

Presentation Overview

- This presentation will review the landscape of genetic counseling in Iowa. Presenters will describe models that community cancer care centers and providers may use for genetic counseling and examples of how to implement them.

Genetic Counseling in Community Cancer Care – How to Identify and Implement Genetic Counseling Services

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University of Iowa Carver College of Medicine

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Disclosures:

- Colleen Campbell is:
 - a paid consultant for Novartis
 - an employee of the University of Iowa Hospitals and Clinics which offers genetic counseling services
 - Secretary/Treasurer of the National Society of Genetic Counselors

Learning Objectives

- **Discuss the landscape of genetic counseling in Iowa (Campbell)**
- **Discuss options for models that hospitals use for genetic counseling (Campbell)**
- Describe an example of how to implement a model into a community cancer center/service (McCullough)

Genetic counselors aid in the delivery of precision medicine

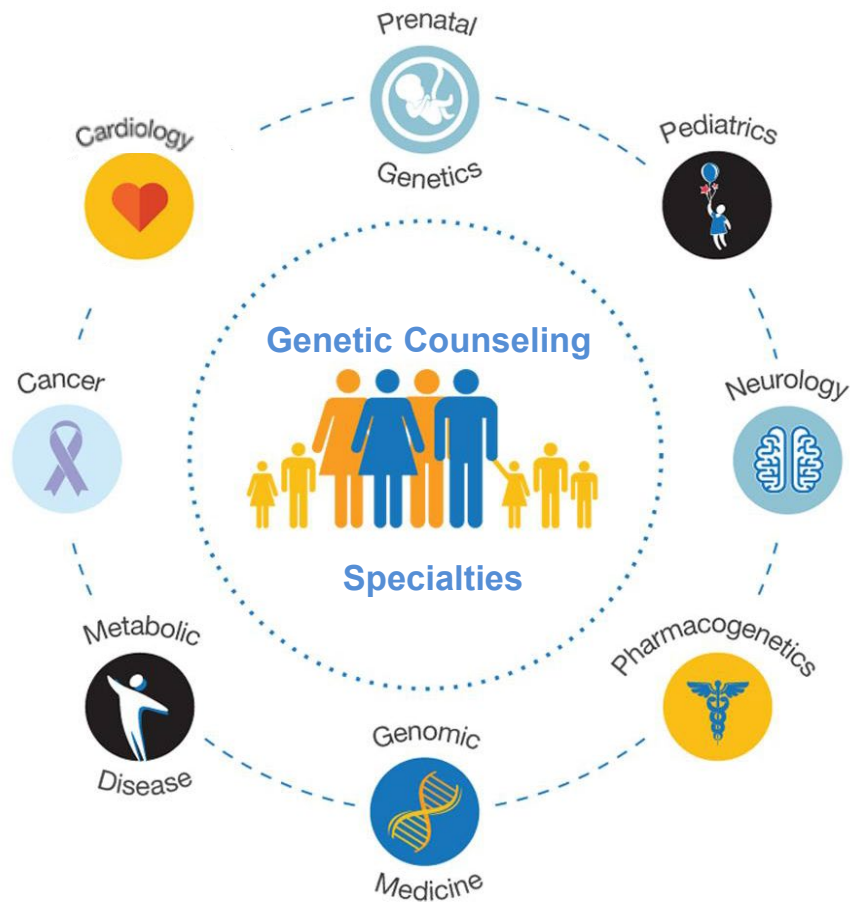
National Society of Genetic Counselors, 2005



Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease

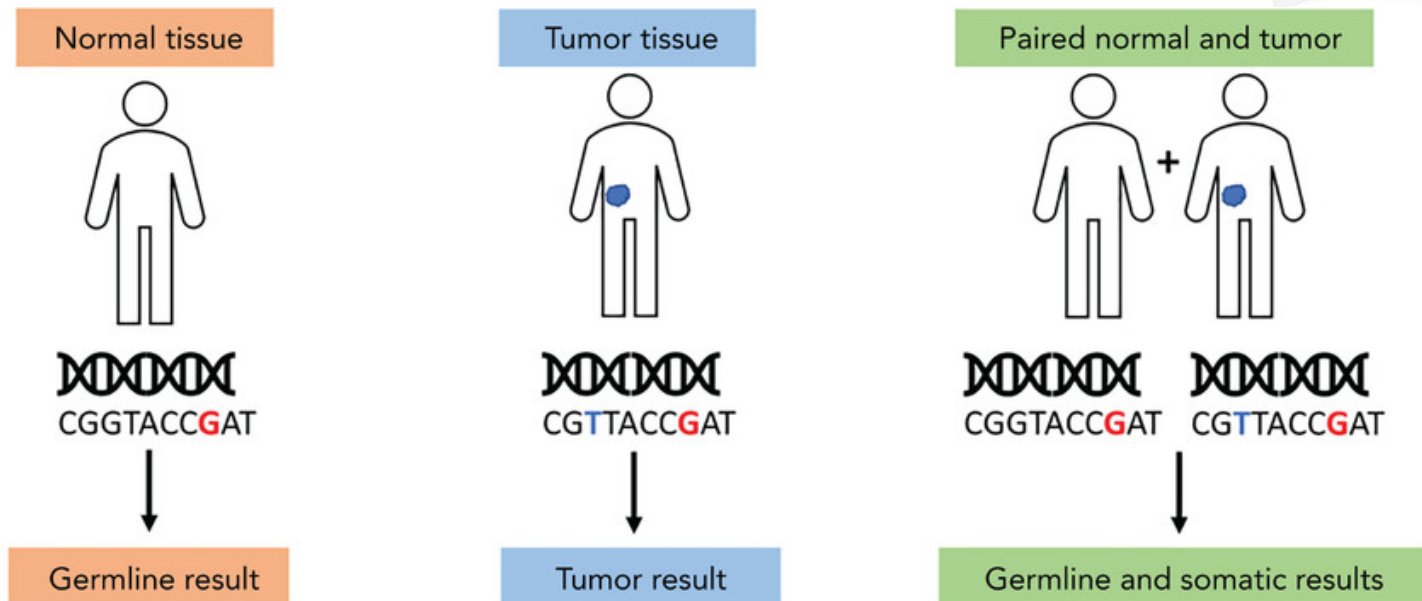
Trained as Generalists, Then Specialize

Therefore can serve multiple clinics



"National Society of Genetic Counselors 2014 Professional Status Survey"

Types of genetic testing



| | | | |
|------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pros | <ul style="list-style-type: none"> Assess inherited risk Cancer screening Counseling for families Reproductive planning | <ul style="list-style-type: none"> Inform diagnosis and prognosis Guide therapeutic decisions for targeted therapies Assess MSI for immunotherapies | <ul style="list-style-type: none"> Differentiation and integration of germline vs somatic variants Guides therapy Allows genetic counseling, screening, and reproductive planning |
| Cons | <ul style="list-style-type: none"> Limited to patients who meet guidelines Testing interpretation difficulties (eg. clonal hematopoiesis and mosaicism) | <ul style="list-style-type: none"> Inability to distinguish somatic vs germline variants. Inadequate surrogate for direct germline testing Need for further genetic testing and potential delays in care | <ul style="list-style-type: none"> Increased costs and resources, particularly related to genetic consents and counseling Specialized curation and interpretation by molecular pathologist |

The Benefits Of Genetic Counseling

CHANGING MEDICINE.
CHANGING LIVES.®

BENEFITS TO PATIENTS

Improve knowledge | Facilitate informed decisions
Increased satisfaction | **Increased adherence to medical management**
recommendations | Decreased barriers to preventive screening | Decreased
fear, anxiety, depression, psychological distress

The Benefits Of Genetic Counseling

CHANGING MEDICINE.
CHANGING LIVES.®

BENEFITS TO PHYSICIANS

Practice expanders | Help incorporate genomic medicine into practice | Recommend testing strategies | Address patient questions | Efficiency | Decrease liability | Can help you **identify good genetic testing labs** – call us!

