



# Community Health Initiative

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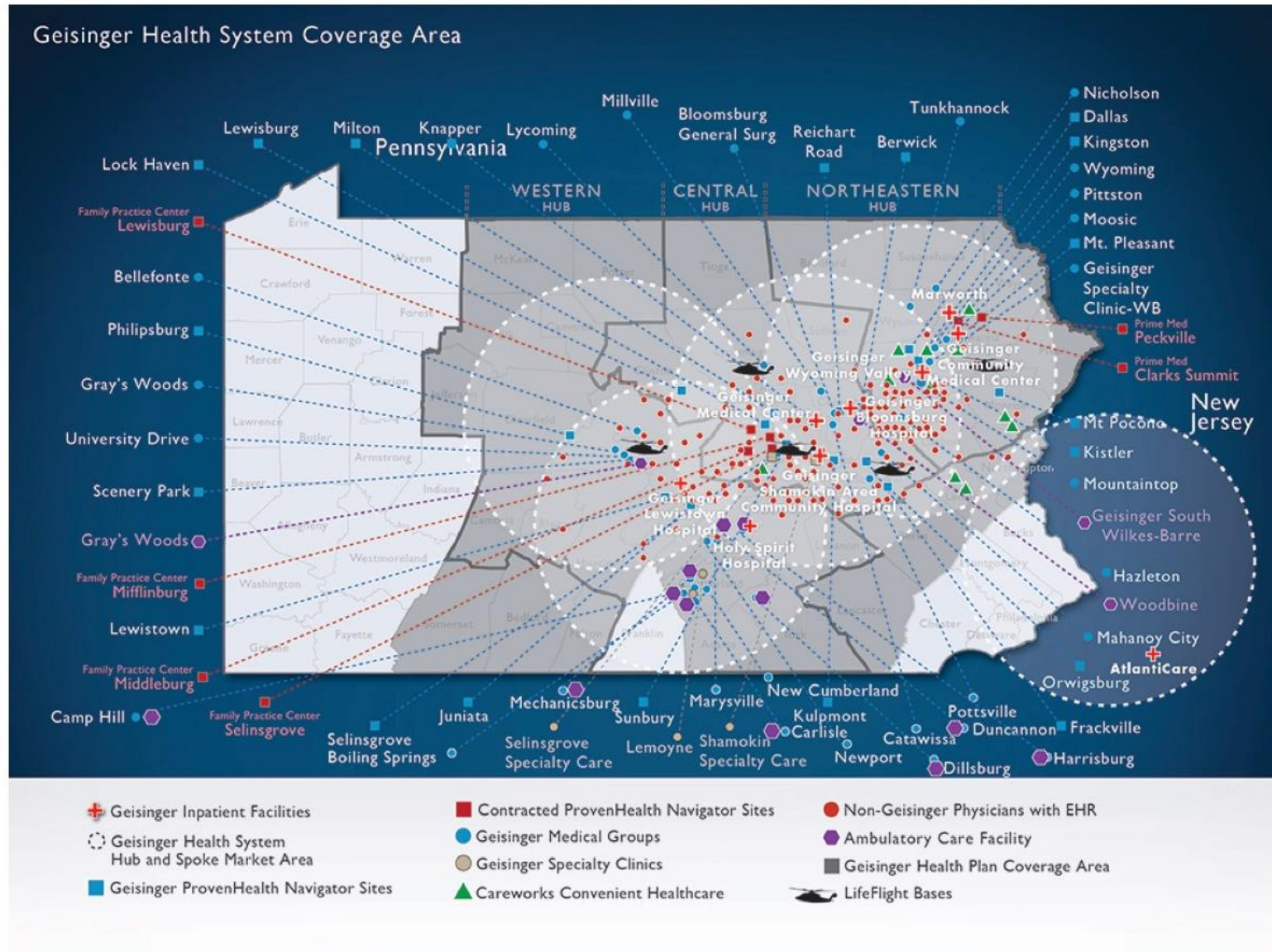
IOM Roundtable on Translating Genomic-Based Research for Health

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[geisinger.org/genomics](http://geisinger.org/genomics)

# Geisinger, Central PA and New Jersey



# Research Strategic Vision 2010

- Vision: Personalized Health Care
- Emphasis on genomics
- Board approved 10 year Vision for Research that translational research is part of, not separate from, Clinical Medicine.

## 2014 Research Vision Update

- **Learning Health Laboratory**, ... a continuous cycle of integrated innovation, implementation, assessment and reengineering in all aspects of the clinical and research mission.
- Embrace engagement of and **partnership with Geisinger patients** and others in the Geisinger community as fundamental ... we learn from every patient and patient encounter.

