

The Penn Telegenetics Program

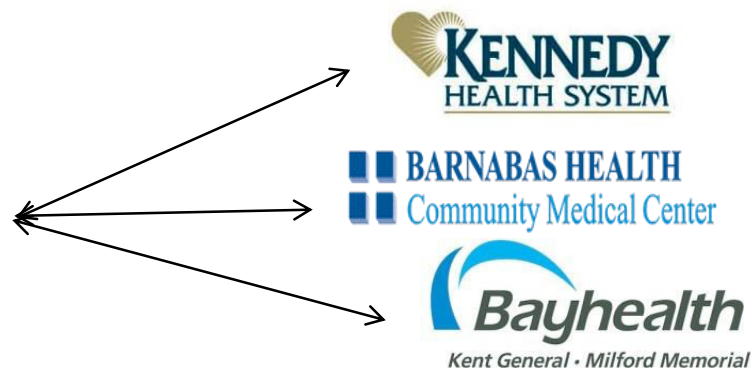
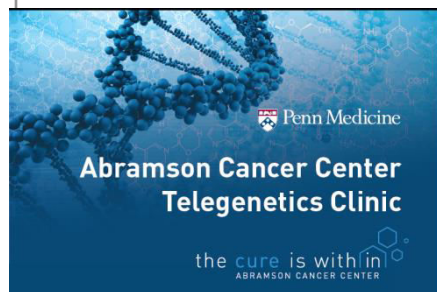
Elisabeth McCarty Wood, MS, LCGC
Senior Genetic Counselor
Penn Telegenetics Program
University of Pennsylvania
elisabeth.wood@uphs.upenn.edu

Origins in cancer genetic services

- ♦ ***BRCA1/2* testing is now standard-of-care**
 - Genetic counseling is recommended but the traditional two in-person visit model can present barriers
- ♦ **Only 37% of patients undergoing *BRCA1/2* testing meet with a genetic counselor**
 - Knowledge and satisfaction are higher when patients have genetic counseling
- ♦ **In-person outreach models are costly, inefficient and limited**
 - Remote delivery models can fill this gap



NIH Feasibility Study Outcomes



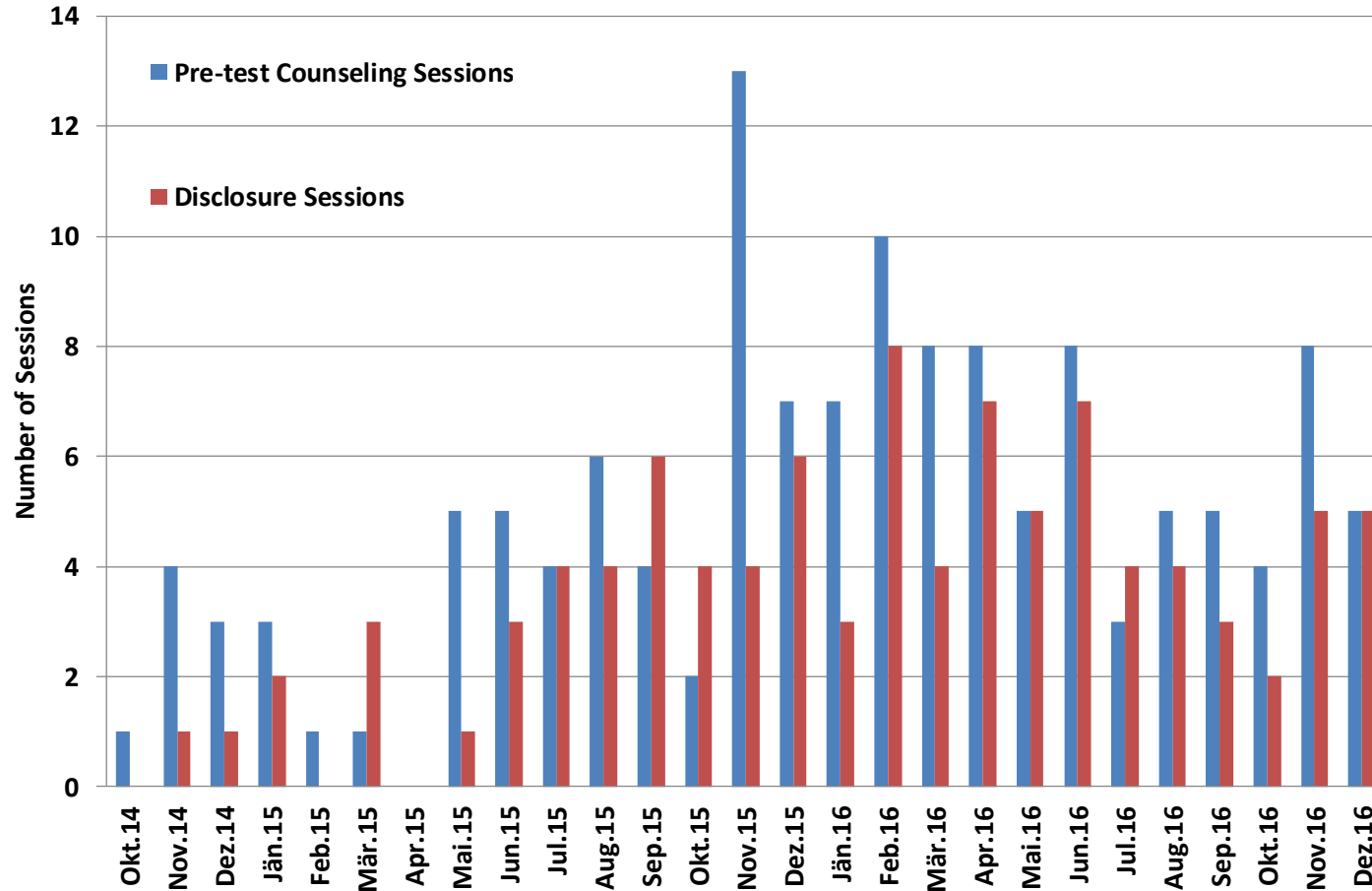
- ◆ **100 patients approached – none declined due to video**
- ◆ **Technology is feasible**
 - Failures are rare (4%)
 - 50% of sessions had technology challenges. Despite this patient satisfaction was very high.
- ◆ **Favorable patient report outcomes**
 - Increase in genetic knowledge, no increase in distress, and 4 genetic carriers were identified (out of 61 tested)

