. driver's license). To request information in person, you must present one identifying document bearing your photograph and signature (i.e. driver's license or passport).*

**Part A: Individual for Whom Data is Requested**

Full Name \_\_\_\_\_

Most Recent Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Social Security Number \_\_\_\_\_ Date of Birth \_\_\_\_\_ Date of Death \_\_\_\_\_

**Part B: Individual Making Request**

*To request information on behalf of a deceased Registrant, the requestor must be next of kin.*

Full Name \_\_\_\_\_ Telephone Number \_\_\_\_\_

Mailing Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Relationship to individual in Part A \_\_\_\_\_

**Part C: Determine Registrant Status**

Did the above individual in Part A donate tissues to the USTUR?

Facilities where the individual worked with or around plutonium, americium, uranium, or other actinides \_\_\_\_\_

USTUR Policies and Procedure Manual

- Provides a formal process for
  - ✓ Asking if someone is/was a USTUR Registrant
  - ✓ Requesting a copy of Registrant records
- Two new forms
  - ✓ F103a “Data Request: Living Registrant”
  - ✓ F103b “Data Request: Deceased Registrant”
- Previously, we required a letter of request





# Structure of Records Request Forms

- Part A: Individual for whom data is requested (the Registrant)
  - ✓ Name, contact information, SSN, date of birth
- Part B: Individual making request
  - ✓ Name, contact information, relationship to Registrant
- Part C: Determine Registrant status
  - ✓ Is the individual a current or former Registrant?
- Part D: Records request
  - ✓ What records are being requested?
- Part E: Checklist and signature
- Administrative Use Only: Director approval





# Who May Obtain Records?

- Living Registrants
  - ✓ The Registrant
  - ✓ Medical power of attorney (must provide signed POA)
- Deceased Registrants
  - ✓ A next of kin





# What Documentation is Required?

- Living Registrants

- Medical power of attorney document (if applicable)

- Notarized signature on this form (if submitting request by mail)

OR

- Photocopy of identifying document bearing your name, signature, current home or business address, and date of birth (e.g. driver's license or passport)

- Photocopy of identifying document bearing your name and signature

- Deceased Registrants

- Death Certificate

- Notarized signature on this form (if submitting request by mail)

OR

- Photocopy of identifying document bearing your name, signature, current home or business address, and date of birth (e.g. driver's license or passport)

- Photocopy of identifying document bearing your name and signature





# Other IRB Modifications

- Personal Medical History Questionnaire
  - ✓ Will only be sent with initial informed consent paperwork
  - ✓ Previously sent every 5 years
  - ✓ IRB raised concerns about the accuracy of information provided by an aging population
- Martin Šefl was added to the IRB



# Thank you!

