

# The eMERGE Network

electronic Medical Records & Genomics

*A consortium of biorepositories linked to electronic medical records data for conducting genomic studies*



**Coordinating Center**



An NHGRI funded consortium

# eMERGE Primary Goals

- Discover new disease-gene associations
- Develop electronic phenotyping from routinely collected clinical information
- Develop methods for storing genomic results in EHR and providing physician decision support
- Develop principles and priorities for returning genomic results
- Develop appropriate consent, consultation, policy recommendations and educational materials
- Assess impact of returning genomic results to patients, physicians and other providers

## eMERGE Network – Genotyped Samples

	eMERGE Phase I		eMERGE Phase II		eMERGE I & II
Site	Participants	Genotyped	Participants (Still enrolling)	Genotyped	Genotyped
<b>GHC</b>	2,820	2,789	5,291	739	3,528
<b>Marshfield</b>	20,000	4,210	20,000	777	4,987
<b>Mayo</b>	3,769	3,755	6,916	6,306	10,061
<b>NU</b>	10,500	1,907	12,000	3,030	4,937
<b>VU</b>	70,000	6,055	155,000	3,565	9,620
<b>Geisinger</b>	N/A	N/A	22,000	4,085	4,085
<b>Mt. Sinai</b>	N/A	N/A	25,000	6,290	6,290
<b>CCHMC/BCH</b>	N/A	N/A	11,799	5,799	5,799
<b>CHOP</b>	N/A	N/A	60,000	6,623	6,623
<b>TOTAL</b>	107,089	18,716	347,090	37,214	55,930

# Example Friction Points

- Enterprise Clinical Data Warehouse (the 100 kg baby problem)
- Tissue reuse
- Streamlined consent materials and data use
- Is returning PGx results research or quality improvement?
- The establishment of clinical practice guidelines
- HFE return of results
- The illusion of privacy vs. need for non-discrimination

# Suggested Actions

- Improve articulation of patient/participant rights and expectations
- Better define investigator obligations and responsibilities
- Improve guidelines for scope of Institutional Review Boards
- Provide better educational information for patients/participants, investigators and IRB members and staff