The Benefits Of Genetic Counseling

CHANGING MEDICINE.
CHANGING LIVES.®

BENEFITS TO HOSPITALS

Increase access to [genetic] services | Improve quality of care |
Ensure quality of genetic tests and accuracy of results interpretation |
Aid in the delivery of precision medicine | Support clinical and research
missions | Train future genetic counselors | Recognition as a leader in genetics
| Generate downstream revenue

Current Status and Future of Genetic Counseling in Iowa

*A roadmap to leadership in genetic
counseling*



November 2014

Key Strategic Challenges

November 2014

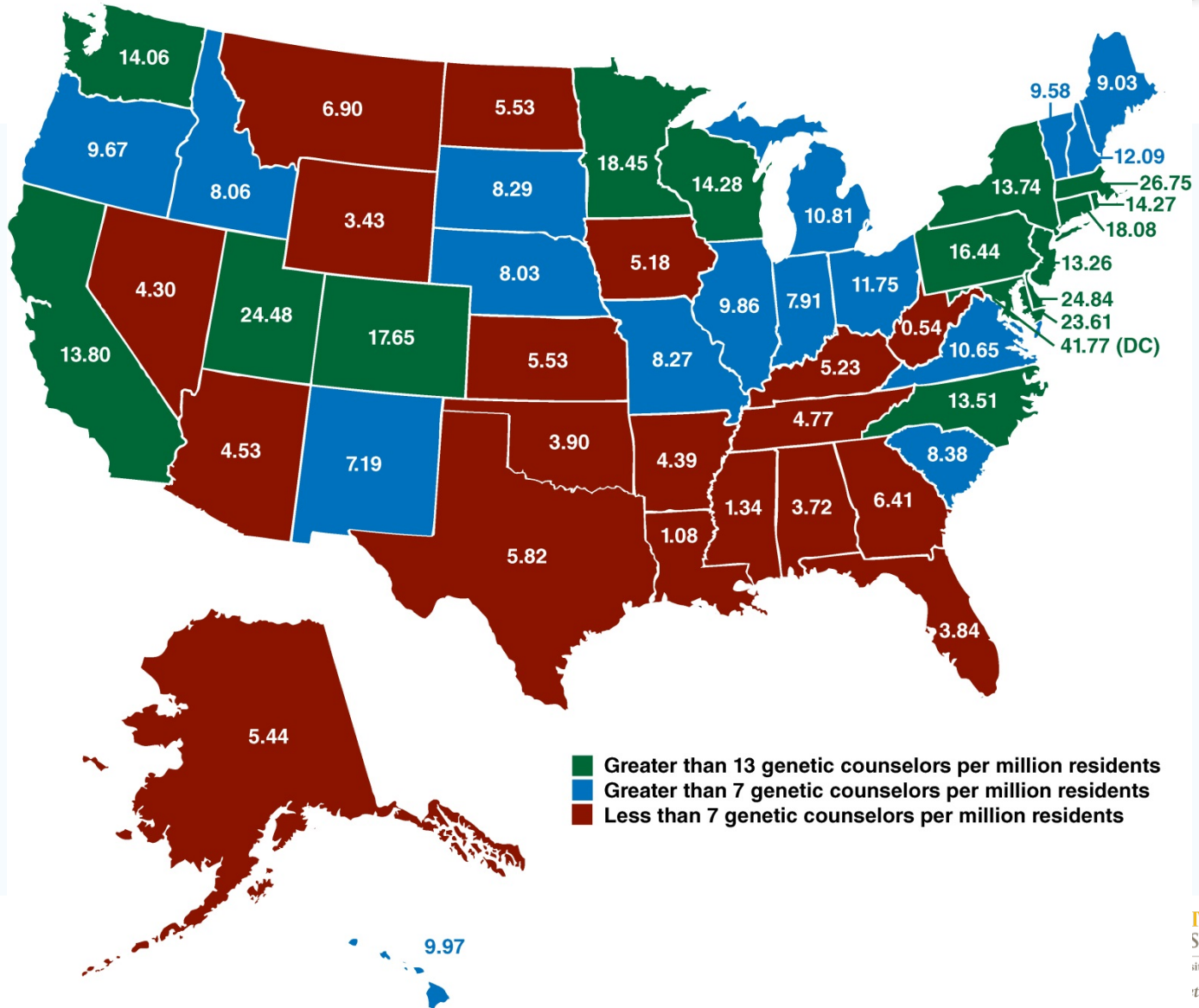


1. Recruitment of Genetic Counselors to Iowa
2. Retention of Genetic Counselors in Iowa
3. Creation of a Genetic Counseling Graduate Program