# **“Geisinger is as close to Iceland as you’ll find in the United States”- Glenn Steele**

Attractive features for community engagement and longitudinal, genomic medicine research and implementation

- Large, stable population – >2.5 M people (>700K active patients) with many 3+ generation families
- Strong and trusting relationship between patients and Geisinger
- Integrated healthcare delivery system
- Longstanding EHR and comprehensive clinical data
  - Epic implementation from 1996 (2<sup>nd</sup> or 3<sup>rd</sup> customer)

# Engaging the Community

- Focus groups in 2006 prior to MyCode launch
- Focus groups in 2012 prior to planning Return-of-Results (eMERGE)
- Commitment to regular updates
- Employee campaign
- Ethics Advisory Board

# Focus Groups / Return of Research Results

- 6 focus groups – main campus & remote
- 93 participants – 57% F, 43% M
  - (Ages match biobank participants)
- 49.5% GHS patients for 20+ years
- 85% receive majority of care at GHS
- Focus group discussion
  - Pharmacogenomics
  - Recessive Carrier
  - Increased Risk for Prevent /Treatable condition
  - Increased Risk for NON Prevent/Treatable condition
  - Genetic changes that we currently do not understand

# What Focus Group Participants Said

- Wanted **ALL** results
- Results should be returned to healthcare provider and participant (most preferred same time)
- Geisinger should develop educational materials and expert support system
- Results should be put in EHR

### Steps to Take

**1** Complete a consent packet. Click [here](#) for a copy or to receive a hard copy, call (toll free) 1-855-636-0019 or write us at [joinmycode@geisinger.edu](mailto:joinmycode@geisinger.edu).

**2** Donate a blood sample when your healthcare provider orders blood work.



### Be Part of Something Big

The MyCode® Community Health Initiative will help researchers understand the relationship between genes and diseases. The goal is to help improve healthcare by finding ways to diagnose medical conditions earlier or before they appear and also to help find new treatments or medications to manage these diseases. Samples are collected from Geisinger patients like yourself and your family.

### Key Links

- [Consent Form](#)
- [MyCode FAQs](#)
- [Family History Project](#)

### Latest Poll

[Previous](#) [Next](#) [More polls](#)

#### MyCode Educational Sessions

The MyCode team is interested in conducting educational sessions about the MyCode initiative for employees. To assist them in scheduling the... [Read more.](#)

- ☐ Prior to the start of the day shift
- ☐ Standard lunch break time for day shift workers (noon-1 p.m.)
- ☐ Anytime during day shift, provided I can get coverage
- ☐ Anytime during second shift, provided I can get coverage
- ☐ Anytime during third shift, provided I can get coverage

[Vote](#)

Created by Geisinger (GHS) on Mar 4, 2015 in MyCode

0 Votes - 0 Comments

### Goal: 250,000

250,000

225,000

200,000

175,000

150,000

125,000

100,000

75,000

58,158

25,000

As of March 16, 2015, 58,158 Geisinger patients have joined MyCode.

### News & Information

[Employees invited to participate in.....](#) by Geisinger (GHS) 2 months ago in MyCode

[Sample blog post](#) by Geisinger (GHS) 2 months ago in MyCode

[Click here to start a discussion or ask a question and have it posted in the Discussion Board below.](#)

### Discussion Board

[Why are you participating?](#) by Geisinger (GHS) 2 months ago

# Employee Campaign

## Two Goals

- All employees know basics of campaign and where to refer
- Employees have opportunity to participate



# MyCode® Community Health Initiative:

## *An Ethics Advisory Committee*

- **Kevin T. FitzGerald, SJ, PhD, *chair***

Jesuit priest, PhDs in molecular genetics and bioethics, Georgetown faculty in oncology and bioethics, former member of the Secretary's Advisory Committee on Genetics, Health & Society (SACGHS)

- **Kyle Brothers, MD, PhD**

Pediatrician with research interests in childhood obesity, genomic research and clinical use of genomic data; trained at Vanderbilt, now on faculty at University of Louisville, lead publication of eMERGE paper on consent for children

- **Joan Scott, MS, CGC**

Certified genetic counselor, Formerly with the National Coalition for Healthcare Professional Education in Genetics (NCHPEG) and the Genetics and Public Policy Center, now at Health Resources and Services Administration [HRSA]

- **Sylvia Mann Au, MS, CGC**

Certified genetic counselor, State Genetics Coordinator for Hawaii Department of Health, and member of SACGHS

- And 4 Geisinger patients!