NATIONAL
CANCER
INSTITUTE

Origins of Clinical Program

- ♦ **At conclusion of NIH feasibility study, one research site wanted to maintain services for cancer genetic counseling**
- ♦ **Established clinical contract**
 - Subscription plan based on # of sessions per year
 - Defined responsibilities of the two parties
 - Flexible enough to allow for adaptation
 - Communication plan (e.g. instituted chart notes, procedures for communication flow, and quarterly steering committee meetings)
 - Video-conferencing is primary, telephone for back-up
- ♦ **Contract began Oct 2014**
 - Initial staff under supervision of Dr. Bradbury:
 - 1 research assistant and 1 part-time GC
 - Director soon hired in early 2015

Nurturing of a clinical partnership



The Telegenetics Program: Two Arms

CLINICAL PROGRAM

Bayhealth: Oct 2014-Current

- Cancer Genetics
- Video
- Contract renewed in Oct 2016

RESEARCH PROGRAM

Basser Study: 2014-2017

- Cancer Genetics (Regional)
- Randomized study of remote counseling (telephone v. video) versus usual care

NCI MATCH study: 2015-2017

- Germline counseling and testing following tumor profiling (National)
- Telephone delivery

Generation Study & CONNECT4

APOE Study: 2015-2018

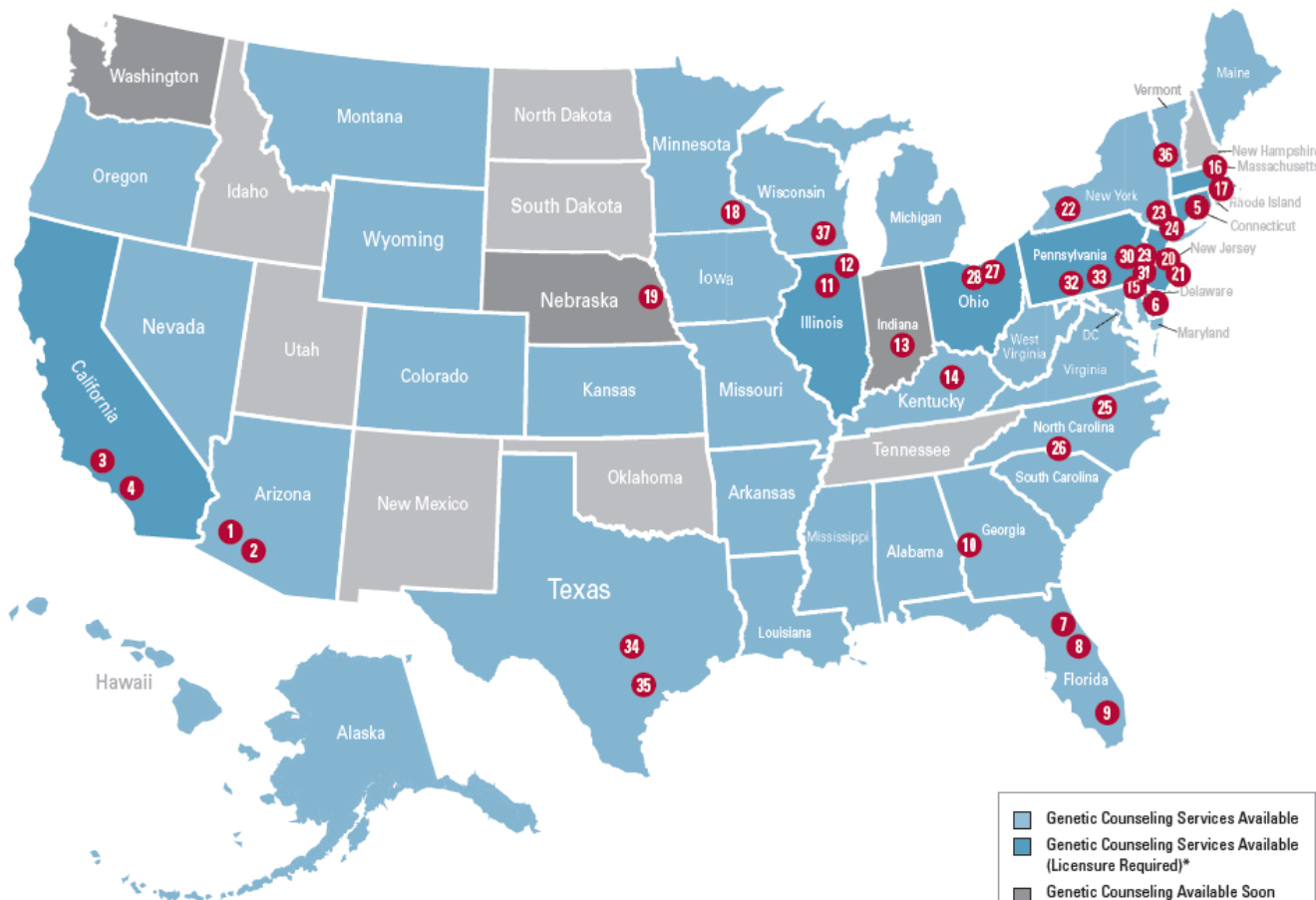
- API/Novartis; APOE testing for Alzheimer's Disease risk assessment (National)
- Generation Study: telephone
- CONNECT: randomized companion study of remote disclosure (telephone v. video)

Scaling to a national program



TELEGENETICS PROGRAM

NATIONAL ACCESS TO GENETIC TESTING



- Genetic Counseling Services Available
- Genetic Counseling Services Available (Licensure Required)*
- Genetic Counseling Available Soon (Licensure Required)*