Infrastructure and Satisfaction

Problem: Shortage of Genetic Counselors

Genetic Counselors per Million Residents



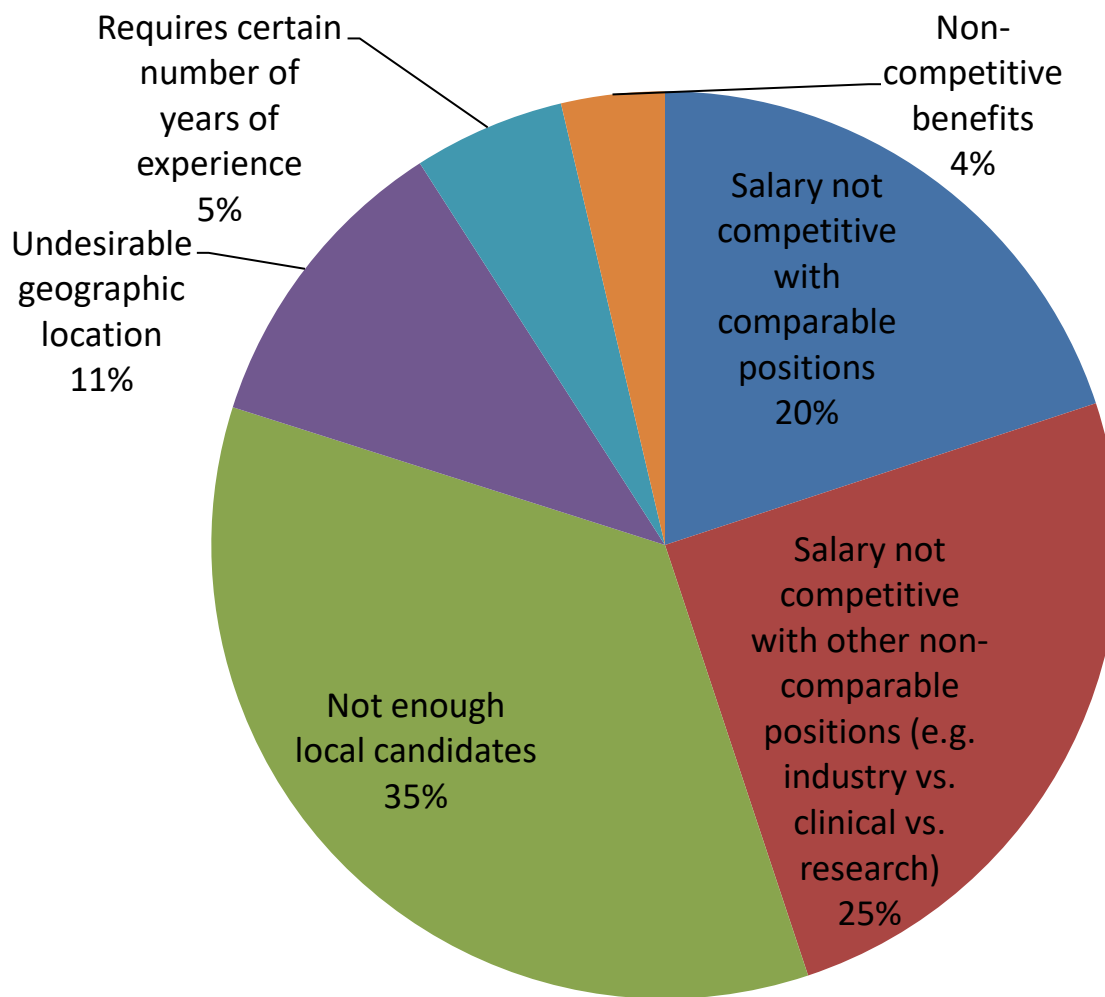
Hurdle to Growth: Recruitment

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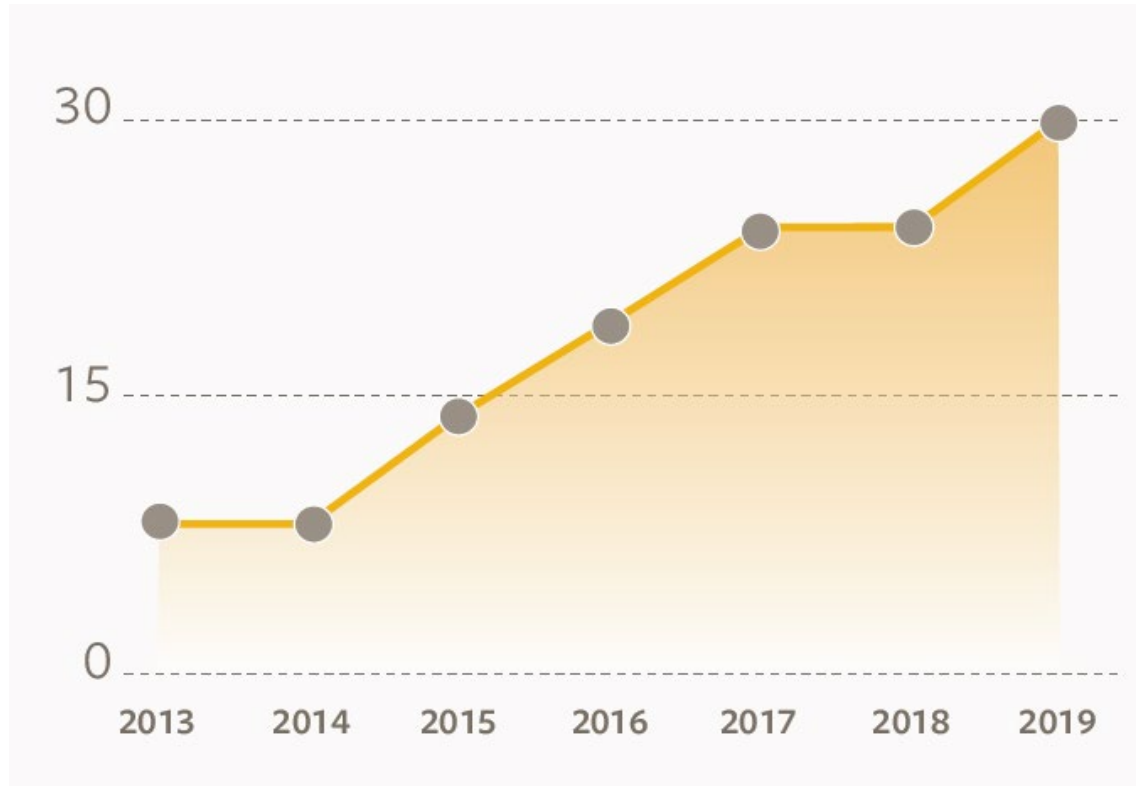
What, if any, have been the impediments to hiring?

NSGC Membership Survey, Genetic Counseling Institutional Models October 2015



Genetic Counseling Workforce Growth

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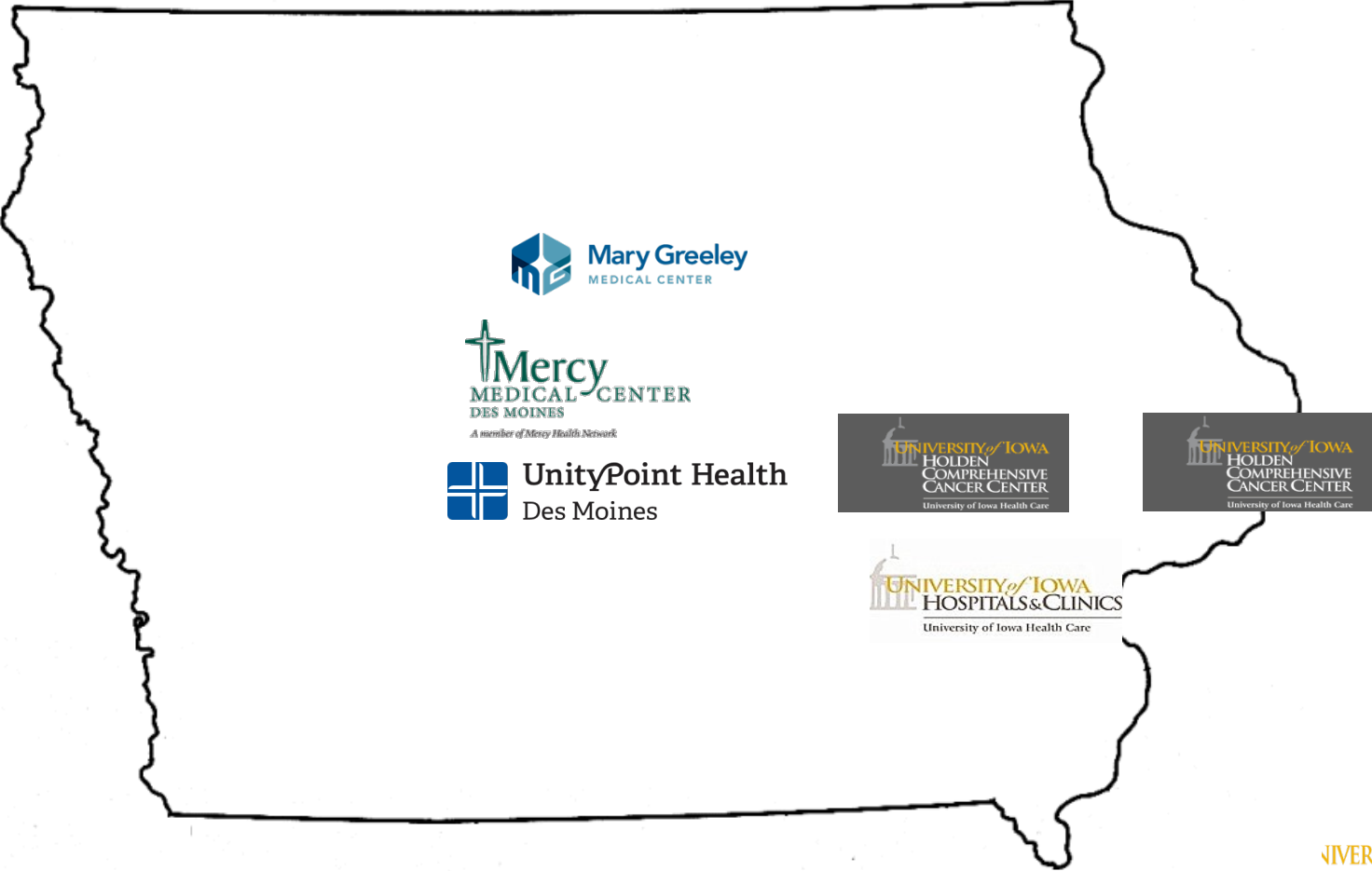
33 LICENSED CERTIFIED GENETIC COUNSELORS

practicing in the state of Iowa

11 specialize in cancer!

