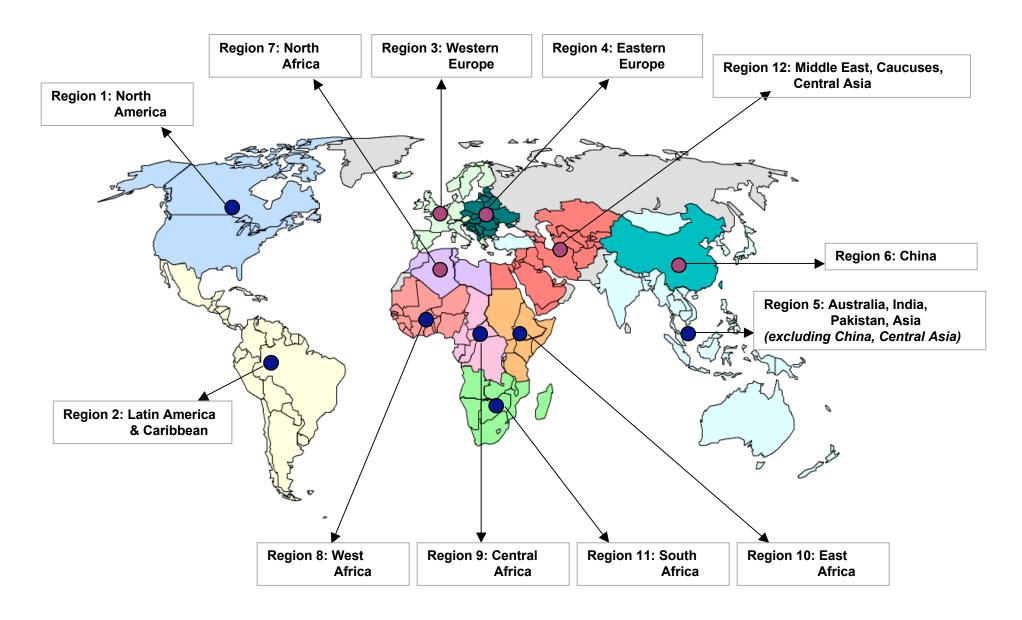
# leDEA & North American 'Control' Cohorts

Stephen J. Gange
Department of Epidemiology
Johns Hopkins Bloomberg School
of Public Health

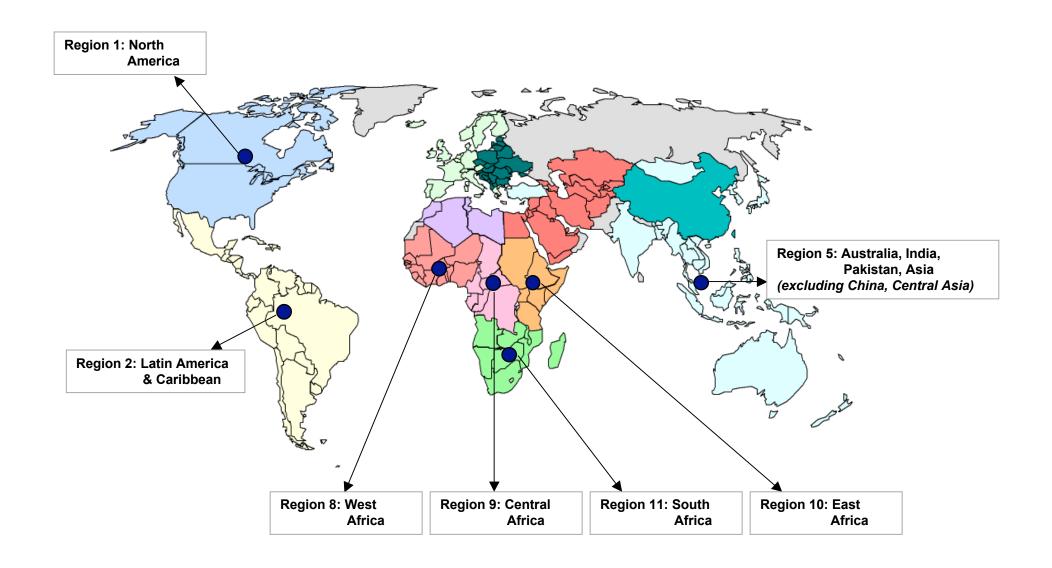
# **IeDEA**

- International Epidemiologic Databases to Evaluate AIDS
- Collaborative group of international regional data centers for the compilation of data to address research questions in HIV/AIDS not possible with currently existing individual cohorts
- Development of regional, generalizable datasets that represent study populations based on data from different settings and populations
- Development of procedures and approaches to allow regions to more accurately address and monitor the HIV epidemic within their populations