- Genetic Counseling Unavailable (Licensure Required)*
- Partners

Cancer Sites	APOE/Generation Study Sites	Total
7	29	36

- Arizona**
1. Banner Alzheimers Institute
 2. Banner Boswell Medical Center
- California**
3. ATP Clinical Research Center
 4. USC Geriatric Studies Center
- Connecticut**
5. Yale School of Medicine
- Delaware**
6. Bay Health Medical Center
- Florida**
7. Compass Research (The Villages)
 8. Compass Research (Orlando)
 9. University of Miami Center on Aging
- Georgia**
10. Medical Research & Health Education Foundation, INC
- Illinois**
11. Great Lakes Clinical Trials
 12. Rush University Medical Center
- Indiana**
13. Indiana University Health Physicians
- Kentucky**
14. University of Kentucky Sanders-Brown Center on Aging
- Maryland**
15. Union Hospital
 16. Massachusetts
 17. Brigham and Womens Hospital
 18. Butler Hospital
- Minnesota**
19. Mayo Clinic (Rochester, MN)
- Nebraska**
19. University of Nebraska Medical Center
- New Jersey**
20. Kennedy Health System
 21. Shore Memorial
- New York**
22. University of Rochester Medical Center
 23. Nathan S. Kline Institute for Psychiatric Research
 24. NYU Langone Medical Center
- North Carolina**
25. Duke University
 26. ANI Neurology
- Ohio**
27. University Hospitals Case Medical Center
 28. Neurological Institute Memory and Cognition Center
- Pennsylvania**
29. Penn Memory Center
 30. Abington Neurological Associates
 31. Drexel University
 32. Lancaster General Hospital
 33. Gettysburg Hospital
- Texas**
34. Senior Adults Specialty Research (Austin, TX)
 35. Clinical Trials Network
- Vermont**
36. Memory Clinic
- Wisconsin**
37. Medical College of Wisconsin