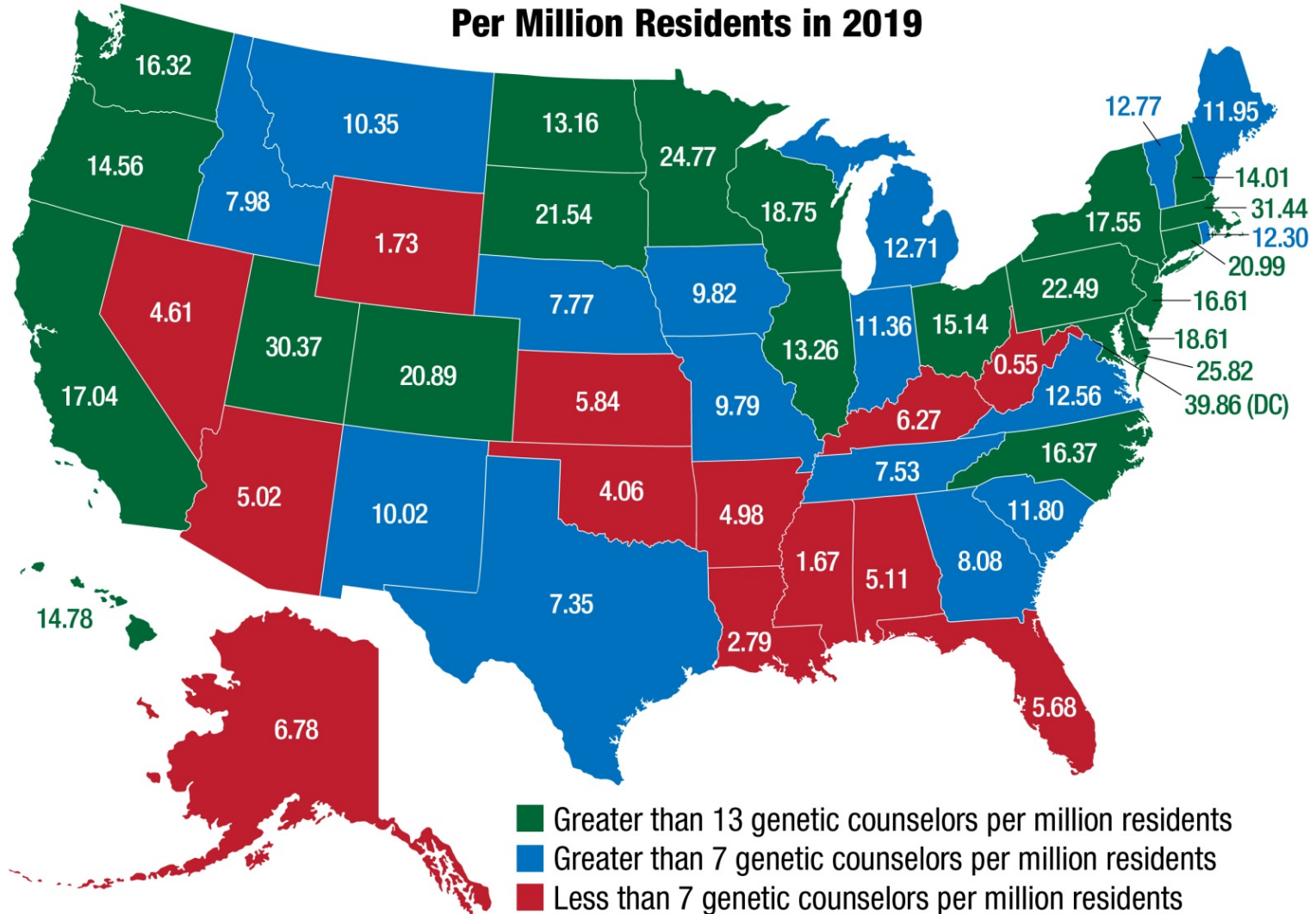
Licensed Genetic Counselors (LGC) in Iowa

272 Genetic Counselors Licensed to practice in Iowa as of August 2021!



Progress...Status in March 2019

Number of ABGC Certified Genetic Counselors Per Million Residents in 2019



- Greater than 13 genetic counselors per million residents
- Greater than 7 genetic counselors per million residents
- Less than 7 genetic counselors per million residents

Find a Genetic Counselor

The screenshot shows the website for the National Society of Genetic Counselors. The browser address bar displays 'aboutgeneticcounselors.org'. The navigation menu includes 'NSGC.org', 'Find a Genetic Counselor', and 'Resources to Help You'. The main header features the NSGC logo and a navigation menu with links: 'WHO ARE GENETIC COUNSELORS?', 'REASONS TO SEE A GENETIC COUNSELOR', 'PREPARE FOR AN APPOINTMENT', 'BECOME A GENETIC COUNSELOR', and 'RESOURCES TO HELP YOU'. A large banner with a blue and orange background contains the text 'Personalized Care For Your Genetic Health' and 'Access to a directory of over 3,300 genetic counselors (US and Canada)'. A prominent button labeled 'FIND A GENETIC COUNSELOR' is visible, along with a smaller button that says 'Find a Genetic Counselor' with a magnifying glass icon. The background of the banner shows a hand holding a smartphone with various icons floating around it.

Genetic counselors help you understand how your family history and DNA influence your health.

