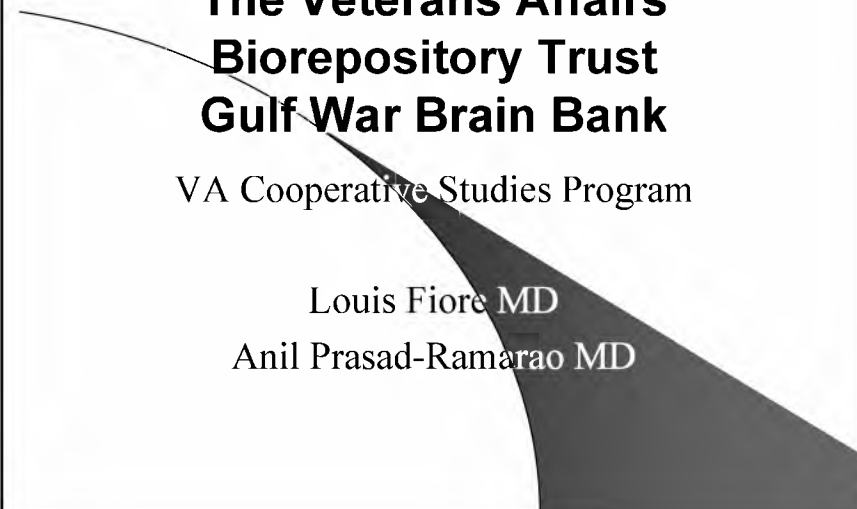


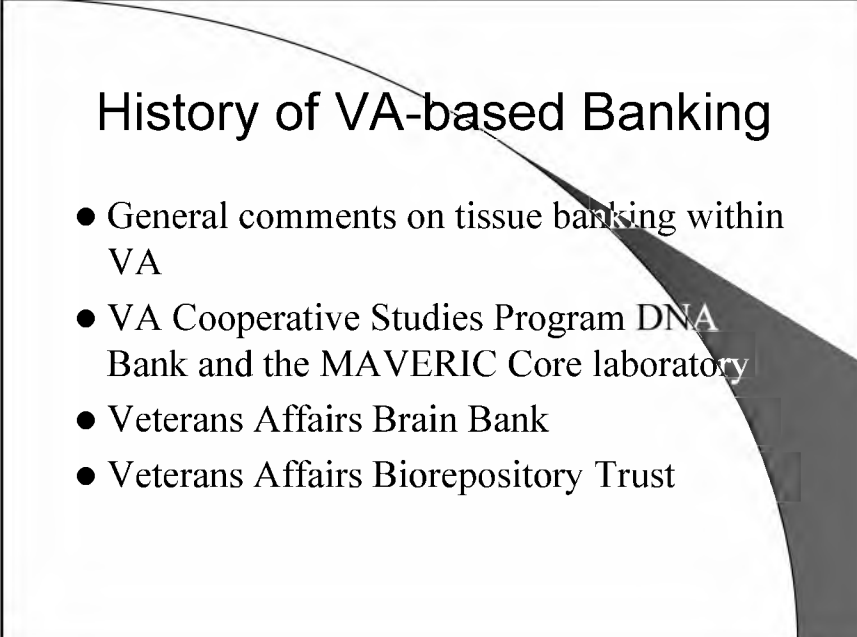
Presentation 11a – Louis Fiore



**The Veterans Affairs  
Biorepository Trust  
Gulf War Brain Bank**

VA Cooperative Studies Program

Louis Fiore MD  
Anil Prasad-Ramarao MD



**History of VA-based Banking**

- General comments on tissue banking within VA
- VA Cooperative Studies Program DNA Bank and the MAVERIC Core laboratory
- Veterans Affairs Brain Bank
- Veterans Affairs Biorepository Trust

## Rationale for Tissue Banking

Emerging micro technologies  
Gene association studies  
Target and marker discovery  
Pharmacogeomics  
Proteomics  
Transcriptomics  
Metabolomics

## Why Bank on the VA?

- Longitudinal data available
- Large stable population
- Allow VA to be a major player in the microtechnologies of the future

A biospecimen is only as valuable as its'  
associated clinical data

## Ethical Issues

- Preserving autonomy
- Assuring privacy
- Appropriate disclosure
- Protection of Individuals
- Avoiding harm to groups
- Dealing with commercial interests
- Stewardship
- Transparency

## Informed Consent Issues

- Broad based consent
  - Ongoing data collection/recontact
  - Open-ended testing
- Levels of consent
- Disclosure
- Confidentiality
- Prevention from harm

## Brain Bank Planning Process

- Internet searches and literature review
- Direct phone contact with thought leaders
- Face to face planning meeting (June 2004)
- Visits to Brain Banks
- Demonstrations of IT products
- Engagement of ALS Cohort Investigators

## Major Realizations

- Complete agreement on the critical need for brain banks
- No agreement on the mode of operation
- No standardized processes for tissue handling
- No standardized data handling, storage or presentation methods

## Brain Bank Critical Elements

- Informatics
- Subject Identification and Consenting
- Tissue Processing Expertise
- Tissue Bank Infrastructure
- Associated Clinical Data Capture
- Governance
- Distribution

## Gulf War Brain Bank

- MAVERIC
  - DNA Bank, Administration
- Palo Alto CSPCC
  - SAC, EOC
- Durham ERIC
  - ALS Cohort
- Southern Arizona Healthcare System
  - Core tissue lab

## Where are we?

- Lab infrastructure development
- IRB approvals
- IT development
- Patient consents
- Committee approvals

## Next steps

- Demonstrate success
- Expand post-mortem collection
  - Non-ALS Gulf War Veterans
    - Non-CNS tissue
  - Controls

## Future proposals

- Access to paraffin blocks
  - Informatics effort
- Post-operative residual tissue