

**2<sup>nd</sup> NCI Epidemiology Leadership  
Workshop:  
Understudied Rare Cancers  
September 11-13 2005**

Site Working Groups  
summary report

# Consortia & Transdisciplinary Science

- **What is the state of the science – what do we know?**
- **Descriptive data available except for rare subtypes**
- **Varies between cancer sites**
- **For some, much of the research comes from international studies**
- **Differences between racial groups**

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- **What are the scientific gaps – what do we not know?**
  - **Biological mechanisms for many**
  - **Molecular subclassification (head and neck, leukemia, brain)**
  - **Latency period between exposure and effect**
  - **Prediagnostic lesions**
  - **Predisposing diseases**
  - **Lack of susceptibility and early detection markers**
  - **Lack of understanding of major biological and physiological processes (energy balance, blood-brain barrier, viral load, immune mechanism, environmental exposure assessment...)**

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- **What obstacles (scientific) impede progress?**
  - Lack of better definitions of histological classification
  - Relatively small sample size achievable by single-site studies
  - Ultra-rapid case ascertainment
  - Difficulty in getting appropriate biospecimens
  - Lack of standardized core questions
  - Data collection costs
  - HIPPA
  - Lack of standard bioinformatics and technology integration
  - Limited collaborations between the different disciplines
  - Lack of appropriate funding mechanism for consortia-interdisciplinary research

# Consortia & Transdisciplinary Science

- **Solutions to these obstacles:**
  - Targeted \$\$\$\$\$\$\$\$\$\$\$\$\$\$ (RFAs Special review and special study sections)
  - Educate members of EPIC
  - Cross training
  - Coordination of resources
  - Involvement of advocacy and private organizations
  - Flexibility of mechanisms of funding to achieve academic credit
  - Build new consortia and coordination, linkages, and communications among existing consortia
  - Communication and coordination between agencies such as the NCI, ACS, and CDC
  - Special National registries of Rare Cancers
  - Higher funding limit for R03's
  - Specific plans for junior investigators