Hurdle: Licensure



Work at the top of scope of practice
Recognition as healthcare providers
Minimum standards for education
Title use
Recruits ask about licensure
Identify trained genetic counselors

Iowa is the 24th state to license genetic counselors (effective January 1, 2019)

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Hurdle to Growth: Billing and Reimbursement

Now bill a facility fee



Hurdle to Growth: CMS Recognition

3rd most common payor among UIHC genetic counseling patients



Access to Genetic Counselor Services Act of 2021 (H.R. 2144/S. 1450)

National Society of Genetic Counselors

House Sponsors: Congressman Brian Higgins (NY-D)

Senate Sponsors: Senator Barrasso (R-WY)
Senator Tester (D- MT)

*Representative Axne is a co-sponsor

Recognition of genetic counselors by Medicare will lead to decreased healthcare costs

- Ensure the appropriate utilization of genetic testing
- Estimate potential savings to Medicare by recognizing genetic counselors as independent practitioners: **10 year savings up to \$4-6.5 billion** (Dobson and Davanzo, LLC; Needleman 2017)

Models of genetic counseling services

- Employee genetic counselors
 - Specialize
 - Split specialties
 - Generalists
- Contract with an academic medical center
- Utilize genetic counselors employed by genetic testing labs
- Contract with telehealth companies

Models - Pros

- Employee genetic counselors
 - Embed genetic counselors in the healthcare team
 - Save a hospital money
 - Practice expanders
 - Support clinical and research missions
 - Cascade testing (at-risk family members)
- Contract with an academic medical center
 - Same as above
- Utilize genetic counselors employed by genetic testing labs
 - Deep knowledge of the laboratory's genetic test options
- Contract with telehealth companies
 - Patient convenience

Models - Cons

- Employee genetic counselors
 - Salary
- Contract with an academic medical center
 - Needs may outgrow contract
 - 84.3% New Patient
 - 9.1% Return Patient
 - 6.6% Misc appointment types
- Utilize genetic counselors employed by genetic testing labs
 - Lab quality
 - Does the lab actually employ a licensed genetic counselor?
 - Limited to genetic tests offered by that lab
- Contract with telehealth companies
 - Less follow up

1. Genetic Counselors aid in the delivery of precision medicine and can help improve quality of care and decrease healthcare costs
2. We have grown the workforce in Iowa through a series of infrastructure and satisfaction initiatives in a time of high demand
3. We believe the growth of this workforce will improve patient access to precision medicine
4. There are multiple models for hospitals to utilize to provide genetic counseling services to their patients

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Iowa Genetic Counselors!

Charlton Collaboratory

Thank you

Questions



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Contact for genetic counselors looking for jobs in Iowa,
General advice on setting up genetic counseling at your hospital or clinic,
Research interests

What do genetic counselors do?

CHANGING MEDICINE.
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INTERPRET family and medical histories and genetic test results

EDUCATE patients and medical professionals about disease risk, management, prevention, testing options, resources and research

COUNSEL patients to help them make informed decisions and help cope with the emotional aspects of a genetic condition or diagnosis

Current Challenges

2014

- Iowans are looking for genetic testing and treatment options and local physicians are not yet comfortable with precision medicine
- Regulatory lag prevents providers from ordering tests that help them diagnose and manage their patients, leading to provider frustration
- There is a need for financial support for statewide expansion of the integration of precision medicine into all Iowa hospitals.
- Retaining students who are interested in careers in precision medicine to stay in the state of Iowa.
 - There is not a Genetic Counseling Master's Degree Program in Iowa due to the shortage of genetic counselors
 - Legislative support for the licensure of genetic counselors in Iowa

The University Of Iowa Difference

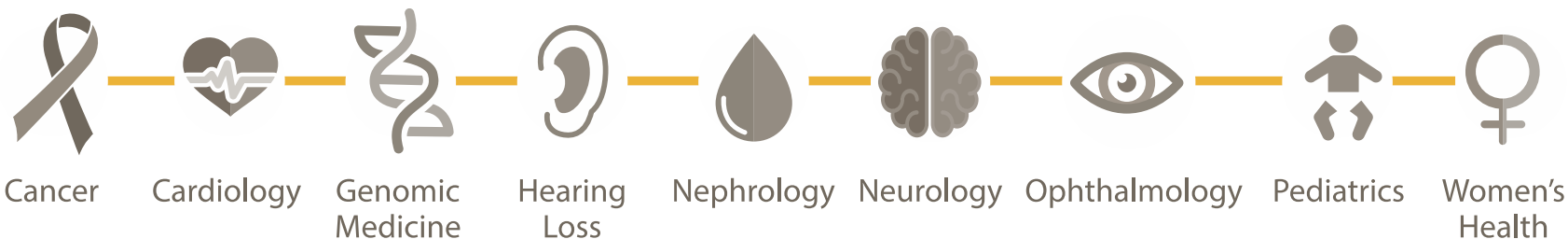
“The Iowa Model”

20 of 30

CERTIFIED GENETIC COUNSELORS

in Iowa are employed by University of Iowa Hospitals and Clinics

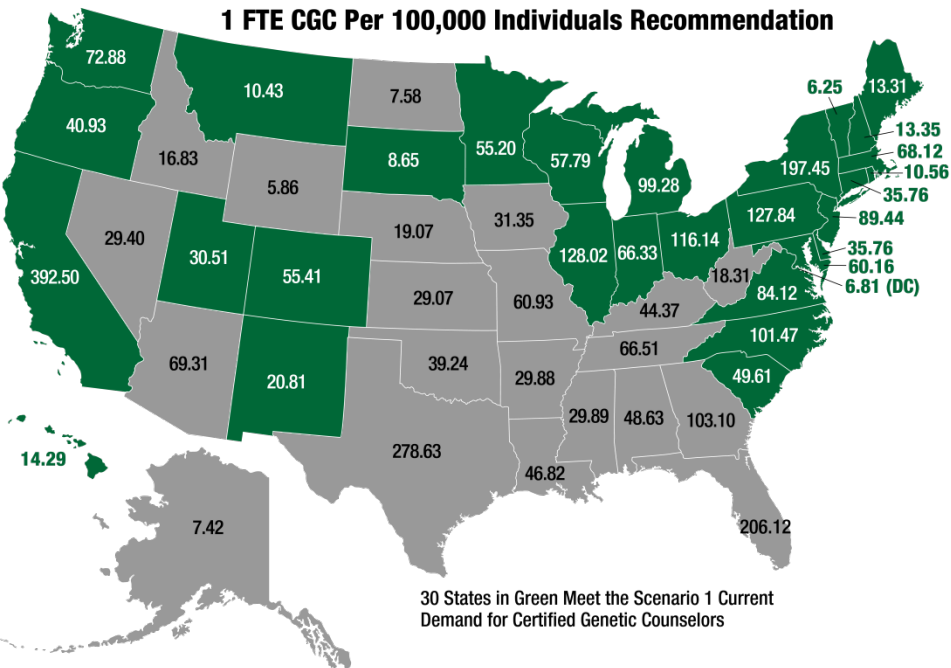
University of Iowa genetic counselors specialize in a **variety of areas**, including:



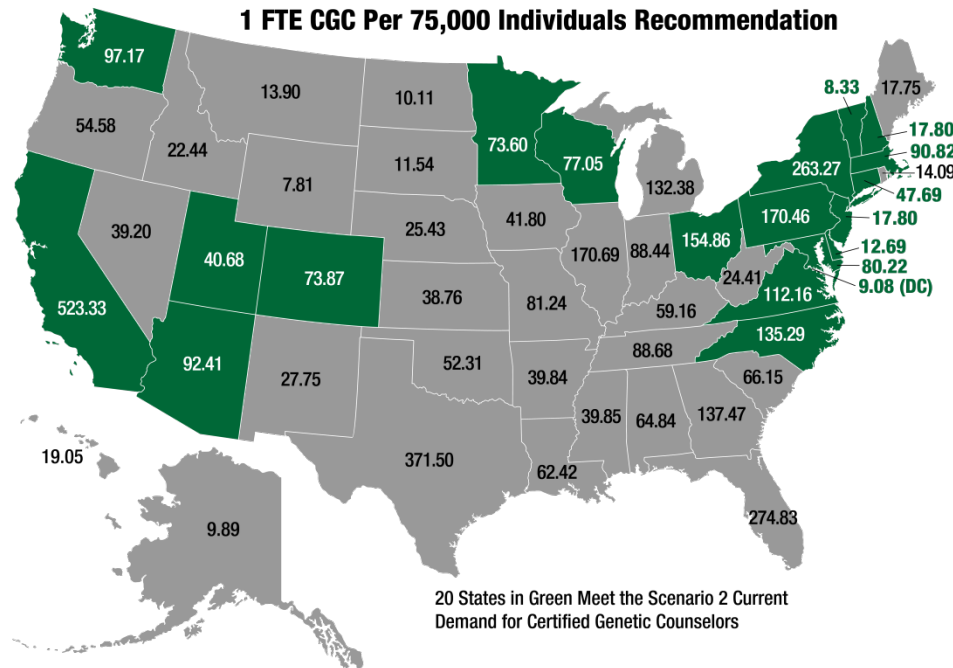
How many genetic counselors are needed in Iowa?