## **All leDEA Regions**



## **Funded leDEA Regions**





REGION	PRINCIPAL INVESTIGATOR	INSTITUTION	
1. North America	Richard Moore	Johns Hopkins University	
2. Central/S. America and Caribbean	Daniel Masys	Vanderbilt University	
5. Australia/Asia	David Cooper	AMFAR	
8. West Africa	Francois Dabis	Victor Segalen University, Bordeaux France	
9. Central Africa	Robert Ryder	UNC at Chapel Hill	
10. East Africa	Constantin Yiannoutstos	Indiana University	
11. Southern Africa	Matthias Egger	University of Berne, Switzerland	







#### North American Region Madison/ ₩A Honolulu, HI O Portland, OR Detroit, MI Rochester, MY Bronx, NY Brooklyn, NY New York City, NY ്റ്റ് Cleveland. 🗘 ⊦ Chicago, IL Stony Brook, NY San Francisco, CA Pittsburgh Philadelphia, PA Oakland, CA Baltimore, MD San Leandro, CA Denver, CO Washington, DC Kansas City, KS Chapel Hill, NC Los Angeles, C O Nashville, TN San Diego, CA O Birmingham, AL ODallas, TX Tampa, FL Los Angeles, CA, USA Dallas, TX, USA

HIV Research Network (HIVRN)

#### Kansas City, KS, USA

HIV Research Network (HIVRN)

#### Rochester, NY, USA

HIV Research Network (HIVRN)

#### Cleveland, OH, USA

 John T. Carey Special Immunology Unit Patient Care and Research Database (PCRD) at University Hospitals of Cleveland (Case Western Reserve University

#### Pittsburgh, PA, USA

Multicenter AIDS Cohort Study (MACS)

• Multicenter AIDS Cohort Study (MACS)

Women's Interagency HIV Study (WIHS)

#### Bronx, NY, USA

Women's Interagency HIV Study (WIHS)

#### San Francisco, CA, USA

- Women's Interagency HIV Study (WIHS)
  - Study of the Consequences of the Protease Inhibitor Era (SCOPE)
  - Research in Access to Care for Homeless (REACH) Cohort

#### Washington, DC, USA

- Women's Interagency HIV Study (WIHS)
  - HIV Outpatient Study (HOPS)

#### Brooklyn, NY, USA

Women's Interagency HIV Study (WIHS)

#### Chicago, IL, USA

- Multicenter AIDS Cohort Study (MACS)
  - Women's Interagency HIV Study (WIHS)
  - HIV Outpatient Study (HOPS)

#### Portland, OR, USA

HIV Research Network (HIVRN)
 San Diego, CA, USA

HIV Research Network (HIVRN)

#### **IeDEA Regional Site Locations**

#### Chapel Hill, NC, USA

 University of North Carolina, Chapel Hill HIV Clinic (UCHC)

#### Nashville, TN, USA

Vanderbilt-Meharry HIV Cohort

#### Birmingham, AL, USA

 University of Alabama at Birmingham, (UAB) 1917 Cohort

#### Denver, CO, USA

HIV Outpatient Study (HOPS)

#### Tampa, FL, USA

- HIV Outpatient Study (HOPS)
  - HIV Research Network (HIVRN)

#### Stony Brook, NY, USA

HIV Outpatient Study (HOPS)

#### Philadelphia, PA, USA

- HIV Outpatient Study (HOPS)
  - HIV Research Network (HIVRN)

#### Oakland, CA, USA

- HIV Outpatient Study (HOPS)
- HIV Research Network (HIVRN)