# Developing the MyCode<sup>®</sup> Consent

- Critical Features

- Re-contact
- Longitudinal EHR data
- Longitudinal samples
- Return of results
- Placement of results in EHR
- Online consent
  - (approved, waiting for EPIC integration)

- Version #26

- Need to get institution & IRB talking

# Engaging Providers

- Return of Results Oversight Committee
- Presentations to clinical leaders
- Regional Strategies
  - Genetic Counselor
- Geisinger GenomeFIRST symposia
  - Familial Hypercholesterolemia
  - BRCA – breast / ovarian cancer
- GOALS courses
- Modify ROR based on real-time feedback

# *“Make My Hospital Right – Make It the Best”* – Abigail Geisinger

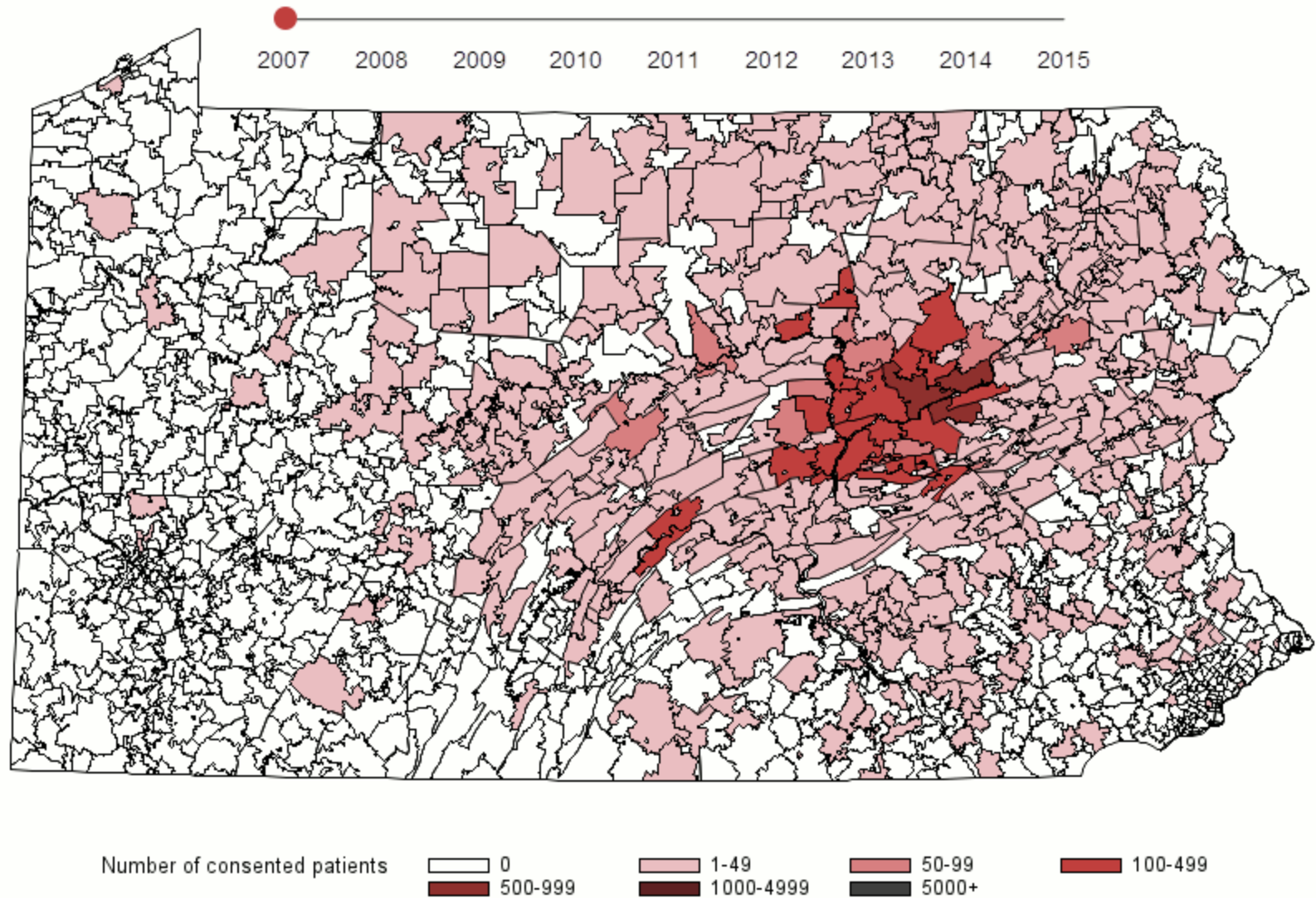
- Consistent message from participants and providers
  - “Geisingerize” the program
  - Start with the national recommendations
  - Geisinger clinicians and researchers need to make final decisions
- Gatekeeper – critical to participation



## History:

- MyCode® began in 2006
- High consent rate – 85%+
- Geisinger / Regeneron collaboration
- Biobank CLIA certified
- **Current Enrollment** **98,323 (88,674)**
- **Current WES** **52,157 (44,084)**
- **Max Consenting per week** **1,000**
- **Sequencing capability per week** **1,500**
- **Enrollment Goal** **250,000**

## MyCode Expansion By Year



animation and map created by Ryan Colonie and Craig Wood

# Geisinger Cohort Value

- Snapshot of biobank data
  - 11.96 Median years of EHR data
  - 47 Median number of clinical encounters
  - 455 Median number of lab test values
  - 94 Median vital measurements
- Geisinger Health Plan (GHP) – *sweet spot*
  - 2/3 GHP coverage at some point
- Large families
  - For every result, expect 6-10 1<sup>st</sup> degree relatives