*Numbers below include non-clinical genetic counselors

Number of Certified Genetic Counselors Needed to Meet 1 FTE CGC Per 100,000 Individuals Recommendation



Number of Certified Genetic Counselors Needed to Meet 1 FTE CGC Per 75,000 Individuals Recommendation



Needs are expected to increase with advancements in precision medicine

Based on Dobson DaVanzo & Associates, LLC. "Projecting the Supply and Demand for Certified Genetic Counselors A Workforce Study." (2016)

Iowa Genetic Counseling Workforce Growth

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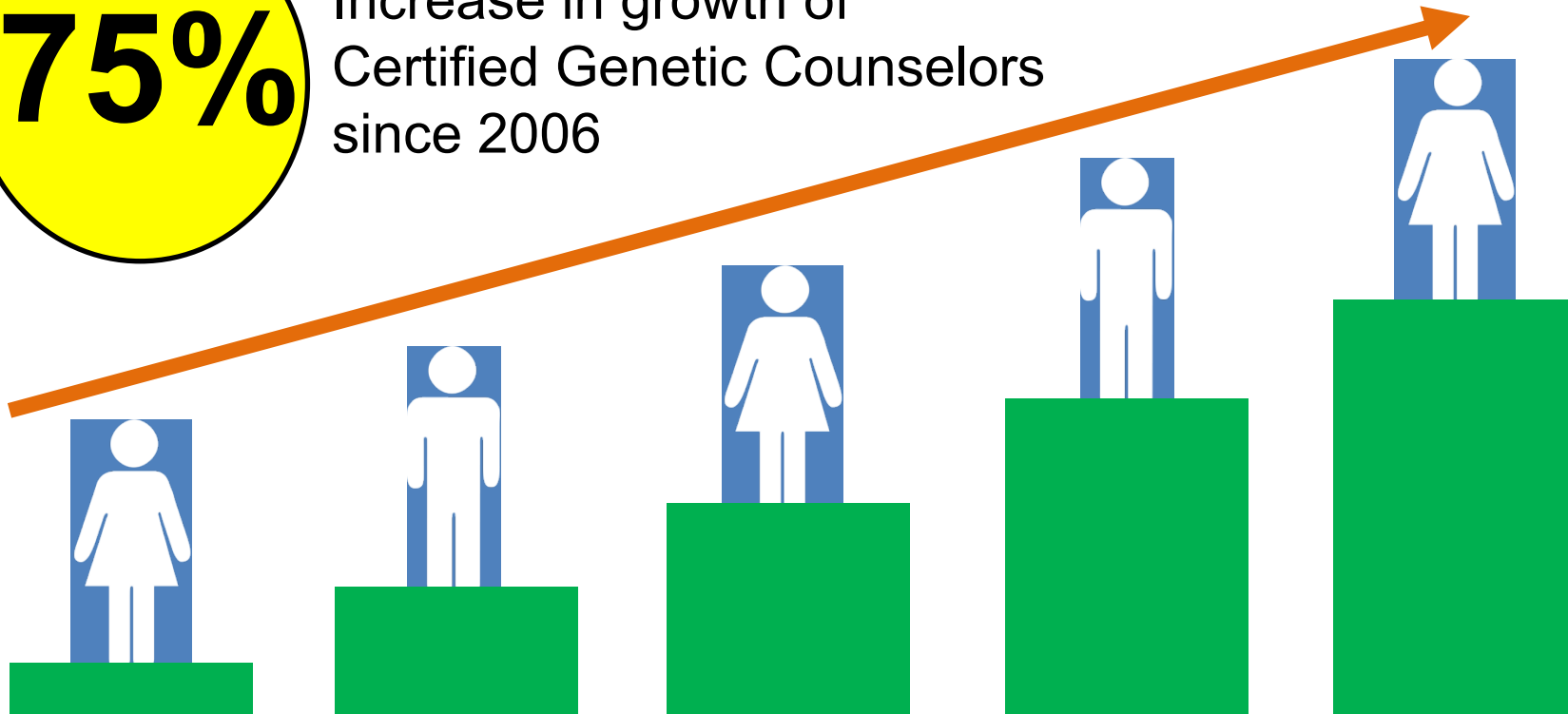
STUDENTS ACCEPTED

into genetic counseling master's degree
programs were from Iowa in 2017

Job Growth

75%

Increase in growth of
Certified Genetic Counselors
since 2006



Bureau of Labor Statistics projection for above-average growth in the number of genetic counseling jobs from 2012 – 2022

Hurdles To Growth Of Genetic Counseling in Iowa

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Status in November 2014

- Nationwide shortage...not unique to genetic counseling
- Salary
 - 33rd / 42 states with 5 or more genetic counselors
 - 2012 national range \$45K-250K
- Job satisfaction
 - 34th/ 42 states with 5 or more genetic counselors
- Reputation
- State Licensure
- Accredited Genetic Counseling Master's Degree Program
- CMS Recognition – national issue



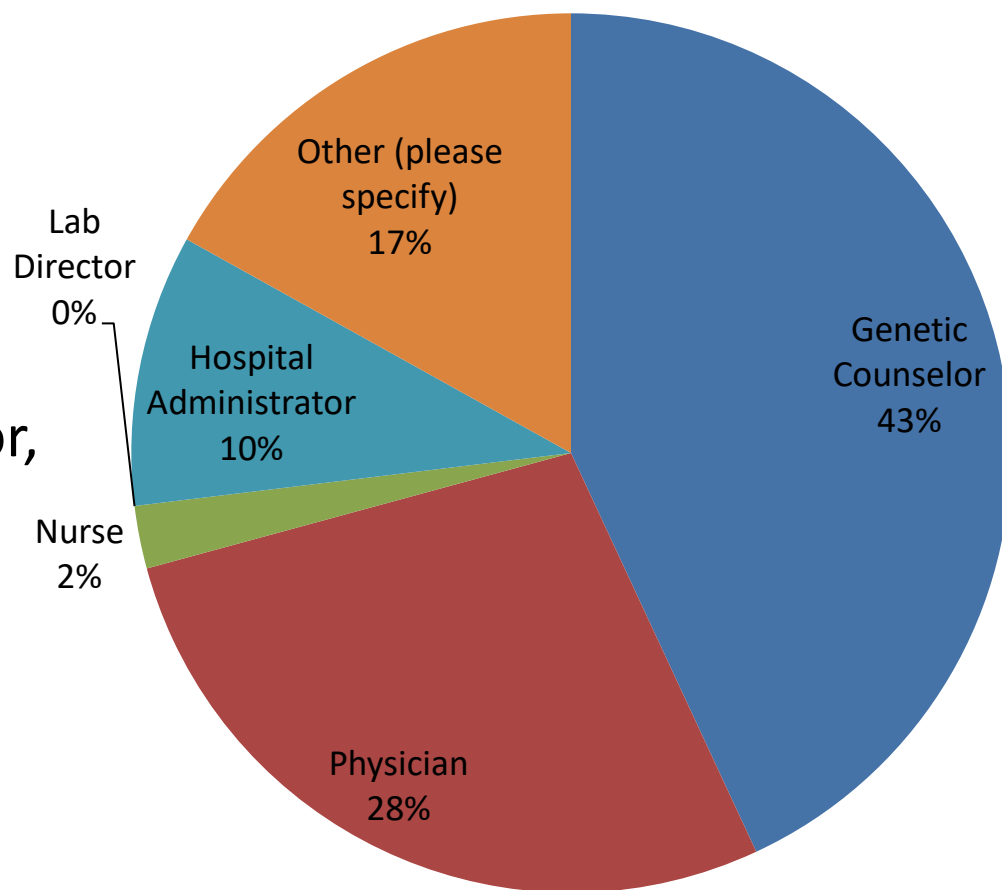
Lack of recognition negatively impacts access to certified genetic counselors