#### San Leandro, CA, USA

HIV Outpatient Study (HOPS)

#### New York City, NY, USA

• HIV Research Network (HIVRN)

#### Detroit. MI. USA

HIV Research Network (HIVRN)

#### Madison, WA, USA

 University of Washington Cohort (UW)-US Harborview Medical Center, Madison, WA

#### Honolulu, HI, USA

Women's Interagency HIV Study (WIHS)

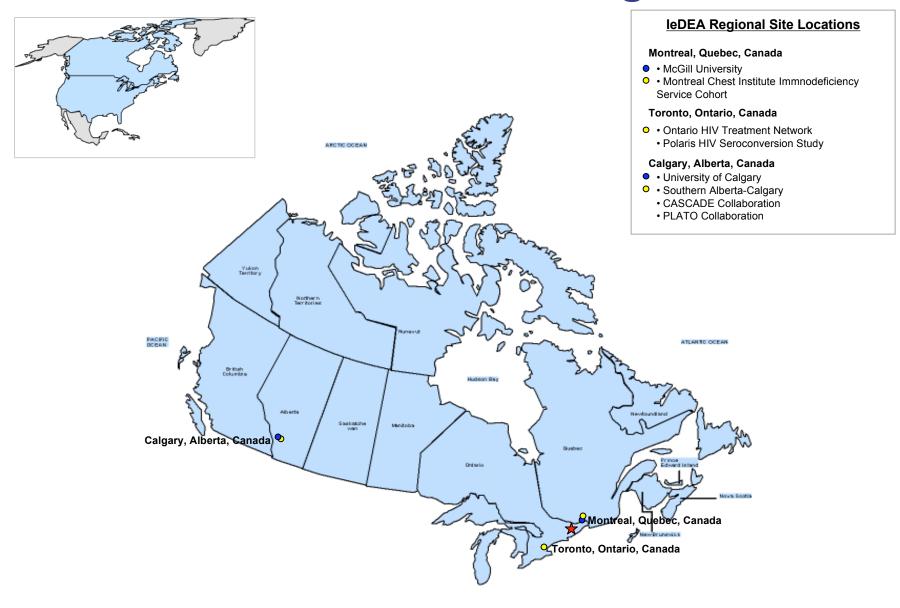
#### Random ACTG Sites, USA

 Adult AIDS Clinical Trial Group, Longitudinal Linked Randomized Trials (ALLRT)

#### Baltimore, MD, USA

- Johns Hopkins University
- Multicenter AIDS Cohort Study (MACS)
- AIDS Link to the Intravenous Experience
   (ALIVE)
- · Johns Hopkins HIV Clinical Cohort (JHHCC)

## **North American Region**



## **Additional NA Cohort Networks**

## Clinical:

- HIV Research Network (HIVRN)
- Centers for AIDS Research Network of Integrated Clinical Science (C-NICS)
- Interval/Protocol Cohorts:
  - Multicenter AIDS Cohort Study (MACS)
  - Women's Interagency HIV Study (WIHS)

# Clinical vs. Interval Cohorts

### CLINICAL

Data and Visits Part
 Data and Visit
 of Medical Care
 Schedule External

## INTERVAL

- Data and Visit
   Schedule External to
   Medical Care
- Protocol-driven
- HIV-negatives

Interval Cohort	Clinical Cohort	Issue
Advantage	Disadvantage	Information quality may vary across medical records
Disadvantage	Advantage	Medical records may provide precise information on prescribed medications
Advantage	Disadvantage	Standardized tools for data collection
Advantage	Disadvantage	Subject to medical surveillance bias
Disadvantage	Advantage	Information collected reflects actual health care needs

# Observational Studies are a Key Tool for a Spectrum of Investigations

- Characterization of HIV natural history
- Nested studies of HIV pathogenesis
- Identification of non-interventional factors influencing HIV disease progression
  - Host genetics (e.g. CCR5)
  - Biomarkers (e.g. CD4+, HIV RNA)
  - Co-infections (e.g. HCV, GBV-C)
- Evaluating therapies and interventions
  - Factors affecting response
  - Adverse effects
  - Intended (beneficial) effects