Current Program Team

- ♦ Executive Director: Angela Bradbury, MD
- ♦ Director: Jan Jaeger, PhD
- ♦ 3 FT Genetic Counselors: Beth Wood
Neeraja Reddy
Cara Cacioppo
- ♦ 1 Research Assistant: Demetrios Ofidis
- ♦ Work closely with 5 other members of Dr. Bradbury's research staff for specific research protocols

Snapshot of Technology

*Must be HIPAA compliant

	Magpi	MediSprout	BlueJeans	UPHS Vidyo
<u>Use</u>	Used in feasibility study; no longer in use	Used in clinical program and research	Used for research only	New institutional platform Piloting in clinical program
<u>Pro</u>	Good service and support	Great service and support Able to customize	Easy to use Good success rate	No extra cost to our program In-house support
<u>Con</u>	Expensive	Also uses Vidyo, same as new institutional platform	Requires license per user; more expensive	Newest platform, still piloting

Challenges

♦ Licensure & Telehealth Laws

- Genetic Counselor Licensure: Variation in which states require licensure, possible exemptions, and actual application process
- Telehealth laws: Variation in which practitioners are covered, scope of practice, definition of telehealth activities, and possible exemptions
 - Getting legal analysis may be difficult, can be costly
- Our current approach:
 - If we are providing services, research or clinical, to a site located in a state with GC licensure, we get licensed.
 - Costly, in both time and finances

Upcoming publication addresses some of these issues:

- Roberts, M, et al. (In Press.) Genetics in Medicine. “Possible Barriers to Returning Actionable Research Results across State Lines.”

Challenges

♦ Technology

- Institutional differences
 - Infrastructure, firewalls
 - Availability/willingness to support needs of telegenetics
- Multiple sites, multiple site team members to train and keep updated
- Platforms and overall technology constantly evolving
- Staying current vs. expense

♦ Still have traditional challenges

- Staffing
- Scheduling
- Genetics is not a revenue generating field
 - Interested clinical partners have competing priorities

Successes

♦ Improving access

- Offering services to patients that would otherwise be unlikely to receive genetic counseling services

♦ Navigating technology challenges

- Increasing quality, decreasing cost
- Experience

♦ Adapting to provide innovative research solutions

- National clinical trial needs for genetic services
- Ongoing research of remote delivery

♦ Increased understanding of legal issues

- Licensure, scope of practice

Successes

♦ Evidence-Based Communication Protocols

- Patrick-Miller LJ, Egleston BL, Fetzer D, et al. **Development of a communication protocol for telephone disclosure of genetic test results for cancer predisposition.** *JMIR research protocols*. 2014;3(4):e49
- Patrick-Miller L, Egleston B, Daly MB, et al. **Implementation and outcomes of telephone disclosure of clinical *BRCA1/2* test results.** *Patient Education and Counseling*. 2013 Dec;93(3):413-9.
- Bradbury AR, Patrick-Miller L, Harris D, et al. **Utilizing real-time videoconferencing to expand access to cancer genetic services in community practices.** *J Med Int Res* 1:18(2):e23, 2016.

Acknowledgments

- ♦ Angela Bradbury, MD
- ♦ Jan Jaeger, PhD
- ♦ Brian Egleston, PhD
- ♦ Diana Harris, PhD
- ♦ Linda Fleisher, PhD
- ♦ Colleen Sands, MPH
- ♦ Beth McCarty Wood, CGC
- ♦ Neeraja Reedy, CGC
- ♦ Cara Cacioppo, CGC
- ♦ Shea Rauch, CGC
- ♦ Rebecca Mueller, CGC
- ♦ Amanda Brandt, CGC
- ♦ Jill Stopfer, CGC
- ♦ Syeda Abbas
- ♦ Demetrios Ofidis
- ♦ Stephanie Jideama
- ♦ Kyle Smith
- ♦ Pat Higgins
- ♦ Carolina Lista
- Bassett Center Study sites, investigators and staff
- Generation Study sites and investigators
- MATCH-COMET Research Team, investigators and sites
- ♦ Numerous patient participants across all sites and all studies



ALZHEIMER'S
PREVENTION
INITIATIVE