- Current Medicare regulation limits physician referrals for genetic counselor services.
 - Because genetic counselors are not recognized providers under Medicare, their services have to be delivered under “incident to” rules when seeing Medicare patients.
- Removal of the “incident to” rules by recognition of CGCs, will make it easier for physicians to utilize genetic counselors by referring patients outside their practice and/or hospital directly to a CGC

Who oversees the genetic counselors?

NSGC Membership Survey, Genetic Counseling Institutional Models October 2015

- Director of Genetic Counseling Services
- Varies by department
- Some have physician supervisor, others have GC supervisor
- There are supervising GCs who oversee most GCs and the supervisors are overseen by hospital administrators.



A photograph of the June E. Nylen Cancer Center building at dusk. The building is a multi-story structure with a prominent glass facade that is illuminated from within, casting a warm glow. The sky is a mix of deep blues and oranges from the setting sun. In the foreground, there is a paved area with a circular landscaped island containing a flagpole and some greenery. A tall light pole stands to the left of the building. The overall scene is serene and professional.

June E. Nylen
CANCER CENTER

Genetic Counseling Services

About Us

- Mission: To provide the highest quality, compassionate care through prevention, treatment, and research.
- Vision: Be the region's preferred choice for hope and healing.
- Principles That Guide Our Organization:

People

Service

Quality

Cost

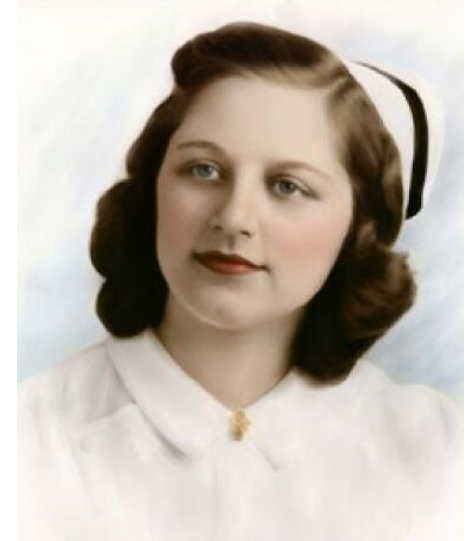
Growth

Community



Our History

- 1980 – Siouxland Hematology Oncology Associates formed by Dr. Michalak
- 1995 - Siouxland Regional Cancer Center opens
- 2005 – Name changes to June E. Nylén Cancer Center
- 2015 – JENCC purchases Siouxland Hematology Oncology Associates



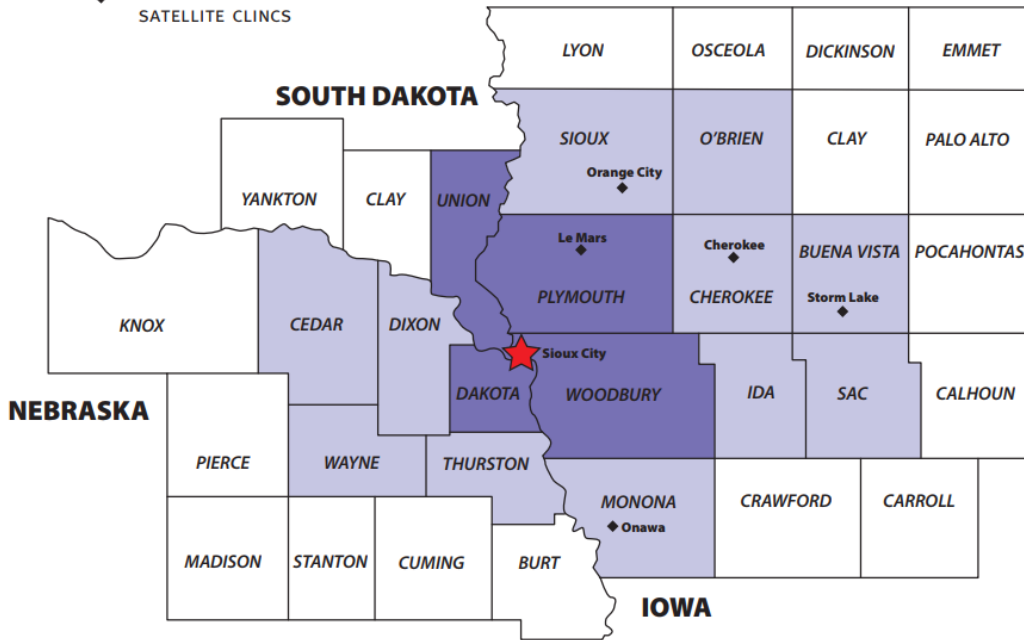
Our Numbers Today

- **5** Hematology/Oncology Physicians + Actively Recruiting **1**
- **1** Radiation Oncologist + Actively Recruiting
- **1** Nurse Practitioner + Actively Recruiting
- **100+** Total Employees
- **30 - 40** New Patients Each Week
- **150** Patients Seen Per Day
- **300+** Clinical Trials Offered
- **7,000** Patients Last Year
- **41,000** Patient Visits Last Year



5 Satellite Outreach Clinics In Service Area

- PRIMARY SERVICE AREA
- SECONDARY SERVICE AREA
- TERTIARY SERVICE AREA
- MEDICAL ONCOLOGY SATELLITE CLINICS



- Cherokee
- Le Mars
- Storm Lake
- Onawa
- Orange City

Past Genetics Program

- Previously used a national lab when ordered genetic testing was ordered by oncologists
- Coordinating was responsibility of our Nursing Director
- Service outsourced - relied heavily on the outside lab to educate and provide patients with the tools to make informed decisions
- Our oncologists wanted to see more patients benefitting from the advantages of genetic testing and counseling, but because of their patient load, they cannot be the ones physically counseling the patients



The Why

“There is a significant rise in cancer diagnoses linked to germline etiology (inherited or hereditary); noting that **10% of breast, prostate, colorectal and pancreatic cancers** may have a germline link. This association is **even higher in ovarian cancers, 20%** - so counseling and testing are recommended in all women with ovarian cancer by the NCCN guidelines. Genetic counseling is very important to identify as much as possible, carriers before the development of the disease. **Huge numbers of high-risk patients who could be identified through genetic counseling/testing are instead developing cancer and dying** (Hughes, JCO 2017). Our current set-up for breast and ovarian cancers of identifying a woman after she develops the cancer is a failure of cancer prevention (King et al, JAMA 2014). **One of the long-term goals and expectations is that robust genetic counseling services as our new project entails will afford us the opportunity to start making the required changes to improve cancer care and outcomes** in the Iowa cancer patient.”

- *Dr. Matthew Obinna Nwaneri, Medical Director at JENCC and Current President of Iowa Oncology Society*



Expanding Genetic Counseling & Testing at the June E. Nylen Cancer Center

- How do we staff the program?
- How do we implement efficient workflow?
- How do we ensure all patients regardless of their ability to pay have access to our program?
- How do we support a patient financial assistance program?
- What metrics do we look at in expanding the program?
- How do we educate our staff, patients, and community?



How Do We Staff?

- Nationwide shortage of certified genetic counselors - difficult to recruit this specialized position to cancer centers serving a more rural region
 - Formed new partnership with the Munroe-Meyer Institute for Genetics and Rehabilitation (MMI) - a non-profit university-affiliated program with the University of Nebraska Medical Center (UNMC)
 - Established in 1954 – Dedicated to offering the services of professionals trained in research, education, and patient care to support individuals with developmental disabilities
 - Strong commitment to applied and basic research related to the prevention and treatment of genetic disorders and developmental disabilities
 - Located in Omaha, NE - Provides comprehensive interdisciplinary clinical and laboratory genetics services, genetic counseling, professional education, patient education, and support groups
-
- virtual telehealth consultation



Our Program's Plan

- Expanding in different stages
- First 6 months (July – December 2021): Piloting the new work process
- Starting with breast cancer patients because we have an established Breast Tumor Board Conference – already offers seamless follow-up and collaboration
- Address hiccups in workflow, communication, and technology
- Then for any cancer types
- Second 6-month time period (January – June 2022): Expand the genetic counseling services for immediate family members of patients



Our Program Staffing Structure

- National benchmarks of a 1.0 FTE cancer genetic counselor = established at 10 patients per week = approximately 500 patients per genetic counselor per year
- Initial 6-month pilot of our program (July – December 2021): 0.2 FTE of a designated certified genetic counselor = two patients per week
- + Genetic Counseling Assistant at 0.10
- Referral and clinic workflow coordinated with Navigation Team



Additional Program Details

- Serve a minimum of 48 patients in 6-month pilot
- 2 patient appointments per week in the first 6-months of piloting the program
- Our 6 providers are currently placing orders for genetic testing on an average of 2-4 per week
- We do not want to expand too quickly until we ensure the new work process is effective and quality for patients
- Recently expanded to other diagnosis



Role of Navigation Team

- Extensive family history being gathered by the evaluation staff and the physicians during their first visits to the clinic
- This team proactively identifying patients
- Schedules and works directly with the MMI staff
- Reviews the patient's insurance coverage
- Identifies financial concerns and prepares report for patient assistance
- Arranges for blood draw, telehealth, and escorts the patient to conference room for appointment
- Coordinates recommendations with the patient's primary care physician or medical oncologists or our NP



Cost of Counseling and Testing

- Cancer genetic testing ranges from \$300 to \$5,000 depending on the test
- A consultation with a genetic counselor to determine what tests are needed and then analyze results is an additional cost, ranging from \$150 to \$250 – not covered by insurance
- Key aspect of our program = financial assistance to support the patients who cannot pay to access these services
- **Equal access** to genetic testing and counseling through our program – whether patients are insured, underinsured, have a high deductible, or no insurance at all



Financial Assistance Is Key

- Since being founded in 1995 we have been inclusionary in the treatment of its patients as our practice cares for any patient regardless of ability or inability to pay
- We frequently see patients who struggle with medical costs due to high deductibles
- If a patient says they are not able to pay the established payment structure for the genetic counseling, we will provide financial assistance in some sort to ensure they can get the testing and counseling



Our Fee Structure

- \$150 charge for the genetic counseling/testing
- Navigation Team explains the cost and payment options
- Due the day of the appointment
- All-inclusive cost for the consultation, testing, and follow-up session with the certified genetic counselor



Grant Awards and Securing Donations

- Expanding Genetic Counseling and Testing at the June E. Nylen Cancer Center; Iowa Cancer Consortium
- Community Donations & Grants
- Patient Donations



Sustaining our Program

- Pilot this project for a year in 2 phases - July to December 2021 and January to June 2022
- At that time, a “departmental” budget will be developed and incorporated into the organization’s overall operational budget that runs on a fiscal year starting July 1
- The June E. Nysten Cancer Center has an established Patient Assistance Fund, funded through donations. Frees up funds for patients’ out-of-pocket treatment costs by providing support to aid with: mortgage/rent, utilities, groceries, and transportation
- Genetic Counseling financial assistance will be kept separate from this current Patient Assistance Fund. Donations would continue to support those patients who could not pay for genetic counseling



Legislation Reference and Template

- <https://www.congress.gov/bill/117th-congress/>
 - <https://www.congress.gov/bill/117th-congress/house-bill/2144/text?r=1&s=1>
 - <https://www.nsgc.org/Policy-Research-and-Publications/Federal-Advocacy>
-
- The first link is the language from last year's bill
 - The second is Congress' website for the current bill, but the text has not been added yet. It is expected to be the same as last year's language
 - The 3rd link is to the National Society for Genetic Counselors that provides some templated letters that you can send to your representative in support of the bill



2018-2022 Iowa Cancer Plan

- Program implemented from goals in the 2018-2022 Iowa Cancer Plan
- Goal #8: “Increase access to cancer risk assessment and genetic counseling services”
- Goal #10: “Increase access to genetic tumor testing to identify the most appropriate treatment for patients” which impacts the goal of increasing access to quality cancer care and services



Project Objective:

Track the commitment and action of the patients who completed the genetic counseling, in hopes they are acting per the recommendations.

- We will have a designated nurse practitioner who will continue to help manage the recommendations from the genetic counseling and create a care plan to ensure the patient is getting the appropriate screenings and treatment
- Our nurse practitioner will communicate and collaborate with the patient primary practitioner for clear understanding, follow-through, and continued monitoring



Long-Term

- Genetic testing can help people understand their risk for cancer, help them make medical decision, and take steps to lower their cancer risk or detect cancer early. If done when cancer is already diagnosed, genetic testing helps make informed decision on the most effective course of treatment
- Misunderstanding the benefits of genetic counseling and a lack of awareness about the accessibility to counseling and testing in our service area will be addressed through the marketing and education strategies of our program
- Identifying risk and preventing cancer: Opening up genetic counseling and testing to family members and the public will be a shift that we are providing care pre-diagnosis



Genetic Counseling & Testing Benefits

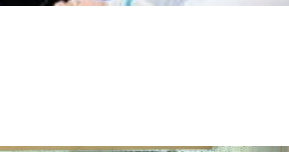
Expanding genetic testing within our practice's patient population leads to more effective cancer treatments, and thus outcomes.

Additionally, we can impact actual diagnosis numbers by offering the opportunity for genetic counseling to family members and equipping them with a care plan to address risk factors and ultimately prevent cancer.

“One of the long-term goals and expectations is that robust genetic counseling services as this project entails will afford us the opportunity to start making the required changes to improve cancer care and outcomes in the Iowa cancer patient,”

- *Dr. Matthew Obinna Nwaneri, Medical Oncologist and Medical Director at the June E. Nylen Cancer Center as well as current President of the Iowa Oncology Society*





June E. Nylen CANCER CENTER

nylencancercenter.com
(712) 252-0088

